

# 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 77. Autumn 2023 Edition



The Bridgewater Canal at Worsley.  
This historic 39-mile canal stretching from Runcorn to Leigh in West. This was the first ever canal built. Normally the water is brown due to Iron deposits from the nearby disused mines. With thanks to Andy whose narrowboat can be seen moored to the left.



**You write in.**

*A selection of topics from you, the Pathways Readers.*

**Aileen Writes:** I am looking for advice on magnesium supplements. I am sure you have tackled this topic previously in a Pathways, but I cannot find it. A few months ago, I had an overnight stay in hospital because of stomach problems. A subsequent endoscopy has shown that I have esophagitis, gastritis and a hiatus hernia (which I have known about for many years). I initially was prescribed omeprazole 2 x 40mg daily for six weeks and now I am taking 2 x 20mg every morning. I know that taking this drug affects absorption of magnesium and calcium and I have tried to cut back on the medication but cannot at the moment. I have taken magnesium supplements for many years, and they have helped my fatigue levels and also joint pain and leg pain. I have previously tried magnesium oil spray, but my skin became very irritated with it. What would be the best topical magnesium I could try? I have been looking at various creams/lotions but do not know what would be best for me. Even if you could point me in the direction of the correct Pathways where you have discussed magnesium.

*I am not convinced that external applications for magnesium have any benefits for ME/CFS. It may be worth trying bathing in commercial magnesium sulphate (Epsom salts). It is available in big quantities for this purpose.*

*The jury is still out on magnesium injections. Some private doctors will give it, but generally it is not recommended for GPs to prescribe because of insurance restraints. Just remember that 'Milk of Magnesia' (magnesium oxide or hydroxide) is sold for indigestion and as a mild laxative effect. There are some magnesium salts e.g., citrate, malonate and taurate which are sold as a magnesium supplement. I have pasted details to the right.*

*The version I prefer to use is Magnesium Phospholipid Complex. This comes in capsule form, the shell having to dissolve before the contents are released. Biocare do this product, but I would expect similar products to be available from other supplement suppliers. The phospholipid variety is fat soluble rather than water soluble.*

## Forms of Magnesium

**Chloride:** detoxing, metabolism, kidney function

**Citrate:** not recommended, as it interferes with Ceruloplasmin & can cause iron dysregulation & health issues

**Glycinate:** relaxing, good absorption rate, leaky gut, nerve pain

**Malate:** energizing, fibromyalgia, muscle pain

**Oxide:** good in small doses throughout the day

**Sulfate:** small oral doses, best in bath

**Taurate & orotate:** cardiovascular health

**Threonate:** brain injuries, PTSD, depression, neuro conditions, anxiety

**Pauline writes:** I am well into my 80's. For the past four week I have been in hospital following a fall. I am a widow, there are no relatives to look after me. I am told I have to have a care package in place before I can go home. I have been pressured to sign a contract with a new care agency for two visits a day for the next month before I can go home. They tell me that the monthly cost will be £1,500. I feel that I am before fleeced for money. Is this right?

*Firstly, the hospital cannot discharge you until a plan of care and safety has been established.*

*Secondly, in a month you will receive 60 visits, which works out at £25 per call. You must understand that the person who visits you has to be trained and registered as a Carer. Although the contact time for each visit is 30 minutes, you have to recognise that travelling, reports and other essential items have to be included and charged to you. You are not being fleeced and the cost is about right. For comparison. If you have to call in a repair person e.g., for a washer or TV set, I would expect a charge of about £60 for them to walk through the door.*

*Thirdly I know you are receiving your private and states pensions, but you are also receiving a disability benefit like PIP, AA or DLA. These benefits are paid directly to you, so you can buy the care you need. You may also be able to get a direct payment, a council tax reduction and other payments through your local council.*

**Shaney Writes:** I need to renew my Blue Badge, but they are wanting proof to ensure that I am entitled to it. I am getting the high-rate DLA Mobily, but I cannot find my award letter. What can I do about it?

*If you cannot find it, I suggest you contact DLA at Warbeck House as shown on the letter and explain your problem. They will usually send a statement or replacement letter as proof of your award.*

*You can apply for or renew a Blue Badge online. You will need the following:*

- *A recent digital photo showing your head and shoulders.*

*You will also need a photo or scan of your:*

- *proof of identity (such as a birth certificate, passport or driving licence)*
- *proof of address (such as a Council Tax bill or government letter)*
- *proof of benefits (if you get any)*

*You will also need to know:*

- *your National Insurance number*
- *the details of your current Blue Badge (if you are reapplying)*

*To apply, or renew a Blue Badge visit: <https://www.gov.uk/apply-blue-badge>*

**Kevin writes:** Has anyone tried a *QUILITY* weighted blanket. I have purchased one of these blankets to see if it helps with my sleep. It was £20, which is very good value, as they are at least £50 online. It was from Misson Mills cash & carry near Bawtry. Not sure if anyone has tried one of these before? Does anyone have an answer?

*We asked around our group and two members responded:*

**Ian said:** *'I have a weighted blanket and I find that it does help me a lot'*

**Ann reported:** *I use quite a thick home crochet blanket which is quite heavy on my legs when they ache or when I feel exhausted and shaky and find the weight helps.*

*There are good reasons why these heavy blankets help. Firstly, these are good heat insulators, so keep you warm. By wearing insulation, you reduce the energy you need to keep your body warm running, and allow more energy to be reserved for helping thus reducing exhaustion. Secondly, the weight of the blanket act as a counter irritant, which can help with reducing the low level abnormal neurological sensations associated with fatigue syndromes. Sleeping in a heavy tracksuit or dressing down will achieve the same.*

**DWP**
Department for  
Work and Pensions

Disability and Carers Service  
Website: [www.direct.gov.uk/disability](http://www.direct.gov.uk/disability)

**Disability Living Allowance**  
Your reference is   
Please tell us this number  
if you get in touch with us  
  
DLA Adult  
DLA For Adults  
Warbeck House  
Warbeck Hill  
Blackpool  
FY2 0YE  
  
Phone 0800 1214600  
TEXTPHONE for the deaf/hard of  
hearing ONLY 0800 1214523

Date 12 Apr 2023

Dear

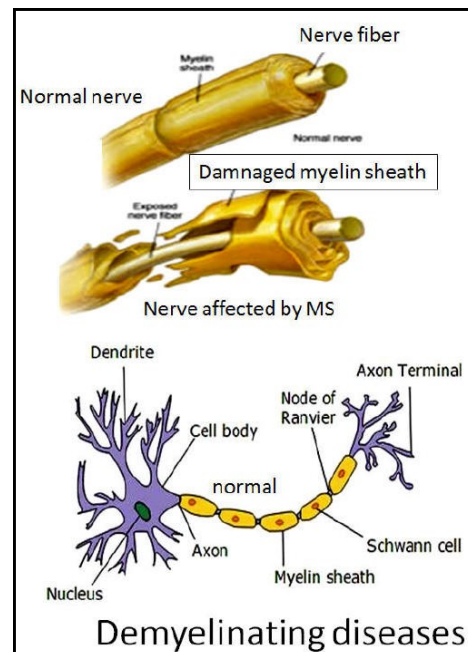
ABOUT THE AMOUNT OF MONEY WE PAY YOU

Please keep this letter safe, as it is proof of your entitlement to benefit.

**Gwen writes:** I have just seen a neurologist who has said I have got Clinically Isolated Syndrome. He has told me this after I have had several MRI scans. Just to refresh things, I got ME/CFS after a vaccination about ten years ago. Since then, I have not improved in any way. Can you tell me what it means?

*What it means is you have Clinically Isolated Syndrome of Demyelination. When people suddenly get ME/CFS it usually is from a single event life event, and in your case, it was most likely the vaccination. The fact things have been stable since is a further indication of the cause.*

*You have a disease that damaged with myelin sheaths in your nervous system. This damage disrupts the transmission of signals through the affected nerves, resulting in a decrease in their conduction ability. Consequently, this reduction in conduction can lead to deficiencies in sensation, movement, cognition, or other functions depending on the nerves affected. Various factors can contribute to the development of demyelinating diseases, including predisposition, reactions, and other unknown factors. It is possible with treatment for the myelin sheath to regenerate, but when it does there may be nerve damage and loss of performance. There is a test for demyelination that look for slower nerve conduction than usual.*



*Proposed causes of demyelination include genetic predisposition, environmental factors such as viral infections or exposure to certain chemicals. Additionally, exposure to commercial insecticides like sheep-dips, and flea treatment preparations for pets, which contain, can also lead to nerve demyelination. Chronic exposure to may also cause demyelination, deficiencies in B12 result in demyelination.*

*Demyelinating diseases are traditionally classified into two types: myelinoclastic diseases leukodystrophy diseases. In the first group, a healthy and normal myelin is destroyed by toxic substances, chemicals, or autoimmune reactions. In the second group, the myelin is inherently abnormal and undergoes degeneration. The most well-known demyelinating disease, multiple sclerosis, evidence suggests that the body's immune system plays a significant role. Immune system, specifically-cells, are found at the site of lesions. Other immune system cells could also contribute to the damage.*

*With the course of your condition— i.e., just one episode of demyelination and no significant change since make an exact diagnosis difficult to confirm. While you meet the criteria for ME/CFS you don't fully meet the criteria for multiple sclerosis (MS). You are effectively in the no man's land between MS and ME/CFS. In this case a neurologist would diagnose you has having Atypical MS, also sometimes knows a Benign MS. Other doctors describe it a Secondary Progressive which means that further demyelination may reoccur after a period of time.*

*You need to do the following*

- You are legally obliged to inform DLVA because unlike ME/CFS, MS is a prescribed condition.
- Stop smoking and vaping as this activity is toxic.
- Avoid live vaccinations. Killed or viral antigen vaccines are OK e.g., Flu.
- If you get severe pain due to optical neuritis or sudden loss of sight on one eye, it is a clinical emergency which need immediate steroid treatment otherwise you could become permanently blind.
- There are reports that high dose linoleic acid, a component of many vegetable oils (e.g., olive) at about 20g daily help recovery. Something similar applies with ME/CFS, but with omega 3-6 combinations.
- Consider taking early retirement if you have an occupational pension, but take specialist advice.



## ***Welfare Rights Matters***

*With thanks to Steve Donnison from Benefits and Work.*

### **Consultation On Slashing Support Group Launched By DWP.**

The DWP has begun a consultation on changing the WCA to make it much harder for claimants to be found to have Limited Capability for Work-Related Activity (LCWRA) for universal credit or to be in the support group of ESA. The consultation document sets out a range of possible alterations to four activities: mobilising, controlling your bowels and bladder, coping with social engagement, and getting about. The most extreme proposal is to simply do away with all these activities as well as the vital substantial risk rule. Rule is often the only way that people with severe mental health conditions, including those at risk of self-harm, can enter the LCWRA group.

The DWP's excuse for these drastic cuts is that employment has changed, especially since the pandemic, with many more opportunities to work from home. They argue that if claimants no longer have to travel or mix with other people in order to work, then they will be able to manage their health conditions at home whilst also earning a living. But, at present, claimants in the LCWRA group do not get any support with looking for work. So, according to the DWP's twisted logic, it is a kindness to take away the additional £390 a month they receive, push them into the limited capability for work group and subject them to the threat of sanctions instead. Or, as the DWP put it in their consultation document:

*It is not right that so many people are left without support, and we must not hold people back from opportunity.*

According to the consultation document, any changes will be legislated in 2024 and come into force in 2025. They will affect new claimants from 2025 and existing claimants when their award is reviewed from 2025 onwards. These proposals are separate from the plan to entirely abolish the WCA from no earlier than 2026/27 for new claimants and 2029 for existing claimants. The timetable for slashing the support group would allow any proposed savings to be included in the government's future spending plans, possibly as early as the Autumn statement. This would set the scene for the Conservatives to offer tax cuts funded by welfare savings as part of their forthcoming election manifesto. The consultation on the proposals lasts until 30 October.

Many readers will be extremely sceptical about the value of taking part, believing that the DWP will already have made up its mind what it is going to do. That may well be true, but to build any real opposition to measures which could undoubtedly be life-threatening for some claimants, it is vital that the DWP cannot argue there is broad support for the proposals. And if there is a sufficiently ferocious response, it may dissuade the DWP from going for the most extreme options it has outlined in the consultation.

### **Is This the Person Who Will Save The WCA?**

In his latest cabinet reshuffle, Keir Starmer replaced Jon Ashworth with Liz Kendall as shadow work and pensions secretary. If, as seems increasingly likely, Labour wins the next election, it will be Kendall who will make major decisions about the future of welfare benefits. Perhaps the most important of those will be the fate of the work capability assessment. On the plus side, Kendall supported the uprating of legacy benefits such as ESA and JSA during the pandemic, which was only given to UC claimants. And when the proposal to make it harder to be found to have LCWRA was announced by the government, Kendall criticised them for failing to look after people's health in the first place due to soaring hospital waiting lists and failing social care.

But there has been no promise to reverse any of the Conservative proposals around the WCA. And in the 2015 Labour leadership election, Kendall said that the party had to support welfare benefits reforms or face being out of power for decades. She was the only leadership candidate to back the Conservative government's benefits cap.

If the Conservatives include any savings from changes to the WCA in their spending plans, it places

Labour in a difficult position. Labour says they will not implement any changes, they will consider themselves obliged to say where they will get the cash from to cover what will now be the additional cost of keeping the WCA as it is. Taking cash from another budget to cover welfare payments seems likely to be something Labour will be particularly reluctant to do. So, as things stand, hopes that an incoming Labour government will immediately begin to relieve the pressure on disabled claimants seem slim.

### Pharmacists Now Do Pip Assessments

49 pharmacists (chemists) are now employed by Capita to conduct PIP assessments, a Freedom of Information request has revealed. On the other hand, just 3 out of a total of 1,458 Capita assessors are GPs. No one could reasonably doubt that pharmacists are highly qualified professionals. undertake 5 years of training and have to be registered with the General Pharmaceutical Council. But we would question whether their training enables them to adequately assess the functional abilities of claimants with mental health conditions or severe physical illnesses or disabilities. Rather than pharmacists having skills that Capita especially needs, it seems likely that they have begun employing them simply because there is an increasing shortage of other health professionals available to conduct PIP assessments. Not all our readers agree though, with one telling us:

*Pharmacists are present on every ward round and contribute to all clinical decisions when it comes to patient care and best courses of treatment. Educate yourself before making such flippant comments.*

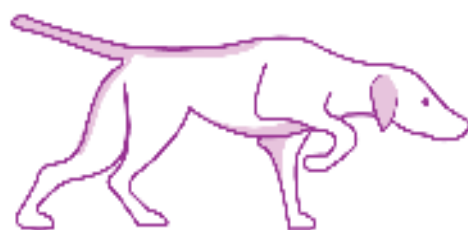
Would you be happy to have your PIP assessment conducted by a pharmacist? Use the comments section to let us know what you think.

### Pip Review Delay Claimants Missing Out On £24 Million A Month

Disabled claimants are missing out on £24 million a month because of delays to PIP reviews, a Citizens Advice report published last month has claimed. A shortage of staff, particularly health assessors, initially led to delays of six months in assessing new PIP claims. However, the backlog of new claims has now been reduced, but only by failing to process reviews in a reasonable time. This means that claimants are having to wait many months for a higher payment, because their request for a review due to a change of circumstances is yet to be looked at.

Claimants who are waiting for a planned review whose needs have increased are facing a lottery in decision making Citizens Advice claim. Sometimes the DWP backdates any higher award to the date on which the review form was returned, but in other cases it is only backdated to the date of the decision. The number of people waiting for a PIP review has hugely increased, with over 430,000 PIP claimants now in the queue. Citizens Advice estimates that 100,000 of these are likely to be missing out on higher payments. Delays also cause difficulties with issues such as Motability vehicles and Blue Badges.

**Benefits and Work**  
Guides you can trust



**SUPPORTING CLAIMANTS SINCE 2002**

**Leger ME has a group subscription to Benefits and Work. As part of the membership deal fully paid-up members can request the relevant B & W guide to assist with DWP form filling. Please contact the office for further details.**



## **Current Health News Headlines**

### **Covid-19: New “Pirola” variant BA.2.86 continues to spread in UK and US**

The new BA.2.86 variant of SARS-CoV-2—nicknamed “Pirola”—is now likely to be spreading in the community in the UK, the government has said after an outbreak was reported in a care home. The variant, which contains many mutations to the spike gene and was first detected in Denmark in late July, has been identified in several countries including Canada, Israel, Portugal, South Africa, and Sweden, as well as the UK and US. The UK Health Security Agency (UKHSA) had detected 34 cases in England to 4th September, of which five people were admitted to hospital. Notably, 28 cases were from a single outbreak in a Norfolk care home. The UKHSA has said that there is currently “not enough evidence to know if the variant has altered clinical severity or will predominate in the UK.”

In the US the Centres for Disease Control and Prevention (CDC) had reported cases of the variant in nine states as of 8 September. Despite this it has said that the current increases in covid-19 cases and hospital admissions “are not being driven by BA.2.86 and instead are being caused by other predominantly circulating viruses.” The US—which is expected to roll out its 2023-24 covid-19 vaccine from mid-September—reported an 8.7% rise in hospital admissions in the week to 2 September, while deaths increased by 10.5% over the same period. The CDC said that early analysis suggested that “existing antibodies work against the new BA.2.86 variant.”

### **Diabetes: Doctors are told not to start new patients on GLP-1 agonists because of shortages**

Clinicians in England are being advised that they cannot prescribe appetite suppressants for patients with type 2 diabetes until at least the middle of next year, because of ongoing shortages.

Until supplies return to normal, clinicians should avoid starting people with newly diagnosed type 2 diabetes on glucagon-like peptide-1 (GLP-1) receptor agonists, the Department of Health and Social Care and NHS England have said. Patients already taking any of the drugs affected may need to be switched to alternative glucose lowering therapies such as insulin if prescriptions can’t be filled, the guidance advises. The alert applies to medicines including semaglutide (marketed as Ozempic or Rybelsus), dulaglutide (Trulicity), liraglutide (Victoza or Saxenda), Lixisenatide (Lyxumia), and exenatide (Byetta or Bydureon).

Why are there shortages? Semaglutide has recently been approved for weight loss under the brand name Wegovy. However, this version of the drug has not yet been launched in the UK. A separate brand of semaglutide for use on the NHS as a treatment for managing blood glucose levels in people with type 2 diabetes, has increasingly been prescribed off label (outside of its approved license) for weight loss as an alternative to Wegovy. This has created a knock-on effect for people with type 2 diabetes are prescribed GLP-1 RAs as supply is not currently meeting demand.

The company that makes semaglutide, Novo Nordisk, has stated that supply chain issues are unlikely to be resolved until 2024. The Department for Health and Social Care (DHSC) and NHS England have issued guidance to clinicians on what to do. DHSC has advised that supply of GLP1-RAs is not expected to return to normal until at least mid-2024. Novo Nordisk has also advised that Ozempic is likely to be impacted by intermittent supply shortages running into 2025.

### **New Insomnia medicine recommended by NICE**

Daridorexant (Quviviq), due to launch this month, has been provisionally approved by the National Institute for Health and Care Excellence (NICE) for the treatment of long-term insomnia. Conventional medicines used for insomnia are only intended to be used in the short term. For people with long-term sleeping problems as with ME/CFS this is welcome news.

Daridorexant (QUVIVIQ; Idorsia) is a pill taken once per night, within 30 minutes before going to bed, which blocks the action of two types of orexins — chemicals that regulate wakefulness — to improve night-time sleep and daytime functioning. In a statement published alongside the final draft guidance on 15 September 2023, NICE said it estimated that “just over 20,000 people in England” could receive Daridorexant treatment in its first year as uptake would be dependent on receiving a diagnosis of long-term insomnia that has not resolved through improved sleep hygiene or through cognitive behavioural therapy for insomnia (CBTi) — if available and suitable — from a GP. The treatment will be offered to adults with insomnia, who have symptoms lasting for three nights or more per week for at least three months and whose daytime functioning is considerably affected.

## Food Fact Sheet: Fat facts

Fats play an important part in our daily diet. You need a small amount as part of a healthy balanced diet. Fat provides the body with energy, essential fatty acids and helps with the absorption of vitamin A, D, E and K. However, some types of fats, especially those found in processed foods, are not good for us. This Food Fact Sheet explains the different types of fat we eat, how they affect our health and how much we should be eating.



### Fats are important, as they:

- **Provide energy.** Fats provide nine calories per gram (kcal/g) and are an energy dense nutrient. Compared to carbohydrates and protein (four calories per gram), they contain more calories and energy
- **Help absorb fat-soluble vitamins.** Fat helps with the absorption of vitamins A, D, E and K, which are essential for our health.
- **Provide essential fatty acids**, which are better known as omega-3 and omega-6. These are essential for keeping our nervous system and brain healthy.

### Types of fat

There are two main groups of fat – saturated and unsaturated. Foods tend to contain a mixture of both saturated and unsaturated fats but are classed with whichever type is the highest. For example, butter is classed as a saturated fat product, as it contains more than 50% saturated fat.

#### Saturated fats

These types of fats are mainly found in animal products such as fat on meats, meat products, butter, ghee, lard, and dairy products including cheese. Products made using these types of fats and combined with cereal products such as cakes, biscuits, pastries are also classed as foods high in saturated fat. Some vegetable fats are also high in saturated fat such as cocoa butter, palm, and coconut oil.

#### Unsaturated fats

These are found generally in plant foods such as seeds, nuts, olives, and avocados. They can be either polyunsaturated such as sunflower, soya, corn, and sesame oils/spreads or monounsaturated such as olive and rapeseed oils/spreads.

#### Essential fatty acids

These are a type of polyunsaturated fat and known as omega-3 and omega-6 fats. They cannot be produced by the body, so a small amount is needed from your diet. Oily fish is the best source of omega-3 fats, such as sardines, salmon, or mackerel. If eating fish, it should be from a sustainable source. Plant sources of omega-3 include walnuts, flaxseeds, linseeds, or green leafy vegetables. Some food such as eggs or fish products may be fortified with omega-3 fats. Omega-6 fats are found in nuts, seeds, and vegetable oils/spreads, such as rapeseed, corn, or sunflower.



## Trans fats

Trans fats are found naturally present at low levels in some dairy foods and meats but are also found in processed & hardened vegetable oils. They can be found in 'partially hydrogenated vegetable fats/oil', which is often used by food manufacturers to help prolong shelf life. Products that contain trans fats include margarines, cakes, biscuits, and fast foods. However, intake in the UK is now very low, due to UK Government recommendations for food manufacturers to reduce the amount of trans fat added to food.

## Fat and health

High intake of saturated fats is associated with higher blood cholesterol levels. Reducing intake of saturated fat and replacing it with a smaller amount of unsaturated fats may help to maintain normal blood cholesterol levels. This will have a positive impact on associated health conditions, such as reducing the risk of heart disease or stroke. High intakes of fat are also associated with weight gain, which can increase the likelihood of developing problems such as type 2 diabetes, joint problems, and some cancers.

## How much fat should we be eating?

A third of our daily energy should come from fat, the majority of which should be unsaturated. This is approximately 70g fat per day for an adult female and 90g per day for an adult male. Saturated fat intake should be no more than 10% of total daily energy (20g for an adult female and 30g for an adult male). Trans fat should be no more than 2% (5g) of our daily energy. We should increase our intake of essential fatty acids, especially omega-3. The recommendation is to eat two portions of fish per week (from a sustainable source), one of which should be an oily fish. Plant-based sources, such as green leafy vegetables or walnuts contain small amounts.

## Food labels

All packaged food products must provide nutritional information on the label. This information helps us to make healthier choices. Nutrition panels on the back or side of a label will provide information per 100g and/or per portion, which means you can compare like-for-like products. Some products will provide a traffic light summary on the front of pack. Traffic lights for fat and saturated fat per 100g is shown below: A product which is 'red' should be eaten with caution and less often. We should be aiming to eat more green and amber products. There are guidelines around nutritional claims such as 'low in fat':

Level	Low	Medium	High
Fat	3g or less	3g to 17.5g	17.5g or more
Saturated Fat	1.5g or less	1.5g to 5g	5g or more

- 'Low in fat' – 3g or less per 100g
- 'Fat free' – 0.5g or less per 100g
- 'Low in saturated fat' – 1.5g or less per 100g
- 'Saturated fat free' – 0.1g per 100g

## Summary

- Fats are in much of the food we eat – either naturally or added to processed foods.
- A small amount is required as part of a healthy balanced diet.
- Fat can affect our health in many ways, and we should reduce our overall intake of fat.
- Replace saturated fats with smaller amounts of unsaturated fats, remembering to include sources of essential fatty acids (omega-3 and 6).
- Reading food labels can help you make healthier choices.

## **Medicine Safety Matters**

### **Hyoscine hydrobromide patches**

(Scopoderm 1.5mg Patch or Scopoderm TTS Patch): There is a risk of anticholinergic side effects, to which people with ME/CFS are prone. This includes hyperthermia. There have been a small number of reports of serious and life-threatening anticholinergic side effects associated with hyoscine hydrobromide patches, particularly when used outside the licence. Healthcare professionals, patients, parents and carers should be aware of the signs and symptoms of serious side effects and the need to seek medical help if they occur.

The same medicine can be purchased over the counter in some tablet based products for travel sickness. SO always read the instructions..

### **Codeine linctus:**

There is a public consultation on the proposal to reclassify to a prescription-only medicine. This is due to the possibility of opiate addiction.

### **Non-steroidal anti-inflammatory drugs (NSAIDs) in pregnancy:**

There are potential risks following prolonged use after 20 weeks of pregnancy. We want to remind healthcare professionals that use of systemic (oral and injectable) NSAIDs such as ibuprofen, naproxen, and diclofenac is contraindicated in the last trimester of pregnancy (after 28 weeks of pregnancy). A review of data from a 2022 study has identified that prolonged use of NSAIDs from week 20 of pregnancy onwards may be associated with an increased risk of oligohydramnios (low levels of amniotic fluid surrounding the baby) and damage to the babies' kidneys. Some cases of constriction of the ductus arteriosus (narrowing of a connecting blood vessel in the baby's heart) have also been identified at this early stage.

If, following consultation between the patient and a healthcare professional, use of a systemic NSAID after week 20 of pregnancy is considered necessary, it should be prescribed for the lowest dose for the shortest time and additional neonatal monitoring considered if used for longer than several days. This is in addition to giving advice to discontinue use of any NSAID in the last trimester of pregnancy.

NSAIDs are good for dealing with pain and inflammation, but in the long term can cause kidney damage in adults. Anyone taking a NSAID type of medicine regularly should have their kidney function checked by their doctor. Several Leger ME members have experienced kidney damage which from the NSAID Ibuprofen and Voltarol, which fortunately returned to normal when the medicines were stopped. With these medicines there is also a risk to stomach ulceration. Generally, when prescribed, a doctor will prescribe additional medicines to protect the stomach wall. This warning applies to products like Voltarol gel which pass through the skin.

### **GLP1 Medicines Suicidal thoughts.**

Reports of suicidal and self-harming thoughts in patients taking GLP-1 agonists are being reviewed by the MHRA. They have received five Yellow Card reports of suspected adverse drug reactions associated with 'suicidal and self-injurious behaviour' involving semaglutide and 12 involving liraglutide. It is not clear whether the reported cases are linked to the GLP-1 agonists themselves or to the patients' underlying conditions or other factors. Liraglutide is marketed as Victoza for the treatment of type II diabetes and as Saxenda for weight management in people with obesity, or with overweight and related morbidity. Semaglutide is available in injectable form (Ozempic) and as tablets (Rybelsus) for type II diabetes. It is also approved as Wegovy for weight loss in people with obesity or overweight, but has not yet been launched in the UK for this indication. The MHRA said the GLP-1 agonists exenatide (Byetta/Bydureon), lixisenatide (Lyxumia) and dulaglutide (Trulicity), all used to treat type II diabetes, are also included in the review. Currently the supply of these types of medicines are in short supply. Much of this is because of unexpected demand due to suspected illegal use. All are prescription only medicines.



# Food Fact Sheet: Myalgic Encephalomyelitis (or Encephalopathy) / Chronic Fatigue Syndrome (ME/CFS)

*This is the latest version of the BDA factsheet. Where our members experience differs from the basic guidance, I have commented in italics.*

Myalgic Encephalomyelitis (or Encephalopathy) / Chronic Fatigue Syndrome (ME/CFS), is a complex, chronic medical condition affecting multiple body systems. It varies between individuals and can fluctuate over time. Although some people recover or have a long period of remission, many will need to adapt to living with ME/CFS.

The impact of symptoms on everyday functioning varies widely in severity. People with mild ME/CFS may be able to do some light domestic tasks such as cooking (sometimes needing support), whereas people with moderate or severe ME/CFS may be more restricted in their activities. People with very severe ME/CFS may need help with eating, have difficulties chewing and swallowing, and/or require tube feeding.

## What are the symptoms of ME/CFS?

Symptoms, lasting three months or more, include:

- debilitating fatigue and post-exertional malaise (worsening of symptoms that can follow minimal cognitive, physical, emotional, or social activity, or activity that could previously be tolerated)
- unrefreshing sleep.
- cognitive difficulties (difficulty remembering, concentrating, or thinking)

People may also experience:

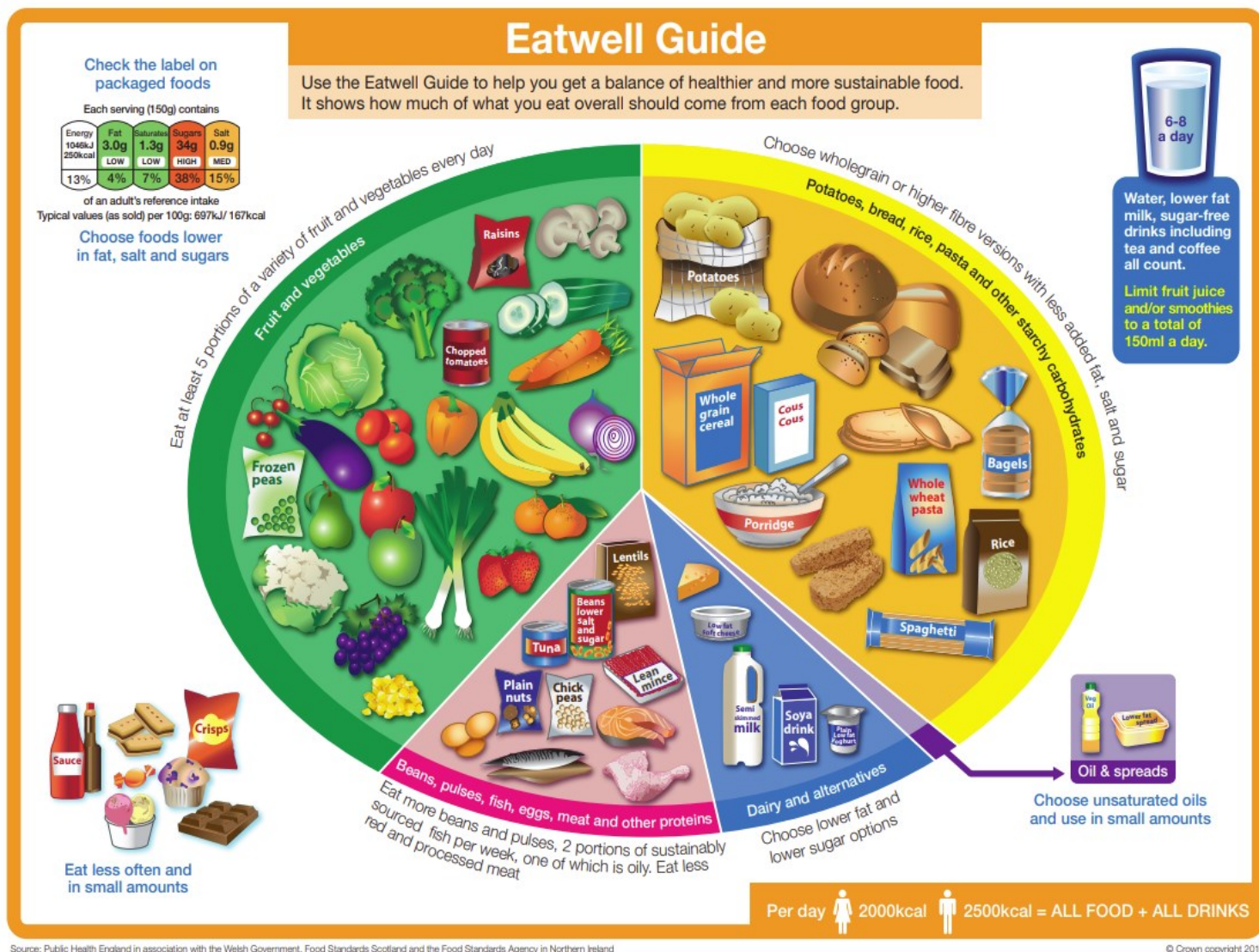
- orthostatic intolerance (symptoms on standing up)
- temperature hypersensitivity
- neuromuscular symptoms (e.g., twitching and jerks)
- flu-like symptoms
- intolerances to alcohol or certain foods
- heightened sensory sensitivities (including taste and smell) pain.

## Can diet help with ME/CFS?

Your diet should be assessed by your healthcare professional when you are diagnosed. They will determine if you would benefit from a referral to a dietitian.

If you suspect or have a diagnosis of ME/CFS, it is important to maintain a healthy, balanced diet with adequate fluid intake. This will aid energy management and help manage your symptoms.

The NHS Eatwell Guide shows how much of what we eat overall should come from each food group to achieve this. You do not need to achieve this balance with every meal but try to get the balance right over a day or even a week.



### The basics of the Eatwell guide.

- Base your meals on potatoes, bread, rice, pasta, or other starchy carbohydrates, as they are a good source of energy.
- Aim to choose 'lower GI' carbohydrates that release energy more slowly (e.g., wholegrain bread, porridge) to help keep your blood glucose levels steady.
- Beans, pulses, fish, eggs, and meat are good sources of protein, vitamins, and minerals.
- Aim for at least two portions of fish every week, one of which should be oily, such as salmon or mackerel.
- Milk, cheese, and yoghurt are a source of protein and some vitamins. They're also an important source of calcium, which helps keep bones healthy.
- If choosing dairy alternatives, ensure you select versions that are fortified with calcium. Aim for at least five portions of a variety of fruit and vegetables each day for vitamins, minerals, and fibre – fresh, frozen, tinned and dried all count.
- Choose unsaturated oils and spread in small amounts.
- Drink plenty of fluids – water, milk, and sugar-free drinks all count. Fruit juice and smoothies also count, but limit these to 150ml per day.
- Some people with ME/CFS find that they are more sensitive to caffeine, so you may find it helpful to reduce tea and coffee, or switch to decaffeinated.
- If caffeine affects your sleep, avoid caffeinated drinks in the late afternoon and evening.

You may find it helpful to plan your meals in advance, and to batch-cook and freeze meals in individual portions for days when you are lower in energy.



There is a lot of conflicting information about ME/CFS and diet online. There is no scientific evidence to support the use of restrictive diets in ME/CFS, which can use up time, energy, and money, as well as leaving you vulnerable to nutritional deficiencies. Such diets include the ketogenic (e.g. Atkins) and anti-candida diets.

*Our experience is that the above advice is not strictly accurate. For example a ketogenic diet would help people with mitochondrial abnormalities, and an anti candida diet would help people with gut fermentation. However, these conditions can be tested for. Also, if you have coeliac and on a gluten free diet, diabetic, have allergies or have another health problems where dietary modifications are needed this will override any advice in this feature.*

## Weight loss

This can occur if you are restricting your diet, have a reduced appetite (for example due to taste changes or nausea), or are having difficulty swallowing and chewing. If you become malnourished, this could make you more vulnerable to illness. It may help to eat little and often, choose softer foods that are easier to eat, and have nourishing snacks and drinks between meals. For ideas, see the BDA Food Fact Sheet on malnutrition.

## Weight gain

On the other hand, you may find that you gain weight because you are less physically active or have an increased appetite. If this is the case, try to reduce sweet or fatty snacks and drinks and consider your portion sizes. Think about ways you can make healthier foods, such as fruit and vegetables, more easily accessible to you. For ideas, see the BDA Food Fact Sheet on weight loss, but bear in mind that weight loss may be slower and more gradual in ME/CFS.

## Gastrointestinal symptoms

Many people with ME/CFS report IBS-like symptoms, including constipation, diarrhoea and/or bloating. You will find helpful dietary advice in the BDA Food Fact Sheet on IBS, for example advice on reducing caffeine, fizzy drinks, and rich/fatty food.

If your IBS symptoms persist after following the advice in the leaflet, talk to your GP. You may benefit from referral to a dietitian, who can assess your suitability for the low FODMAP diet. This is a short-term, three stage food elimination and reintroduction process. As it is a complex and restrictive diet, you will require the support of a trained dietitian. Your GP may also be able to discuss pharmaceutical options to relieve your symptoms and advise you on psychological therapies if your symptoms are triggered by stress or anxiety.

## Nausea

If you are experiencing nausea, make sure you keep up adequate fluid intake and eat regularly, having small amounts often. Not eating or drinking may increase your nausea.

## Food intolerances

Some people with ME/CFS report sensitivities to different foods, however it is not clear why this is the case. Reactions are more likely to be intolerances rather than allergies, which means that they do not involve the immune system. You may find that you can continue to have small amounts of the food without triggering a reaction.

*I understand from my colleagues that with ME/CFS intolerance and allergies can change over time. This is possibly due to an abnormal immune response due to the ME/CFS disease process itself.*

Discuss suspected intolerances with your GP. Avoid commercially available tests that claim to diagnose food hypersensitivity, as these have no scientific basis. Overly restricting your diet may make you vulnerable to malnutrition and worsen your ME/CFS symptoms.

## Are there supplements I can take?

There is not enough evidence to support taking regular specific vitamin and mineral supplements to cure or manage ME/CFS. You may be at risk of side effects if you take doses above the recommended daily amount.

However, people with ME/CFS may be at risk of vitamin D deficiency, particularly those who are bedbound or do not go outside. It is recommended to take a daily supplement containing 10½µg (micrograms) or 400IU (international units) vitamin D.

*It is our experience that most people with ME/CFS are depleted in vitamin D when blood tests are carried out. Low levels of this vitamin can increase pain and fatigue in ME/CFS, which is corrected by supplementation.*

*The specialist doctors recommend a dose of 800-1000 units a day. Low vitamin D levels are a common in other neurological diseases, and may be somehow a contributing factors in the development of these diseases.*

Most people should get all the nutrients they need through a balanced and varied diet, however if you are concerned, you could take a daily multivitamin containing no more than 100% of recommended daily intake.

*According to Sarah Myhill, main nutritional deficiencies seen in ME/CFS are magnesium, Zinc, the B vitamin group and vitamin D. Most Leger ME members find that an A-Z multivitamin supplement makes a difference. There is no point in taking separate vitamin products when they can be covered by a single multivitamin supplement. We call this vitamin insurance.*

## Seeing a dietitian

Your GP should refer you to a dietitian with a special interest in ME/CFS if you are:

- Losing or gaining weight unintentionally
- Following a restrictive diet
- Living with severe or very severe ME/CFS
- Children and young people with ME/CFS who are losing weight, have faltering growth or dietary restrictions should be referred by the GP to a paediatric dietitian with a special interest in ME/CFS.

## Top tips

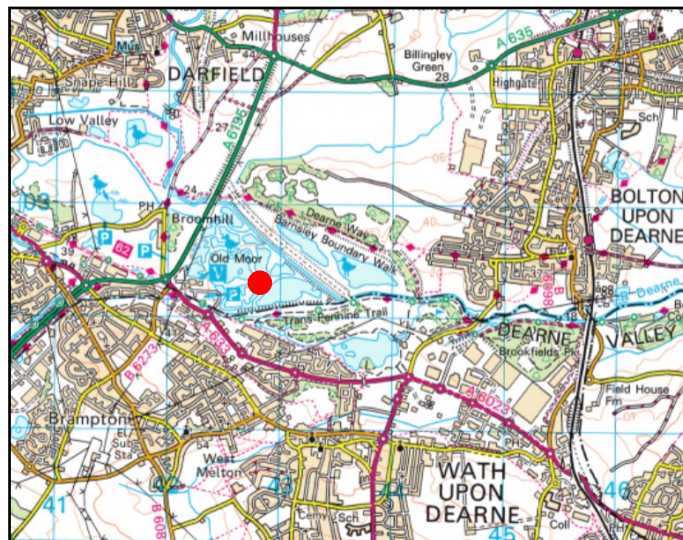
- ME/CFS affects multiple body systems, affects people differently and can fluctuate over time.
- Maintaining a healthy diet and adequate fluid intake can aid energy management and help manage your symptoms
- Choose 'lower GI' carbohydrates that release energy more slowly.
- Batch cook and freeze meals in individual portions for days when you have less energy for cooking.
- There is no scientific evidence to support the use of restrictive diets like the ketogenic diet *unless you have other health problems which demand such a diet.*
- If you are losing weight, try to eat little and often.
- If you are gaining weight, consider how to make healthier foods more accessible to you.
- You may benefit from dietary advice to manage gastrointestinal symptoms.
- Discuss suspected food intolerances with your GP before unnecessarily restricting your diet .
- Take a daily vitamin D supplement.



## ***Out and About Around Doncaster: The local RSPB Nature Reserve 'Old Moor'***

It was the Friday afternoon on the Bank Holiday weekend when Mike suddenly said 'shall we have a ride out this weekend' and followed it up with 'where shall we go'? There was silence from me, I was thinking ..... Brodsworth Hall, too near, The Old Mill for a meal, likely too busy, A walk by the canal at Thorne, done that not long ago. Then I remembered it – Old Moor, somewhere we had often passed but never been to. We decided we would go on the Sunday.

There are a few routes from home to Old Moor but having been asked if I would be driving, we would be going the country route!



*The location of the RSPB at Old Moor  
with thanks to Ordnance survey*



*The Old Moor site from the Air. The visitor centre is based around the old farm buildings*

We arrived to find an excellent car park complete with disabled bays. Parking up close to the reserve entrance the charge for this, no charge, it's free!

We paid £5 each entrance fee and walked into the courtyard where we found a spotlessly clean toilet block, a very tempting gift shop and a lift which will take a wheelchair straight up to the reasonably priced Café which is pleasant and airy with a Veranda that opens out to look over the treetops of the reserve, you can sit inside or out depending on the weather.

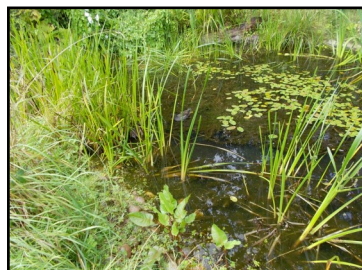
Having enjoyed a light lunch, we ventured out to walk the 336 metres to the 'Bittern Hide'. No bittern to be seen or heard booming (as they do!), but lots of other birds and the Mere itself was a delight with nests on small islands and sandy areas full of birds, we saw Swans, Coots, Waders. On the way back down the pathway we enjoyed seeing all the wild plants, Mike was particularly interested in the Wild Carrot flowerheads, and I enjoyed coming across a patch of 'honesty' in amongst the colours of the wild flowers and grasses.



*Wild carrot flowers and its seed heads. One strange feature about the flower cluster is a single red or orange flower in the centre of the cluster.*



*Examples of the many ponds at Old Moor.*



We walked back past a large pond with brown fishes coming to surface for insects but we couldn't name them; then as we walked on a real treat, spotted a Red Dragonfly in flight, such a beautiful creature. We entered another Hide and watched the Blue Tits feeding. I was struck by how different and free they looked as they darted back and forth over the long grasses and in and out of the trees, no need to be watchful and wary as they can be when feeding in our enclosed garden.

By the way if any of you think of going but are worried about the walking around the reserve, there are benches all along the routes on which to sit and take a breather.



*Red Dragonfly*



Back at the courtyard it was time for an ice-cream, and another look around the shop where I chose a few cards to bring home.

This day out had been a real change, a breath of fresh air, hopefully we will do it all again sometime in the future.

**Disability issues:** If you need to use a wheelchair or scooter, the paths are flat and wide enough, but we recommend that you take along someone to help because some ramps are rather steep. The shop and toilets are disabled friendly. There is a lift big enough to take a wheelchair to the café above of the shop. You will also need to take binoculars or a telescope, or some other optical aid to enjoy the birds. The site shop has a good selection of optical aids which you can purchase.



*All around the site there are hides. These are basically garden sheds with benches and openings to see the birds. There are special observation points to accommodate wheelchairs users. On the back wall of the hides are identification charts to help identify what you are seeing.*

### Things you might see at Old Moor



## Old Moor

### The Discovery Zone

Step straight into nature in our Discovery Zone, taking in our wildlife gardens, adventure playground, family hide and heritage games trail.

Take a break at one of the picnic benches and listen to the lazy hum of insects in the summer. There are four pond dipping points where little explorers can investigate the wonders of water life. Perfect for all young and young at heart, wildlife lovers.

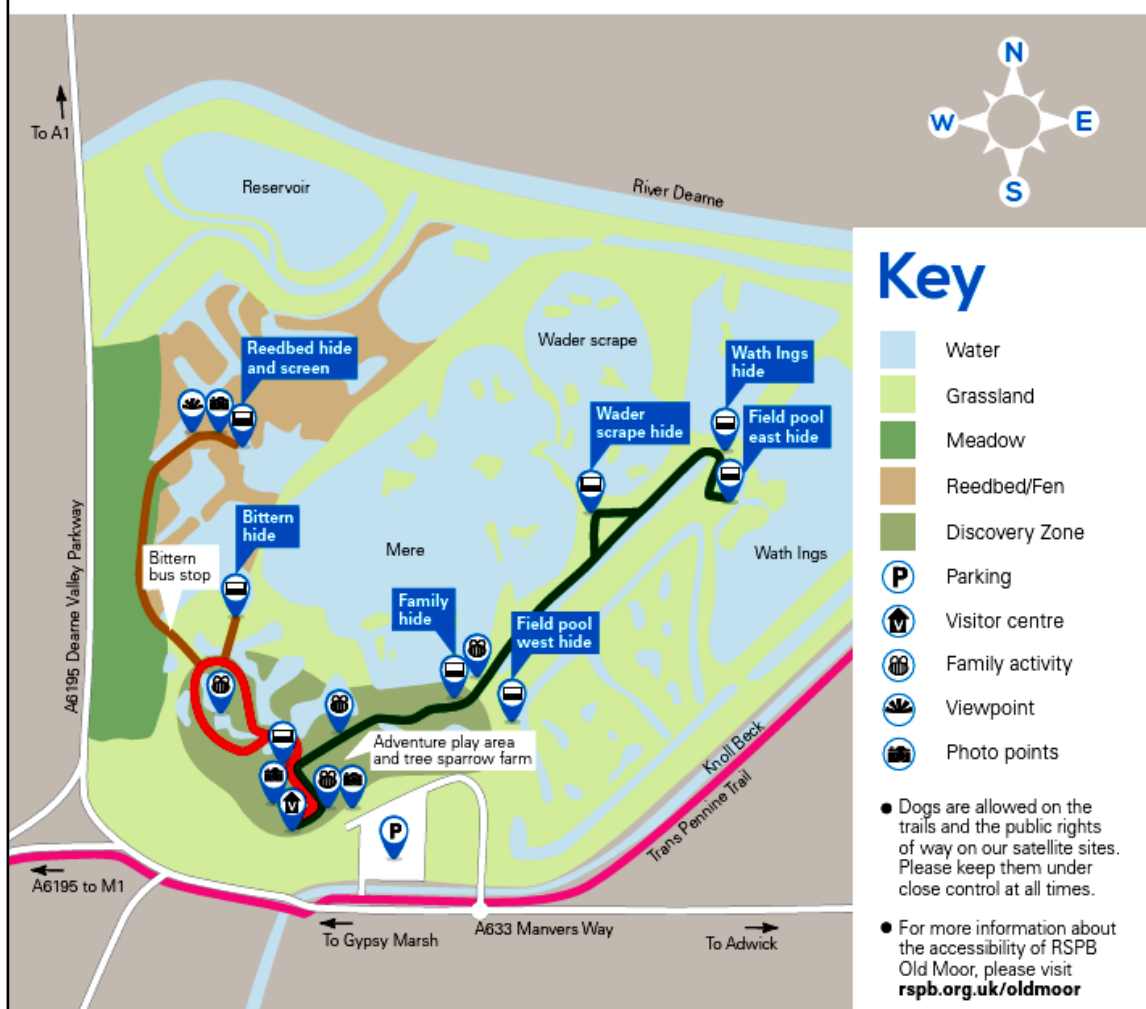
### Green Lane trail

To walk to the end of this trail takes about 15 minutes if you don't stop off at any of the hides. You return along the same route. It offers brilliant views of wildlife for everyone to enjoy. Watch the ducks, geese and gulls on the Mere. Wath Ings hide is the perfect place to see thousands of wading birds swirling across the sky.

### Reedbed trail

This trail takes about 15 minutes to walk without any stops.

It takes you through the reedbeds, which are home to one of our most secretive birds, the bittern. Enjoy panoramic views of the valley from the Bittern Bus Stop and try to get close up views of kingfishers from the Reedbed Screen.



## Demystifying Occupational Therapists: What do they do?

*While everyone knows what a doctor, pharmacist or nurse does, what the Occupational Therapists do is a bit more of a mystery. Most commonly someone with ME/CFS will only come into contact in the early days after diagnosis at a special clinic or may be assessed by an OT for welfare benefits. I recently attended a session presented by Jo Boker, an OT at the Local RDASH Hospital Trust designed to educate health professionals about the world of the OT.*

Occupational therapy is a healthcare profession that involves the use of assessment and intervention to develop, recover, or maintain the meaningful activities, or occupations, of individuals, groups, or communities. The field of OT consists of health care practitioners trained and educated to improve mental and physical performance. Occupational therapists specialise in teaching, educating, and supporting participation in any activity that occupies an individual's time. It is an independent health profession sometimes categorized as an allied health profession and consists of occupational therapists (OTs) and occupational therapy assistants (OTAs). While OTs and OTAs have different roles, they both work with people who want to improve their mental and or physical health, disabilities, injuries, or impairments. An OT is defined as:

*Someone who helps people across their lifespan participate in the things they want and/or need to do through the therapeutic use of everyday activities.*

Typically, occupational therapists are university-educated professionals and must pass a licensing exam to practice. Individuals must pass a national board certification and apply for a state license in most states. Occupational therapists often work closely with professionals in physical therapy, speech–language pathology, audiology, nursing, nutrition, social work, psychology, medicine, and assistive technology.

### What is Occupational Therapy?

OT has evolved from biological, medical, and social sciences. There are six key Schools of thought used by OT's-

- 1) **Physiological** (genetic and electrochemical functions)
- 2) **Psychoanalytical** (unconscious memories)
- 3) **Behavioural** (environmental demands)
- 4) **Cognitive** (thoughts and perceptions)
- 5) **Developmental** (time and change)
- 6) **Humanist** (personal choice)

### The Humanist Approach

The humanist approach is person centered. It demands that the individual should be valued and respected. The individual has the potential to control their own life. This approach assumes that change will only if the patient wants it to happen, and any change has to be meaningful to the individual. For people with ME/CFS this applies to Adaptive Pacing.

### The Neurodevelopmental Approach

The Neurodevelopmental Approach is typically used in learning disabilities and stroke re-education. The approach using sensory Integration was developed by Jean Ayres, an OT in 1972. It is based on multisensory processing of environmental information/stimuli. It takes into account people ability to move around (Ambulant) and the terrain. Important factors for assessment are observation and

#### Common health interventions used by Occupational Therapists.

- Helping children with disabilities to participate in school and social situations (independent mobility is often a central concern)
- Training in assistive device technology, meaningful and purposeful activities, and life skills.
- Physical injury rehabilitation
- Mental dysfunction rehabilitation
- Support of individuals across the age spectrum experiencing physical and cognitive changes
- Assessing ergonomics and assistive seating options to maximize independent function, while alleviating the risk of pressure injury
- Education in the disease and rehabilitation process
- Advocating for patient health
- Finding vocational activities



balance. In older people there are problems with sensory loss and this include problems with vision, hearing, ability to touch and feel, (tactility, and proprioception, the perception or awareness of the position and movement of the body: For the neurodevelopmental Approach to be successful the OT has to take into account that an individual has sensory loss and adapting their environment their environment may be compensatory. For people with ME/CFS issues like parasthesia, balance, visual disturbances and fatigue are typical. Many alter their daily routines subconsciously to compensate for their sensory issues. Examples of strategies used this treat this approach include improved or modified lighting, removing trip hazards, providing mobility equipment, decreasing background noise and provide opportunities for patients to engage with appropriate sensory stimuli.

## The Cognitive Approach

Allen Cognitive Levels and Modes of Performance and Level of Care the Allen Cognitive Scale of Levels and Modes of Performance (Allen Cognitive Scale) associated with the Cognitive Disabilities Model (CDM) is used by practitioners to guide interventions with persons who have or are suspected of having cognitive disabilities that impact safe performance of everyday activities. Evaluation and intervention in the CDM focus on creating a fit among a person's assets/strengths, including the person's functional cognitive capacity described by the Allen Cognitive Scale ("ACL") and other relevant person and contextual factors to optimize safe, satisfying, and successful performance of a person's valued self-care, work, leisure, and social activities. Practitioners use the Allen Cognitive Scale to identify the cognitive complexity of valued activities the person needs and wants to do to determine whether activities are likely to be done safely. When activities do not fit a person's available functional cognitive capacity, practitioners recommend modifications which may include assistance from caregivers, to ensure safety and success. Typical levels of care required to ensure safety in common everyday activities at each level/mode of performance on the Allen Cognitive Scale.

### Allen's cognitive levels

- Level 1: total care
- Level 2: total care, may do very basic adls such as self feed or ambulate
- Level 3: 24 hr. care on site, uses familiar objects, needs help and cues, poor safety
- Level 4: daily on site supervision, learns with repetition
- Level 5: needs daily/weekly supervision
- Level 6: lives independently

*An example of Allens cognitive levels for use within a Care environment. These carry echos of many DWP forms.*

## The Pool activity Level

The Pool Activity Level is easy to administrate. It checks a list of nine everyday activities that people would do routinely. There are four possible answers that indicate level of ability. Whichever scores the highest {frequency} is the level the individual is assessed at. The sections are: -

- Planned,
- Exploratory,
- Sensory
- Reflex.

The net results are a Handy guide generated to give advice about how best to support the individual.

### The Pool Activity Level (PAL) Checklist (Pool, 2008)

- |                           |  |
|---------------------------|--|
| 1 Bathing / washing       | 7 Practical activities<br>(craft, domestic<br>chores, gardening) |
| 2 Getting dressed         |  |
| 3 Eating                  | 8 Use of objects   |
| 4 Contact with others     | 9 Looking at a<br>newspaper /<br>magazine                        |
| 5 Groupwork skills        |  |
| 6 Communication<br>skills |  |



## The Teepa Snow Positive Approach to Care

This approach is about a *Doing 'with', not 'to'* approach. It focuses on what the individual can do rather than what they can't do. If we focus exclusively on the loss of skills, we miss a huge opportunity to provide meaningful moments of engagement, happiness and connection. The Teepa Snow Positive approach to Care works with 'GEM' states. Here is a summary of how the scheme works.

Gems	Basic Characteristics	Interests
<b>Sapphire</b> 	<ul style="list-style-type: none"> <li>Normal Aging</li> <li>May feel blue due to the changes of aging</li> <li>No significant changes in cognition</li> <li>Difficulty learning new things</li> </ul>	<ul style="list-style-type: none"> <li>They like to choose</li> <li>May need help or modifications to enjoy interests</li> <li>Leaving a legacy, fulfilling promises, or making a difference</li> </ul>
<b>Diamond</b> 	<ul style="list-style-type: none"> <li>Can do OLD habits and routines</li> <li>Becomes more territorial OR less aware of boundaries</li> <li>Likes the familiar and has difficulty with change</li> <li>Tells the same stories, asks the same questions</li> </ul>	<ul style="list-style-type: none"> <li>Things that make them feel competent and valued</li> <li>What they enjoy and who they like</li> <li>Where they feel comfortable but stimulated</li> <li>What gives them a sense of control</li> </ul>
<b>Emerald</b> 	<ul style="list-style-type: none"> <li>Gets lost in past life, past places, past roles</li> <li>Gets emotional quickly</li> <li>Loses important things and thinks someone stole them</li> <li>Needs help, DOES NOT know it or like it</li> </ul>	<ul style="list-style-type: none"> <li>Doing familiar tasks</li> <li>Engaging with or helping others</li> <li>Having a job or a purpose</li> <li>Does better with a friend than a boss</li> </ul>
<b>Amber</b> 	<ul style="list-style-type: none"> <li>Need to have sensation (touch, look, feel, smell, or taste)</li> <li>Private and quiet or public and noisy</li> <li>Will get into things</li> <li>Can't wait or put up with things that take time</li> </ul>	<ul style="list-style-type: none"> <li>Things to mess with or explore</li> <li>Textures, shapes, colors, movement</li> <li>Verbal sounds that are familiar (music)</li> <li>Tastes—usually more sweet or salty</li> </ul>
<b>Ruby</b> 	<ul style="list-style-type: none"> <li>Fine motor skill is lost or stops in the mouth, eyes, fingers, and feet</li> <li>Hard to stop and hard to get going</li> <li>Limited visual awareness</li> <li>One direction – forward only, can't back up safely</li> </ul>	<ul style="list-style-type: none"> <li>Walking a routine path</li> <li>Watching others, checking them out</li> <li>Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap</li> <li>Rhythmic movements and actions</li> </ul>
<b>Pearl</b> 	<ul style="list-style-type: none"> <li>Not aware of the world around them (most of the time)</li> <li>Hardly moves</li> <li>Problems swallowing</li> <li>Hard to get connected</li> </ul>	<ul style="list-style-type: none"> <li>Pleasant and familiar sounds and voices</li> <li>Warmth and comfort</li> <li>Soft textures</li> <li>Smooth and slow movement</li> </ul>

You will possibly notice that none of the methods takes into account the assessment of Fatigue and variability. This may explain why many OT's working for the DWP do not understand the peculiarities of ME/CFS and Fibromyalgia when assessments are carried out..

## Recipe Corner

### Spaghetti Bolognese

This is a complex dish, with a preparation time of half an hour and cooking time of about two hours.

#### Cooking Method

- 1) Put a large saucepan on a medium heat and add 1/2 tablespoonful vegetable oil. Add 4 finely chopped bacon rashers and fry for 10 mins until golden and crisp.
- 2) Reduce the heat and add the onions, carrots, celery sticks, garlic cloves and a leaf from the leaves from sprigs rosemary, all finely chopped, then fry for 10 mins. Stir the veg often until it softens.
- 3) Increase the heat to medium-high, add 500g beef mince and cook stirring for 3-4 mins until the meat is browned all over.
- 4) Add the plum tomatoes, the finely chopped leaves from small pack basil, 1/2 teaspoonful dried oregano, bay leaf, tablespoonful tomato purée, 1 beef stock cube, 1 deseeded and finely chopped red chilli (if using), 125ml red wine and 3 halved cherry tomatoes. Stir with a wooden spoon, breaking up the plum tomatoes.
- 5) Bring to the boil, reduce to a gentle simmer and cover with a lid. Cook for 1 hr 15 mins stirring occasionally, until you have a rich, thick sauce.
- 6) Add the 75g grated parmesan, check the seasoning and stir. When the Bolognese is nearly finished, cook 400g spaghetti following the pack instructions.
- 7) Drain the spaghetti and either stir into the Bolognese sauce, or serve the sauce on top. Serve with more grated parmesan, the remaining basil leaves and crusty bread, if you like.

### Garlic chicken

Preparation time: 10 mins, cooking time 30 mins

#### Cooking Method

- 1) Tip the chicken into a shallow bowl and sprinkle over the flour. Season well. Heat the oil in a large frying pan over a medium-high heat and fry the chicken, shaking off any excess flour first, for 1-2 mins until lightly golden all over. (You may need to do this in batches.)
- 2) Reduce the heat to medium and add the butter. Peel as many garlic cloves as you prefer, and drop these into the pan. Cook for 5 mins until the garlic has turned lightly golden, stirring to keep the chicken from burning.
- 3) Pour in the stock and simmer for 10 mins until the garlic is tender. Add the cream and cheese and simmer for a further 5 mins until the sauce thickens slightly. Taste for seasoning and adjust as needed. Scatter with the chopped parsley, if using, and serve hot with rice and green beans, if you like..



#### Ingredients

1 tablespoonful Vegetable oil  
 2 slices bacon, finely chopped  
 1 medium onions, finely chopped  
 1 carrots, trimmed and finely chopped  
 1 celery stick, finely chopped  
 1 garlic cloves finely chopped  
 1 sprigs rosemary leaves picked and finely chopped  
 250g beef mince

#### For the Bolognese sauce

400g tin plum tomatoes  
 small pack basil leaves picked, finely chopped and the rest left whole for garnish  
 1/2 teaspoonful dried oregano  
 1 fresh bay leaf  
 1 tablespoonful tomato purée  
 1/2 beef stock cube  
 11/2 red chilli deseeded and finely chopped (optional)  
 4 oz red wine  
 3 cherry tomatoes sliced in half

#### To season and serve

30g g parmesan grated, plus extra to serve  
 200g spaghetti



#### Ingredients

2 medium chicken breasts, skin removed, sliced crosswise into thick strips  
 40g plain flour  
 1 tablespoonful olive or rapeseed oil  
 25g unsalted butter  
 10-15 small garlic cloves, or to taste  
 100ml hot chicken stock  
 50ml double cream  
 15g Parmigiano-Reggiano, finely grated  
 small bunch of flat-leaf parsley, finely chopped (optional)  
 cooked rice and steamed green beans, to serve (optional)



## ***To Jab or Not to Jab? Seasonal Flu and COVID-19 Vaccinations***

Vaccination is an essential part of protecting people over the colder months. The approach being taken to timing and coadministration maximises clinical protection, and therefore the resilience of health and care services, over the later winter months when flu and COVID-19 are most likely to be prevalent.

The groups to be offered a COVID-19 booster vaccine are:

- Residents in a care home for older adults
- All adults aged 65 years and over
- Persons aged 6 months to 64 years in a clinical risk group, as laid out in the Green Book, COVID-19 Chapter (Green Book)
- Frontline health and social care workers
- Persons aged 12 to 64 years who are household contacts (as defined in the Green Book) of people with immunosuppression
- Persons aged 16 to 64 years who are carers (as defined in the Green Book) and staff working in care homes for older adults.

### **Advise from the ME Association: Covid Autumn Booster Vaccine Information (2023)**

Even though Covid-19 hasn't gone away, many people have been slowly returning to normal or near normal life. However, while official statistics indicate that levels of Covid infection are still fairly low this reflects the fact that very little testing is being carried out. There are new variants of the virus appearing, hospital admissions are steadily rising, and other indicators of Covid in the community confirm the rising numbers. So, as we have been pointing out on ME Association social media, people do need to start taking sensible precautions to reduce the risk of catching Covid and should seriously consider having a Covid Autumn Booster.

#### **New Covid Variant**

A new Covid variant is spreading in England and is behind an outbreak at a care home in Norfolk, health officials say. There have been 34 confirmed cases of BA.2.86, with 28 of those at the care home. There have been no deaths. It is too early to draw conclusions on whether it is more serious than past variants, the UK Health Security Agency (UKHSA) said.

Anyone with ME/CFS who wants to have an Autumn Covid Booster and is aged under 65 will have met one of the above eligibility criteria in order to do so. In most cases you will need to be considered in a 'clinical risk group' as defined by the Covid Chapter of the UK Health Security Agency (UKHSA) Green Book (updated 04 September 2023). Table 3 (page 23) and Table 4 (page 25) refer to people with a 'chronic neurological disease' being eligible (adults and young people).

While it doesn't specifically mention ME/CFS, it does include Multiple Sclerosis and states that the list of examples is 'not exhaustive' and can include 'related or similar conditions.' As ME/CFS is classified as a neurological disease by the World Health Organisation (which is accepted by the NHS) and can cause a similar level of disability to Multiple Sclerosis it should therefore qualify. In addition, the statement on page 19 says:

*"The examples in tables 3 and 4 are not exhaustive, and, within these broad groups, the prescriber may need to apply clinical judgment to take into account the risk of COVID-19 exacerbating any underlying disease that a patient may have, as well as the risk of serious illness from COVID-19 itself."*

As there is good evidence of a Covid-19 infection causing an exacerbation or relapse of ME/CFS, we believe that people with ME/CFS should be able to have an Autumn Booster if they want to have one, especially if they are severely or very severely affected and potentially at greater risk. We have produced a Template letter that you can use when speaking with a GP if you aren't called for a Booster vaccine automatically and decide to try and get one.



## Should I have a Covid Booster?

Before deciding if you want a Covid Booster it's important to take note of the pros and cons of having this vaccine:

### For

On the positive side, it is likely to produce a significant degree of protection against catching Covid-19 over the coming 6 to 12 months (if you have had all the Covid vaccines). We know that people with ME/CFS who catch Covid are (as with any other infection) at increased risk of having an exacerbation or relapse of their ME/CFS especially if they are severely or very severely affected.

### Against

On the other hand, we know that a small but significant number of people with ME/CFS have experienced an adverse reaction to a Covid vaccine – sometimes severe and persistent. In this situation deciding to go ahead and have another vaccination is a difficult decision to make.

*“On a personal basis I have had 4 Covid vaccinations without any problems. I had the Pfizer Autumn Booster last year which was followed by a fairly severe adverse reaction – a red swollen leg that was probably the result of a vasculitis.*

*“Having had 4 vaccinations without any problem I am probably going to go ahead and have an autumn booster but not with the Pfizer vaccine. However, other Trustees and staff members with ME/CFS have had different experiences with the Covid vaccines and Boosters and may not make the same decision as me.*

*“It became quickly apparent from the large number of reported experiences that we received last year, and which we continue to receive, that people’s reactions or non-reactions are very mixed, and that no clear determination or recommendation can be made in regard to ME/CFS. Therefore, it is very much a personal decision.”*

### Dr Charles Shepherd reports.

Another option, which is currently being considered by the DHSC, is to allow people who are not in an eligible group to purchase a Covid Booster – probably from a pharmacy – like you would if you wanted to pay for a Flu vaccine. But no firm decision on this proposal has yet been announced.

Whatever decision you make it's also important to also keep to all the usual ways of reducing the risk of catching Covid by:

- Handwashing frequently.
- Avoiding contact with people who have infective symptoms.
- Avoiding crowded or badly ventilated indoor spaces.
- Wearing a mask in places where you are in close contact with other people.

### Weather you have a Covid vaccination or not is your personal choice.

I find most people tend to get some reaction usual mild—but that proves it is working. The time to worry is when you don't get a reaction. If you have a vaccination try to take things steady on the day before and give yourself several easy days after.

Due to the nature of the vaccine, it has a very short time where it protects, and this protection rapidly fades. There is there for a need to update protection. Also, the variants will change frequently, so it is essential that any vaccination protects against the latest strains. These comments also apply to flu vaccinations.

## ***North of Doncaster – Goes West***

*Personal thoughts from Trevor Wainwright*

### **My Visit to Austin, the State Capitol of Texas.**

In the last issue I wrote that Congress Avenue started at The State Capitol Grounds the building located on a hilltop overlooking downtown Austin, housing the offices and chambers of the Texas Legislature and of the Governor of Texas. Designed in 1881 by architect Elijah E. Myers, it was constructed from 1882 to 1888 under the direction of civil engineer Reuben Lindsay Walker. It was opened to the public in 1888 before its completion.

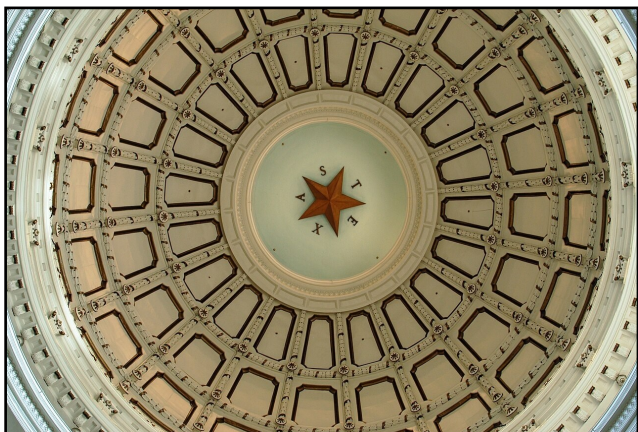


*The Texas State Capitol at sunset.*

The Texas State Capitol is 302.64 feet (92.24 m) tall, making it the sixth-tallest state capitol and one of several taller than the White House in Washington D.C. It is the third building to serve that purpose. The first was a two roomed wooden structure that had served as the national capital of the Texas Republic and continued as the seat of government upon Texas' admission to the Union. The second Texas capitol was built in 1853, on the same site as the present capitol in Austin; it was destroyed by fire in 1881, but plans had already been made to replace it with a new, much larger structure. The iconic pink granite from which it was built was not part of the original plan, however, the intended Oak Hill limestone had a high iron content which caused it to undesirably discolour when exposed to the elements. Owners of Granite Mountain near Marble Falls, TX donated the “sunset red” granite as an alternative.

It can be seen from Interstate 35 which bisects Austin and I remember in 2014 my due flight had been cancelled at Leeds/Bradford due to fog, the following day I was sent from Manchester and only two flights instead of the usual three, meaning I got there in daylight, and was able to register for the festival, even perform. Driving back to my motel I was crossing the Colorado River when I saw downtown Austin lit up and amongst it, The Capitol Building; it really felt like I was coming home. No surprise as my poet friend Thom will say when I arrive “Trevor welcome home”.

The building is open to visitors, entry is free, although at the time I was there it was late afternoon and they were ready for closing. It is a roughly rectangular building with a four-story central block, symmetrical three-story wings extending to the east and west, and a dome rising from the centre. It is built in an Italian Renaissance Revival style and modelled on the design of the United States Capitol, but with its exterior clad with local red granite which was not part of the original plan. However, the intended Oak Hill limestone had a high iron content which caused it to undesirably discolour when exposed to the elements. Owners of Granite Mountain near Marble Falls, TX donated the “sunset red” granite as an alternative. It contains 360,000 square feet (33,000 m<sup>2</sup>) of floor space (not including the Capitol Extension), more than any other state capitol building, and rests on a 2.25-acre (0.91 ha) footprint. The building has nearly 400 rooms and more than 900 windows.



The Dome's interior

The interior of the central portion forms an open rotunda beneath the dome. Massive cast iron staircases flanking the rotunda connect the various levels of the building. The two chambers of the Texas Legislature (the Texas Senate and Texas House of Representatives) meet in large, double-height spaces in the centres of the two wings on the second floor, overlooked by public galleries on the third floor. The central rotunda is hung with portraits of all the past presidents of the Republic of Texas and governors of the State of Texas; the rotunda is also a whispering gallery.



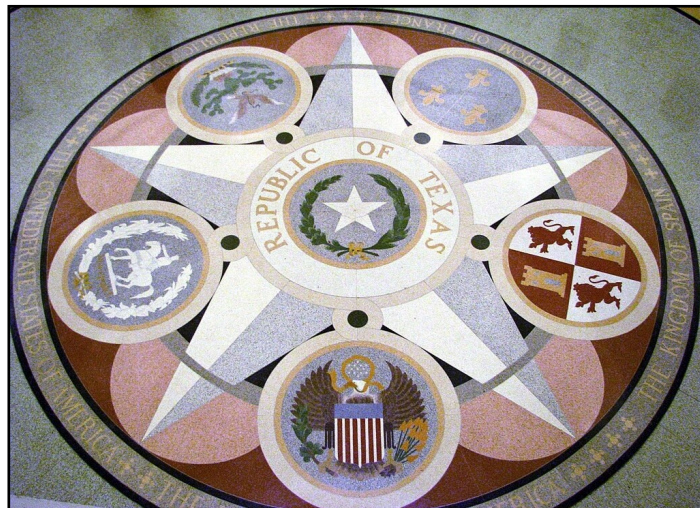


Davy Crockett

At the bottom can be seen a Terrazzo mosaic depicting the seals of the six nations that have governed Texas, Spain, France, Mexico, the Republic of Texas, the Confederate States of America and the United States of America.

The south foyer features a large portrait of David Crockett, a painting depicting the surrender of General Santa Anna at the Battle of San Jacinto, and sculptures of Sam

Houston and Stephen F. Austin made by Elizabeth Ney, a German born sculptor who by the early 1880's was a Texas resident, has her own museum in Austin. The Texas Confederate Museum was held in a room



*Terrazzo mosaic depicting the seals of the six nations that have governed Texas below the Rotunda Dome*



*The Battle of The Alamo*

on the first floor from its opening in 1903 until 1920, when it was moved into the General Land Office Building.

The Capitol building is surrounded by 22 acres (8.9) of grounds scattered with statues and monuments. William Munro Johnson, civil engineer, was hired in 1888 to improve the appearance of the grounds. By the time the first monument, commemorating the Heroes of the Alamo, was installed in 1891, the major components of Johnson's

plan were in place. These included a "Great Walk" of black and white diamond-patterned pavement shaded by trees. The four oldest monuments are in chronological order the Heroes of the Alamo Monument (1891), Firemen Monument (1896), Soldiers Monument (1903) and's Texas Rangers Monument (1907), and these flanks the tree-lined Great Walk. In the spring of 2013, ground was broken for the Capitol Vietnam Veterans Monument; dedication took place on March 29, 2014.



*The Confederate Memorial*

My visit was in 2011. I decided to wander round the grounds as the building was ready for closing, I was not disappointed, a great way of spending the remainder of the afternoon before another open mic at night on my first foray into the Texas City that would become my Spiritual Home.



*Tribute to Childhood statues*