Pathways

Price £ 4.00 (Free to members)

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

Welcome to Pathways No. 58. (Winter 2018)

Merry Christmas & Happy New Year

You Write In

Camilla writes: I wonder if you have heard a report about Staff working at a nearby Atos benefit assessments contractor threatened to call the police after a claimant asked about the mental health qualifications of the nurse who was assessing his eligibility for payment of PIP.

The story goes that Bill began to tell the assessment nurse that he had stayed up all night because of the anxiety he experiences when dealing with institutions. He reports working for three days three days putting together a 10-page description of his complex mental health problems – and he says is the "continual failure to even listen to his problems by multiple institutions" – in the hope that the assessor would help him secure the financial and health support he needed. (1)

He explained that he had been unfairly described in the past as "violent" by the NHS after a telephone argument, although the assessor told him that Atos had no record of this. the assessor appears to have wrongly blamed the decision to refuse him a home assessment on the Department for Work and Pensions (DWP), when such decisions are taken by the assessment companies, Atos and Capita. (2)

The assessor can then be heard leaving the room after Bill began asking about her experience and qualifications in mental health. She told Bill that she was "not happy to sit in this room with you" because she said he had questioned her qualifications and was "being difficult for no reason". Bill, who did not raise his voice or threaten the assessor at any point in the conversation, told her: "You seem to have had a bit of an attitude from the start, a bit of a blasé attitude. "You didn't look at me, you didn't say hello to me, you didn't treat me like a human." (3)

Despite the lack of any aggression or threats from Bill, a colleague of the assessor then told him he needed to leave the building "or we'll call the police", before repeating: "We'll call the police if you don't leave." Bill tried to explain to Atos staff that he had "wanted to make sure that somebody understands my illness" and added: "When ill people come in you need to have compassion, not treat them with an attitude." A third member of staff then denied that they had threatened to call the police, before a colleague said: "He's just wanting an argument… just shut the door !!!" 4

The story has been posted on number of internet forums and covered in greater depth. Atos has now launched an investigation into what happened at the assessment centre in Leeds, which saw the nurse abandon Bills assessment after just a couple of minutes. She did not realise that Bill, 'a composer and trained sound engineer', had been recording the assessment. Asked for an explanation for what happened and whether Atos would apologies, a spokesman for the company said: "We are aware of the recording and an investigation is underway."

1 Documents should be submitted along with the PIP forms beforehand. If necessary, any additional information taken to an assessment and should be no longer than a single page, as the staff are under no obligation to read it.

2 Decisions as to if a home visit is needed are made by the assessment centre and are usually based on the response of a discreet enquiry send to the doctors' surgery. So, if you want a home visit, you must make this clear to you doctor beforehand (before the form goes in), but you must have good reason, and preferably have it recorded in your doctors' records.

3 I certainly wouldn't deal with anyone behaving in such an unreasonable manner.

4 The correct way to treat ATOS and Capita staff is as you would a police man, with respect, caution and dignity. Their job is to find the truth as far as the system allows.

What is unclear about this posting is the exact nature of Bills disabilities or Mental health. Regarding assessment centre staff qualifications. In the case of a benefits dispute, when I receive copies of the ESA 85 or the RV4 forms the name of the assessors are stated. As a matter of course, these are checked against the relevant national registers by us. We think that If bill had engaged the services of a welfare rights advisor like Leger ME members are advised to do, I'm certain that this incident would not have happened.

Gwendolyn writes— Is it safe to take VegEPA with prescription medication? I take fluoxetine, amitriptyline and losartan. I've asked one pharmacist and she said she wouldn't recommend mixing VegEPA with fluoxetine as it may cause a reaction. The pharmacist I spoke to said it was the evening primrose oil in the VegEPA that may react as she said not to mix herbal supplements with antidepressants. I'm only taking fluoxetine at the moment though. The main reason I wanted to try VegEPA was to see if it improves my brain fog, as it's definitely got worse. Is that what it is used for?

What the Pharmacist is doing is playing safe because she doesn't understand the product and the research behind it. She is possibly thinking in terms of St John's Wort, which definitely reacts with SSRI's and almost everything else on the medicines shelf.

There is no recorded interaction between omega 3 or 6 oils found in VegEPA and fluoxetine in the BNF land other literature I've searched. In fact, if you search the internet there are reports of positive effects mixing the two., for example https://healthfully.com/493779-prozac-fish-oil.html.

For more information see http://drmyhill.co.uk/wiki/VegEPA and see later pages in this issue of Pathways.

VegEPA has two constituents which I know may react adversely in certain circumstances: -.

a) Omega 6 oils are not recommended for people with epilepsy (GLA is found in many food products e.g. Olive oil) this may be what your Pharmacist friend is thinking about.
b) Omega 3 oils may cause problems with anticoagulation used to stop blood clotting. EPA 'thins blood', but this is not a well know side effect and is only significant in people having dental treatment, operations or taking anticoagulant medicines to stop blood clotting.
c) There is an favourable side effect from fish oils on triglyceride levels found in cholesterol tests. About 20-30 years ago fish oils (omega 3) were used to treat a certain type of raised cholesterol that ran in families. The practice has gone out of favour.

The problem is that you must decide for yourself. VegEPA is a food supplement and not a medicine. It's more like the Cod liver oils capsules we were all given at school than anything else. All I would say is if you want to try it, start at one capsule daily, and work up. Most people I've spoken to find a twice a day dosage helps. The manufacturers say up to 8 a day, but I think this excessive. The easiest thing to do is try it at a lowest dose and see how you feel. There are plenty of other omega 3-6 products available from suppliers like Biocare with alternative formulations.

VegEPA certainly does helps brain fog in most of the people I've talked to. Dr Puri wrote a book about the research for VegEPA, and we have a copy in the group library.

Julie Writes - Here is aa photograph of a couple of birds that appeared in my garden in the summer. I wonder in any Pathways readers can guess what they are?

I not going to say what the answer, is, but have a look at the later pages of this edition of Pathways

Winter motoring tips

with thanks to the AA

As the seasons change and days become shorter, we`ll soon be driving in the dark more often. If driving in the dark worries you here are some expert tips from the AA towards staying safe: -

A Clear View`

It may sound obvious, but before setting off check your wipers. Are they working properly or are they making smearing worse? Be sure to clean the inside of your windscreen to make sure the dirt isn`t on your side of the glass. If you can, dim your dashboard lights, this will help reduce reflections onto the screen, giving you better night vision.

Ditch the Dazzle`

If you find yourself being dazzled by oncoming car lights, focus on the left-hand side kerb and keep your speed steady. If that doesn`t work, slow down or pull over and stop until your eyes have fully adjusted. As we age it takes longer for our eyes to recover from dazzling lights. It increases from one second as a teenager to nine seconds as we reach retirement.

'Let it Shine'

As a simple rule of thumb, turn your car lights on about an hour before sunset in the evening and an hour after sunrise in the morning, this should ensure you are clearly visible in dimly lit conditions.

Take it Steady`

At 60mph your headlight`s reach is around 180ft on low beam. When travelling at 60mph it takes more than 200ft to come to a complete stop, so it is advisable to drive slower at night than you would during the day. When driving on country roads avoid reducing your speed when there is oncoming traffic and then speeding up again. This makes it very confusing for drivers travelling behind you. Drive at a speed you can maintain and stick to it, even if there are times you could go faster.

Help others overtake you`

If someone is overtaking you, keep your full-beam lights on until they are alongside you, slowing down if necessary. This will help them see the road better and avoid any accidents.

Safe Driving

Introduction to Universal Credit (UC) *by Susan Harrison*

After reading Mike's recent email about the roll-out of Universal Credit, UC, I wanted to find out more. I've found information on lots of different websites and the ones I've taken notes from for this article are listed below.

Universal Credit will be a single benefit, rolling together and replacing these 6 benefits:

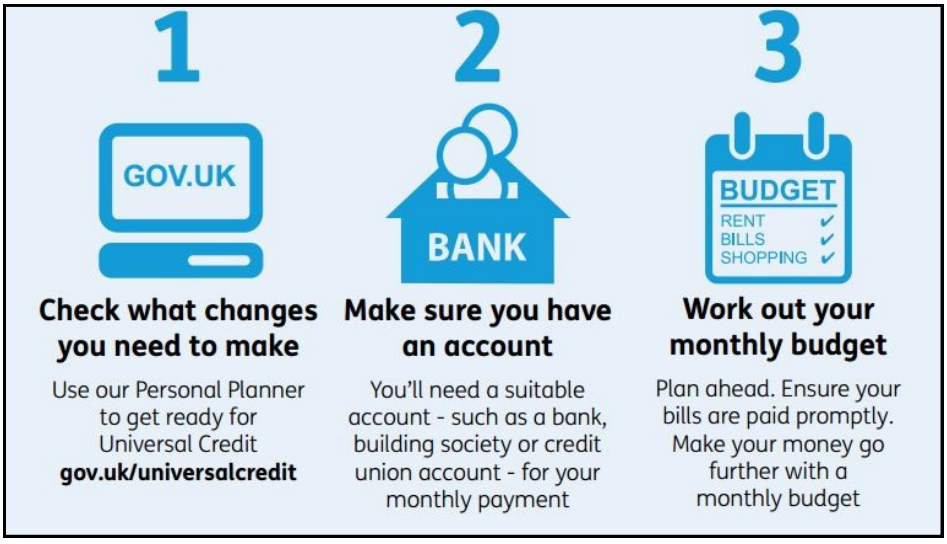
Those benefits not subject to means testing will continue to be paid separately. Therefore, Disability Allowance, Personal Independence Payments, Carers Allowance and Child Benefit payments will not be affected. Anyone on contribution-based ESA or contribution based JSA stays out of UC whatever their circumstances until they move to income-based benefits.

There are separate rates for people under 25 years of age or over. The payment categories are also lower than for ESA and paid monthly in arrears instead of twice weekly. There has been huge criticism over the wait period for the first payment, which has caused hardship and stress for people with no savings to fall back on to fill the gap. This has been amended and shortened and may yet be looked at again.

There are two categories for moving to Universal Credit, **Managed Migration** and **Natural Migration**

- **Natural Migration** happens, for example, when you move house from an ESA Local Authority area to one with UC already in full use, or your circumstances change in any way.
- **Managed Migration** happens after your Local Authority has fully changed from ESA to UC. It should then only be triggered by changes of circumstances or when your review is due.

After many delays and rescheduling, the government is now planning to start Managed Migration in July 2019 and finish in 2023. We do not yet know if our area will start Managed Migration next July or if we will be one of the (lucky) later ones. Having searched extensively to try to find out and failing, it may well be that the DWP do not know themselves yet. Some people have already gone through the process of transferring to UC and one main issue seems to keep cropping up.



The JobCentre Plus offices, when they make the change from ESA to UC, must continue to honour and pay, without question, the Limited Capability element a person was already receiving on ESA. This is the extra money you get for proving you are presently incapable of working or seeking work and therefore in the Limited Capability for Work Related Activity or the Support Group. This guarantee is covered in Regulation 19 and part of this is below in blue.

Regulation 19 of the Transition Provisions Regulations 2014

" This regulation applies where –

a. An award of Universal Credit is made to a claimant who was entitled to old Style ESA on the date on which the claim for Universal Credit was made ("the relevant date") and

b. on or before the relevant date it had been determined that the claimant was entitled to the work-related activity component or to the support component"

This clearly states that the government intends you should keep any existing Limited Work Capability or Support Group payments you have previously been awarded. A migration from ESA to UC should not trigger a new Work Capability Assessment. Bear in mind though, that the DWP can legally re-assess you at any time.

However, sadly it appears that as each new JobCentre Plus office rolls out UC, they are all getting this wrong and not honouring existing Limited Capability allowances, so starting the reassessment process. The *Disabled Living Foundation website* advises the following if this happens to you: Politely tell the person at the Jobcentre Plus office that they are wrong and ask to see a Supervisor if they persist in telling you they are right.

Quote the government **Transitional Provisions Regulations and Regulation 19** (In blue, above) If they insist on not letting you automatically keep your Limited Capability for Work or Support Group allowance then they have made a decision to re-assess you, even if they say they haven't. As mentioned, they can legally decide to re-assess someone at any time, but the change from ESA to UC should not be a reason to trigger a re-assessment.

Sadly, once you are issued a UC50 form (the equivalent to ESA50) to complete, you are in the system and have to complete and return and potentially go to a face-to-face assessment.

The CAB, Citizens Advice Bureau, is apparently fully aware of this fault and might be able to help. The CAB has come under fire from some quarters to agreeing to work with the DWP on the transition from ESA and other benefits, to Universal Credit. It appears to signal that they agree with Universal Credit. Writing a letter to the DWP about this apparent disregard for Regulation 19, with a copy to your MP is also an option but it not likely to stop the process of re-assessment once it has started.

Please don't forget that Leger ME members should contact Mike the minute they get any communication or form from DWP, as getting it right first time is much better that trying to go it alone and then having to work through and endure the stresses of the appeals process.

Finally, I've seen mention of people being told they can only complete forms online. I haven't been able to work out who this might apply to but I'm sure if we get any more details, we will let you know.

Best wishes with getting through the transition everyone.

Susan Harrison

Websites used for information for this feature:

www.gov.uk,
Disabled Living Foundation,
www.Entitledto,
www.bbc.co.uk,
www.turn2us.org.uk,
www.researchbriefings.files.parliament.uk,
www.revenuenenefits.org.uk,
www.moneyadviceservice.org,
www.disabilityrightsuk.org,
www.scope.org,
www.cpag.org.uk
(Child Poverty Action Group).

BDA The Association of UK Dietitians

Food Fact Sheet

Supplements

If you walk around your local pharmacy, health food shop or supermarket you will see a huge selection of vitamins, minerals and other nutritional supplements in a bewildering range of doses, formulas and combinations.

What are supplements?

As the name implies supplements (dietary / nutritional) is any product that aims to 'supplement' the diet in nutrients that could potentially be missing. There are hundreds of different supplement products, from well know vitamins and minerals to bee pollen, green tea and gingko biloba. However do we really need these supplements or are they just a waste of money? How much should you have? Are they safe? Mixed messages from the media, family and friends can make things even more confusing. This Food Fact Sheet will help you decide.

Who needs supplements

People take supplements for a wide variety of reasons, predominantly these reasons relate to health and improving health outcomes. However it is important to note that most people can get everything they need to be healthy by eating a varied, balanced diet.

You can do this by eating:

- plenty of fruits and vegetables – aim for a variety and at least 5-a-day
- plenty of starchy foods such as bread, potatoes, rice and pasta – include these with each meal
- some milk and dairy foods (or suitable dairy free alternative which is fortified with calcium) – adults need 2-3 servings a day to reach the recommended amount of calcium (if you are managing less than this consider talking to your doctor who may advise a supplement)
- some meat, fish, eggs, beans or other foods rich in protein
- limit foods which are high in salt, sugar and fat.

It is important to note that a healthy balanced diet doesn't just provide you with essential vitamins, minerals and nutrients, but also other elements which cannot be obtained from nutritional supplement. For example, fibre, which is essential for healthy gut function.
There are certain groups of people who may benefit from taking supplements.

See the table overleaf to see who The Department of Health recommends take supplements.

Some women who are pregnant or who have a baby under one year of age and children from six months of age until their fourth birthday may qualify for Healthy Start vitamins. Healthy Start women's vitamins contain folic acid, vitamin C and vitamin D and Healthy Start children's vitamin drops contain vitamins A, C & D. Speak to your doctor, midwife or health visitor to see if you qualify. If you think you are not having enough of one or more nutrients and are thinking about taking a supplement, always consult your doctor, or ask to see a dietitian.

Choosing a supplement

- always buy supplements from a reputable source. For example your local chemist/pharmacy or supermarket, and not from an unknown company on the internet
- check the label – it should tell you the amount in each dose and should have an expiry date
- make sure you really need the supplement by asking your doctor, dietitian or pharmacist/chemist.

Risks

Although most nutritional supplements are safe if taken in the correct doses, there are some risks.

Quality – internet products may not meet UK standards and may not have gone through the same checks as products from a more reliable source. There could be less of the active ingredient than claimed, or the product could contain ingredients harmful to your health.

In some cases, a supplement have benefits, however they are not a substitute alternative for a healthy diet.

Who?	Which supplement?	Why?
All children from six months to five years (in some cases breastfed babies from one month old)	7 – 8.5 micrograms of vitamin D (unless having 500ml fortified infant formula a day)	To prevent vitamin D deficiency
Women who are trying to conceive and women who are in the first 12 weeks of pregnancy	400 micrograms of folic acid daily	To reduce the risk of neural tube defects in the unborn baby
Women who have had a previous pregnancy affected by a neural tube defect or they or their partner have neural tube defect or women who have diabetes	5 mg of folic acid daily	To reduce the risk of neural tube defects in the unborn baby in this high risk group.
Women who are pregnant or breastfeeding	10 micrograms of vitamin D daily	To prevent vitamin D deficiency in both the mother and the baby
People aged 65 years and older	10 micrograms of vitamin D daily	To prevent vitamin D deficiency as they do not make enough under their skin
People with darker skin or who receive very little exposure to sunlight	10 micrograms of vitamin D daily	To prevent vitamin D deficiency as they not make enough under their skin

If you want to buy supplements via the web choose a recognised high street retailer that also trades online.

Quantity – taking too much of a vitamin can be dangerous. Some vitamins dissolve in water 'water soluble', and any that your body doesn't need will leave your body when you pass urine. You cannot store 'water soluble' vitamins. Your body can store the fat soluble vitamins A, D, E & K though and you can become unwell if too much is taken.

You can make sure you don't take too much of any vitamin by only ever taking the recommended dose on the label (unless advised by your doctor). If you take more than one supplement, make sure that you are not doubling up on any nutrients. For example, if you take a multivitamin tablet which includes vitamin D, don't take an additional vitamin D supplement unless advised to by a health professional.

Other risks

- Wasting your money! Supplements can be expensive and a lot of them have no proven benefits at all. They may claim to delay ageing, boost your metabolism or make you slimmer but in fact there is little or no evidence to back up many of these claims.
- Supplements may have interactions with some medication and some are unsafe if you suffer from certain medical conditions. This is why it is important to talk to your doctor before taking any supplements.
- Fish liver oil should not be taken by pregnant women as it contains vitamin A; large amounts can be harmful to babies.
- Vitamin E supplements should be avoided by people with cardiovascular disease as it can increase the risk of further heart attacks.
- Effervescent (fizzy) vitamin supplements contain approximately a gram of salt per tablet. Therefore you might want to consider changing to a non-effervescent alternative, especially if you have been advised to limit your salt intake.

Summary

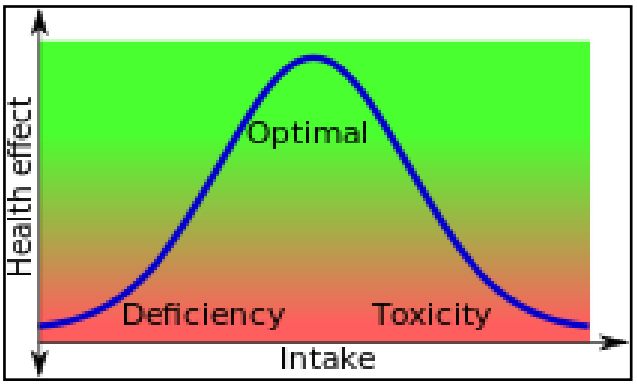
Most people can get all of the vitamins and minerals they need from a balanced diet and some time in the sunlight. In some cases, a supplement have benefits, however they are not a substitute alternative for a healthy diet. Before taking a supplement, make sure your information is reliable and speak to your doctor, dietitian or pharmacist/chemist.

Further information:

Food Fact Sheets on other topics including *Vitamin D and Calcium*, are available at:
www.bda.uk.com/foodfacts

Multivitamins and Mineral products and Fatigue Syndromes

A recent BBC Horizon programme on the topic investigating whether supplements are necessary, unnecessary, maybe even dangerous? In the programme Dr Giles Yeo argued that most people weren't deficient in vitamins and minerals and can get most of their nutrients from a balanced, diet, even take-aways and curly fries! So why use supplements then? His argument ignores the widespread evidence from recent National Diet and Nutrition Surveys that a large proportion of UK adults may not be achieving adequate vitamin and mineral levels, because they do not follow healthy diet guidelines. Even if those foods mentioned contain some nutrients, it ignores the effect of eating a high calorie, high sugar processed diet on depleting those nutrients and negatively affecting health. More importantly, what's the right level of nutrient for you, considering diet, lifestyle, and disease. Are the baseline Government recommended levels enough, especially if, as the programme acknowledged, you're young, old, or pregnant? But also, what if you have severe fatigue, heavy periods, take medications that might deplete your nutrients, or have a stressful lifestyle?



So, what's the answer? Things are often more complex than they seem. The programme rightly concluded that we need more research, and we agree. In the meantime, we should recognise our nutritional needs are complex, unique, and that supplements should be suited to those needs. As multiple studies have shown, supplements are neither miracle nor myth, but in the right hands are safe and beneficial ways of supporting our health.

Do multivitamins and minerals have a role to play in ME/CFS/Fibromyalgia?

Certainly, if you are a follower of Dr. Myhills strategies you realise that she has definite nutritional ideas. In the twenty something years I've been dealing with ME/CFS/Fibro at Leger ME, it is noticeable that those who have engaged her strategy have done better as a group than those who have not. We know for example that almost all local ME/CFS cases have depleted vitamin D3 levels, which can increase fatigue and pain, which can be relieved by vitamin D3 medicines from their GPs. The problems are that vitamin D2 is included in many multivitamin products, and it is the inactive form requiring sunlight for activation. It is available from vegetarian source. The B vitamins taken as a group improve the fatigue and neurological symptoms in certain individuals, but not everyone. On one occasion I asked Dr Myhill why she didn't test for specific deficiency in her patient. The answer that came back was it was not necessary as most of her patients are deficient in the B group, zinc and magnesium. Also, antioxidants are needed to protect from further oxidative damage at cellular level. We know for example that many people with ME/CFS are deficient in vitamin B3, Niacinamide. This is a key vitamin within the energy and respiratory chain that exists within the mitochondria, the powerhouse of the cell. Coenzyme Q10 is also involved. Magnesium is also involved. Many Leger ME members often ask me what is the best to go for. There is no definitive answer. To help clarify the situation we've compared the contents of three commonly sold types multivitamin products.

- **Centrium Advance** s a well know pharmacy supermarket brand. Cost is approximately 10p per day. There are many variants e.g. 50+, children's.
- **Biocare multivitamins** are a well know brand within ME/CFS circles. The cost is about 25p per day. The formulation contains higher doses of many of the ingredients of the supermarket brand, which seems to insure against known ME/CFS problems. Again, there is a range which includes many products targeted at ME/CFS.
- **Forceval** has been around for many years as a prescription multivitamin product. It is intended for malignancy and immune deficiency syndromes, such as AIDS, anorexia or cachexia, special or restricted diets and food intolerances. Formulation is very similar to Centrium. Cost is about 50p per day for the Pharmacy based product. The medicines-based product will be far more expensive

I prefer to look at multivitamins as 'Vitamin Insurance' to ensure you get some of the right amounts somewhere along the line. As to what to buy, *you take your choice and pay your money*

	Centrium Advance	Centrium RDA	Biocare MV	Forceval Capsules:	Biological Function
Calcium	162 mg	20%	6mg	108mg	Necessary for the formation of bones and teeth and plays a vital role in cell function, muscle contraction and in the nervous system
Chromium	40 mcg	100%	50mcg	200mcg	Helps the body to use glucose by its action on insulin
Copper	500 mcg	50%		2mg	Required for growth and forms part of enzymes involved in blood and bone formation
Folic Acid	200 mcg	100%	400mcg	400mcg	Required to regulate the growth of cells including red blood cells and protein synthesis
Inositol			12mg		Intracellular processes, insulin sensitivity
Iodine	100 mcg	67%	98.7mcg		Involved in functioning of the thyroid gland which regulates many of the metabolic processes in the body
Iron	5 mg	36%	38mcg	140mcg	Forms part of red blood cells which carry oxygen round the body
Magnesium	100 mg	27%	22mg	30mg	Magnesium is essential for the formation of bones and teeth, and for the release of energy from food
Manganese	2 mg	100%	300mcg	3 mg	Helps the body to utilise calcium and potassium and maintain the structure of cells
Molybdenum	50 mcg	100%	98.7mcg	250mcg	Involved in the enzyme processes for protein metabolism.
P.A.B.A. (para amino benzoic acid)			10mg		Essential for skin and large intestine function. (IBS)
Phosphorus	125 mg	18%		83mg	Necessary for the formation of bones and has an important role in many varied chemical reactions in the body
Potassium			8.9mg	4mg	Essential in muscle function and in the transmission of nerve impulses
Selenium	30 mcg	55%	50mcg	50 mcg	Helps to protect the cells and lipids from free radical damage
Vitamin A (RE)	800 mcg	100%	600	750mcg	essential for growth, maintenance of skin and mucous membranes such as the linings of the mouth, nose, lungs, digestive system, colon and for vision, particularly at night
Vitamin B1 (Thiamine)	1.4 mg	127%	25mg	1.2mf	Involved in the proper functioning of the heart muscles and for the release of energy from protein, fat and carbohydrate, needed for growth, normal appetite and digestion. Thiamine has also been shown to play a vital role in the normal functioning of the nervous system
Vitamin B12	2.5 mcg	100%	30mcg	30mcg	Often called the 'red vitamin' because it is required for regulating blood cells. Powerful antioxidant.
Vitamin B2 (Riboflavin)	1.75 mg	125%	25mg	1.6mg	Plays a key role in energy metabolism, and is required for the metabolism of fats, carbohydrates, and proteins
Vitamin B3 Nicotinamide Niacin	20 mg	125%	50mg	18mg	Essential for a healthy nervous system and energy. Usually low in people with fatigue syndromes
Vitamin B5 Pantothenic Acid	7.5 mg	125%	100mg	4mg	Plays a vital role in the process of releasing energy from foods, the role of fat metabolism and the provision of the immune system with antibodies
Vitamin B6 Pyridoxine	2 mg	143%	25mg	2mg	Helps protein metabolism, along with the maintenance of the nervous and immune systems
Vitamin C	100 mg	125%	241mg	60mg	An essential vitamin with an important role in maintaining the health of our cells, blood vessels and our resistance to infection. helps bones, teeth, gums, skin and assists the absorption of iron from the blood
Vitamin D	5 mcg	100%	6.25mg	10mcg	Vitamin D2 helps the body absorb calcium, potassium and phosphorous, all of which are vital for healthy bones and teeth
Vitamin E (α-TE)	15 mg	125%	50mg	10mg	A highly effective antioxidant, helping to protect the body from the effects of free radicals. It also helps to maintain healthy skin and blood cells
Vitamin K	30 mcg	40%			Essential for blood coagulation and bones
Zinc	5 mg	50%	8.5mg	15mg	Required for growth and cell function, bone metabolism, taste, insulin production and the body's immune system.

Slow - cooked Garlic and Tarragon White Wine Chicken

with thanks to Carolyn

His recipe serves four people. Preparation time is 15 minutes and cooking time is 1hour and 10 minutes

Cooking Method: -

1) Preheat the oven to 200C/400F/Gas Mark6.

2) Heat the oil in a large lidded casserole over a medium-high heat. Season the chicken all over, add to the pan and brown in the oil, then remove and set aside.

3) Add the onion to the pan and cook gently for 10 minutes until softened. Add the garlic cloves, chicken, tarragon, white wine and stock and bring to the boil.
4) Cover with a lid, transfer to the oven and cook for 45 minutes.

5) Remove the lid and cook for a further 20 minutes or until the chicken is very tender.
Transfer the chicken to a serving dish to rest, then return the casserole to a medium-high heat and bubble the sauce away a little more until it coats the back of a spoon.

6) Add the cream or crème fraiche, check the seasoning then stir in the parsley. Spoon the sauce over the chicken and serve.

Per serving: - 360 cals 12g fat (3g sat fat) 4.5g sugar 0.5g salt

Ingredients:-

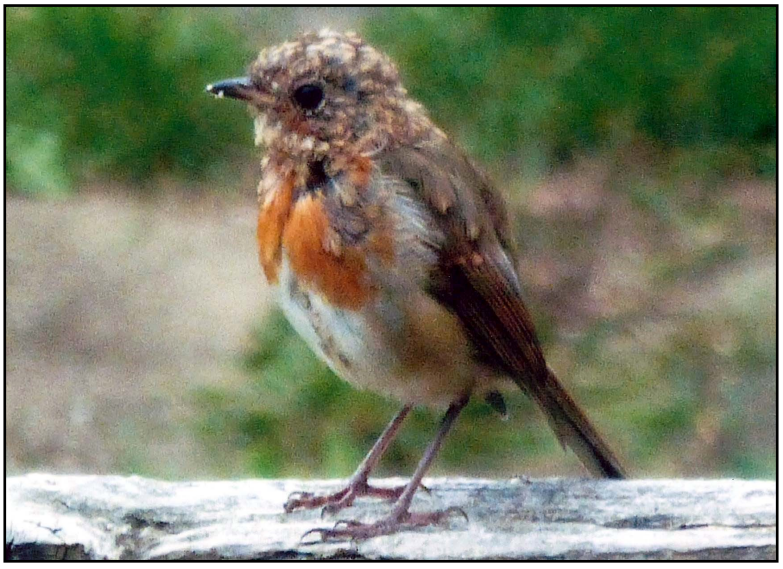
2 tbsp olive oil
4 chicken legs
1 large onion, thinly sliced
1 head of garlic, cloves separated and peeled
3-4 tarragon sprigs
600ml (1pt) white wine
500ml (17fl oz) gluten free chicken stock
Splash of double cream or crème fraiche
Handful of chopped flat-leaf parsley
Sea salt and black pepper

Out and About: Moon Visits Doncaster

With Thanks to Julie Evans

In late November Luke Jerram's art installation 'Museum of the Moon' visited Doncaster. The 7-meter moon model based on NASA images was exhibited in Doncaster Minster.
After visiting Doncaster, this exhibition will be dismantled and move to Romania. Further exhibitions are planned for the UK in 2019. For further details please see: -
https://my-moon.org/tour-dates/

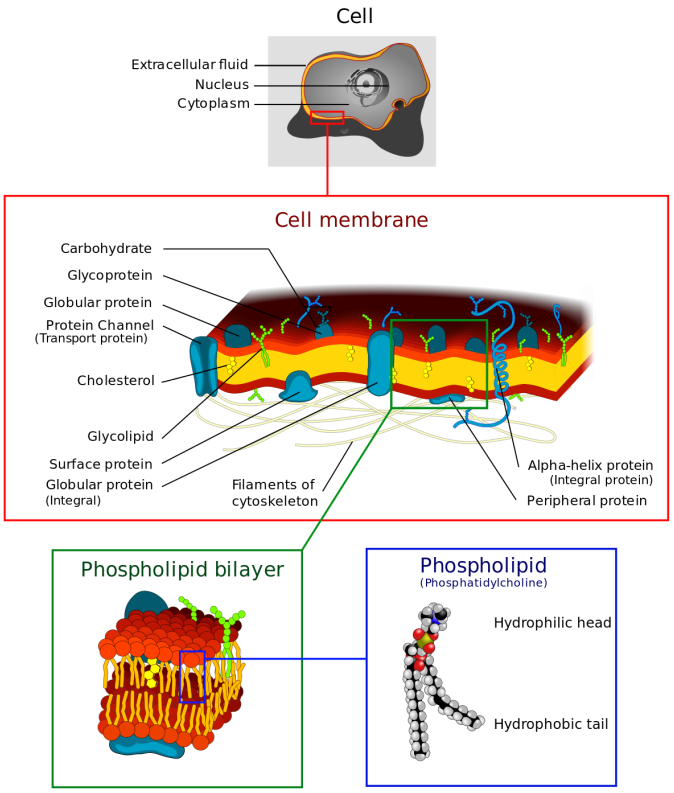
Bird Puzzle from page 2.



The photograph on the right was taken a couple of weeks after the picture on page 2. The original picture is of two fledglings just after they left the nest. The feathers are for camouflage rather than show. The photograph is of an adolescent bird who is losing his fledgling plumage and the adult plumage is beginning to show through. There are no prizes for guessing the species of bird.

Lipids, Fats and Essential Fatty Acids

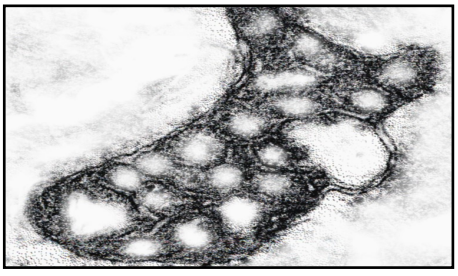
With Thanks to Dr. S. Myhill



Fats, Membranes, the Healthy Brain and Mitochondria

The vast majority of cell metabolism takes place on, in, or around cell membranes. If you took all the cell membranes in one person and spread them out flat, they would cover 100 square kilometers and if you were to run around this, then you would be running a marathon! The structure of cell membranes is identical throughout the animal kingdom. They are made up of fatty molecules which have a water loving end and a fat loving end - these combine in a sandwich so that the fat loving end forms the core of the membrane and the water loving end forms the outside of the membrane. The structure of the membrane and how liquid it is depends on the fats that are in it. If the composition of membranes change, then they will either become stiffer or more liquid.

There are a great many effects which result from a change in the composition of membranes, for example increased irritability and sensitivity. These effects could, in turn, explain many symptoms such as intolerance of chemicals and foods, intolerance of heat, light and touch, low pain threshold, cardiac dysrhythmias and so on. Indeed, a great many drugs work because of their effects on changing membrane structure. Drugs such as general anesthetics, tranquillisers, pain killers and anti-inflammatories work in this way.



Above: A normal mitochondrion. Below: An abnormal mitochondrion from a ME/CFS patient

Mitochondrial membranes are different from cell membranes because they must be a little stiffer in order to hold still the bundles of enzymes, called cristae, on which oxidative phosphorylation takes place. They have an additional fat namely cardiolipin to create this extra stiffness. Having the correct oils in the diet is essential for energy supply to the brain. A poor energy supply means brain fog - poor memory, difficulty thinking clearly etc.

What are these lipids and where do we get them?

1. The body cannot make many of these lipids and so they must be taken in through the correct diet. Membranes are largely made up of phosphatidylcholine (they also require phosphatidylserine, phosphatidylethanolamine and phosphatidylinositol) and these are present in foods which are made up from other animal cells i.e. meat, fish and eggs. They are present in non-meat foods for example lecithin (present in soya) is a particularly concentrated form of phosphatidylcholine. Furthermore, for all these fats to be available we need a good digestive system.
2. We then have "specials" which have special functions within these membranes. These are, namely, omega 6 and omega 3 essential fatty acids. Omega 6 essential fatty acids come from evening primrose oil, borage oil, star flower, blackcurrant and other such foods.
3. Omega 3 oils. These come from fish, nut seed and vegetable oils especially linseed oil.

What healthy cell membranes require?

1. Healthy cell membranes need the correct fats from the above diet.
2. They also need freedom from toxins from the outside world such as heavy metals, pesticides and other such volatile organic compounds. These fat-soluble toxins get into cell membranes where they disrupt normal membrane fluidity with multitudinous effects.

3. Freedom from endogenous toxins (substances that originate from within the organism) - these are largely produced as a result of normal cell metabolism, from the fermenting gut Fermentation in the gut and CFS and from immune overactivity Inflammation and are mopped up by antioxidants. Having a good antioxidant status is, therefore, essential for the maintenance of normal membranes.
4. Stabilisation of membranes. This is largely carried out by methylation. The methylation cycle needs essential B vitamins such as B12 folic acid and pyridoxal-5-phosphate.

All the above factors are necessary for the maintenance of healthy cell membranes.

What happens when problems arise?

When problems develop, this almost always results from toxins building up in membranes (which could be toxins from the outside world or toxins from normal metabolism), and this can result in the buildup of very long chain fatty acids called ceramides which again disrupt normal membrane fluidity. Indeed, this happens as part of the normal ageing process.

Blockage of the delta-6-desaturase enzymes occurs very easily and again may well be a feature of the normal ageing process. This blocks the availability of certain essential fatty acids and we may have to get around this by tweaking the diet or taking supplements for the essential fatty acids. One example of this is blockage of delta-6-desaturase by viruses or toxins which may trigger a chronic fatigue syndrome. The most difficult to make essential fatty acid in this case is DHA which is at the end of the metabolic line. When things get complicated it is essential to measure the different fatty acids in order that the correct supplement or diet can be put in place.

Implications for Treatment

The idea was motivated as a result of a day of lectures organised by the British Society for Ecological Medicine at which Dr Patricia Kane spoke. She is a leading advocate of lipid therapy and largely uses this in the treatment of diseases involving the brain. She presented a stunning array of case histories in which patients with incurable diseases such as Motor Neurone Disease, Parkinson's disease, Multiple Sclerosis and Alzheimer's had shown improvements, often dramatic. In addition, there were case histories of treating children with autism or severe hyper-activity or developmental delay who had gone on to make substantial improvements as a result of her lipid therapy. Of course, it is not just lipids that can bring about these changes - there are many ways to skin a cat! We all have different approaches to disease but essentially the basic package is the same. All patients need to pay attention to eating a stone age diet, essential micronutrients, sleep, the correct balance between pacing and exercise and detox.

A great many conditions could be further improved by attention to lipids. How I, (SM) see this affecting my practice is that I need to pay more attention to the exact fats that are present in the blood. Initially one can work on a best guess policy since common things are common, but if we are not getting results then the next thing to consider is tests of fatty acid profiles in order to make the correct dietary and supplement adjustments. It is very likely that vegetarians and vegans are going to be short in phosphatidylcholine
.
Patients with fatigue syndromes will benefit from using VegEPA which contains the correct Omega 6 and 3 fatty acids in the right ratios. Vegetarians need to ensure high intakes of polyunsaturated fatty acids from egg yolk, nuts and seeds. Taking high dose lipids also facilitates detoxification and should be done in addition to improving nutritional status and saunaing regimes.

VegEPA

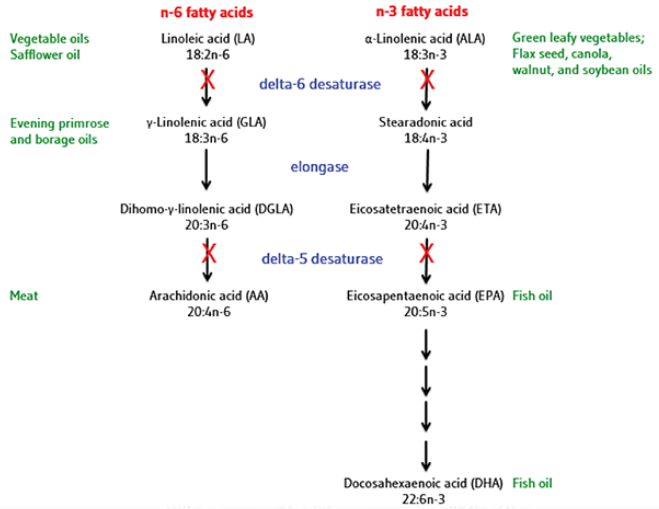
During the 1980s Professor Behan from Glasgow demonstrated that essential fatty acids could be very helpful in treating fatigue syndromes and indeed he conducted a placebo controlled double blind trial using ‘Efamol Marine’ – a mixture of evening primrose oil and fish oil, with beneficial results. Professor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

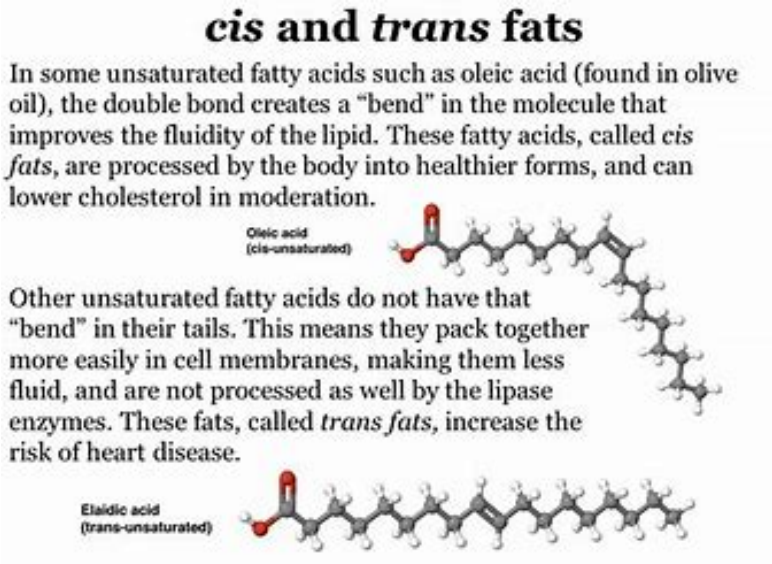
Professor Puri's main work is to do with neuro-development in children and he demonstrated that getting the right balance of essential fatty acids was essential for normal brain development, behaviour and intelligence.

Correct balance of essential fatty acids in the body is essential for many normal processes. They are vital to maintain the correct structure of cell membranes. Without EFAs the cell membrane becomes more rigid and this reduced flexibility may result in abnormal functioning of receptors and enzymes that lie in or are held on membranes. One of the things that I often find in the people on whom I do mitochondrial function tests are problems with oxidative phosphorylation. The bundles of enzymes which are responsible for oxidative phosphorylation lie on mitochondrial membranes and are called cristae. If these enzymes are not held in their correct configuration, then they cannot work properly and so this could be a reason why oxidative phosphorylation goes slow in some patients. There is a phospholipid peculiar to mitochondrial membranes, called cardiolipin, and by doing cardiolipin studies, this gives us some insights into what is going wrong with mitochondrial membranes.

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

EFAs protect us from viral infection. Chronic fatigue syndrome is often triggered by viral infection. Normally we can get all the essential fatty acids we need from natural oils in the diet such as sunflower oil, safflower oil (Omega 6) and linseed oil (Omega 3). However, the first step for these fats to be converted into essential fatty acids requires an enzyme delta 6 desaturase. This enzyme is inhibited by viruses. So, the viruses have worked out a very clever way of ensuring their survival in the body. If they inhibit delta-6-desaturase, then the body cannot make the essential fatty acids it needs in order to kill the virus. Professor Puri and Professor Behan therefore worked out that we can get around this problem by supplying essential fatty acids, which are already converted, namely evening primrose oil and fish oil. The actual preparation of oil and the dose seems to be quite critical. That is why Professor Puri specifically recommends a product called VegEPA.





Good fats and bad fats

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

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

OMEGA-3 FATTY ACIDS - alpha-linolenic acid, i.e. linseed oil (otherwise known as flaxseed oil)

Garden Watch: December

Outdoors

The gardening season this year has been strange. During midsummer, with the heatwave in August many plants were set back due to the lack of rain. Some of the trees went into an early Autumn, while the winter flowers plants seem to be doing quite well, with the key colour being yellow. The Mahonia is coming in flower and is winter Clematis with its bell-shaped pale-yellow flowers. Also, in parts of the garden the primroses normally a spring flowering plant are flowering again out of season. Our variegated holly has just managed two berries this year possibly because of the midsummer dry season. Back again are the winter pansies with their multicolor show. Normally these will flower until Christmas and then die back, and resume flowering again early in the new year.

Garden Visitors

This year the hedgehogs disappeared in early October, presumably hibernating. We've had millions of sparrows, raids by flocks of starlings and a new resident robin. We've nor seen our resident blackbird since April. Some sort of predator raptor does pay a frequent visit, and this tends to deter the regular visitors away from the feeder for a day or two. The unwelcome visitor the squirrels still pay us visits feasting on the bird's food.

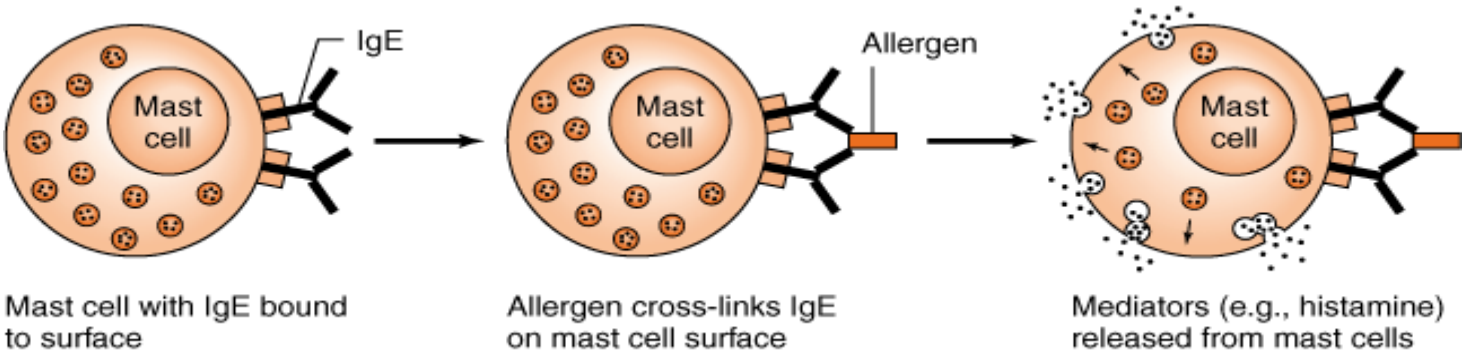
Indoors Gardening

The white Christmas cactus came into flower in early November. This plant must be at least 20 years old. The more common Christmas cactuses are read or orange. The spotted begonia has grown well. This has grown from a single cutting acquired from a holiday cottage several years ago. It has never flowered so far.

Surprisingly as well, two of our orchids have produced some brilliant floral displays. These are horticultural varieties, which have been grown on our windowsill. Over the year it has been necessary to keep these plants sparingly watered and give them specific orchid fertilizer. The flowering is long lasting. The Zygopetalum Trozy Blue produced an unusual flower and the Phalaemnopsis Grandofflorum Alassis produced a flower stalk about eighteen inches high.

Mast Cell Activation Syndrome (MCAS).

Have you ever been the only person in a street, and walked by a house, where a dog starts barking? Have you noticed that once one dog start, all the other dogs in the neighborhood start barking? Well the job of the Mast Cell is a bit like a watchdog for antigens. Antigens things like bacteria viruses or that is anything suspect of causing harm).



Mast cells are "master regulators" of the immune system. They come from bone marrow and go into all tissues of the body. Each mast cell contains secretory granules (storage sacs), each containing powerful biologically active molecules called mediators. These can be secreted when mast cells are triggered, leading to allergic and inflammatory diseases.

It has been suggested in the literature for decades; however diagnostic criteria have been proposed only in 2010. MCAS is a relatively new diagnosis, being unnamed until 2007, and is believed to be under-diagnosed. Many people with ME/CFS have multiple sensitivities, and this may be related in some way.

Symptoms. MCAS is a condition that affects multiple systems, generally in an inflammatory manner. Symptoms typically wax and wane over time, varying in severity and duration. Many signs and symptoms are the same as those for mastocytosis, because both conditions result in too many mediators released by mast cells. It has many overlapping characteristics with recurrent idiopathic anaphylaxis, although there are distinguishing symptoms, specifically hives and angioedema.

Causes. There are no known causes, but the condition appears to be inherited in some patients. Symptoms of MCAS are caused by excessive chemical mediators inappropriately released by mast cells. Mediators include leukotrienes and histamines. The condition may be mild until exacerbated by stressful life events, or symptoms may develop and slowly trend worse with time.

Common symptoms of MCAS include:

Constitutional General fatigue and malaise, food, drug, and chemical allergies or intolerances (especially fragrances), Cold and Heat Intolerance
Dermatological: Flushing, hives, easy bruising, either a reddish or a pale complexion, itchiness, burning feeling, dermatographism
Cardiovascular, lightheadedness, dizziness, presyncope, syncope, arrhythmia, tachycardia
Gastrointestinal, diarrhea and/or constipation, cramping, intestinal discomfort nausea, vomiting, swallowing, difficulty, throat tightness,
Psychological & Neurological, brain fog, short term memory, dysfunction, difficulty with recalling words, headaches, migraines, co-morbid psychiatric and behavioural symptoms as a result of mast cell mediators being released in the brain (i.e. anxiety, depression, mood swings, etc.)
Respiratory, congestion, coughing, wheezing, Nonallergic rhinitis with eosinophilia syndrome (NARES), Obstructive Sleep Apnea
Vision/Eyes ocular discomfort, conjunctivitis, redness
Musculoskeletal osteoporosis and osteopenia (including young patients)

Diagnosis. MCAS is often difficult to identify due to the heterogeneity of symptoms and the "lack of flagrant acute presentation. Patients often see many different specialties due to the inherent multisystem nature of the condition, and do not get diagnosed until a holistic view is taken by a diagnostician. Lack of awareness of MCAS by many medical professionals is currently a hurdle to proper diagnosis. Mast cell activation was assigned an ICD 10 code (D89.40, along with subtype codes D89.41-43 and D89.49) in October 2016.

Laboratory evidence of mast cell mediator (elevated serum tryptase, N-methyl histamine, prostaglandin D2 or 11-beta- prostaglandin F2 alpha, leukotriene E4 and others). Improvement in symptoms with the use of medications that block or treat elevations in these mediators. The World Health Organization has not published diagnostic criteria.

Treatments: Common pharmacological treatments include:

- Mast cell stabilizers, including cromolyn sodium and natural stabilizers such as quercetin
- H1-antihistamines, such as cetirizine or ketotifen, H2-antihistamines, such as ranitidine or famotidine, Ant leukotrienes, such as montelukast or zileuton as well as natural products (e.g., curcumin or St. John's wort extracts but not recommended)
- Nonsteroidal anti-inflammatory drugs, including aspirin can be very helpful in reducing inflammation in some patients, while others can have dangerous reactions

Fillers, binders and dyes in many medications are often the culprit in causing reactions, not necessarily the active agent, so alternative formulations and compounding pharmacies should be considered.

Lifestyle changes may also be needed. Avoidance of triggers is important. It should be emphasized that MCAS patients can potentially react to any new exposure, including food, drink, medication, microbes and smoke via inhalation, ingestion or touch.

A low histamine diet and other elimination diets can be useful in identifying foods that trigger or worsen symptoms. Many MCAS patients already have high histamine levels, so ingesting foods with high histamine or histamine liberators can worsen many symptoms such as vasodilation that causes faintness and palpitations.

There are no known causes, but the condition appears to be inherited in some patients. Symptoms of MCAS are caused by excessive chemical mediators inappropriately released by mast cells. Mediators include leukotrienes and histamines. The condition may be mild until exacerbated by stressful life events, or symptoms may develop and slowly trend worse with time.

Prognosis: There is no cure for MCAS. For most, symptoms wax and wane, but many can experience a general worsening trend over time. Lifespan for those with MCAS appears to be normal, but quality of life can range from mild discomfort to severely impaired. Some patients are impaired enough to be disabled and unable to work.

Anaphylaxis

If too many mediators are split into a patient's system, they may also experience anaphylaxis, which primarily includes: -

- difficulty breathing,
- itchy hives
- flushing or pale skin,
- feeling of warmth,
- weak and rapid pulse,
- nausea, vomiting,
- diarrhoea,
- dizziness and fainting.

Symptoms can be caused or worsened by triggers, which vary widely and are patient-specific. This is what commonly causes death.

Common triggers include:

- specific foods and drinks (especially alcohol, high-histamine content foods, and histamine releasing additives such as sulphites used in jams and certain drinks)
- temperature extremes
- airborne smells including perfumes or smoke
- exercise or exertion
- emotional stress
- hormonal changes, particularly during adolescence, pregnancy and menstruation.

Anaphylaxis's is a clinical emergency. So a 999 call is obligatory. People prone are often prescribed self injections of adrenalin.

Mast Cell Activation Syndrome (MCAS) is one of these conditions that is in some way related ME/CFS, POTS and Fibromyalgia, and can occur at the same time. Locally knowledge is limited.

Holly: A Tree Associated with Christmas.

Ever since medieval times Holly is the most common pant associated with Christmas period. Holly branches have long been used to decorate homes in winter and make wreaths at Christmas. The tree was a fertility symbol and a charm against witches, goblins and the devil. It was thought to be unlucky to cut down a holly tree. As well as the plant maintaining its green colour of the winter, the spiked leaves carry a religious symbolism to help to recall the crown of thorns worn by Jesus; the red berries serve as a reminder of the drops of blood.

The most common species of Holly (Ilex aquifolium), is a slow group tree or shrub which can grow as high as 45 feet and live for 300 years. We most commonly see them in parks and gardens. The bark is smooth and thin with numerous small, brown 'warts', and the stems are dark brown. The leaves are spiky leaves, but strangely the leaves of the uppers part of tree, and younger plants are often smooth. These smooth leaves can provide food of deer in winter when all the other trees have shed their leaves.

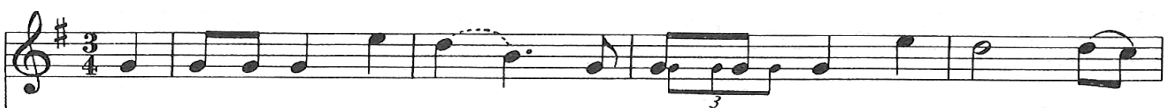
Male Flower

Female Flower

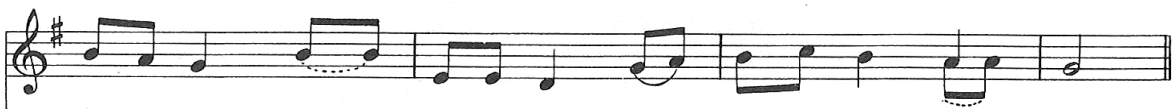
Holly inflorescence

Very often you hear about a holly trees that do not produce berries. This is not unusual because holly is dioecious, meaning that male and female flowers occur on different trees. The flowers of both sexes are white with four petals. The flower of both male and female are very similar. The male flows provide pollen, but the carpels from which the berries would grow do not develop. In the female flower the stamens are present, but don't produce pollen. There are however some horticultural varieties that self-pollenate. The tree provides pollinating insects like bees with nectar and pollen. The female tree bears the berries, which are usually red in this country. However, some varieties produce yellow berries. Mistle thrushes are known to strongly defend holly trees from other birds. Holly, being slow growing produces white hard and fine-grained wood, useful for carving and furniture. Holly berries are poisonous and can cause vomiting and diarrhoea. Holly plants similarly are also toxic to pets and livestock.

THE HOLLY AND THE IVY
(NATIVITY: LENT: AUTUMN)



1, 6. The hol-ly and the i - vy, When they are both full grown, Of_
2. The hol-ly bears a blos-som, As white as the li - ly flower, And
3. The hol-ly bears a ber - ry, As red as a - ny blood, And
4. The hol-ly bears a prick-le, As sharp as a - ny thorn, And
5. The hol-ly bears a bark,_ As bit - ter as a - ny gall, And



all the trees that are in the wood, The_ hol - ly bears the_ crown:
Ma - ry bore sweet_ Je - sus Christ, To_ be our sweet Sa - viour:
Ma - ry bore sweet_ Je - sus Christ, To_ do poor sin - ners_ good:
Ma - ry bore sweet_ Je - sus Christ On_Christ-mas Day in the morn:
Ma - ry bore sweet_ Je - sus Christ For_ to re - deem us_ all:

An example of Christian symbolism as expressed in the well-known Christmas carol "The Holly and the Ivy", in which the holly represents Jesus and the ivy represents the Virgin Mary

North of Doncaster. *Personal comment by Trevor Wainwright*

Travel Diary to the Holy Land Part 8: Finale

I would also find out later with regards to the Church of the Holy Sepulchre that in 1841 a very influential publication argued against the authenticity of the traditional location "Researches in Palestine", by Dr. Edward Robinson which at the time was considered to be the standard work on the topography and archaeology of the Holy Land. Robinson had concluded that: "Golgotha and the Tomb shown in the Church of the Holy Sepulchre are not upon the real places of the Crucifixion and Resurrection" because he concluded that the traditional location would have been within the city walls also during the Herodian era, primarily due to topographical considerations. He was careful not to propose an alternative site concluding that it would be impossible to locate the true location of the holy places. However, he did suggest that the crucifixion would have taken place somewhere on the road to Jaffa or the road to Damascus. (Skull Hill is located in close proximity to the Damascus road, about 200 m. from Damascus gate). Whatever the arguments, we still could not get in so re-entering the old city through the Damascus Gate made our way back to the hotel.

Later I was stood outside when two of our group came past, they'd just been to the tomb at the Church of the Holy Sepulchre they said the queue was small so off I went. I joined the queue we moved slowly along to the sound of a choir singing, it was a lovely atmosphere. The singing stopped, and I read the story of the crucifixion from John; the events of the third day; behind me a man began singing a gentle lilt, again it added to the atmosphere. The queue continued to move and then I was there, I went through the curtain and sat in a moment of reflection, a place I had long dreamed of visiting and now I was there. Then the sound of the monk tapping on the door frame, it was time to go. Back to the hotel to pack but first coffee and more poems to write.

The 10 Shekel coin

The following morning, before going to the bus I went to the roof top garden to take some photos of Jerusalem beyond the old city walls, I had been up the night before and taken some of the skyline at sunset.

Following this there was something else I wanted to photograph, a 10 Shekel coin fixed into the footpath. Someone had done it for fun, you could see it was embedded but I was amazed at the number of people who tried to pick it up. Then it was to the bus, where our guide Joseph and our driver Karim were waiting. Luggage stowed we boarded and were away. The sun was shining as we made our way to Abu Ghosh 10 kilometres to the West of Jerusalem. We passed the new Mosque as we drove in, Joseph explained that Abu Ghosh was an Arab Israeli village, famous for its hummus, history and neutrality towards the state of Israel. As a result, its restaurants are well patronised by Israelis.

Looking out over Jerusalem from inside the old city wall

Our first stop, for our final act of worship was the Church of the Resurrection built by the Crusaders as a fortress in 1141 when they came to Abu Gosh hospital. It is probably as a result of this that it is referred to as The Crusader Church. m It was probably a Byzantine church, and this in turn was built on a Roman fortress. Roman soldiers would have helped build it as we saw a stone that depicted the Legion that did.

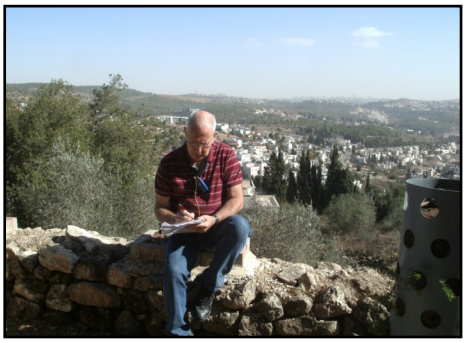
Joseph our guide and Karim our driver

In 1187 the Crusaders were driven out of place by Sultan Saladin, although the church, unlike many other Christian crusader churches, this was not destroyed or converted into a mosque. To conform to Islamic custom the faces were removed from the murals and still remain removed to this day as part of the church's history.

The Crusader Church faces removed from images as per Islamic Custom, the church is part of a complex mixed Catholic Monastery for men and women

In 1899, the church was bought by the French State from 1901 and used by the Benedictines of France. Today the church is part of a complex mixed Catholic monastery for both men and women.

The church is located in a place that was interpreted as described in Luke as Emmaus. We went into the church past a sarcophagus, which our guide Joseph said could be the final resting place of a traveler. We entered the church to celebrate our final mass, what amazed me was the ceiling of the nave a bright blue background with a central framework of Crusader style crosses with an angel at each corner after mass which centered on the story of The Road to Emmaus. We were sat outside, I began writing a poem about the event. The view over Abu Ghosh was wonderful with Jerusalem in the distance.



Writing a poem about the Road to Emmaus, Jerusalem is in the background

After lunch we drove to the Monastery of Latrun known as the monastery of the silent monks which was built in 1890, and until 1960 its articles included a vow to refrain from idle talk and to uphold silence at all times except during prayer. It was closed and looked like we would not be able to go in, until a monk came out put some litter in a dustbin saw us and without speaking opened the gate for us to enter, nodding and walking away as quietly as he came. We walked into the grounds past brightly coloured flower bushes over which the monastery tower loomed as if in watchfulness,

Arrival at the Monastery of Latrun, our final stop.

We walked up the main steps into the Monastery and then inside to a large but simple interior, built of grey/white blocks and consisting of a mosaic floor, simple wooden pews and above the altar a simple statue of Mary and Jesus, to the right a simple crucifixion monument Jesus nailed to a cross made of two logs. After a moment of reflection and prayer it was back onto the bus for the final part of our journey, back to the airport.

Inside the monastery beautiful in its simplicity

We said goodbye to our Drive Karim, Joseph came with us into the airport, I gave him a pen, he said he had got one, I told him this was special, it was the one that I had written the poems I gave to him with, and not for anything else, he accepted it with thanks and a smile. We shook hands saying how nice it had been. Then it was through customs after a few checks then waiting for departure time, time to reflect. I has enjoyed the pilgrimage I had captured it in both poetry and photographs, but most of all I had captured it in my memory, a memory I will always treasure of the trip of a lifetime. There may be memories of trips to come but only one memory where I had walked where Jesus had walked; I had followed "In His Footsteps":

The end.

Making our way to the departure gate with many good memories

Pathways would like to thank Trevor for sharping his experience over the last eight issues.

IN THE UPPER TRIBUNAL Case No. CPIP/2377/2015
ADMINISTRATIVE APPEALS CHAMBER

Before: L T Parker Judge of the Upper Tribunal

Decision: The appeal is allowed.

The decision of the First-tier Tribunal (Social Entitlement Chamber) sitting in Weymouth on 11 May 2015 (the tribunal) is wrong in law. I set aside the tribunal's decision and return the appeal to a new tribunal for a wholly fresh hearing. The Upper Tribunal is not in a position to remake the decision under appeal as further findings of fact are required and these are cases which rely heavily on the expertise of the members. Permission to appeal was given by a First-tier Tribunal judge and the appeal is supported on behalf of the Secretary of State in a submission to the Upper Tribunal dated 29 October 2015. After careful consideration of all the case papers, I agree with that support.

It is important in the present case to focus on the circumstances as they were on 13 October 2014, the date of the relevant decision under appeal. This is already over 14 months ago, the appellant had an arthroscopy on his left knee three days after the original decision on the award, and the appeal has yet to reach a re-hearing. Therefore I make my reasons brief. The appeal to the Upper Tribunal concerns only the mobility component of Personal Independence Payment (PIP) but, as the tribunal's decision is set aside, the case becomes once again an appeal against a total disallowance.

REASONS FOR DECISION

Issues relevant to the satisfaction of the mobility component

1. The tribunal clearly erred in law in a way not mentioned either by the First-tier Tribunal judge when granting permission to appeal, nor by the Upper Tribunal judge giving case directions, nor in either of the submissions from the parties to the Upper Tribunal. The tribunal found, as fact, that the appellant:

"… could not reasonably manage to move 20 metres unaided within the meaning of Regulation 4."

However, the tribunal went on to find that the appellant could reasonably move further using crutches but not "… over 200 metres safely, repeatedly and within a reasonable time period"; the tribunal then concluded that he satisfied activity 2(b) in Part 3 of Schedule 1 ("the mobility activities") to the Social Security (Personal Independence Payment Regulations 2013) ("the regulations").

2. But that a claimant can stand and move more than 50 metres when aided does not stop him from also qualifying under mobility activity 2(c) if he cannot move unaided more than 20 metres; such a claimant may satisfy both mobility activities 2(b) (giving 4 points) and 2(c) and is then entitled to the higher score of 8 points which is appropriate under the latter descriptor; (under regulation 7(1)(b) of the regulations, always provided the claimant satisfies the higher scoring descriptor on over 50% of the days in a required period); this would establish qualification to mobility component at the standard rate.

3. In the present case, the inference from the tribunal's findings is that the appellant could not reasonably ever move unaided even 20 metres. This is a worse case scenario even than under 2(c) but, notwithstanding, it could not satisfy any higher point-scoring descriptor, given the tribunal's finding that the appellant could reasonably move up to 200 metres with his crutches.

4. Fresh findings and conclusions on this matter are now for the new tribunal but, as the tribunal clearly erred in law in failing to consider the potential application of 2(c) standing its own findings, its decision must be set aside on that basis. I discuss other matters raised in the submissions, only insofar as to give guidance to the new tribunal.

5. As is submitted on behalf of the Secretary of State to the Upper Tribunal, a tribunal:

"… does have to assess whether any activity can be achieved both on the terms of the

New Upper Tribunal Decisions on PIP
with thanks to the BuDS Benefit Information Team.

In decision CPIP/1623/2016, the Upper Tribunal has given two important new protections to people who have their PIP awards reviewed and then stopped by the DWP. The decision will hopefully bring to an end a shocking abuse of the system by DWP.

First New Protection
Many people on PIP are told by DWP that they must have another face-to-face assessment before their existing PIP award has finished. Sometimes this happens up to a year before the finish date of their existing award. Up until now, DWP have treated this second face-to-face assessment as giving them complete freedom to change or end an award based purely on the opinions of the latest assessor. The DWP and the assessor does not look at why the original award was made in the first place or say what has changed since the first award.

The Upper Tribunal has now said that this is illegal. The UT accepted that Regulation 26 (of the Decisions and Appeals Regulations 2013) allows the DWP to supersede or change an existing award of PIP based on the medical evidence from an assessor. But the UT said that the DWP could only do this after considering all the relevant evidence including the previous award and why it was made. The UT was clear that the DWP cannot legally change or remove a PIP award on a snapshot assessment which doesn't look back at the previous award as well. The Upper Tribunal then went further and said that the DWP must also give an adequate explanation of why an existing award has been reduced or stopped referring back to the previous award.

Second New Protection
In Regulation 11 of the PIP Regulations 2013, DWP gave themselves the power 'at any time and for any reason' to review all PIP awards, including those granted by Tribunals and to 'determine' or decide whether the award should continue. This power has been used by DWP to arbitrarily change and stop PIP awards, usually by requiring a new face-to-face assessment but sometimes just on their own say-so.

The Upper Tribunal has now said that DWP does not have this power. The UT accepts that the DWP has the power to determine or decide that in theory an award should reduce or stop, but they say that stopping the award has to be done under other legal powers set out in the separate Supersession and Appeal Regulations. What that means is that DWP must follow the same procedure as they do for reviews after a new assessment (First New Protection, above). They must consider all the relevant evidence including the previous award and why it was made and give an adequate explanation of why an existing award has been reduced or stopped referring back to the previous award.

What This Means For Claimants
What this means for you is that, when your PIP award is reviewed or changed for any reason, the DWP must look back at why they made the award in the first place and look at the evidence they used to make that award, including perhaps a more favourable assessment report or Tribunal decision. If they do decide to reduce or remove your award, then they must say why they have done this given the evidence that you used to be entitled to an award. And of course, you can appeal any decision if the DWP does not do any of this.

This analysis is brought to you free of charge by BuDS Benefit Information Team.

It is only general information and you should take advice on your own case.
You can read the full judgement here: http://administrativeappeals.decisions.tribunals