



Price £ 4.00 (Free to members)

Pathways

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

Welcome to Pathways No. 59. (Spring 2019)



You Write In

Aileen writes: I'm very shortly to have a knee replacement operation soon. I am having a my pre-op appointment.

a) Do you have a leaflet that I can download that explains to NHS staff about ME/CFS and surgery?

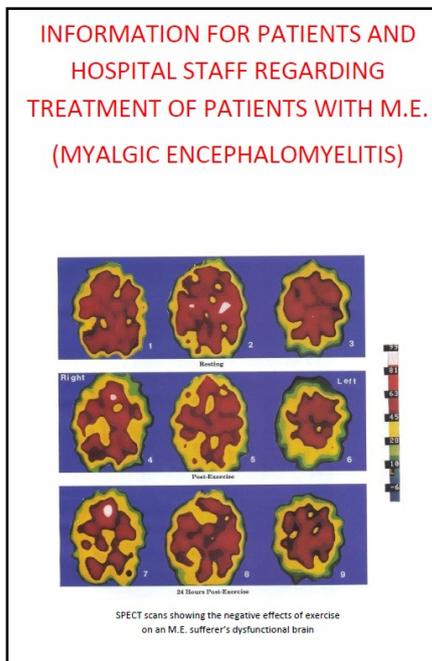
b) Also has there been an article in Pathways about anyone whom has had this surgery?

I would be very grateful for any information as I have been suffering with a relapse since I moved house at the end of January and I'm worried about the surgery.

Firstly, a house move is bound to be stressful to anyone, with ME/CFS it's something extra stressful. It's something that commonly happens. However, once things get sorted out, they usually return to normal.



Front page: Many trees blossom in early spring before the leaves appear. This is a Greengage tree (a type of plum) and hopefully will yield a heavy crop in July.



The front page of grace Charities handbook.

The images show the effect of exercise on brain metabolism

The most informative information about ME/CFS and hospital admission I've seen is the Grace Charity handbook for hospital admission. This is available to download online or from the office.

My partner had a hip replacement under local anaesthetic in August. Six months on she is much better and pain free. The ME didn't become again significant until the three months stage, because the problems from the operation were greater, and she had to rest. The main issue for such an operation is that you have to prepare your home and ensure everything as needed is organised. I attended all my partners pre-op appointments, and it was made perfectly clear by the hospital what would happen, when and what was needed. The biggest problem was getting a suitable high seat chair which was expensive. Help was at hand if needed from the hospital. If anything, you need to take your daughter with you at the assessments so she understand everything and can intervene is necessary.

I haven't done a feature in Pathways because I feel that with joint replacements in this part of the country there is a high level of support, unlike with ME these problems can be seen and there are no question marks. It might be worth asking the hospital to check if you are sensitive to any of the new joint materials

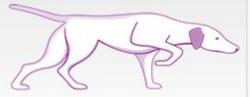
Susan Writes: With reference to the Conisbrough Outreach Meeting.

We held a Leger ME Outreach meeting at Conisbrough Library on Wednesday 6th March. Notices were put out on local Facebook pages, in the Conisbrough in Focus magazine and via email to members. Although only two people turned up, three other people mentioned afterwards that they were hoping to attend but couldn't on the actual afternoon. (Mostly due to the nature of ME/CFS/Fibromyalgia!).

The people who came to the meeting were pleased just to come and talk through how their illness affects them. As with most people, they found comfort in talking and realising they were not the only ones suffering in this way.

They put very positive remarks on Facebook and told us they would certainly like us to hold another meeting local to them in the future. They mentioned other possible free or cheap places to meet. We are planning to hold an Outreach Meeting in Thorne later this year.

Thank your for the hard work.

Welfare Rights Matters*With Thanks to Benefit and Works Steve Donnison***Benefits and Work**
Guides you can trust**DWP's foul expletive about PIP claimant**

A DWP decision maker used an expletive so foul to describe a claimant that we can't include it in this newsletter, because it will mean that most of them get stopped by spam filters. Not only did the decision maker use despicable language, they also displayed a shocking lack of knowledge of the benefits system. At one point they stated that the claimant was in receipt of *middle rate carers allowance component*, a benefit as yet unknown to humanity. The standard of the submission was not improved by errors of grammar and of spelling, such as the reference to the claimant's ability to use a foot pedal for *breaking* a car. It is no surprise that the DWP is currently losing 73% of its PIP appeals, if the hate-filled prejudice and ignorance on display here is a reflection of the professionalism of the staff it now employs.

Claimants health put at risk by fit note scandal

Contempt for claimants and actions which put their lives at risk are combined in the changes to a letter sent to GPs by the DWP. The ESA65B letter automatically sent to doctors when their patient is found fit for work tells them that they should no longer issue the claimant with fit notes. In the past, the letter went on to explain that they would need to start reissuing fit notes if the claimant appealed against the finding that they were capable of work. However, a new version of the ESA65B entirely omits this information, leading to GPs refusing to issue further fit notes.

The result is that the claimant cannot claim ESA whilst appealing and must either manage without income or claim benefits as being fit for work and meet job seeking requirements that may harm their health. The possibility of more inquests being carried out because vulnerable claimants like Mark Wood are left without income is all too clear. Yet the DWP have so far failed to change the letter back again, claiming that the new letter is '*simpler and clearer*'.

Increase in ESA claimants placed in the support group

The latest ESA statistics show a considerable rise in the proportion of ESA claimants making it into the support group. In the quarter to September 2018, for ESA initial assessments:

- 47% were placed in the support group, up 5% on the last quarter.
- 21% were placed in the work-related activity group, up 1%.
- 32% were found fit for work, down 6%.

For repeat ESA assessments, the figures are:

- 72% support group. (Aka Health Write off).
- 16% work-related activity group.
- 12% fit for work.

PIP and ESA appeal success

More positive statistics for claimants with an appeal were released by the Tribunals Service this month. Overall, an extraordinary 70% of social security appeals are successful, with the claimant getting a better award than they originally received from the DWP. The success rates for benefits include:

- Employment and Support Allowance (ESA) 74%
- Personal Independence Payment (PIP) 73%
- Disability Living Allowance (DLA) 66%
- Universal credit (UC) 58%

The success rate for PIP is up 4% on a year ago, whilst the success rate for ESA has risen 5%. So, if you have been turned down at mandatory decision stage, please don't give up. The odds are most definitely on your side.

Supply rules change to Gabapentin or Pregabalin, commonly prescribed for pain control in ME/CFS.

Are you taking gabapentin or pregabalin, aka Lyrica, Alzain, Neurontin.



The law is changed from **1st April 2019**.

Pregabalin and gabapentin are being reclassified as controlled drugs. This is a change in legal classification for purposes of supply and distribution. Similar rules already apply to opiates, diazepam and related medicines. Your GP and local pharmacy will ensure you continue to get the medicines you need. Please remember to order your repeat medicine in good time. There will be some changes to the rules:

- Up to 30 days supply is normally allowed on one prescription.
- You must collect medicines from the pharmacy within 28 days of the date on the prescription (which is not always the date the prescription was signed).
- Any medicine 'owed' to you by the pharmacy must also be collected by that date.
- For some GP practices it may no longer be possible to send prescriptions electronically to the pharmacy. This does not apply if your GP practice uses the electronic prescription service for controlled drugs.
- All patients will need to request repeat prescriptions each month from their GP practice. It will no longer be possible to get your medicine from the pharmacy using repeat or 'batch' dispensing.
- If your GP practice does not use the electronic prescription service for controlled drugs, you or your representative (or prescription collection service) will need to visit the GP practice in person to collect your prescription each month. To set up someone as your representative, please contact the practice.
- You or your representative will need to sign and show proof of identity at the pharmacy to be able to collect your medicine.
- If you run out or need an emergency supply, you will need to phone your practice or GP out-of-hours service.

Your GP practice will make these changes before the law changes on 1 April 2019.

Please note that these regulations also prohibit supply other than by legal means. This means you could be breaking the law by giving them to a friend or obtaining via the Internet.

Background. Gabapentin is a medication that is used to treat different types of neuropathic pain as well as to control seizures in individuals who have epilepsy. It can also be used to treat the symptoms of restless leg syndrome. Gabapentin is in a class of medications called anticonvulsants and treats seizures by decreasing abnormal activity in the brain. It also changes the way the body senses pain.

While gabapentin has many positive uses, it is only meant to be taken as prescribed by a doctor and should not be used at higher doses to experience euphoria. Gabapentin can cause intense adverse side effects and has recently become a common drug of abuse, though addiction most often occurs with individuals who already have a history of addiction. People abuse gabapentin because of the desirable effects it causes when abused. The drug's effects vary with the user, dosage, experience, psychiatric history, and expectations. Because the medication has not been studied at great lengths for its abuse potential, the syndrome caused in those who take it recreationally is not as well-defined as with other drugs of abuse. However, it is becoming more understood that gabapentin abuse is a legitimate concern, and that is the reason for the new supply restrictions.

Out and About in Doncaster: Conisbrough Castle

Most of us will know Conisborough castle from school history trips. In the past we have been and walked on the top of keep (tower), and looked at the magnificent Panorama from the top.

However, more recently we attempted a visit, but were disappointed, especially with the lack for disabled facilities. The car park of the castle site is at the bottom of the Hill. It is a pay and display car park with several disabled bays. If you park there, there is a several hundred yards walk up a steep hill to the visitor centre. Although there are a couple of disabled places there, they are on a first come first served basis.

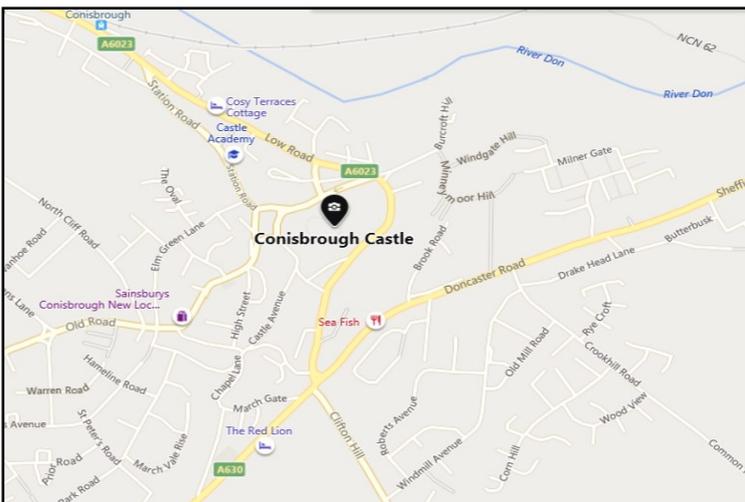


Much of the grounds have been tidied up and is wheelchair accessible, but unfortunately the tower does not have any disabled access. If it were not for the visitor centre which shows the history in vivid detail, all that we would see is a grassed over ruin. However there are special days when re-enactment days when and other activities take place. It would be an interesting place to take children on a day out. See the English heritage website for further details:

<https://www.english-heritage.org.uk/visit/places/conisbrough-castle/things-to-do/>



An air photograph showing the Mott and Bailey layout. Thanks to Wikipedia



Ivanhoe's Castle

Ivanhoe is a historical novel by Sir Walter Scott, first published in 1819. At the time it was written it represented a shift by Scott away from realistic novels set in Scotland in the comparatively recent past, to a somewhat fanciful depiction of medieval England.

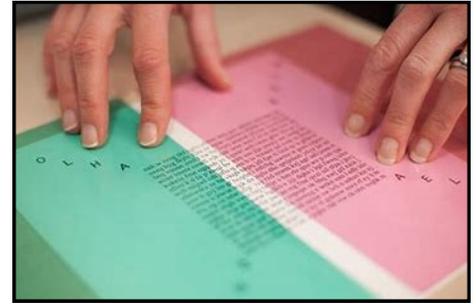
The story includes the creation of a British identity, which is situated in Conisborough castle. The inspiration for the local involvement is reputed to have originated when Sir Walter Scot passed Conisbrough castle in a mail coach. There are shades of Richard the Lionheart and Robin Hood.

Ivanhoe is the story of one of the remaining Anglo-Saxon noble families at a time when the nobility in England was overwhelmingly Norman. It turned out to be to be one of the best known and most well-known of Scott's novels. Ivanhoe is set in 12th-century England, with colourful descriptions of a tournament, outlaws, a witch trial and divisions between Jews and Christians.

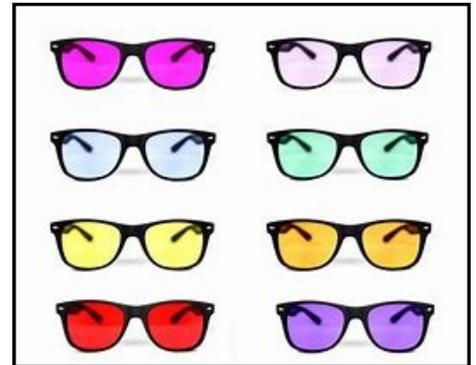
The plot involves a tournament, capture and rescue, Rebecca's trial and Ivanhoe's reconciliation.

Meares-Irlen Syndrome like symptoms in ME/CFS

While dealing with a couple of Leger ME members DWP case reviews, I notice a couple of people had reported that they used coloured overlays to help with reading, one member has got coloured prescription glasses.

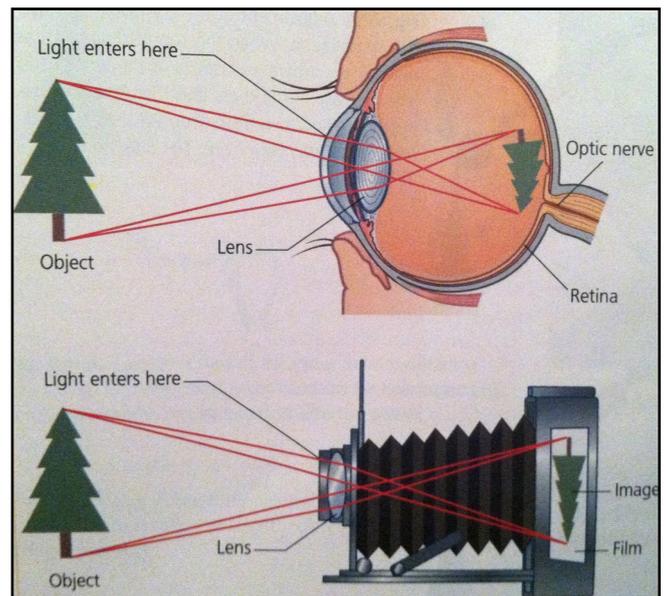


In the early 1980s, a teacher in New Zealand, Olive Meares, was the first to provide a detailed written account of the spatial distortions affecting text being read, by some individuals. Olive Meares also reported that the effects she cited could be reduced or eliminated using coloured paper or by using coloured plastic overlays. The overlay being placed over the text to be read.

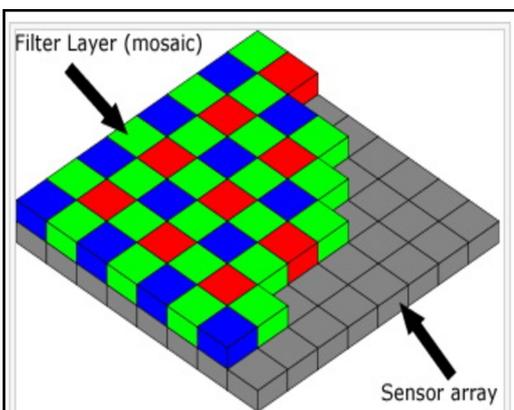


A psychologist working in California, Helen Irlen, wrote a paper describing symptoms as Olive Meares had done. Ms. Irlen, named the effects as Scotopic Sensitivity or Irlen Syndrome. The syndrome was one in which reading is impeded by distortions of print. She reported that the distortions were positively affected if text was viewed through a coloured filter or overlay. Ms. Irlen went further and established a protocol for screening for scotopic sensitivity and a system for dispensing coloured overlays as a result of the assessment.

There followed a period during which the scientific community discussed these findings with a great deal of skepticism. The problem being that there was no satisfactory explanation as to why the treatment of visual distortion of text with coloured overlays should work. Of course, this did not mean that it did not work. In fact, medicine is littered with examples of treatments working first followed by an understanding of why much later. The best example being anaesthetics.



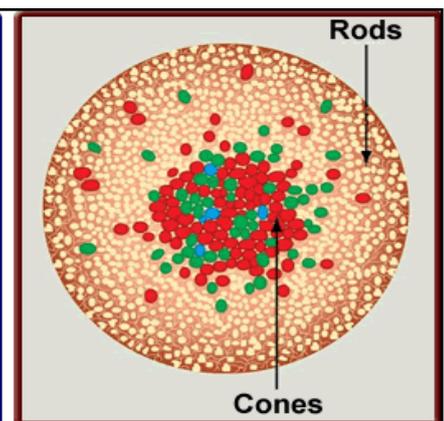
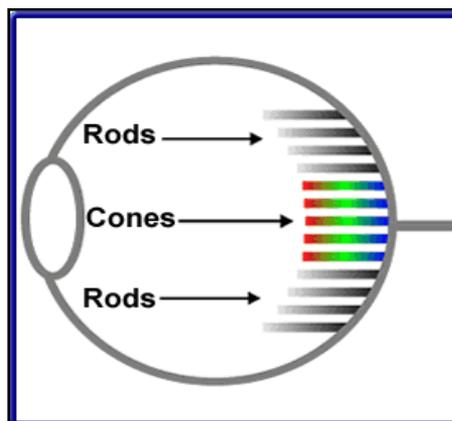
While Meares-Irlen syndrome is a problem within its own right, many people with ME/CFS have reported similar problems, particularly in fatigue periods.



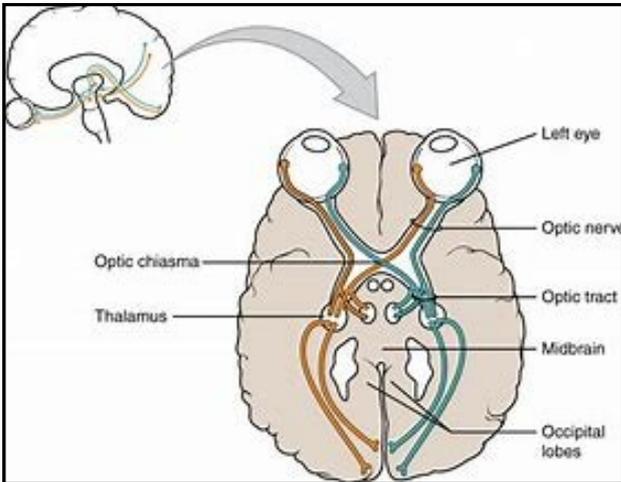
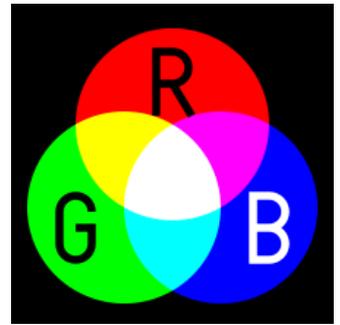
So, what is the possible mechanism?

The eye works like a camera, the lens focuses the image onto the retina or film. In a modern camera the film is replaced by an image sensor. In front of each pixel there is a coloured filter either red, blue or green, the green has twice as many pixels as the blue or red.

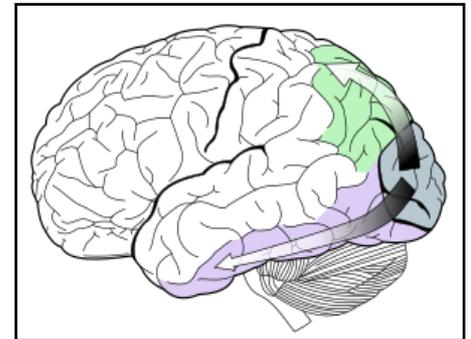
In the human eye there are three sorts of cones cells sensitive to red, blue and green. Additionally, in the human eye there are rod cells which are not sensitive to colour but are to dim light. The cones are mainly in the centre of the retina, while the rods are mainly on the outside.



Each rod or cone is conned to a nerve cell, and it sends the signal via the optic nerve to the back of the brain. The three primary colours red green and blue are somehow combined in the brain to sense the other colours yellow, cyan and magenta. White is when all three primaries combine. Not all colours are equal. Blues seems stronger than red, green seems to be less stressful, and red seems more relaxing.

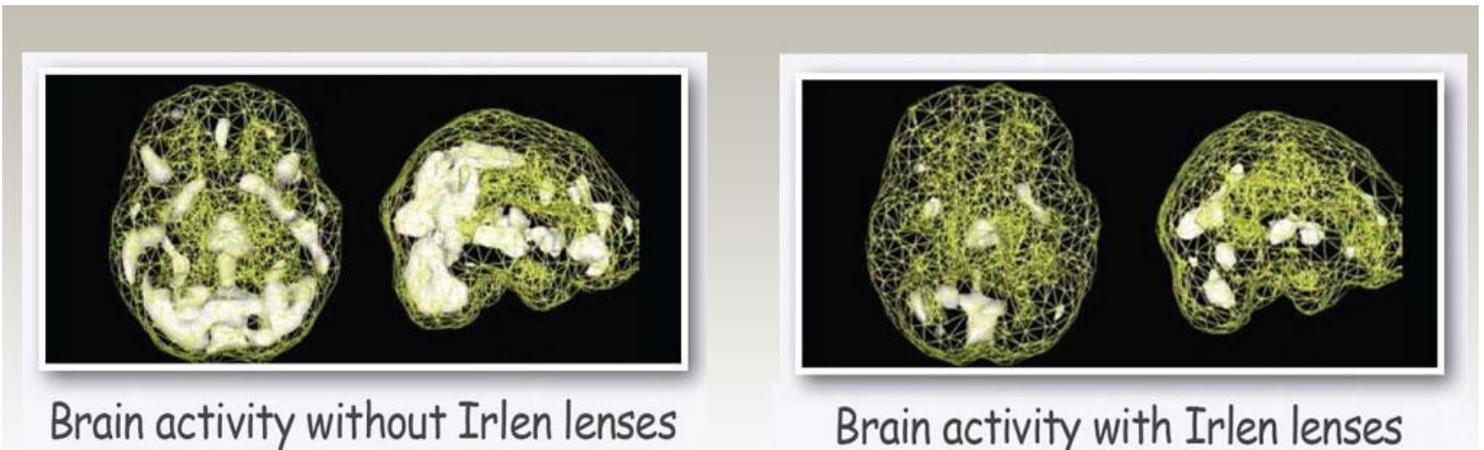


A further complication is that the optic nerve wiring crosses over within the brain, and the signals are copied to other parts of the brain. The right hand side image is processed in the purple area and left side in the green area. There is a common area grey where both images are combined.



In effect, the eyes are a camera, and it is the parts of the brain that actually 'see'. Any disturbance to brain

function –e.g. reduction of blood flow to the brainstem due to ME/CFS causes problems with brain function and of course fatigue, and all sorts of strange things. The image below is from an Irlen's patient reading. The white areas without an Irlen's filter show more white parts than when the brain is looking through an Irens filter. Less white parts mean less activity and less fatigue. This could explain why they are effective with some people with ME/CFS.



We tried using acetates at a monthly meeting with mixed results. In order to demonstrate for Pathways readers, I've included a well know poem on different coloured backgrounds. It gives you a chance to experience the effects of colour backgrounds, and different font sizes. We have a set of coloured acetates you could try in the group library just to see if it would be worthwhile following up.



The main use of the coloured acetates is to allow children such as reading problems with dyslexia or attention deficit problems to overcome difficulties with their reading. Also available are pads of coloured paper.

If you think you have a problem, it will be worthwhile to discuss this with your doctor or optician.



<p>The Owl and the Pussy-cat went to sea in a beautiful pea green boat, They took some honey, and plenty of money, Wrapped up in a five pound note.</p>	<p>The Owl and the Pussy-cat went to sea in a beautiful pea green boat, They took some honey, and plenty of money, Wrapped up in a five pound note.</p>
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Demonstration above: The effect changing the background colour as colour filters do and how stressful it is to read. Which colour do you find most relaxing, and which one is most stressful ? Below. Which size text do you find easier to read?

24 point

The Owl and the Pussy-cat went to sea in a beautiful pea green boat,
They took some honey, and plenty of money,
Wrapped up in a five pound note.

18 point

The Owl and the Pussy-cat went to sea in a beautiful pea green boat,
They took some honey, and plenty of money,
Wrapped up in a five pound note.

14 point

The Owl and the Pussy-cat went to sea in a beautiful pea green boat,
They took some honey, and plenty of money,
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12 point

The Owl and the Pussy-cat went to sea in a beautiful pea green boat,
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10 point

The Owl and the Pussy-cat went to sea in a beautiful pea green boat,
They took some honey, and plenty of money,
Wrapped up in a five pound note.

8 point

The Owl and the Pussy-cat went to sea in a beautiful pea green boat,
They took some honey, and plenty of money,
Wrapped up in a five pound note.

Recipe corner by Carolyn**Make the `Perfect Cheese on Toast`**

Taken from the BBC TV programme `Inside the Factory`, Gateshead cheese Factory.

I know many of you will prefer to use Wholemeal/Brown bread these days but it is no good for making the `Perfect Cheese on Toast` as the ingredients of Brown Bread interfere with the flavour. Only White Bread will do the job and it needs to be White Medium Sliced.

Toast your pieces of white medium sliced bread until light golden brown.

Spread butter very carefully onto your toast making sure to spread into all the corners, to bring out the flavours when cooking in the oven later on.

Add 2 ounces exactly of grated `Light or `Medium` Cheddar Cheese. (Don't be tempted to use Mature Cheddar, it drowns the flavours).

Preheat your oven to 130 degrees, and then place the prepared toast on a rack in the middle of the oven. Cook until melted, browned and slightly bubbly.

Take out of the oven and place on a plate, add a sprinkling of Worcester Sauce and enjoy eating the `Perfect Cheese on Toast`.

**Cherry and Almond Easter cupcakes****Method**

Heat oven to 180C/fan, 160C/gas4

Place 24 cupcake cases into cupcake tins.

Beat the butter and sugar together with electric beaters or a table top mixer until light and fluffy.

Add the eggs, 250g flour, baking powder, orange zest and juice and beat well until thick, creamy and evenly mixed.

Toss cherries in the extra 2 tbsp flour and fold into the batter along with grated marzipan and almond essence (if using). Spoon into the cupcake cases and bake for 20-25mins, or until well risen and golden. Leave to cool in the tin for 10 mins, then place on a cooling rack to cool completely.

Mix the icing sugar with around 1tbsp water to make a loose but not too runny icing.

Ice the tops of the cupcakes and top each one with about 3 mini chocolate eggs.

**Ingredients:-**

250g pack butter, softened, plus extra for greasing.
 175g golden caster sugar
 5 eggs, beaten
 250g self-raising flour, plus an extra 2 tbsp
 1 tsp baking powder
 Zest of one orange, plus 2 tbsp of the juice
 250g natural marzipan, coarsely grated (easiest if chilled before grating)
 ½ tsp almond essence, optional
 200g glacé cherries, halved

For the decoration:-

About 100g/4oz icing sugar, sifted
 Mini chocolate eggs, to decorate

Other features typical of ME/PVFS

Clinical features vary. The following are supportive, but not essential, for diagnosis: -

- **A viral trigger:** in 75% of cases, onset follows a viral infection in a previously fit and active person.
- **Symptoms suggestive of chronic infection:** low grade fever, tender lymph glands, sore throat.
- **Muscle symptoms:** exercise-induced muscle weakness, taking days for recovery. Problems arise from sustained muscle use (although, after rest, muscle power may initially be normal). The commonest muscles affected are the 'girdle muscles': glutei, trapezii, quadriceps. Inability to stand for long periods is typical, as is difficulty holding up arms (e.g. to brush hair or hold a telephone) or carrying bags. The muscles feel sore and ache after minimal exercise (myalgia), and on palpation there are commonly acutely tender foci in thighs, upper arms and shoulders. Visible muscle fasciculation or twitching is common after overuse. Difficulties reading or writing a letter are also typical muscle fatigue symptoms. Patients who exceed the early warning signs of fatigue on exercise may collapse and be ill for days after with myalgia and severe malaise.
- **Autonomic disturbance:** palpitations, rapid pulse, inappropriate sweating, sudden pallor, poor temperature control, nausea, diarrhoea, bladder dysfunction, hormonal disturbances. (Recent research has confirmed hypothalamic dysfunction.)
- **Sensory disturbances:** hyperacusis, tinnitus, photophobia, paraesthesia.
- **Disequilibrium and clumsiness**
- **Sleep disturbance:** initially hypersomnia but, in the chronic stage, insomnia, loss of non-rem sleep and vivid, unpleasant dreams.
- **Emotional lability:** (like that of MS) is very common. Depressive symptoms of profuse weeping, despair and even suicidal thoughts may last for less than a day, days or weeks. However, typical features of classic 'depression' - apathy, anhedonia and feelings of guilt - are usually absent in ME/ PVFS patients, who retain their ability to enjoy what life they still have. Their low moods are usually directly associated with exhaustion and other symptoms such as sore throats and pain. Their 'depression' resembles the low mood and weepiness experienced in post-'flu' convalescence and may be mediated by cytokines.
- **Pain:** sometimes intractable headache, abdominal pains, back, neck or facial pain, unlike any previous pain, and changing from day to day. Joint pain with or without swelling is also common.

The onset of ME/PVFS

Usually the onset of ME can be traced to an infection (often considered trivial at the time), e.g. sore throat, lymphadenopathy, a gastrointestinal upset or muscle pains. Other 'triggers reported include immunisations, chemical exposure (especially pesticides), antibiotics and trauma such as surgery or accidents. In about 10% of patients the disease develops gradually with no apparent 'trigger'. In the UK about 60% of patients with ME/PVFS have evidence of enterovirus infection, most commonly Coxsackie B. This has been demonstrated by the finding of enterovirus RNA in muscle and enteroviral protein (VP1) in blood. (*N.B. VP1 is not a specific test for ME/PVFS.*) Many other patients have reactivated Epstein Barr virus. At present it is not clear whether the 'triggering' virus becomes persistent or whether damage to the immune response allows reactivation of some other virus.

Differential diagnosis

Other conditions must be excluded: muscle disorders, other neurological diseases (e.g. multiple sclerosis), connective tissue diseases, primary psychiatric illness, thyroid disease, diabetes, GI disorders, autoimmune diseases, cancer, chronic infections (e.g. HIV, TB, toxoplasmosis), parasites, tropical infections, nutritional deficiencies. *This is included in the current NIHCE guidelines*

Physical examination

Physical examination rarely reveals gross abnormality. On palpation of large muscles such as quadriceps or trapezii there may be foci of acute tenderness. Testing of muscle power may show weakness in different muscle groups, more pronounced after exercise, e.g. walking upstairs (if the patient is able) or squeezing a rubber ball for a few minutes. Muscle power may be normal after rest or at the start of the day, but muscle exhaustion is reached abnormally early and the weakness may last for hours or days.

Neurological examination

Parasthesia can occur uncommonly and may raise the suspicion of early MS. However, eye movements are usually normal. Tests of balance and coordination are frequently abnormal. The plantar response is usually flexor, but tendon reflexes may be brisk.

Investigations

Investigations should be carried out to exclude other conditions as seems appropriate for the patient. There is at present no one specific test for ME/PVFS. Routine blood tests rarely reveal any abnormalities. The most likely findings to support a diagnosis of ME/PVFS are:

Haematology

Maybe a few abnormal lymphocytes, an abnormal ratio of T4:T8 lymphocytes, reduced NK cell cytotoxicity. Mild anaemia and low serum ferritin are common. Plasma viscosity is usually normal or low. Raised IgM to Coxsackie virus. Routine tests for EB virus are unhelpful as over 90% young adults have positive EB IgG. However, positive tests of Early Antigen (EA), viral capsid antigen (VCA), and EB nuclear antigen indicate an active or reactivated EB infection. Mildly elevated liver enzymes are common.

More specialised tests (not routine):

Muscle biopsy; MRI or SPET brain scans. (In the USA 50% of MRI scans revealed inflammatory lesions and 80% of SPET scans revealed areas of hypoperfusion. In the UK, SPET scans have shown hypoperfusion in the brainstem significantly lower than that found in both depressed patients and healthy controls. (SPET scans demonstrate abnormal function and are more sensitive than MRI in ME/PVFS.). Neuropsychological tests may differentiate between ME/PVFS and affective disorder.

Complications in ME/PVFS

Complications in ME/PVFS may give presenting symptoms, thus confusing the clinical picture:

- **Myocarditis:** the heart muscle may be affected, especially if the triggering virus is Coxsackie. Such patients may have rapid pulse and intermittent ectopic beats. One follow-up study of patients with enteroviral infection found an incidence of cardiac complications (which may include mitral valve damage) of up to 30%.
- **Vestibulitis and labyrinthitis:** leading to disequilibrium and unsteadiness when moving about. Such symptoms may be as disabling as the fatigue.
- **Acute psychiatric disturbance:** depressive symptoms, including risk of suicide, panic attacks, irrational crying, even mania. Such episodes often coincide with symptoms of exhaustion, sore throat, muscle pain, fasciculations and severe malaise—signs of disease relapse - which, unlike in primary depression, may only last hours or days.
- **Allergies:** The development of hypersensitivities to a range of foods and/or chemicals is common in ME/PVFS. This may be due to altered immune function or to the absorption from the gut of incompletely digested food molecules. Pre-existing allergies may become worse. Exclusion of a few commonly allergenic foods (e.g. wheat, dairy products, eggs) may improve symptoms and a few patients improve on a gluten-free diet. However, very restricted diets may lead to nutritional deficiencies and weight loss and do not cure the disease. Allergic patients should minimise exposure to chemicals in the house. Intolerance of alcohol is a near universal complaint of ME/PVFS patients.
- **Gut problems:** gut problems are common: irritable bowel, bloating, pain, sometimes malabsorption and diarrhoea alternating with constipation. These may be due to enteric viral infection - which can disrupt digestive enzymes and flatten villae lining small bowel mucosa - or to disturbance of the normal bowel flora (dysbiosis). This latter is suggested by the frequency of these symptoms after a patient has taken broad-spectrum antibiotics for the precipitating viral illness.
- **Fungal overgrowth:** candida (yeast) overgrowth and hypersensitivity to moulds seems to be common in ME/PVFS. Candida albicans is a universal commensal which proliferates in conditions of altered T- cell function. It affects mainly mucosal tissues -mouth, vagina (thrush) or anus. In the gut it may affect the bowel endothelium and be part of a gut dysbiosis. Symptoms

suggesting candidiasis are alternating diarrhoea and constipation, perianal itching or rash, persistent thrush, fungal infection of skin, mouth thrush or ulcers, PMS, sour sweat, chemical sensitivities and unexplained depression.

- **Symptoms are made worse by damp and sugar or alcohol intake.** The gut fermentation test - measuring various fermentation products in the blood following a test ingestion of glucose - is helpful in confirming overactivity of yeast in the gut.

Prognosis

This is variable and unpredictable. Many patients recover gradually over a period of months or years. After the initial acute illness, most patients follow a relapsing and remitting course. The commonest causes of relapse are physical or mental exertion beyond tolerance limits (see 'Fatigability' above). Clinical observation suggests that approximately 20% of patients recover in two years, usually those who received an early diagnosis and were able to take enough rest. 60% of patients learn to manage their illness, usually through diet, rest and learning not to exceed their activity tolerance levels, but never regain their pre-illness capacity for work. The remaining 20% of patients will still be affected after 10 years. A small but significant number deteriorate steadily despite good management and become severely disabled.

Management

There is no single treatment for ME/PVFS. The illness must be managed in a way most appropriate to each patient.

Early diagnosis:

Early diagnosis can make it much more possible for the patient to take a period of complete rest in the acute stage. Patients who 'battle on' through the illness are more likely to become chronically ill. Diagnosis allows sickness certification and (hopefully) understanding from employers, teachers, family and friends.

Rest:

Advise the patient to rest (but not total bed rest) and to alter their lifestyle to reduce symptoms. The patient may need to give up work or school for six months or longer. Their return to work needs to be very gradual. A child may be able to return to school part day but will have to avoid sports for a long time. Cases are known where children recovering from ME/PVFS have been forced to do sports and have relapsed severely for months.

Exercise:

Exercise must be within the patient's capabilities. Each patient's activity tolerance level is different and variable. Some can quite quickly manage a 100-yard walk without relapsing whilst, for severely affected patients, getting to the bathroom and back may be the equivalent of a marathon run! Where improvement is sustained a cautious increase in activity should be encouraged, but never more than 70% of what the patient feels capable of. The daily exercise quota (e.g. walking, reading) should be split up and alternated with rest periods. If overdone it may lead to relapse.

Graded Activity & Exercise Programmes

- such as those used in the treatment of depression or for rehabilitation of post-operative patients, or physiotherapy to develop muscles, are generally not appropriate in ME/ PVFS and may cause prolonged relapse or deterioration.

Diet:

Encourage a healthy fresh-food diet, which avoids alcohol, coffee, tea, sugar, processed and 'junk' foods.

Chemical avoidance:

ME/PVFS patients and those around them should not smoke. Exposure to chemical-based products in the house should be reduced.

Sleep:

Hypnotics may be needed from time to time. If sleep is severely disrupted a sedative type of tricyclic in a low dose (e.g. amitriptyline or doxepin, 25-50 mg nocte.) should be tried. Pain relief is essential at night. Common painkillers, NSAIDs and tricyclics can all be used.

Antidepressants:

Extremely small doses of antidepressants help some patients by improving sleep patterns and reducing pain and fatigue. However, some patients experience severe side effects and there is no evidence that antidepressant therapy cures ME/PVFS itself. The most helpful, if sleep is disrupted, are sedative tricyclics. Sertraline and other 5HT reuptake inhibitors raise serotonin levels without the side effects of tricyclics and can improve mood, cognitive function and energy. They may, however, cause insomnia and nightmares. They are also cumulative so dosage should be low. Controlled trials of antidepressant therapy for ME/PVFS are currently under way.

Magnesium treatment:

Research funded by Action for ME and published in the Lancet (Vol 337: March 30th, 1991, pp. 757-760) demonstrated that red blood cell magnesium was significantly lower in a sample of ME/PVFS/CFS patients than in healthy controls. In a double-blind trial patients were given intramuscular injections of either magnesium sulphate (2ml of 50%) or a placebo weekly for six weeks. Symptoms improved in the majority on active treatment and their red cell magnesium's all returned to normal. Apart from some pain at the injection site the treatment appears to have no side effects. (N. B: Intravenous magnesium can be dangerous). Magnesium taken orally alone may not be so effective - there may be problems with absorption - but can enhance the efficacy of magnesium injections.

Efamol Marine:

Efamol Marine is a combination of evening primrose oil and marine oils, providing Omega 3 and 6 essential fatty acids. A trial in Glasgow showed significant improvements in 80% ME/PVFS patients. At least 3 gm daily is needed for any effect. (*Nearest current product is VegEPA-ed*)

Other nutritional supplements:

Many patients feel better from taking supplements of vitamins A, B complex, C, and E as well as zinc. Patients with possible impaired digestion and absorption probably need these extra nutrients, which are all essential for immune function. Mega dosing is wasteful and may be harmful.

Probiotics:

These concentrated cultures of beneficial bacteria (e.g. Acidophilus preparations) help restore the balance of organisms in the colon, especially after a course of broad-spectrum antibiotics.

Anti-fungal treatment:

Patients whose symptoms suggest a yeast problem may benefit from a course of prescribed Amphotericin B in combination with a low yeast and sugar diet and a course of probiotics. Controlling secondary fungal infection (if present) does not cure ME/PVFS but can alleviate many symptoms.

Complementary therapies:

Many ME/PVFS patients turn to alternative medicine for help with an illness for which allopathic medicine has few answers. It is important to consult practitioners who are properly qualified. Patients need to understand that no one therapy is likely to provide a magic cure. Patients expending large amounts of money or energy looking for an instant cure may be disappointed. (This also applies to 'orthodox' treatments).

Acupuncture

may help pain and insomnia.

Massage

with essential oils (e.g. lavender) seems to reduce pain and muscle spasms.

Homeopathy and osteopathy

have been found helpful by many patients.

Relaxation and meditation

These techniques can be beneficial for those well enough to learn them. Their practice encourages mental as well as physical rest.

Anaesthetics, immunizations and antibiotics

Anaesthetics, immunizations and antibiotics may be detrimental in ME/PVFS and are best avoided unless essential. If antibiotics are judged essential probiotics should be recommended at the same time.

Dental treatment

Dental treatment makes many ME/PVFS patients worse temporarily but any septic foci in the mouth need to be cleared up so regular dental examination should be encouraged.

The importance of the doctor-patient relationship

A good doctor-patient relationship is always important but particularly so in a disease where there is still much controversy and misunderstanding. Early diagnosis and subsequent support and follow-up are crucial for recovery and diagnosis is the starting point for social and welfare benefits. Hardship and anxiety resulting from loss of income hinder recovery and encourage despair. Mothers with small children may need home help. Patients who can rest properly in the early stages of the disease have a better chance of early recovery.

Dr Anne Macintyre died in November 2018. She was a doctor with a longstanding personal and professional involvement with all aspects of M.E.

Unfortunately, in addition to having the disease herself, Anne had other serious health problems and had been in poor health for quite some time.

Unfortunately, as with tuberculosis and multiple sclerosis in the past, many people with ME/PVFS have been met by skepticism and criticism by doctors. Rather than believing their patients, doctors have taken their multi-system range of symptoms as evidence that ME/PVFS is not a clinical entity. Adult patients are frequently accused of malingering or exaggeration. Parents of child patients are told their children are 'school-phobic' or 'withdrawing' from a negative family environment. This skepticism merely increases the confusion, misery and isolation caused by this disease as even friends and family are influenced by a doctor's disbelief. These attitudes have made many people with ME/PVFS defensive, hostile to doctors and fearful of psychiatry.

Most ME/PVFS sufferers retain their motivation and want to get better and rejoin the rest of the world. Studies have shown that the rates of depression in ME/PVFS are like those found in cancer and multiple sclerosis patients, i.e. what would be expected in any chronic illness. Because ME/PVFS tends to affect fit, healthy people who enjoy life, many find the advice to take adequate rest extremely difficult. A common cause of relapse is to overdo it the momenta patient has a good day. It is important that doctors understand the frustration and enthusiasm of patients with ME/PVFS and encourage them to pace themselves and to take their illness seriously.

Welfare benefits

The new benefits awards are supposed to be based not on the patient's illness but on their level of disability. The reality is different for two reasons. Firstly, awards are based on a 'snapshot' examination which is inappropriate to a fluctuating illness. If the patient is examined on a 'good day' no account may be taken of the reaction to activity or 'bad days'. *This is still an ongoing problem especially with PIP claims*

Secondly, the patient's diagnosis and medical records are important, as those whose disability is deemed to stem from 'psychological factors' are barred from the higher rates of benefit. Supportive documentation from a GP may therefore be crucial for a patient who needs financial help. The ability to obtain (e.g.) Disability Living Allowance and Invalidity Benefit may make all the difference between recovery and chronicity.

Disability Living Allowance is now being superseded Personal Independence Payment (PIP) Invalidity which has now been Superseded by Universal Credit UC And Incapacity Benefit (ICB)

Things NOT to say to someone with a chronic long term condition like ME/CFS.

ME/CFS and Fibromyalgia are chronic conditions just as MS, Asthma, COPD, lupus, Crohn's disease, and fibromyalgia. Long term conditions often in around 30% of cases involve reactive mental health problems like anxiety and depression which due to loss of health. Grieving for loss of health or status is also a common problem. As anyone with a long-term health problem issue knows, well-meaning friends, colleagues, relatives, and even strangers will sometimes go in feet first. While their intentions are usually positive and honourable, unintentionally they be offensive, insulting or cause hurt feelings. Here are some common gaffs: -

1. "This condition is all in the mind."

Well-meaning people sometimes try to "help" by telling you that someone can think their way out of feeling ill. We still sometime see this, despite the Chief Medical Officers Report and NIHCE guidelines. With chronic disease, people need to be aware that while a positive attitude may help in some situations, you never want to make someone feel bad about feeling bad.

2. "You don't look ill to me."

About 30% of people living with chronic conditions say that they experience significant limitations in daily activities, but many of those people don't have visible symptoms. This is typical of someone with ME/CFS on a better day. People have been asked things like "Why do you need a wheelchair?"

3. "You look great! Have you lost weight?"

Many people with chronic health problems lose weight. For example with anorexia, coeliac disease diabetes or cachexia. The more weight is lost, the more ill a person is. so it's pretty offensive and disturbing to hear people congratulated for weight loss.

4. "I'm sorry to see you like this."

While most chronic conditions are lifelong, they are definitely not all terminal. Condolences are totally out of place.

5. "I'm sure things will get better."

Empty comments about "getting better" can make a person feel misunderstood. In many long-term conditions getting better is not an option as they are often lifelong. Many people sometimes find obscure ways to manage their problems. Very often a sympathetic ear will benefit someone a lot more.

6. "Did you get this because you *?"**

insensitive people often ask whether a person's actions contributed to a condition. Blame is the last thing that a person whose health has been impacted by an illness or accident needs. Any comments that imply "I told you so" are going to cause trouble problems. Do you really need to hear this in order to help or provide support? Very often someone with a chronic condition will tell this to anyone with a listening ear.

7. "My uncle has the same problem and is doing well. "

ME/CFS like many chronic conditions is very variable and can affect people in very different ways. Everyone's case is different, so they can't really be compared.

8. "I know exactly how it feels to have a ME/CFS. I have * treatment every week"**

It's wrong to imply someone should follow a particular treatment course without expert guidance. It's more positive to enquire about how the person is and open a conversation.

9. "You should try this amazing herbal remedy."

Depending on a person's condition, inexpert advice could be dangerous. The best example of this is St John Wort which reacts with many other conventional medicines.

10. "It could be worse."

Condescending remarks like this only add to a person's feelings of aloneness. It is important to avoid measuring a person's suffering, pain, or discomfort unless absolutely necessary. Knowing that things could get worse is hardly cheerful news. Very often people research the internet and get to know things anyway.

Research Corner: Muscle Abnormalities In ME/CFS

With thanks to ME research UK

Preliminary results from Newcastle are starting to narrow down the source of muscle function abnormalities in ME/CFS

It has been only a year since we announced funding for a new research project for Prof. Julia Newton's team at Newcastle University, continuing their investigations of the abnormalities in muscle function experienced by people with ME/CFS. But the work is already bearing fruit, and the group published their first results earlier this year. For a more detailed discussion of the background to this research, have a read of the article on pages 12 to 15 of the Autumn 2017 issue of Breakthrough (available on our website). But here it is in a nutshell.

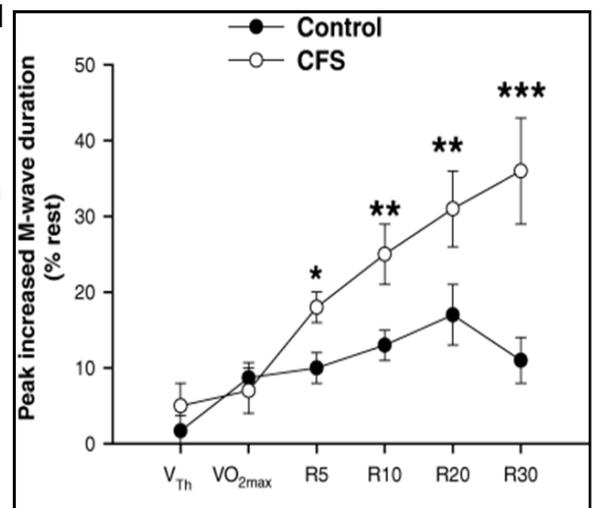
In their exploration of the mechanisms underlying the abnormal muscle fatigue commonly reported by people with ME/CFS, the Newcastle team has previously obtained muscle biopsies from patients, from which muscle cells were cultured and examined in standardised laboratory conditions. Electrical pulses were applied to these cells to simulate the muscle contraction that occurs during exercise impaired AMPK activation AMP-activated protein kinase (AMPK) has an important role in regulating energy in the cell and is normally activated during muscle contraction.

The researchers found that this was impaired in the cultured muscle cells, and that the uptake of glucose was reduced. Although AMPK was not activated by simulated muscle contraction in these cells from ME/CFS patients, later experiments suggested that it could be activated by treatment with metformin. This raises the possibility of whether a drug such as this could improve muscle function in patients. To look at these abnormalities in more detail, and to trace where they occur in the signaling pathway, ME Research UK awarded further funding to Dr Audrey Brown, Prof. Newton and colleagues to continue their investigations.

The first part of this work, published in Bioscience Reports, used a similar methodology to that in their previous study to investigate whether AMPK and glucose uptake in muscle cells from ME/CFS patients could be activated by treatment with pharmacological agents. metformin and compound 991 Skeletal muscle cells were obtained from eight patients with ME/CFS and seven healthy control subjects. The cultured cells were then treated with metformin or with compound 991. Metformin is a drug commonly used to treat diabetes, and is known to activate AMPK indirectly via other mechanisms. Compound 991, on the other hand, was designed specifically as a direct activator of AMPK.

Treatment with metformin increased both AMPK activation and glucose uptake, and this was true for muscle cells from ME/CFS patients and from healthy control subjects. Similarly, compound 991 treatment also significantly increased both parameters in patient and control cells, and the effect on glucose uptake was like that expected following treatment with insulin. Therefore, while AMPK from ME/CFS patients was not activated by electrical stimulation of the cells, it could be activated pharmacologically, and there are two important conclusions that might be drawn from these findings.

Firstly, this abnormality in signaling can potentially be bypassed by pharmacological treatment, and the investigators suggest that this adds further support to the idea of conducting a clinical trial of an AMPK activator in ME/CFS patients. Secondly, their results indicate that the signaling defect lies further up the molecular chain, possibly involving upstream enzymes such as LKB1 or CAMKK. These findings represent the fascinating first step of this project, which will continue to look more closely at the mechanisms underlying muscle fatigue in ME/CFS, and hopefully to identify potential targets for therapy.



After activity, the recovery of muscle power is slower than in any other disease. This chart demonstrates that M.E. sufferers (CFS) produce high levels of oxidative stress (isoprostanes, i.e. highly toxic by-products of abnormal cell membrane metabolism) from increased exercise, compared to healthy controls.

Income Tax: Decoding Your Tax Code

Around this time of year main people will received a letter from HMRC with their tax code. The tax code, if correctly issued by HMRC, enables your pension provider or employer to collect the correct amount of tax in the year. If it is wrong, HMRC will issue a tax calculation at the end of the tax year. To check your tax code is correct, you need to know what it is. It should be on your pay slip, or you can call HMRC and ask. You can also find your PAYE code online by accessing your Personal Tax Account: gov.uk/personal-tax-account. It is your responsibility to check your code and contact HMRC if you think it is wrong.

Your tax-free amount

This is the amount of tax-free allowances you are entitled to, less any deductions. Check that all the allowances you are entitled to are given:

- The tax-free Personal Allowance (£12,500 for 2019/20)
- If either you or your spouse were born before 6 April 1935, you may be entitled to Married Couple's Allowance (maximum 10% of £8,915)
- If you were born after 6 April 1935, you will not be entitled to the Married Couple's Allowance, but your spouse may have applied to donate 10% of their Personal Allowance to you, and if so the transfer will show on your tax code (£1,250 for 2019/20)
- If you are registered blind, then the Blind Person's Allowance should be shown (£2,450 for 2019/20).

Some deductions and adjustments you may have, include:

- The State Pension (SP)- this is taxable, but tax is not deducted before you receive it, so the tax due is collected by deducting SP from your Personal Allowance
- Other taxable benefits, such as contributions-based Employment Support Allowance (ESA) - but if you receive income-based ESA it is not taxable and will not be included on your tax code
- Marriage Allowance - if you have transferred it to your spouse
- Underpayments for a previous tax year - call HMRC if you don't understand this adjustment as you should have been sent paperwork to explain the underpayment previously
- Restrictions - usually to collect tax on income paid gross e.g. savings interest above £1,000 for basic-rate taxpayers or above £500 for higher-rate taxpayers
- Benefits from your job or previous employer, e.g. medical benefits

How do I check the tax code notice?

Check you understand the numbers in each line of the letter and the HMRC notes on the back. The names of all pension providers, or employers who pay you, should be listed at the bottom. It will also tell you the tax-free amount you are entitled to, less any adjustments.

The Final Tax Code

The total of the allowances, less deductions and adjustments, usually leaves a figure of unused allowances, which is converted into a code by removing the last digit and adding a letter, so an allowance of £12,500 becomes a code of 1250L.

L	Entitlement to the personal tax-free allowance
M	10% of your spouse's Personal Allowance has been transferred to you (Marriage Allowance rules)
N	10% of your Personal Allowance has been transferred to your spouse (Marriage Allowance rules)
T	HMRC will review the code
X	HMRC will review tax paid at the end of the tax year
K	Negative tax-free allowance, which means no net tax-free allowance is due, but rather tax is due on the excess of adjustments over allowances
C	Resident in Wales (different tax bands)
S	Resident in Scotland (different tax bands) m
BR	Income taxed at basic rate, 20%
NT	No tax to pay on this income
DO	Income taxed at higher rate, 40%

Spring Garden Watch 2019

By Carolyn

This has been such an `odd` winter weather wise with weeks in February when it felt like Spring had already arrived and made it tempting to start planting things in the Garden, but luckily we didn't really believe it and have held back. However, it did give a window of opportunity to do a really good clear up in the garden and for the man of the house to scarify the lawns which was well overdue. (Couldn't believe how much moss was removed at the first attempt with the brand new scarifier)

First out were the `Snowdrops` looking like pearl drops and which were an absolute joy to see as they had been planted over a year ago and there was no sign of them last Spring. The picture shows a few and there were many more all along under the hedge, so in a couple of years time I hope to divide and replant them to hopefully spread in other parts of the garden.



The `tete a tete` daffodils left have been a joy this year and some of the clumps are now getting so big that I intend to divide them and fill in any gaps under the long hedge.

The other day I found these little gems were out. The `Wood Anemone`, have spread since last year. They look lovely in amongst the blue Grape Hyacinths and Narcissi.



The pots and containers are looking colourful along the wall with viola, mini daffs, mini tulips and alpines here and there.



In the orchard strip our half Plum half Greengage tree is full of blossom for the first time. It is maturing nicely and we live in hopes of having Plums as well as delicious Greengages to eat this summer!

The native primroses that were planted last year have flowered on and off since last November and they are doing really well in both the back and front garden. (The picture is of those in the back garden along with some mini Lupins that were a free gift with some bulbs. It will be interesting to see how the lupins do in what is a rather shady spot). A new clematis has been planted and already has new leaves growing and there are orders in for other plants which will arrive in May to be planted after the danger of frost is over. There are bulbs growing under cover and seeds are planted indoors for now until the frosts have gone.



We have a new resident Blackbird 'Blackietwo', who we think is 'a real chip of the old block' and we think a new 'Mrs Blackietwo' has also arrived. Two Robins are very much with us and the Goldfinches and Chaffinch are back along with all the other little garden sparrows and larger birds.

We also have a 'Sparrowhawk' visiting regularly, more than we would wish, but have to admit it is a fascinating bird of prey to watch as it silently swoops the length of the back garden and luckily our little birds are quick to disappear into the hedge when it is around, well, mostly!



And last, but not least, we have a new visitor in the shape of a lovely rust coloured Fox! We have seen him regularly through winter, making his way along the field walking closely along the edges of our fencing. So far I haven't been able to take a picture of him but we know it is the same Fox each time by a dark patch on the top of his bushy tail.



My gardening helper.

Magnesium Deficiency in ME/CFS

With thanks to Dr. S Myhill

I have struggled for over twenty years to try to make sense of red cell magnesium blood test with my patients. It seems that they are almost invariably low in patients with chronic fatigue syndrome. Furthermore, so many patients with chronic fatigue syndrome do benefit from magnesium by injection. You could argue that I have been a bit naughty in the past by using a low intracellular magnesium as an excuse for trying magnesium injections! This is really to encourage GPs to use the injections because clinically they are so helpful. Often, paradoxically, when I repeat a red cell magnesium, it is only marginally better, but nonetheless the magnesium injections often afford marked improvement clinically.

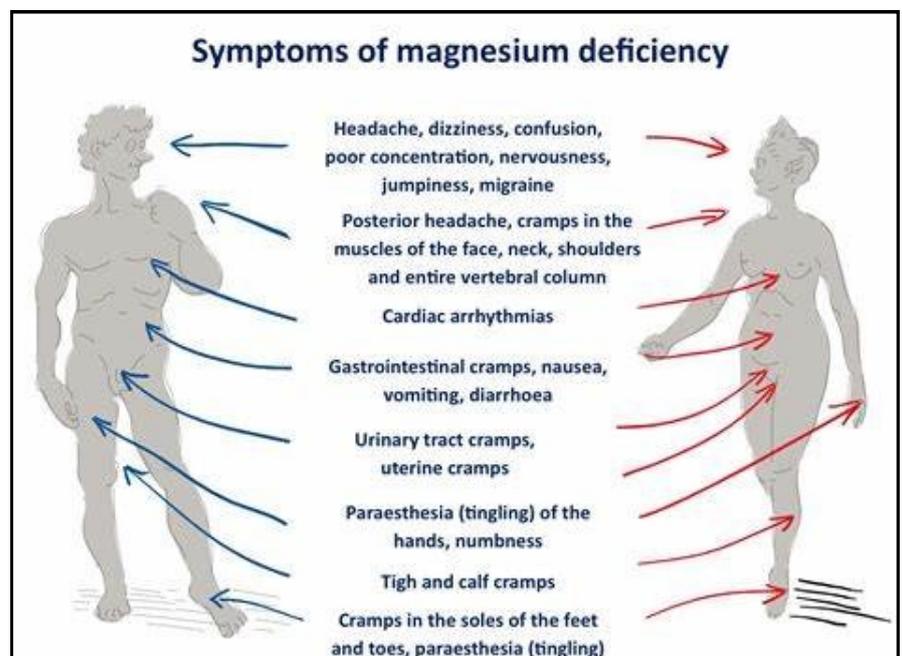
I actually now believe that a low red cell magnesium is a symptom of mitochondrial failure. It is the job of mitochondria to produce ATP for cell metabolism and about 40% of all mitochondrial output goes into maintaining calcium/magnesium and sodium/potassium ion pumps in body cells. I suspect that when mitochondria fail, these pumps malfunction and therefore calcium leaks into cells and magnesium leaks out of cells. This, of course, compounds the underlying mitochondrial failure because calcium is toxic to mitochondria and magnesium necessary for normal mitochondrial function. This is just one of the many vicious cycles we see in patients with fatigue syndromes. The reason for giving magnesium by injection is in order to reduce the work of the calcium/magnesium ion pump by reducing the concentration gradient across cell membranes. So, a low red cell magnesium is an indication for giving magnesium by injection. Doing this makes the work of the ion pumps less hard and therefore helps mitochondria to work better. This explains why it is a waste of time measuring serum magnesium. Serum levels are maintained at the expense of intracellular levels. If serum levels change this causes heart irregularities and so the body maintains serum levels at all cost. It will drain magnesium from inside cells and indeed from bone in order to achieve this.

Correcting a deficiency.

Having said that, getting serum levels as high as possible will make the job of the calcium/magnesium ion pump much easier. Therefore, intracellular levels can be improved by taking magnesium supplements. There are lots of different ways one can do this. The only way I can guarantee to get magnesium levels up is by using Magnesium by injection. I have yet to see a red cell magnesium result which is too high. However, it is theoretically possible to overdose with magnesium in people with kidney failure. Some people never manage to get their red cell magnesium levels into the normal range, and one has to settle for low normal or levels just outside the normal range. Dr John McLaren Howard tells me that there is actually a biphasic normal distribution of magnesium. Because I see low magnesium almost routinely in patients with fatigue syndromes, I just wonder if this vicious cycle of low magnesium and fatigue has a genetic predisposition.

Magnesium by mouth.

Are you taking enough magnesium in the diet? The recommended daily allowance is 300mgs for men, 350mgs for women. Magnesium is extremely safe by mouth – too much simply causes diarrhoea. Try increasing the amount of magnesium you take by mouth until it causes diarrhoea, then reduce the dose slightly so it does not. This is called taking magnesium to bowel tolerance (just like using vitamin C to bowel tolerance). The richest source of magnesium in the diet is from chocolate (yippee, but care with the sugar!), nuts, green vegetables and seeds. Use a magnesium rich salt such as Solo. Use a bottled water rich in magnesium. Hard water also contains more magnesium than soft water. Most processed foods are low in magnesium.



Is magnesium's absorption blocked?

Calcium and magnesium compete for absorption and so too much calcium in the diet will block magnesium absorption. Our physiological requirement ratio for calcium to magnesium is about 2:1. In dairy products the ratio is 10:1. So, consuming a lot of dairy products will induce a magnesium deficiency. Tea contains tannin, which binds up and chelates all minerals including magnesium. If tea is to be drunk, don't have it with food. Incidentally, tea drinking is a common cause of iron deficiency anaemia in the UK for this same reason.

Vitamin D is necessary for the body to utilise magnesium. The only significant source of vitamin D is direct sunshine on the skin (the effect is not the same through glass). Only a small amount is required to make a difference – 1 as little as 10 minutes a day on the face and hands has an effect. One hour of whole-body sunshine in summer can produce 10,000iu! The RDA for Vit D is set ridiculously low at 400iu – in America it has just been raised further, but I like people to have at least 2,000iu and many people I recommend 10,000iu daily. At this level of dosing there are no side effects and no toxicity. In winter, in our climate, we should all be taking vitamin D.

Hypochlorhydria – magnesium requires an acid environment for its absorption and hypochlorhydria will result in poor magnesium absorption. I see this problem very commonly in CFS!

Are you a magnesium loser?

- All diuretics will make you pee out magnesium. By this I do not just mean drugs, but also tea, coffee and alcohol. Even some herbal teas are mildly diuretic.
- Hyperventilation makes you pee out magnesium. This is because hyperventilation induces a respiratory alkalosis, the body pees out bicarbonate to compensate, but each bicarbonate is negatively charged and carries a positively charged cation with it – in this case magnesium. Heavy exercise makes you pee out magnesium. This should not be a problem for CFS patients (although many are ex-athletes!) but does explain why long-distance runners may suddenly drop dead with heart dysrhythmias.
- Magnesium is lost at times of stress. This also includes hypoglycemia, food allergy reactions and detoxification.

Can you hang on to magnesium?

For magnesium to be retained inside cells you need good cell membranes. The two important facets of cell membranes are: to have good antioxidant status and have good levels of fats and Essential Fatty Acids in the diet. Boron is necessary for normal calcium and magnesium metabolism. Calcium and magnesium metabolism is of critical importance in livestock. Indeed vets will tell you about the dramatic effects that injecting these minerals has on cows at calving time. What is interesting is that they don't just inject calcium and magnesium, they actually inject calcium, magnesium borogluconate - i.e. it seems that the boron is also important in calcium/magnesium metabolism. Boron is also of proven benefit in arthritis.

Magnesium comes in many different forms. Supplement manufacturers produce a wide range of supplements which can be confusing. A single ingredient supplement is not likely to work very well. They need to be balanced with fatty acids (EPA, GLA) and as well as a full spectrum of A-Z vitamin and mineral supplements.

<u>Magnesium Salt</u>	<u>Absorption</u>	<u>Reputation</u>
Oxide or Hydroxide (Milk of Magnesia)	Poor	Causes diarrhoea in higher doses
Sulphate Epsom salts	Poor	Laxative
Taurate	good	Heart health
Glycinate	good	Best tolerated for sensitive bowels
Citrate	good	Cost effective
Malonate	good	Good for fibromyalgia

North of Doncaster Personal thoughts from Trevor Wainwright

Inspiration Part 1

Sometimes I'm asked what gives me inspiration for my poetry, it's hard to say because it can come at any time and I never know when it will end. It could be music or a comment, it might be totally unexpected from something I decide to do. Like in 2015 when I decided to find and listen to *Out Along the East Coast*, a Yorkshire folk song that depicts a tour of the Yorkshire Coast. I had heard it years ago and liked the chorus and so downloaded it and began listening, Pictures of the Yorkshire coast went through my mind, then I thought maybe I could change it, keep the chorus but change the words to depict a trip down the Texas Coastline I did in 2012. So, it began, and the first thing was to read the lyrics and where they needed to be changed, then look at the photos I had taken. First, I needed a title 'Along the Texas Coastline' was chosen and so it began with reading through the lyrics.

1) *Out along the East Coast, breakers sweep the shore, Harbour lights are smiling, and the lighthouse keeper is turning up his lamp more Out along the East Coast, lovers keep the view And the seabirds tell me that those lovers look a bit like me and a bit like you. Chorus: The sea rushes in, castles crumble and die, And I walk along with the ocean and I talk to the sky.*

The first verse would begin with the title words to start the poem and say where I was. The remainder would stay, but I would change a word in the chorus

2) *Down the cliffs at Scarborough, on a tram car ride, out across the water there's a red sailed vessel leaning over on its side, By the fishnet harbour, an old sea captain smiles, sailing home through smoke-rings while the windswept ocean tells me clearly that all the while, Chorus:*

The second verse would mention whereabouts I was and what I was and wasn't going to do.

3) *Lies a town at evening, cradled in the bay, out along the headland there's fine-looking sunset; curtain of brand-new day, Cayton Bay to Flamborough, Hornsea round to Spurn, stands a whitehorse army, and a lonely coastguard waiting for the tide to turn, Chorus:*

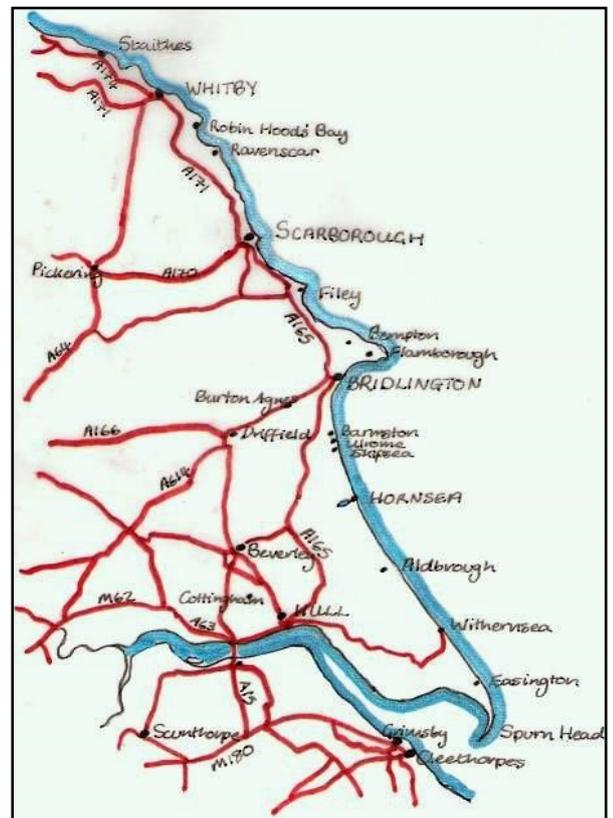
As with the second verse I would give a geographical location and add the first character to the poem, someone I had met during the drive, later he would become very relevant

4) *Down the beach at Aldeburgh, on the silent sands, spins a wing-ed maiden with a seagull's long lost feather waving in her hand, Out along the East Coast, lovers keep the view, And the seabirds tell me that those lovers look a bit like me and a bit like you.,., Chorus: Verse 4 the last*

The Verse in the original song would be a completely new verse, again with a geographical location and what it was about. Verse 5 would take the structure of verse 4 from the Yorkshire version and verse 1 with just a location change

And so, it became as it is seen over the page. It went down a storm in Texas in 2015 and earned me the title: Trev the Journalistic Poet

Next issue: Who was Hugh?



Photos over page.

*Breakers sweeping the shore and seabirds.
Bluewater Highway.
Just in case the sea does rush in.
Port Isabel Lighthouse.
Dolphin Sculptures near South Padre
Harbour.
Will this castle crumble and die.
(background)*

Along the Texas coastline

1



Along the Texas Coastline, breakers sweep the shore,
 It's 2012 and I'm in Texas once more
 Along the Texas Coastline, lovers keep the view
 And the seabirds tell me that those lovers look a bit like me and a bit like you.

*When the sea rushes in, castles crumble and die,
 I walk along the ocean and I talk to the sky.*

2

Down Bluewater highway, an early morning ride,
 Out beyond the beach the sun is shining on an incoming tide,
 Along the Texas Coastline, many miles to go
 I'm not gonna rush, I'm gonna let the poetry flow

*While the sea rushes in, castles crumble and die,
 I walk along the ocean and I talk to the sky.*



3



Port Lavaca at evening, cradled in the bay,
 To the Western horizon hangs the firestained sunset curtain of another day,
 Galveston to Corpus Christi, under a bridge a guy called Hugh
 Plays his guitar and if you stop and listen, he'll sing a song for you

*While the sea rushes in, castles crumble and die,
 I walk along the ocean and I talk to the sky.*

4

Port Isabel lighthouse seen from 16 miles away
 Brought sailors home to safety at the end of the day
 It's been a long drive, for solitude I yearn
 So find a quiet beach and wait for the tide to turn

*When the sea rushes in, castles crumble and die,
 I walk along the ocean and I talk to the sky.*



5



Along the beach at South Padre, across the silent sand,
 Runs a fair Texas maiden with a seagull's long lost feather waving in her hand,
 Along the Texas Coastline, lovers keep the view,
 And the seabirds tell me that those lovers look a bit like me and a bit like you

*When the sea rushes in, castles crumble and die,
 I walk along the ocean and I talk to the sky.*

By Trevor Wainwright