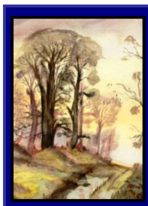


Pathways

Price £ 3.75 (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 the spring 2014 Edition of Pathways.

Over the last 12 months we've seen quite a significant number of changes affecting members.

The letter finally came from DMBC about room hire charges which started as from the 1st November. We had to increase the group subscription to cover this.

The first PIP applications are now being processed. As Helen Butler from SYCIL said at the recent Leger ME meeting it will be a while before the full implications of the changeover emerge. On the positive side it looks like the powers that be are catching up with ATOS and the changeover from DLA to PIP has been put back in our area. Many members are experiencing the changeover from Incapacity Benefit to ESA and its knock-on effects, especially when the ESA becomes means-tested after the first year, which for a number of members is causing hardship.

For this edition we have many of the usual *Pathways* features which we hope will interest our readers. This is because it is become clear to me that many people with ME/CFS have increased risks of cardiovascular disease. There are the obvious causes like lack of strenuous exercise, comparatively low physical activity level and a diet that is less than ideal. Many cardiologists would, without thinking, prescribe a statin type drug—but in my experience ME patients as a group are very sensitive to statins and a least 50% are adversely affected. I have included a recent feature from the BBC about the statin debate. The heart itself is a bag of specialised muscle with its own neurological network. What many doctors don't realise is that the heart muscle and its associated neural network are affected by ME/CFS like any other muscle, particularly in cases with proven mitochondrial problems (e.g. Myhill studies). What I am hearing about are cases a of mild cardiomyopathy where the heart muscle thickens due to ME/CFS and results in a smaller pumping chamber. There are some cases where this may have led to arrhythmias and aneurisms. I am looking into this further for a *Pathways* feature for the future.

While there is very little we can do to change the fatigue with medicines, the way we eat can massively affect our health. I have included in this issue information from the British Dietetic Association.

Finally in our 'Out and About' series we include a feature about the Yorkshire Sculpture Park– *Mike*

You Write

Liz writes: One of my neighbours was contacted by a company called ‘Target Review’. They made an unsolicited phone call to a neighbour who is 89, and persuaded her to take out a financial health check/membership which cost £299, paid via a debit card. My neighbour was very upset, and had no idea what she was paying for. Fortunately her son quickly picked up on this, and got the deal cancelled. A refund was promised by cheque within 30 days. However some 70 days later, nothing had been received. I have concerns that my neighbour should have realised she could not understand what was being sold. Any ideas what to do???...

I’ve even heard of these types of financial products being offered to people in residential care homes. You are right to be concerned about ‘Target Review’. Because the money was paid via a debit card there is very little chance of getting it back and she has revealed her banking details. She needs to contact the bank urgently and cancel the debit card. Certainly a credit card gives some degree of protection but really information about your financial affairs should not be given over the phone. The sort of company offering this appears to operate from overseas bases like Gibraltar outside the reach of the Financial Services Authority. There is an interesting thread on the ‘Money Saving Expert’ web forum on which numerous people complain that this firm has targeted the elderly to sell them a financial health check for sums around £300. There are data protection issues as well.

Personally, for this sort of service I would contact my bank. I have always found their advice clear and impartial. In my own experience the Nat West and HSBC banks offer this sort of service which I have always found to be free. Most of the high street retail banks will offer a similar service. They will do a full financial review and does a financial health check. Other matters such as Wills, Inheritance Tax and financial pitfalls will be discussed and appropriate services offered. At that point the bank would offer some sort of financial management plan which you would take away and think about. In retrospect, I have always found the banks’ advice beneficial. Your neighbour, being 89, should really take along a family member or someone she trusts if she goes to her bank. There is a safeguard with the banks that any advisors have to be approved and FSA registered.

A good idea would be for your neighbour to register with the Telephone Preference Service—this is a free opt out service enabling you to record your preference on the official register and not receive unsolicited sales or marketing calls. I’ve found that by just telling someone you are registered will usually make them hang up quickly. http://www.tpsonline.org.uk/

As for the £299—I think you have to write that one off.

The Telephone Preference Service (TPS)

The Telephone Preference Service (TPS) is a free service. It is the official central opt-out register on which you can record your preference not to receive unsolicited sales or marketing calls. It is a legal requirement that all organisations (including charities, voluntary organisations and political parties) do not make such calls to numbers registered on the TPS unless they have your consent to do so.

Organisations with which you have an ongoing relationship, for example those who regard you as a customer, (or in the case of charities - a donor) may well gather your consent during the early stages of your relationship with them and will therefore be entitled to call you even if your number is registered on TPS, unless you have previously told them specifically that you object to them calling you for marketing purposes.

The TPS can accept the registration of mobile telephone numbers; however it is important to note that this will prevent the receipt of marketing voice calls but not SMS (text) messages. If you wish to stop receiving SMS marketing messages, please send an 'opt-out' request to the company involved.
As TPS registration only prevents marketing calls, organisations will still be able to call you for the purposes of genuine market research.

Carol Writes: Further to your network email of 20th Feb 2014 on the subject of Social Meeting and Broadcasting Information about yourself publicly. You wrote:

Based on what I've heard at the Leger ME meeting this afternoon, could I make it clear that it is not in most members' best interests to release personal details and matters on social media such as Facebook and Twitter. Details posted can be accessed by anyone anywhere, and that means you could be targeted by criminals or DWP investigators or even salesmen.

Perhaps the most humorous misunderstanding from Social Media in the ME world was when Sarah Myhill reported that she had been delivering babies over Christmas. The General Medical Council somehow got to know about it and she was duly summoned as she was "not licensed to deliver babies". Sarah lives on a working farm with her husband, and it turned out that the 'babies' were in fact a litter of piglets to which her pet pig had given birth.

It is better to use an SMS text or email system as the recipients can be selectively targeted and this is intrinsically more secure.

Carol postscript. Thanks for the email warning. I always make sure I do not post anything publicly. However I have some questions.

a) If you change your Facebook security settings so your posts can only be seen by friends (and not anyone in the world), do the DWP try to access them. I have heard that the DWP, employers and insurance companies can access posts on your timeline accessible to friends if they ask special permission from Facebook, but I'm not sure if this actually happens often or how easy it is for them to do this. I assume they cannot access private Facebook messages? Salesmen certainly can't access private posts.

b) If DWP can access private timelines can they access "closed" Facebook groups too?

I am just asking as I post a lot on the closed Facebook group for followers of Dr Myhill's regime which is very useful. That group is not listed publicly on my profile. I am very careful to make sure that nobody tags me in photos on Facebook and rarely post on my timeline. I am careful to discuss only protocol and diet and ME and not what I do in my private life just in case though.

I don't use Twitter but it is possible to alter privacy settings so only followers can see your tweets. Again I don't know if DWP could gain special access.

P.S. Sorry to say that Rosemary the pig is now bacon!

Apart from knowing that GCHQ can monitor almost everything in the interests of national security, I don't have expertise in Social Networking. Can any Pathways reader answer this question?

Pearl Writes: I was reading the information leaflet the other day that came with my thyroxin tables. I notice that it says I've not to take them with calcium salts. This seems a bit strange because my doctor gives me Adcal which is Calcium Carbonate for my Osteoporosis. Do I have a problem??

You have been given thyroxin as a substitution to replace the natural thyroxin your own thyroid is not making. Adcal is combined Vitamin D and Calcium Carbonate treatment mainly for bone problems. E.g. osteoporosis. I would say that continuing both these medicines is important to your wellbeing. It is a well-known fact the calcium salts reduce the absorption of thyroxin into the blood from the stomach. This does not mean you can't take both medicines at the same time and your doctor will want you to carry on taking both medicines. How your doctor takes account of this is done by adjusting the thyroxin dose during your routine blood tests for checking your thyroxin level. If you stop taking Adcal or change the dose you need to have words with your doctor. As thyroxin has a long half-life in blood, the odd missed dose or indigestion tablet (many of which contain calcium carbonate) will not make any difference.

News from Fairlawns

The Fairlawns Medical Centre in Sheffield is the home of Sheffield ME/CFS clinic. I attended a meeting of the Local Patient Involvement Group at the Sheffield ME/CFS clinic in January, along with representatives from the Sheffield and the Derbyshire ME Support Groups. Here is a digest of the more important issues raised at that meeting.

The main issue was as a direct knock-on effect from changes in the NHS and the way the service is funded. The Sheffield clinic been classed as part of the Long Term Neurological Conditions (LTNC) services for Sheffield. Over 2013 there have been changes to the LTNC. Most people within the ME/CFS world follow the World Health Organisation view that ME/CFS is a long term neurological condition and this was where the clinic was put administratively. However over the past year, following a review, LTNC Services were transferred to Sheffield Hospitals so a Review was undertaken to look at how neurological services fitted in with existing services that the Trust already provided.

The Review looked at ways the existing arrangements could work within very challenging financial constraints. Recommendations were made. One of the key factors was that there had to be a clearly identified manager for the Clinic. Another one of the major changes is that Mark Adams, who has been involved with the clinic from first start up around ten years ago, will transfer to manage the Sheffield Brain Injury services, and as a consequence his involvement with the Clinic will be phased out gradually to avoid compromising patient care. I wish Mark well in his new position and I personally would like to thank him on behalf of Leger ME members for his work with ME/CFS patients. The money released will allow the service to be financially reorganised and to employ replacement clinicians.

Some good news is that there has been confirmation of Dr. Czauderna’s permanent funding for a full day which was previously only half a day a week. The Clinic is trying to fund a full time Occupational Therapist (OT). The Clinic can only take on 252 new cases per year. New referrals have been increasing since the service started and it has been agreed to put referrals on temporary hold for a period of time once the allowed limit of 252 new cases has been reached, rather than just continuing to extend the waiting list to unacceptable lengths of time. I personally don’t like it, and I find this very disturbing—but there is a real world out there. Let me know if you are affected.

Another issue that I don't like is the news that the Clinic will move over administratively to Mental Health. Something similar happened to the Leeds ME/CFS clinic which caused two key staff to resign and set up the York Fatigue Clinic. I did question this on behalf of Leger ME members, and the explanation I was given was that the management of ME/CFS mainly involves mental strategies like Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET) and Adaptive Pacing. Similar strategies are used in the treatment of Alzheimer's which has been firmly regarded as mental health for many years although having a physical cause.

While I am disappointed, it has to be remembered that the Clinic still exists, albeit is a reduced form and I think we have to be grateful that it is still in business. There are plans to close some ME/CFS services in other parts of the country—so I think as things stand we are one of the lesser affected areas. – *Mike*

Contact details:

CFS/ME Service
“FAIRLAWNS”
Middlewood Medical Centre
621 Middlewood Road
Sheffield S6 1TT

Telephone : (0114) 229 2937

The Statin debate: A bitter pill to swallow? (or Sense about Statins)

By Michelle Roberts Health editor, BBC News online 6th March 2014

Guidelines out for consultation this month are calling for millions more people to be put on cholesterol-lowering statin drugs. But some fear such a move would do more harm than good. The National Institute for Health and Care Excellence says the scope for offering statin treatment should be widened to save more lives. The pills protect against heart attacks and strokes. Opponents argue that for low-risk groups, the overall harm caused by taking statins would actually outweigh the benefits.

Who's right? Cardiovascular disease remains the leading UK killer. It claims about 180,000 lives a year. Currently, doctors are meant to offer statin tablets to the estimated seven million people who have a one-in-five chance of developing cardiovascular disease over 10 years, based on risk factors such as their age and whether they smoke. This includes people who have had a heart attack in the past. And experts agree that in high-risk populations, the benefits of statins clearly outweigh the risks. NICE is now suggesting that people with as low as a one-in-10 risk should be offered statins. This could include someone who is in their 40s and otherwise fit and healthy, but has high cholesterol, as well as practically anyone over the age of 65 since age is a big risk factor. Some doctors say targeting these people is misguided and will ultimately do more harm than good.

Not for the healthy? A recent survey of 500 GPs by the magazine Pulse revealed only half would personally take a statin or recommend them to a family member based on the new lower risk score. Former GP and deputy chairman of the British Medical Association Dr Kailash Chand has first-hand experience of the side effects of statins. "A few years ago I started taking statins knowing that it has all the benefits and after perhaps a few weeks I started having muscle aches and sleep disturbance." He says much of the data on which the new NICE recommendations are based comes from pharmaceutical companies that make statins, which, arguably, have a vested interest in the drugs' success. He says there is not enough evidence that wider use would be wise and that the benefits have been hyped up. He is also concerned that it will give people false assurance that they are protected for life and can ignore other risk factors such as poor diet and smoking. Then there are the side effects to consider.

Common side effects, affecting between one in 10 and one in 100 people, include headache, nausea and insomnia. For between one in 100 and one in 1,000 people they can cause inflammation of the liver, blurred vision and weakness. Severe side effects such as memory problems, jaundice and damage to nerves and muscles are rare, affecting fewer than one in 1,000 people. Each person will need to weigh these risks against any potential gains, and some may decide that it's not worth taking statins preventatively.

Lives saved: It is estimated that statins save 7,000 lives a year in the UK. NICE says extending their use would save thousands more lives and, in the long run, would save the NHS money. But it is estimated one in every 10,000 people who takes statins will experience a potentially dangerous side effect *(ed I think for MEs it is 5000 in 10,000)*. Experts calculate that to save one life you would need to treat 11 high-risk patients for 10 years. To save a life among low-risk patients the number you need to treat increases to 23. But different studies have looked at different types of patients and have yielded different results, so it is difficult to know if this pans out. US researchers estimate that for every 100 people without known heart disease who take statins for five years, 98 would see no benefit, and only one or two would avoid a heart attack that they might not have otherwise. NICE guidelines are not compulsory, so even if the recommendations of treating low-risk people go ahead, some may not do this. Prof Peter Weissberg of the British Heart Foundation says that ultimately it will be up to patients and their doctors to decide. "Life-threatening side effects are thankfully extraordinarily rare. But troublesome side effects are relatively common, although that's true of any drug."

At last some sense! My experience is that a high proportion of our members are abnormally sensitive to statins as they are with many other medicines. My view is that unless there is a proven need to take statins or their alternatives due to e.g. heart disease or high cholesterol they are best avoided.

The future: Switching off food allergies using food or Oral Immunotherapy

by Dr. S. Myhill

Comment: Almost all of the people I come across with ME/CFS have some sort of allergy or abnormal substances-sensitivity. While in some cases of ME/CFS this shows often as a minor issue like food sensitivity which can be avoided, a high proportion of cases have major problems. The allergy or sensitivity appears to be part of the uprated immune activity associated with the ME/CFS disease process. With the NHS, allergies or sensitivities are mainly treated by avoidance. The classic skin prick test (RAST) test is usually unhelpful because with many patients the allergy is not IgE (Immunoglobin E) meditated. It is possibly an uprating of the Complement system. To date there have been two treatment techniques available, EPD (for multiple substances) & Neutralisation. None are available via the NHS locally, but privately at a cost of around £400 per year. If substance sensitivity is an issue and addressed, there is a definite improvement in overall health of the ME/CFS patient which, apart from the allergy sensitivity, includes reduction of migraine type headaches, eczema, pain and hay-fever. Dr Myhill now has a third option which is the subject of this feature in clinical presentation style. Mike.

The Theory

Oral immunotherapy (OIT) was first proposed as a method of treatment for allergic disease in the early 1900s. In the 1980s, properly designed clinical trials first demonstrated a dose-dependent therapeutic response with specific and well-characterised aeroallergens. In 2006, the World Health Organization recognised the cumulative evidence that OIT represented a viable alternative to subcutaneous immunotherapy (SCIT) and encouraged continued clinical investigation to characterise optimal techniques.
(*Reference to WHO recognition - Bousquet J., Sublingual Immunotherapy: Validated! Allergy 2006; 61 (supplement 81):5-6.)*

We now have several studies that demonstrate how allergy can be switched off by using tiny doses of the offending allergen given by mouth. For example, studies have shown efficacy in switching off allergies to peanuts, birch pollen and grass pollen using OIT as follows:

Anagnostou, K. et al. Assessing the efficacy of oral immunotherapy for the desensitisation of peanut allergy in children (STOP II): a phase 2 randomised controlled trial. The Lancet 2014 (http://www.thelancet.com/journals/lancet/article/PIIS0140-6736 (13)62301-6/abstract). The interpretation of the abstract from this paper reads thus – 'OIT successfully induced desensitisation in most children within the study population with peanut allergy of any severity, with a clinically meaningful increase in peanut threshold. Quality of life improved after intervention and there was a good safety profile. Immunological changes corresponded with clinical desensitisation.'
2)Kopac, P. et al. Continuous apple consumption induces oral tolerance in birch-pollen-associated apple allergy. Allergy 2012 Feb;67(2):280-5 (http://www.ncbi.nlm.nih.gov/pubmed/22070352). The conclusion to this paper reads thus – 'In patients with OAS (Oral Allergy Syndrome) to apple, tolerance can be safely induced with slowly, gradually increasing consumption of apple.'
Multiple studies assessing the efficacy of treating grass pollen allergy via the use of grass pollen sublingual tablets Sublingual and oral immunotherapy for allergic rhinitis. For example, one study (Dahl, R. et al. Efficacy and safety of sublingual immunotherapy with grass allergen tablets for seasonal allergic rhinoconjunctivitis.J Allergy Clin Immunol. 2006;118(2):434-40.) concluded that 'Mean rhinoconjunctivitis symptom scores and medication scores (30 and 38 percent, respectively) improved significantly compared with placebo. Additionally, there were significant increases in the number of well days (53 versus 44 percent) and improvements in quality of life in the treatment group.'

The idea of Oral Immunotherapy is to start with tiny doses, build these doses up slowly, and as a result, over time, the immune system will develop tolerance to that particular substance. This technique was used in the NHS during the 1970s to treat pollen allergies. At that time, it was given by injection, starting off with tiny doses, and then the dose would be increased every week until after about ten weeks tolerance to grass pollen was achieved in the majority of patients.

Unfortunately, this type of low dose immunotherapy was banned because some authorities started to use multiple allergens. This use of multiple allergens meant that, in order to prevent immediate reactions, the allergen mixes were put in an oil soluble medium so that the antigens would be released slowly. The effect of this change in administration technique was that, if a patient was going to suffer a serious reaction, then this serious reaction invariably happened at home because of the delayed release effect. This in turn meant that patients were suffering serious reactions where basic resuscitation assistance was not available – i.e. at home. As a result some patients died, leading to a ban of this kind of low dose immunotherapy. Recently, a new study, (study number 1 above), has been published demonstrating how anaphylactic reaction to peanut can be ‘’switched’’ off by administering tiny doses of peanut given by mouth and then by gradually increasing the dose of peanut slowly over time.

Turning this to practical use, I do not see why this idea could not be extended to all foods and with this in mind I am preparing some food mixes. The idea here would be to have different mixes for different food groups say, meats, vegetables, salads, nuts, fruits or whatever so that people could choose the group of food that they wish to try. One would then start off with a very low dose, say 1-2 mg a day (i.e. the same dose as the peanut anaphylactic study). If this was not tolerated, then one would reduce the dose. If it was tolerated, then one would gradually increase the dose. I think one reason why low dose immunotherapy is so successful has to do with the mechanism by which the immune system identifies good and bad, or, to put it another way, right from wrong. It is a very difficult job for the immune system to recognise a piece of DNA from something safe, such as cabbage, as opposed to a piece of DNA from something potentially unsafe such as a virus. The way it achieves this is by constantly looking at what is normally present in the background environment and, largely speaking, this means the gut. This is because 90% of the immune system is gut associated. When the immune system identifies something that is new and novel, this will flag up a concern which may or may not result in an immune system reaction such as inflammation. The reason for the immune system reacting in this way is because inflammation, of course, is very good at killing viruses. The problem with modern Western lifestyles is that we are constantly exposed to new immunological challenges. This may arise as a result of a number of factors:

We can now eat a wider variety of foods than ever before:-

- International travel, which means that we are now exposed to more viruses than ever before,
- Exposure to substances such as antibiotics which change the normal gut flora
- Exposure to adjuvants such as vaccinations and toxic metals which fire up the immune system.

Of course, what should happen in Nature is that we should all be born and bred in one place, live our lives in that place, only eat locally grown foods and perhaps meet the occasional traveller once a year. (Although even this lifestyle can result in disaster! Think of poor Tess of the d’Urbervilles and her chance meeting with the traveller Angel Clare! However, here, love was the killer not exposure to a new antigen……)

The New-born Baby Theory

A baby is born with the ‘’hardware’’ of an immune system. This hardware then needs programming with the ‘’software’’. So, how is the software downloaded onto the hardware? Primarily it is by exposure. This early programming of the software is vital to the immune system. This is because it is at this stage that the immune system learns what is normal background ‘’stuff’’ which can be safely ignored. It is when the immune system experiences a new substance later on in life that there is a potential for it [the immune system] to be switched on to this new substance. A good example of how this "plays out in real life" can be demonstrated by looking at peanut allergy again. In Israel allergic reaction to peanut is extremely rare. One possible explanation for this is that a commonly used baby rusk contains peanut i.e. those Israeli babies are routinely exposed to peanut early in life and so the "software" that "says" peanuts are "normal" is downloaded very early in these children's lives. So, the immune system of these children learns to accept peanut as normal.

So the idea of low dose food desensitisation is gradually to "introduce" the immune system to tiny and then increasing doses of foods in order to induce immune tolerance. This means these antigens become normal "background noise". Indeed this may be part of the mechanism by which other recognised forms of desensitisation such as enzyme potentiated desensitisation [EPD] work. In EPD, treatment is given intra-dermally with an immune stimulant, namely, the enzyme beta-glucuronidase helps to induce immune tolerance with a once every two to three months injection. In EPD, all the common foods are present.

It is also important that the food is prepared using normal kitchen methods. The reasoning for this is as follows. All foods are contaminated by the gut flora of the cook. At miniscule doses this causes no problems – indeed it generates oral tolerance to normal gut flora and is thus a good thing. We now recognise that many diseases are driven by allergy to gut flora and so developing tolerance to normal gut flora is very helpful to good health in general. Indeed the hygiene hypothesis shows us that those children exposed to normal amounts of "dirt" are likely to be allergic. The mechanism of this is likely to be oral tolerance.

NB: The Hygiene Hypothesis states that a lack of early childhood exposure to infectious agents, symbiotic microorganisms (e.g., gut flora or probiotics), and parasites increases susceptibility to allergic diseases by suppressing the natural development of the immune system. In particular, the lack of exposure is thought to lead to defects in the establishment of immune tolerance.

Practical details

Food mixes can be supplied and each mix will contain ten foods of a particular type. It does not matter that not all foods are represented. This is because similar foods have shared antigens. We know this from practical experience using enzyme potentiated desensitisation (EPD). Not every possible food is present in EPD. So, for example, simply the presence of orange's antigen in EPD will switch off allergy to all the citrus group foods.

Meats – beef, pork, lamb, chicken, duck, goose, venison (red deer, fallow), pheasant, rabbit, egg.
Vegetables – potato, sweet potato, swede, parsnip, carrot, beetroot, cabbage, onions, leek, mushroom,
Salad – lettuce, tomato, cucumber, pepper, radish, celery, pak choi, watercress, chicory, cress
Nuts – peanut, cashew, hazel, walnut, brazil, pecan, macadamia, almond, coconut,
Berries – apple, pear, strawberry, blackcurrant, gooseberry, raspberry, blueberry, grape (white and red), blackberry,
Fruits – melon, pineapple, banana, orange, lemon, grapefruit, rhubarb, papya, mango, lychee
Fish – cod, haddock, trout, tuna, herring, sardine, salmon, crab, prawn, mussel,
Pulses and beans – soya, peas, chick peas, beans (various), lentils, chocolate, coffee,
Cereals – wheat, corn, sweetcorn, rye, oats, barley, rice, quinoa, buckwheat
Dairy – cow's milk, goat milk, sheep milk, cheddar cheese, stilton, yoghurt, cream, butter,
Universal mix – all of the above

If you wish to know more about this technique or are considering this type of treatment or other types of desensitisation, it is important that this is carried out and supervised by a qualified doctor in this aspect of medicine. It is not the sort of thing that an NHS GP could do effectively. Further details can be obtained from Dr. Myhill's website: http://www.drmyhill.co.uk/ 01547 550 331.

Enzyme Potentiated Desensitisation (EPD) is available locally in Sheffield at a local clinic carried out at the clinic by Dr Shena Roper (MB, ChB) who has a special interest in allergies.
Contact details are: Sheffield Clinic of Complementary Medicine, 378 Ecclesall Road, Sheffield S11 8PJ Telephone: 0114 2680236 E-mail: info@acupuncturesheffield.co.uk

Recipe Corner by Carolyn

Mini Chocolate Egg Nests

Preparation method

Line a 12-hole fairy cake tin with paper cases.
Melt the chocolate, golden syrup and butter in a bowl set over a pan of gently simmering water, (do not let the base of the bowl touch the water).
Stir the mixture until smooth.
Remove the bowl from the heat and gently stir in the cornflakes until all of the cereal is coated in the chocolate.
Divide the mixture between the paper cases and press 3 chocolate eggs into the centre of each nest.
Chill in the fridge for 1 hour, or until completely set.

Ingredients

- 225g/8oz plain chocolate, broken into pieces
- 2 tbsp golden syrup
- 50g/2oz butter
- 75g/3oz cornflakes
- 36 mini chocolate eggs

Pasta con sarde

Preparation method:-

Heat 6 tablespoons of the oil in a large frying pan over a low to medium heat. Add the fennel, onions, fennel seeds and the chillies, then half-cover the pan with a lid. Fry gently for 18-20 minutes, or until the vegetables have softened but not coloured.
Add half of the sardines and all of the raisins and pine nuts and stir until well combined.
Remove the lid from the pan, then continue to cook over a low heat for a further 8-10 minutes, stirring and crushing the ingredients with a wooden spoon every now and then, until the sardines have fallen apart and the mixture is well combined.
Increase the heat, add the white wine and the water, and bring the mixture to a simmer, stirring well. Continue to simmer until the volume of liquid has reduced by half, then return the temperature to a low heat and simmer the sauce very slowly for a further 4-5minutes, or until it has thickened.
Season to taste, with salt and freshly ground black pepper.
Arrange the remaining sardine fillets skin-side up, on top of the sarde sauce, side by side, then drizzle over the remaining two tablespoons of the extra virgin olive oil.
Cover the pan again with the lid and cook the sardines and sauce over a low heat for 7-10 minutes, or until the sardine fillets are cooked through.
(NB: There is no need to stir the mixture at this stage)
Meanwhile, cook the linguine according to packet instructions in a large pan of boiling, salted water. When the past is al dente, drain well.
Add the sarde sauce, cooked whole sardine fillets and the remaining two tablespoons of olive oil to the pan with the cooked pasta in it and mix well until the linguine is coated in the sauce.
To serve, divide the pasta con sarde equally among 4 serving plates. Squeeze a little lemon juice, to taste, over each serving. Garnish with the lemon zest and reserved fennel fronds.

Ingredients for 4 people:-

- 10 tbsp extra virgin Olive Oil
- 1 large bulb fennel, trimmed, finely sliced, fronds reserved and finely chopped
- 2 small onions, finely chopped
- 1 heaped tsp fennel seeds, crushed
- 2-3 small fresh red chillies, finely chopped
- 600g/ 1lb 6oz sardines, scaled, gutted an filleted
(the fishmonger will do this for you)
- 75g/30z raisins
- 50g/2oz pine nuts
- 175ml/6floz white wine
- 175ml/6floz water
- Salt and freshly ground black pepper
- 450g/1lb linguine
- 1-2 lemons, zest and juice

ME/CFS management and the Role of Dietitians

From the BDA Website

Registered dietitians are qualified health professionals that assess, diagnose and treat diet and nutrition problems at an individual and wider public health level. Uniquely, dietitians use the most up to date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate lifestyle and food choices.

Dietitians are statutorily regulated, with a protected title and governed by an ethical code, to ensure that they always work to the highest standard. The spectrum of environments in which dietitians practise is broad and includes the NHS, private practice, industry, education, research, sport, media, public relations, publishing, non-government organisations and national and local government. Their advice influences food and health policy across the spectrum from government to local communities and individuals. The title dietitians can only be used by those appropriately trained professionals who have registered with the Health Care Professions Council and whose details are on the HCPC web site.

The British Dietetic Association

Search the BDA site
Go

The BDA is the professional association and trade union for dietitians

The exciting new BDA campaign

Trust a Dietitian

Dietitians are the Gold Standard of Food and Nutrition Professionals

Find out more at www.trustadietitian.co.uk

The Role of Dietitians

Registered dietitians are qualified health professionals that assess, diagnose and treat diet and nutrition problems at an individual and wider public health level. Uniquely, dietitians use the most up to date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate lifestyle and food choices.

Dietitians are statutorily regulated, with a protected title and governed by an ethical code, to ensure that they always work to the highest standard. The spectrum of environments in which dietitians practise is broad and includes the NHS, private practice, industry, education, research, sport, media, public relations, publishing, non-government organisations and national and local government. Their advice influences food and health policy across the spectrum from government to local communities and individuals.

The title dietitian can only be used by those appropriately trained professionals who have registered with the Health Care Professions Council and whose details are on the HCPC web site. We have a leaflet that explains the roles of nutrition professionals further.

Nutrition and Hydration Week

This year, the BDA is proudly supporting Nutrition and Hydration Week (week commencing Monday 17 March 2014).

Nutrition and Hydration Week is a collaboration between the Hospital Caterers Association, National Association of Care Catering and Patient Safety First.

During Nutrition and Hydration Week, individuals and organisations are being asked to pledge their support to raising awareness of the importance of nutrition and hydration as an essential element of care. In addition, on Wednesday 19th March, people are being encouraged to join in the 'World Tea Party' as a way to show your support of Nutrition and Hydration Week.

The Dysphagia Game: Nutrition & Hydration Week 2014

During Nutrition & Hydration Week 2014, a new game has been launched which the BDA helped to develop called *The Dysphagia Game*. It is designed to help

Part of the front page from the DBA website www.BDA.uk.com

Finding a Dietitian Most people will be able to see a Registered Dietitians within the NHS after being referred by an NHS GP, doctor, health visitor or other medical staff. Contact the Dietetic Department at your local hospital to enquire whether they operate a 'self-referral' system. Consultations with dietitians within the NHS are free. Alternatively if you wish to see a Registered Dietitian who practises privately, you can search on-line for a dietitian near you at the Freelance Dietitians web site, which is run by the BDA's Freelance Dietitian Group.

Relevance to ME/CFS. The phrase *'you are what you eat'* very much applies to ME/CFS patients. With there being very little help available to control ME/CFS, many practitioners turn to dietary strategies. I have yet to see a NHS doctor in Doncaster or the Sheffield ME/CFS clinic use dietary strategies. Most of the dietary strategies are confined to a small number of private practitioners who sometimes can charge a lot of money for information that is available free of charge. There is no common consensus about how to treat ME/CFS with diet, apart from where allergies or other health problems intervene and dietary changes are needed. The BDA have published a series of fact sheets. In the following pages I have printed three of what I believe will be the most useful to Pathways readers. They are for ME/CFS, Irritable Bowel Syndrome a complication of ME/CFS from which many members suffer, and Glycaemic Eating which is a strategy to make the best use of limited energy which was mainly use by Dr. Swinbourne before she retired. They are really to be taken as general guidance only and not an absolute 'Tablet of Stone' commandment. Certainly don't agree with everything that they say—and nor will many other practitioners. If you are under the guidance of a health professional or doctor they will advise you within the context of your own case.—*Mike*

The British Dietetic Association

Search the BDA site
Go

BDA Food Facts

BDA THE BRITISH DIETETIC ASSOCIATION Food Fact Sheets

Click for Food Facts terms & conditions including ©

The BDA Food Facts sheets are for you to download and print for your own reference. The fact sheets are for information only: they are not a substitute for proper medical diagnosis or dietary advice given by a Registered Dietitian. The fact sheets are intended for adults unless they sit under the 'babies and children section' or make a specific reference to babies and/or children.

All BDA Food Fact Sheets are Information Standard accredited demonstrating that the information contained within them is from a reliable source.

All the fact sheets are © copyright British Dietetic Association.

Healthy Eating & Lifestyle
Medical Conditions
Babies, Children & Pregnancy
Weight Loss, Detoxing and Health Claims
Nutrients in Food

Found the Fact Sheets Useful? Please give us your feedback? Help us to improve this free service and give us your comments today!

Healthy Eating and Lifestyle

- Alcohol / information sources.
- BBQs / information sources.
- Breakfast / information sources.
- Christmas - eat, drink and be healthy (under review).
  See BDA Christmas press release for relevant seasonal information.
- Cholesterol / information sources - (under review) - alternative information source (NHS Choices).
- Fluid - under review - alternative information source (NHS Choices).
- Food and Mood is being updated. Here is an alternative NHS source of information.
- Fruit and Veg - how to get five a day / information sources.
- Healthy eating - (under review) - alternative information source (NHS Choices).
- Heart (under review) - alternative information source (NHS Chices).
- Packed lunches / information sources.
- Skin health / information sources.
- Snacks under review - alternative information source (NHS Choices).
- Sports under review - (under review) - alternative information source (NHS Choices).
- Vegetarian Diets / information sources.
- What is a dietitian?

Medical Conditions

- Chronic Fatigue Syndrome and Myalgic Encephalopothy (CFS/ME) / information sources.
- Depression and Diet / information sources.
- Diabetes - under review - alternative information source (NHS Choices).
- Eating Problems and Autism Spectrum Disorder / information sources.
- Food allergy and intolerance / information sources.
- Food allergy and intolerance testing.
- Gluten and Casein Free Diet for Autism Spectrum Disorder / information sources.
- Hypertension / information sources.
- Irritable Bowel Syndrome / information sources.
- Malnutrition / information sources.
- Milk Allergy - Practical tips to cutting out milk - (under review) - alternative information source (NHS Choices).
- Menopause / information sources.
- Osteoarthritis / information sources.
- Osteoporosis / information sources.
- Polycystic Ovary Syndrome (PCOS) / information sources.
- Pre-Menstrual Syndrome (PMS) / information sources.

Part of the index page to the food fact sheets folder on the DBA website

From Tony Britton -Publicity Manager, ME Association

The ME/CFS leaflet is written by Sue Luscombe, who has a daughter with ME, is dietary adviser to the Association of Young People with ME and is a regular panellist on the ME Association's 'ME Question Time' panel which tours the UK once a year. Others on the panel are Charles Shepherd, Nigel Speight and Jane Colby, with other prominent folk making occasional appearances.

BDA THE BRITISH DIETETIC ASSOCIATION

Food Fact Sheet

Chronic Fatigue Syndrome/ME and Diet

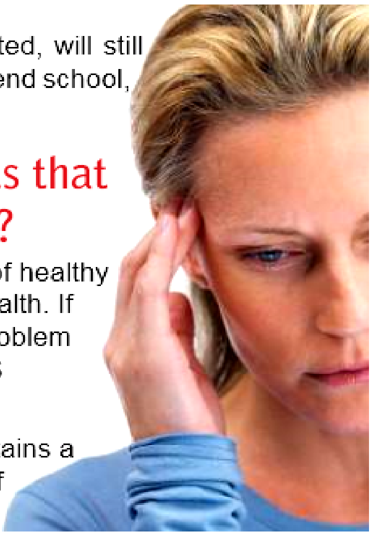
CFS/ME is a chronic, disabling illness affecting both children and adults. It is poorly understood. Diagnosis is made by excluding other causes of the symptoms, as presently, there is no specific diagnostic test. Its name CFS/ ME stands for chronic fatigue syndrome/ myalgic encephalopathy or encephalomyelitis. Doctors tend to use the name CFS for the condition, and patients use ME.

What are the symptoms?

Symptoms include-

- Overwhelming fatigue, present for three months or more in a child or teenager, or over four months in an adult
- Sleep disturbance or unrefreshed sleep
- Muscle pain and/or weakness
- Headaches, poor concentration, poor memory
- Nausea and irritable bowel like symptoms such as wind/bloating and abdominal pain. This is reported in 60-70% of cases
- Increased sensitivities to foods, drugs, household chemicals, alcohol.

As with other chronic illnesses, depression and anxiety may also develop. The symptoms and their severity can vary greatly over time and from person to person. The very severely affected can be completely bed bound and unable to carry out any daily self-care such as feeding or washing. They may also be unable to tolerate any sensory input such as light and noise.



Some, who are mildly affected, will still be able to go out to work, attend school, or university.

Are there any diets that will help recovery?

The body needs a balance of healthy foods to ensure optimum health. If IBS type symptoms are a problem follow the diet advice for IBS symptoms.

A healthy balanced diet contains a variety of foods from each of these groups.

- Bread, other cereals, potato, and rice, especially slow release types of starchy food with a low GI (glycaemic index) such as pasta, porridge or wholegrain cereals. Eat a portion at every meal.
- Fruit and vegetables - aim to eat five or more portions a day. Fruit makes an ideal snack.
- Meat, Fish, and Alternatives - such as meat, chicken, fish, egg, nuts, quorn, beans, pulses, soya alternatives. Include these in two meals.
- Milk and milk products, including cheese and yoghurts. Calcium enriched milk alternatives such as soya based products.

Many find small meals and snacks are helpful. It might be worth trying to add in some slow release or low GI carbohydrates such as pasta, porridge, wholegrain cereals to help energy levels.

There are many diets, (such as the anti-candida diet, or eating dark chocolate), that claim to improve CFS/ ME symptoms. Although some people say the anti-candida diet helps, the scientific evidence, (based on clinical trials), does not support this claim. The study on dark chocolate and ME involved only ten people and hence is too small to make any claims.

Some diets can be very restrictive and can create a lot more work and effort for sufferers and their carers.

> “Many find small meals and snacks are helpful. It might be worth trying to add in some slow release or low GI carbohydrates such as pasta, porridge, wholegrain cereals to help energy levels.”

www.bda.uk.com/foodfacts

Care needs to be taken that the diet remains healthy, nutritionally adequate, and there is no unwanted weight loss or gain. Also, that any benefits do not outweigh the extra demands on the sufferer and carers. We recommend that you ask for the support and advice of a dietitian or health professional if you try these restrictive diets.

Weight changes and concerns

Weight changes are common for those with CFS/ME.

1. Weight increase may result from a much reduced activity level. Typically, exercising can make muscle pain worse, restricting the ability for activity. Also, many find they 'comfort eat' more if they are feeling low. To counteract a lower activity level, or negative feelings, focus on positive healthy foods choices with a good intake, (five or more portions), of fruit and vegetables. However, high calorie, (high fat/sugar), foods such as biscuits, chocolate, cake, crisps and sugary drinks need to be kept to a minimum.
2. Weight loss can occur if the appetite is poor and nausea is present, or if it is difficult to buy and prepare foods due to fatigue. To help minimize this, eat regularly. Try small, quick and easy meals and nourishing snacks.

If you are concerned about unintentional weight loss, or gain, ask your GP to refer you to a registered dietitian.

Food allergy and intolerance

CFS/ME may affect or be affected by the immune system, but exactly how is unknown. Many with CFS/ME report an improvement in symptoms after a change in diet. However, any food related problems are more likely to be food intolerances, (not affecting the immune system), rather than true food allergies. There are many commercially available tests claiming that they can diagnose food intolerance and allergy. However, there is no convincing evidence to support any of these tests and they do not diagnose IgE food allergy. Keeping a food and symptom diary may help identify a particular culprit food. The only reliable way to identify the problem foods is by following an elimination or exclusion diet. Your doctor can refer you to a registered dietitian if you would like further advice on food allergy or intolerance.

What about supplements?

There is need for further research in this area. There are many nutritional supplements, including vitamins, minerals and essential fatty acids, (omega 3s), and co-enzymes claiming to help tiredness. Some are very expensive and contain mega doses of the active ingredient. Large doses, for instance of Vitamin A and B6, can be harmful. If you are concerned about nutritional intake, keep to a multivitamin and mineral supplement, with no more than 100% of recommended daily amount (RDA). If you are housebound, or go outside little, we recommend that you take a Vitamin D supplement at 100% of RDA. This is especially important in adolescence and in women after the menopause to reduce the risk of future bone problems, (osteoporosis and osteomalacia). See BDA Vitamin D Food fact sheet.

Other Food Fact Sheets giving information on topics in this sheet are: Irritable Bowel Syndrome, Food Allergy and Intolerance/Testing, and Glycaemic Index available at www.bda.uk.com/foodfacts

Useful contacts

(these can change, please check website for latest)

Action for ME

0845 123 2380 or 0117 927 9551

www.afme.org.uk

Association of Young People with ME (AYME)

08451 232389

www.ayme.org.uk

The ME Association

0844 576 5326

www.meassociation.org.uk

TYMES Trust - The Young ME Sufferers Trust

0845 0039002

www.tymestrust.org

25% ME Group (Support for Severe ME sufferers)

01292 318611

www.25megroup.org

BDA

Food Fact S

Food Allergy and Intolerance Test

Conventional Allergy Testing

"Alternative allergy testing should be avoided as there is no scientific basis."

"If you need further help, ask your doctor to refer you to a registered dietitian."

Written by Sue Luscombe, Dietitian.
The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts

BDA THE BRITISH DIETETIC ASSOCIATION

BDA THE BRITISH DIETETIC ASSOCIATION

Food Fact Sheet

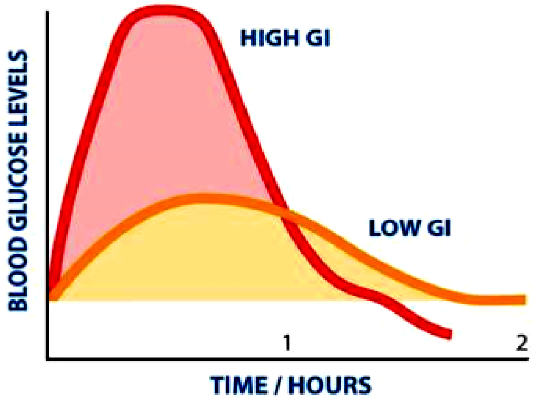
Glycaemic Index (GI)

There are many types of carbohydrates (carbs), but they all behave differently in your body. This is because carbs – or starchy foods – are digested at different rates, which has an effect on your blood glucose (blood sugar) levels. The Glycaemic Index (GI), is a ranking of how quickly these foods make your blood glucose levels rise after eating them.

Which food and drinks contain carbohydrate?

- Starchy foods such as bread, pasta, chapattis, potatoes, yam, noodles, rice and cereals
- Fruit and fruit juice
- Some dairy products such as milk and yoghurts.
- Sugar and other sweet foods
- Non-diet soft drinks
- Pies, pastries, biscuits and cakes

Each time you have a sugary or starchy food or drink, the blood glucose level in your body rises. Some of these foods are quickly digested and cause quick and sharp rises in your blood glucose levels – they are called high GI foods and drinks. Low GI foods and drink, which are more slowly digested, will make your blood glucose rise more slowly. These are sometimes called 'slow release' carbs.



A diagram to show the impact on blood sugar levels of low GI compared to high GI foods.*

** diagram reproduced with kind permission of www.glycemicindex.com*

Foods with a high GI are not necessarily bad foods. For example potato crisps have a medium GI but a baked potato has a high GI. Despite this, a baked potato is better for your health than potato crisps, which are higher in fat and salt. And all lower GI foods are not necessarily healthy – chocolate and ice cream have a low to medium GI rating. So, the key is to use GI in the context of balanced eating.

How to use GI

The GI value of a food is tested on the food when eaten on its own, and there are published lists of high, medium and low GI foods. However, it is not helpful to use the GI values in isolation, as we generally eat food in combination with other foods. GI needs to be taken in the context of varied balanced eating for it to be successfully incorporated into a healthy diet.

Here are some everyday carbs with examples of a lower GI choice:

Carbohydrate food	Lower GI choice
Bread	Multigrain, granary, rye, seeded, wholegrain, oat, pita bread and chapatti
Potatoes	New potatoes in their skins, sweet potato and yam
Pasta	All pasta, cook until *al dente* and noodles
Rice	Basmati rice, long grain and brown rice
Other grains	Bulgur wheat, barley, couscous and quinoa
Breakfast cereals	Porridge, muesli, most oat and bran-based cereals

A healthy way to use the GI principles is to incorporate a range of lower GI carbs that are also low in fat and calories into your meals. So, when you choose a low GI breakfast like porridge, consider making it with skimmed, 1% or semi-skimmed milk and sweetening it with the minimum of sugar and some dried fruit. When you're buying a sandwich, go for granary bread and think about healthier fillings like chicken tikka, tuna, hummus or roasted vegetables.

If you choose pasta, use a flavoursome tomato-based sauce rather than a creamy cheese sauce, which can be high in unhealthy saturated fats, and serve it with plenty of salad or steamed vegetables.

Many low GI foods are a good source of fibre or whole grains. Consider the overall balance of your meals by looking at labels and choosing foods that are lower in saturated fat, salt and sugar, and keep an eye on your portion sizes.

GI and diabetes

There is good scientific evidence to suggest that basing your diet on low GI foods may help to control blood glucose levels for people with Type 2 diabetes.

Choosing low GI foods as part of a balanced lifestyle can help to minimise fluctuations in blood glucose levels. In the long term, this can help reduce the risk of complications of diabetes such as heart and kidney problems. GI is about the physical make-up of a food and it is important to consider the mix of foods you eat, not just the GI value of the carbs.

> “Lower GI foods can help you to manage your weight if they are eaten as part of a calorie-controlled diet combined with regular physical activity.”

We don’t eat single foods, so a lower GI food like granary toast may be digested more quickly if it is smothered with sugar-rich jam! Similarly, a higher GI food like sweet sponge cake will be more slowly digested if it is eaten after a meal. So it’s helpful if you think about how a meal (as opposed to a single food) affects your blood glucose levels, and this is called the glycaemic effect of the meal. People with diabetes can enjoy limited amounts of sugary foods when taken at the end of a meal, so the GI principles help to explain why in diabetes you don’t need to follow a sugar-free diet. And it makes sense that high GI glucose tablets and glucose drinks are the best form of treatment for hypoglycaemia (low blood glucose levels), as they rapidly get your blood glucose up.

GI and weight management

There is some research to suggest that slow, steady rises and falls in glucose may help control appetite. You may notice a claim “feel fuller for longer” on the label of lower GI foods but this is not a permitted claim so food manufacturers cannot relate GI to fullness on a food label. Although many low GI foods are also filling, there isn’t enough evidence to suggest that all low GI foods can help you to feel full. GI is not a magic bullet for weight loss:

- Lower GI foods can help you to manage your weight if they are eaten as part of a calorie-controlled diet combined with regular physical activity.
- Lower GI foods like wholegrains, fruit, beans, lentils, and vegetables are generally low in calories too: they also have a lower GI.
- Some lower GI foods (such as chocolate cake) may be high in fat or calories and so they are not a healthy choice.

Summary

Carbohydrates come in different physical forms and some are healthier than others. ‘Slow release’ or low GI carbs have been shown to help stabilise blood glucose levels and this is particularly helpful in diabetes. The amount you eat is also important and all low GI foods aren’t necessarily good for you. In general, filling lower GI foods such as beans, peas, lentils, porridge, muesli, fruit and vegetables are good choices and can help you to manage your weight and keep to an overall healthy eating plan.

Further information

Food Fact sheets on other topics including Healthy Eating and Carbohydrates are available at **www.bda.uk.com/foodfacts**

Written by Azmina Govindji, Dietitian.
The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts

THE BRITISH DIETETIC ASSOCIATION

The Information Standard
Certified member
This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

BDA THE BRITISH DIETETIC ASSOCIATION Food Fact Sheet

Irritable Bowel Syndrome and Diet

What is Irritable Bowel Syndrome (IBS)?

IBS is the term used to describe a variety of gut symptoms. Symptoms vary from one individual to another and can be worse for some than others. It is a very common condition with around one in five people affected. Typical symptoms are:

- Low abdominal pain which may ease after opening your bowels
- Diarrhoea and/or constipation
- Bloating and wind (flatulence and burping)
- Passing mucus
- Feeling the need to open your bowels even after having just been to the toilet
- A feeling of urgency to open your bowels

It is not normal to pass blood in poo or lose weight unintentionally. So consult your doctor if this happens. It is important to have a diagnosis of IBS confirmed and other conditions such as coeliac disease and inflammatory bowel disease ruled out. Talk to your GP about having a blood test to rule out coeliac disease prior to making any changes to your diet.

Could my symptoms be due to food allergy?

As symptoms usually occur after eating it is not surprising that food is often blamed. True food allergies are rare and are unlikely to cause IBS symptoms. However, they could be caused by food intolerance. There are many tests available commercially claiming that they can diagnose food intolerance e.g. IgG blood test, kinesiology, electrodermal (Vega) testing or hair analysis. There is no convincing evidence to support any of these tests. The only reliable way to identify the problem foods is by eliminating and reintroducing foods. This should be done under the supervision of a dietitian, so if you feel your symptoms are due to food intolerance, ask your doctor to refer you to a dietitian.

What steps can I take?

Try to:

Eat three regular meals a day
Try not to skip any meals or eat late at night. Smaller meal sizes may ease symptoms

Limit alcohol intake to no more than two units per day and have at least two alcohol free days a week

Cut down on rich or fatty foods including chip; fast foods; pies; batter; cheese; pizza; creamy sauces; snacks such as crisps, chocolate, cake and biscuits; spreads and cooking oils; and fatty meats such as burgers and sausages

Reduce your intake of manufactured foods and cook from fresh ingredients where possible

Helpful Hints:

Keep a food and symptom diary whilst you are making changes so you can see what has helped

Take time to eat meals - chew your food well

Take regular exercise such as walking, cycling, swimming

Take time to relax - relaxation tapes, yoga, aromatherapy or massage may help

Make one change at a time so that you can see what has helped

> “Symptoms of IBS vary from one individual to another and can be worse for some than others. It is a very common condition with around one in five people affected.”

www.bda.uk.com/foodfacts

Make changes according to your symptoms

If symptoms include bloating and wind:

- Limit fruit juice to one small glass per serving
- Limit intake of gas producing foods e.g. beans and pulses, broccoli, Brussels sprouts, cabbage, cauliflower, and also sugar-free mints/chewing gum
- Lactose can sometimes cause wind and bloating and IBS-type symptoms. Trial using lactose free cows milk, yoghurts, cream and cheeses instead of ordinary versions for two to four weeks. Using these products will help maintain your calcium intake. If it makes no difference, then return to using ordinary milk and dairy products

If symptoms include constipation:

- Ensure a good fluid intake – about eight glasses/ mugs (two litres) a day
- Increase your fibre intake gradually - any sudden increase may make symptoms worse. Choose whole grains and eat more fruit and vegetables. Oats and linseeds are good sources of fibre and will help to soften poo and make it easier to pass
- Try adding one tablespoon per day of brown or golden linseeds (whole or ground) to breakfast cereal, yoghurt, soup or on salad. Have around a small glass/teacup (150ml) of fluid with each tablespoon of linseeds taken
- Avoid eating extra wheat bran

If symptoms include diarrhoea:

- Ensure a good fluid intake – about eight glasses/ mugs (two litres) a day
- Limit fruit juice to one small glass a day
- Limit caffeine intake from tea, coffee and soft drinks to three drinks per day
- Try reducing wholewheat breakfast cereals and breads and choose white versions instead
- Lactose can sometimes cause diarrhoea and IBS-type symptoms. Trial using lactose free cows milk, yoghurts, cream and cheeses instead of ordinary versions for two to four weeks. If it makes no difference then return to using ordinary milk and dairy products
- Avoid sugar-free sweets, mints and gum containing sorbitol, mannitol and xylitol

Probiotics

You may wish to try 'probiotic' supplements, yoghurts or fermented milk drinks. Take them daily for at least four weeks to see if they improve symptoms. If they do not appear to help then you could try an alternative brand.

Further advice

You need to give your bowels time to adjust to any changes. If your symptoms do not improve after four weeks, re-introduce the foods you have excluded and ask your doctor to refer you to a dietitian. They may suggest you trial a diet which reduces short-chain fermentable carbohydrates (also known as a low FODMAP diet). Most people will be able to see an NHS dietitian after being referred by a doctor, health visitor or other medical staff. You can also self-refer. Alternatively, if you wish to see a private dietitian, you can search online at www.freelancedietitians.org which is run by the BDA's Freelance Dietitian Group.

Summary

Dietary changes can often help IBS symptoms and sometimes simple changes are all that is needed. Remember to monitor your progress by keeping a food and symptom diary. If you need further help, ask your doctor to refer you to a dietitian.

Useful Contacts

The IBS Network

0114 272 3253

www.ibsnetwork.org.uk

Core

020 7486 0341

www.corecharity.org.uk

Self Help IBS Group

www.ibsgroup.org

Steps for Stress

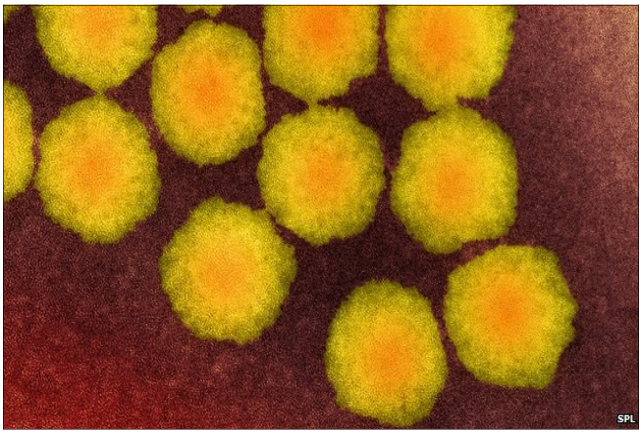
www.stepsforstress.org

Food Fact Sheets on topics in this sheet including *Allergy Testing* and *Probiotics* can be downloaded at www.bda.uk.com/foodfacts

Written by Liane Reeves, Yvonne McKenzie and Marianne Williams, Registered Dietitians on behalf of the Gastroenterology Specialist Group and The Food Allergy and Intolerance Specialist Group of the BDA. The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts

Rare 'polio-like' disease reports

By James Gallagher Health and science reporter, BBC News



US doctors are warning of an emerging polio-like disease in California where up to 20 people have been infected. A meeting of the American Academy of Neurology heard that some patients had developed paralysis in all four limbs, which had not improved with treatment. The US is polio-free, but related viruses can also attack the nervous system leading to paralysis.

Doctors say they do not expect an epidemic of the polio-like virus and that the infection remains rare. Polio is a dangerous and feared childhood infection. The virus rapidly invades the nervous system and causes paralysis in one in 200 cases. It can be fatal if it stops the lungs from working. Global vaccination programmes mean polio is endemic in just three countries - Afghanistan, Nigeria and Pakistan.

Polio-like

There have been 20 suspected cases of the new infection, mostly in children, in the past 18 months; a detailed analysis of five cases showed enterovirus-68 - which is related to poliovirus - could be to blame. In those cases all the children had been vaccinated against polio. Symptoms have ranged from restricted movement in one limb to severe weakness in both legs and arms.
Dr Emanuelle Waubant, a neurologist at the University of California, San Francisco, told the BBC: "There has been no obvious increase in the pace of new cases so we don't think we're about to experience an epidemic, that's the good news. But it's bad news for individuals unlucky enough to develop symptoms which tend to be moderate to severe and don't appear to improve too much despite reasonably aggressive treatment."

'Emerging infection'

The cases have been spread over a 100-mile diameter (160km) so the research team do not think the virus represents a single cluster or outbreak. However, many more people could have been infected without developing serious symptoms - as was the case with polio.
Dr Waubant suspects similar cases in Asia could explain why California is affected, but not the rest of the US. Fellow researcher Dr Keith Van Haren, from Stanford University, said the cases "highlight the possibility of an emerging infectious polio-like syndrome" in California.
He added: "We would like to stress that this syndrome appears to be very, very rare. Any time a parent sees symptoms of paralysis in a child, the child should be seen by a doctor right away."
Commenting on the findings, Jonathan Ball, a professor of virology at the University of Nottingham, told the BBC: "Since the near-eradication of poliovirus, other enteroviruses have been associated with paralysis, but these viruses usually cause a very mild cold-like illness and severe complications are very rare. "Two children showed evidence of being infected by a strain of virus called enterovirus -68, which has become strongly associated with outbreaks of respiratory illness. "Whether or not this strain of enterovirus has caused these or other cases of paralysis are possible but remain conjecture, further studies will be needed to determine this."

Comment:

Coming full circle this feature could be describing ME. Dr. Melvyn Ramsay, in his book 'Myalgic Encephalomyelitis and Post viral Fatigue States', describes something like this: Polio (Poliomyelitis) is a disease rarely seen these days. It starts with a gastric flu-like illness then after an apparent recovery some patients develop permanent lifelong paralysis. It was well known that those who were affected were those who were physically active at the time of infection. There is controversy as to

Obituary: Dr Gordon Robert Bruce Skinner MD, DSc., FRCPath., FRCOG. *By Elizabeth McDonagh*

It is with sadness and regret that we report the death on 26 December 2013 of Dr Gordon Skinner who, over the past twenty years, helped many ME patients to better health. Dr Skinner suffered a massive stroke while attending a medical conference in the West Country. Gordon Skinner was born in Glasgow in 1942 and was educated at Kelvinside Academy where he was a highly successful student. Dr Skinner attended the University of Glasgow, graduating in Medicine in 1965. Following house jobs in Glasgow and the Midlands, he specialised, firstly in Obstetrics and Gynaecology and later in Virology. In 1976 he became Senior Lecturer in Medical Microbiology at the University of Birmingham with Consultant status at the Queen Elizabeth Hospital in that City. The University awarded him a Doctorate of Science degree. He established a Registered Charity, The Vaccine Research Trust and, more recently, a National Directory of thyroid patients. His wife, Janet, sadly pre-deceased him and he leaves a daughter and two sons.

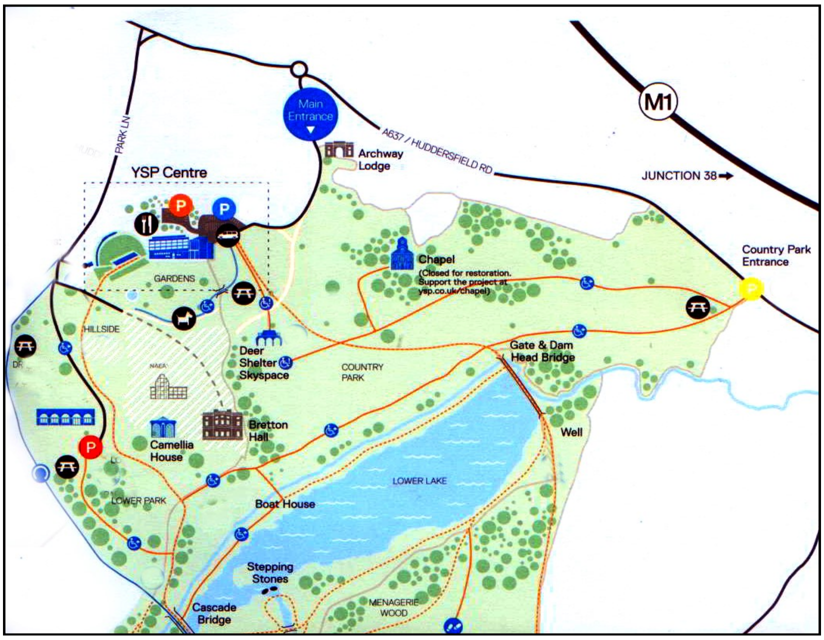
Dr Skinner began seeing ME patients some 20 years ago when the illness was believed to be caused by a persistent virus. He observed that up to 50% of his ME patients had clinical features of hypothyroidism but had been classified, after hospital blood tests, as ‘euthyroid’ (i.e. having thyroid hormone values within the range considered to be normal). Dr Skinner began to treat these patients with thyroid hormone and many of them were returned to health. He was one of seven doctors who signed a letter to the Editor of the British Medical Journal (BMJ Vol 314: 14 June 1997) calling for the official guidelines on diagnosis of thyroid illness to be changed, with doctors giving attention to clinical signs and symptoms rather than relying exclusively on the hospital blood test. Dr Skinner’s book *Diagnosis and Management of Hypothyroidism* explains the rationale behind his treatment of thyroid illness and gives a fascinating insight into his life, thought, decision-making processes and tremendous sense of humour. Following complaints from a small number of doctors and pharmacists, Doctor Skinner’s unorthodox approach to the treatment of hypothyroidism was investigated by the General Medical Council and a regime of restrictions to his practice was imposed. Hearings in the case went on for many years and were observed by a substantial group of Dr Skinner’s grateful patients, who regularly travelled to the Manchester offices of the GMC, from all over the United Kingdom, to demonstrate their support.

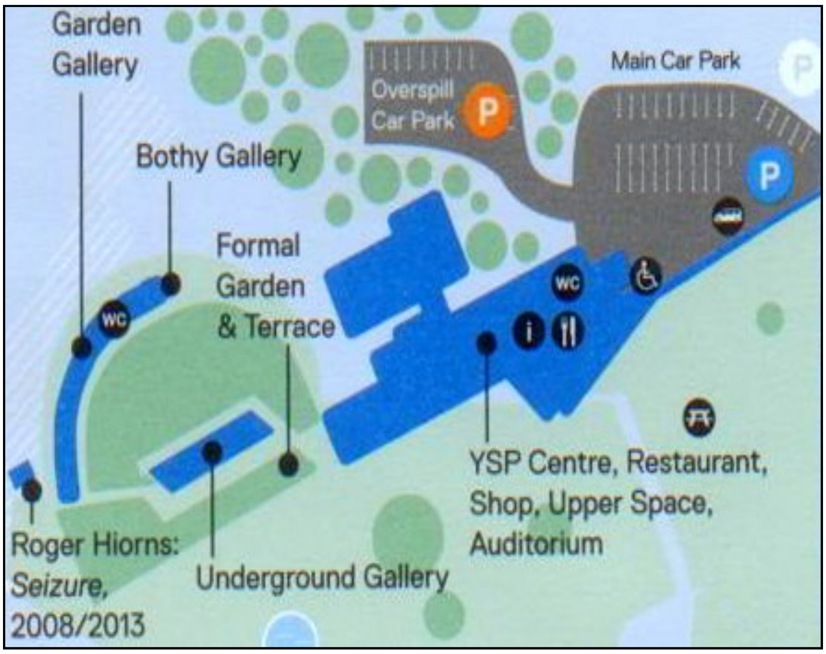
A Fitness to Practise Panel of the GMC completely exonerated Dr Skinner in a ‘Final Determination’ dated 17 November 2011, the last paragraphs of which read: “The Panel is satisfied that the procedures you have in place to safeguard those patients referred to you are adequate. In reference to your prescription of the unlicensed drug Armour Thyroid, the Panel is content with your reasoning behind its prescription. In reaching its decision the Panel has considered all the evidence before it. It notes that you have complied with the conditions on your registration for the past three years, that there is no evidence of patient harm nor any evidence of any misconduct or deficient professional performance. You have referred the Panel to many papers, written over many years, which have addressed the issue of biochemical testing for thyroid disease, and its relationship with the clinical findings. It is clear the issue is a complex one. The Panel is satisfied, however, that your ability to produce these references demonstrates both insight and ability to reflect objectively upon your practice.”

This seemed like victory for Dr Skinner’s cause and might have been expected to end the constant stress of fighting for his right to treat patients according to his firmly-held beliefs. However, within eighteen months the GMC had instituted a further investigation and an extra sanction was added to those that had been previously in place. There is no doubt that Dr Skinner and his patients felt thoroughly discouraged. At the time, he expressed the view that the GMC would pursue him to the end of his life – a prophecy fulfilled last December. His death and the inevitable closure of his clinic has left many distressed patients without the level of medication which keeps them well and which their GPs, less brave than Dr Skinner, will not prescribe. A Memorial Event to celebrate Dr Skinner’s life is to be held in Birmingham in May. Dr Skinner’s family, friends and patients are determined to clear his name , to continue his fight for better treatment for thyroid sufferers and to further, in his memory, the work of The Vaccine Research Trust which he founded.

Out and About: The Yorkshire Sculpture Park

One Sunday afternoon in mid-March we decided to visit the Yorkshire Sculpture Park (YSP). The Park is situated in the grounds of Bretton Hall, in West Bretton, near Wakefield. The 18th-century Hall and estate was a family home until the mid-20th century when it became Bretton Hall College. The Sculpture Park is an open-air gallery showing work by UK and international artists, including Henry Moore and Barbara Hepworth. The Park's collection of works by Moore is one of the largest open-air displays of his bronzes in Europe. Historically, it was the UK's first sculpture park based on the temporary open air exhibitions organised by the Arts Council in London parks from the 1940s to the 1970s. Follies, landscape features and architectural structures from the 18th century can be seen around the Park including the deer park and deer shelter, an ice house, and a camellia house.





Since the 1990s, YSP has made use of indoor exhibition spaces, initially a Bothy Gallery (in the curved Bothy Wall) and a temporary tent-like structure called the Pavilion Gallery. After an extensive refurbishment and expansion, YSP has added an underground gallery space in the Bothy garden, and exhibition spaces at Longside (the hillside facing the original park). It has a rolling programme of exhibits which are frequently changed.

On our visit we travelled north on the M1, and left at junction 38 heading north on the A637 towards Huddersfield. The first signpost is for the yellow car park. This only gives access to the parkland and is more appropriate for walkers. Going a little further there is a roundabout and another entrance gives access to the main car park and visitor centre. The visitor centre has exhibitions, a shop and a café. There is a third entrance by taking a first left after the roundabout which we have used in the past. This gives access to the red car park and the Bretton Hall College site.

Until the 30th March 2014 the times are:
Grounds, YSP Centre and Shop:
1000–1700 hours.
Main Galleries and Restaurant:
1000–1600 hours
Longside Gallery 1100–1500 hours
YSP Café: 1000–1600 hours
Gates are locked at 1800 hours
The Chapel is closed for refurbishment.

Car parking at YSP. There are more than adequate car parks. The red car park surface is a little rough and may cause problems for wheelchair users. The main one is well tarmacked with reserved disabled parking spaces close to the main door. YSP is a charity and the parking fee supports everything they do. You can pay for parking any time during your visit. The charges are: All day: £7.50, 1–2 hours: £5.00 and up to 1 hour: £2.50. There are no concessions as parking charges apply to all visitors including Blue-Badge holders. However, priority parking spaces are offered together with free use of mobility scooters and an offer of a £40 annual parking permit. The No 96 bus runs frequently between Wakefield and Barnsley, and stops at YSP.

The grounds themselves contain sculptures scattered all around, some being very massive. Some part of the pathways have a hard surface, while others are just grass and can get very muddy and slippery during wet weather. There is a wheelchair/scooter-accessible route but it is rough. The main issue for people like us who have difficulty walking is that you have to walk some distance to get the best out of the park. In addition, to see most of the interesting parts you have to walk downhill. The walk back uphill can be a struggle so this is one venue that is for better days and you need to plan for 3-4 days

Coping with ME/CFS and daily stress.

People who suffer from ME/CFS have a reduced ability to deal with stress. Impaired activation of the HPA system is thought to be the physiological reason for this. However no one seems to have come up with a way to effectively control this problem. According to recent research company by AXA Insurance , unsurprisingly, stress levels in this country have doubled during the past four years. Increasing numbers of normal people are finding it difficult to cope with the stress of modern living. Here are the top 10 ways to cope with stress that should be useful in ME/CFS management.

Strategy	Details	ME/CFS Context
1. Manage your time	Prioritise your day and do the important jobs first – the unimportant stuff can wait. And don't put off doing unpleasant tasks, as this can cause a great deal of stress. Give unpleasant tasks a high priority and do them first.	Part of Pacing Strategy
2. Adopt a healthy lifestyle	If you eat a healthy diet, are active and get adequate sleep and rest, your body can cope with stress more effectively.	Most importantly it contributes to your recovered
3. Know your limitations	Much stress is caused because people like to be liked, which means not letting others down. That often means doing more than you should, so learn to delegate effectively and be assertive.	This is so important with ME/CFS pacing
4. Find your triggers	Figure out what worries you and try to change your thoughts and behaviour to reduce it.	A counsellor many be able to help.
5. Avoid unnecessary conflict	Ask yourself if being argumentative is worth the stress it causes. Instead, look for win-win situations where everyone receives a positive outcome.	Stress of conflict triggers ME/CFS rebounds
6. Accept what you can't change	Changing a difficult situation is not always possible. So recognise and accept these situations as they are and instead concentrate on the things you do have control over.	Avoid reacting against things you can't change
7. Recharge your batteries	As well as taking holidays (at least one break of 10-14 continuous days is recommended) take short breaks during your working day. You'll perform more effectively afterwards and easily make up the time you used for relaxing.	Time out is an important part of pacing.
8. See your friends & socialise	Friends may ease work troubles and help you see things in a different way. The activities you engage in can help you to relax and may even boost your immune system	Try not to become a recluse or hide yourself away because of illness.
9. Keep things in proportion	If something is concerning you, try to see it differently. Talk it over with somebody before it gets out of proportion. Often, talking to a friend, colleague or family member will help you see things from a different and less stressful perspective. You may also need to consider professional help to prevent further ill health	More problems become major issues in ME/CFS. Pacing helps with these
10. Avoid crutches	In the long term, using alcohol, nicotine and caffeine will just add to the problem. Caffeine and nicotine are stimulants, and when you have too much of them it increases your body's stress response and can even cause anxiety. In addition, alcohol is a depressant.	Counselling or some prescribed medication can help. Don't use crutches.

Atos is out: Government seeks new company to carry out fit for work tests

Form the Benefits & Work Website as of Thursday, 27 March 2014

There has been much understandable delight about the announcement that Atos will be exiting its contract with the DWP to carry out work capability assessment (WCA) early. But what will and what won't actually change as a result?

WHAT WON'T CHANGE.

The current situation for ESA and IB claimants. Although Atos is quitting the WCA contract early - except in Northern Ireland where they are staying on - they won't actually be going until a new assessment-provider has been put in place next year. In the meantime, IB claimants will continue to assessed for ESA by Atos as will all new ESA claimants.

Nothing changes for existing ESA claimants either. As we revealed last month, the DWP temporarily stopped referring existing ESA claimants for reassessment by Atos at the end of January, in order to try to clear the current backlog of cases. Currently, no announcement of any change in that policy.

The test. On the same day that they announced Atos would be leaving the contract early, the DWP also revealed, rather more quietly, that they would not be changing the WCA. So, whichever company gets the job, they will be administering exactly the same discredited and deeply unfair test.

The software. LiMA, the computer software system used to administer the WCA belongs to the DWP, although Atos have an exclusive licence to sell it to other countries around the world. The WCA is staying, so LiMA will be staying too.

The health professionals. In the statement announcing the early exit of Atos, Penning said: “It is expected that the Transfer of Undertakings Protection of Employment regulations will apply and most of the Atos employees will transfer to the new provider. The new provider should therefore be able to step into the contract without disrupting the service.” In other words, the current health professionals will just be moved across to the new company wholesale.

The assessment centres. The ministerial statement also talked about “using elements of the Atos infrastructure”. It is very likely that all those centres that disabled claimants currently can't park near or get into will be taken over by the new company.

WHAT WILL CHANGE

The money. It's very likely that the profits made by the new company will be greater than those made by Atos. The DWP have been advertising throughout Europe since September last year for another company to carry out some of the WCAs, in order to end the monopoly held by Atos. In all that time they haven't found a single taker. Now they have to try to persuade a company to take over not just a bit of the contract, but the entire assessment system, in spite of all the reputational damage that Atos has suffered as a result if its involvement. The only way that any company is likely to touch the WCA is if either the profits are so big that they justify the risk to their brand or if there is a clandestine guarantee from civil servants and ministers that future bids for other government contracts will be very favourably assessed.

Either way, whichever company gets the Government out of the mess it's currently in with Atos, they are likely to be rewarded very handsomely. So, everything stays the same —except the size of the pay cheque for the new assessment company. For claimants, the fight goes on.

Jim Allison's Opinion *from B&W forum*

Once upon a time before the Dept of Work & Pensions were heard of, we had a government department called the Dept of Health & Social Security (DHSS), who after a short time became the Dept of Social Security (DSS).

At that time, I was a Welfare Rights Lawyer and Social Security Tribunal Member. In those days all medicals were carried out by the government's Benefits Agency Medical Services (BAMS) based in Bootle, Merseyside, but with medical centres throughout the UK. All medical assessments were carried out by one or two doctors, depending upon the benefit claimed, not by nurses, physiotherapists or occupational therapists.

I remember well under BAMS, there were few, if any problems with BAMS, and medical assessments were completed in weeks, not months and months. Solution, bring back BAMS and restore claimants' confidence in medical assessments for benefits.

I started this as 'once upon a time' and end on the same theme, since the Government isn't interested in providing quality medical assessments, only in reducing claimants and paying out hundreds of millions of pounds to companies not fit for purpose.

As soon as the news of Atos' early exit was announced by the DWP; B&W we asked on Twitter;

"Tell us what you would advise any new contractor working for the DWP on ESA tests! "

Here are the responses, where you said:

- The first thing they would need is empathy to put themselves in the disabled person's shoes.
- Doubt they will be any better but would do well to remember "There but for the grace of God could be any of you"
- A review of the WCA itself to ensure that it's actually a fair test, like we have been campaigning for years for...
- To spend a decent amount of time assessing clients, ask questions about how a condition can vary
- Do NOT sign up to a contract which bases solutions around imposed norms—unless you want to be Atos v2.0...
- Courtesy, Consideration and Respect for the Disabled. Not Arrogance, Contempt and Disrespect like IDS DC and GO.
- And kiss goodbye to your reputation, because we #Atos shows we know how to turn your brand toxic.
- Any #Atos 2.0 contractor needs to make urgent reform of the #WCA a condition for taking the contract
- Don't hide the details of the contract you signed from the public, you need to be honest & transparent about ESA tests.
- I would say you, your spouse or adult child might be ill one day. How would you want your own family to be treated?
- Ensure that all staff is accountable for decisions & attend appeal hearings.
- Ensure that senior management are not allowed to hide behind anonymity & are made accountable at local level.
- Do not disregard evidence from GPs as if it does not matter. Our GPs deserve better, and so do we.
- One for Government: return medical decisions to the medical profession and away from assessors with a vested interest in cruelty.

However, Atos will still carry out PIP assessments in our area.

North of Doncaster Personal *Comment by Trevor Wainwright*

My memories of Anne Faulkner. On November 11 last year I received the sad news that Anne Faulkner co-founder of the CFSRF had died on 7th November. We had known each other since October 1997, so how did it come about?

It was 1996 and I had been involved in overseas aid work to Bosnia when a local reporter latched on to the fact that I was driven by the fact that there I could do something and see a result whereas with ME that affected my daughter there was no light at the end of the tunnel. This led to contact with a group of people in Castleford who had been raising money to help Dr's Swinburne and Coyle at St James' Hospital Leeds joining up with them and using my past experience seemed a good idea. Our first collection raised over £200 and there were further events in the pipeline then the sudden death of Dr Coyle put an end to the research. Undeterred we looked for another project; the ME Association seemed a good bet. Given a car to raffle, we approached the then management who said OK but when everything was set up they had changed their mind. The raffle went ahead; the profit, over £4000, was donated to the local hospice and one fundraiser, Jeanette, the organiser, was laid low with exhaustion.

Meanwhile I'd opened a building society account and done some collecting myself from places that had helped me in the past. Then I met with BRAME and begun selling Blue Ribbons, and poetry books which boosted the account, I would learn through BRAME about the PVDRF as they were then known. Mid-October I got their phone number and rang asking if they would like a donation of £100 which we had accumulated. The woman I spoke to was Anne; when asked for their bank account details she said they preferred a cheque. I mentioned my previous work had involved direct payments to bank accounts, which meant they would get it straight away and no messing about moving money. After a brief wait and consultation with others she asked "have you got a pen?" my reply "it's in my hand ready".

The details were given and on October 22th 1997 the money was sent along with a bit more and fundraising began in earnest. Wearing my old fire gear as Fire Aid for ME the money came in and Anne provided me with a letter of permission and details of the Foundation's past work so I could tell the donors what their money was doing, and what we hoped for the future. At the end of 1997 the PVDRF had received £435 most of it from pub collections where I would use the info supplied to explain why I was collecting. In 1998 the year of the first ever Parliamentary ME Awareness Meeting, which, like the Fighting for the Truth Petition the year before, the main groups tried to stop, was also the year of the first ever Hospital Radio ME Awareness Show fronted by me. Anne was interviewed about the work of the PVDRF: again none of the main groups was interested but Anne was more than willing to be interviewed as were other smaller organisations. In 1998 we progressed to street collections with the details of the Foundation's work posted on exhibition boards.

In 1999 the PVDRF decided to change its name to the Chronic Fatigue Research Foundation, and was to hold a press conference. Fire Service management had stopped me from wearing my old fire gear.
I mentioned this to Anne and she asked "do you want me to get our solicitors to look into it for you". "Yes please" I said but sadly there was nothing they could do as it was an internal matter. Talking to Anne on the phone about the name change event I suggested she invite a few politicians. She suggested I come too representing the fundraisers and it would be nice to put a face to the donations, so down I went This would be our only meeting but I would also meet the researchers and learn their stories and the facts behind their work which would be used to great effect at events as people saw who was involved and would, as time progressed, say "We feel we know them as well as we know you". Anne also liked my attempt at satirical writing when she read my article "The Wessley" she told me her daughter Jane also found it amusing.

Our phone calls were more than business-like as we would once the business was sorted have a chat, as I told her what I had been up to campaigning as well as fundraising. One time she said "Oh Trevor, do be careful, you'll end up getting sued" my reply was "With the exception of the current account, all our money is in my wife's name, and they'd be lucky to get thirty bob (£1.50)." Anne mentioned me in the Foundation newsletter as "We have a man in the North who raises money round the clock—we sometimes wonder if the people in his home town have any left", I was always able to ring Anne to find out the latest research news and as a result our supporters were the best informed. The area we worked in was perhaps the most ME-aware area in the UK, people often contacting us for help. We shared the same opinion about overpaid executives in high positions in charities that if they could earn as much in private industry they should work there leaving charity work to those with less mercenary interests. I would tell Anne my latest plans which she would find enjoyable; one thing she found as such was when I made a prison suit out of pyjamas and became Prisoner Cell Block ME.

When I decided to hang up my collection-box Anne wished me well, her thank you letter was so full of gratitude, I said I would keep sending donations and have done along with what I have been doing. Occasionally I would get a letter back thanking me and saying how she looked forward to my news.
The greatest thing she ever said to me during my fundraising was "Trevor it's a pity we can't grant you a sainthood" my reply was simple, "Ann, find a cure and that will be my sainthood".

From that first phone in 1997 call, to me stopping in January 2006, the CFSRF had received from Castleford based projects over £26,470 from a total raised of £37,600 and all because one woman listened to and had faith in a voice on the phone, a voice from the wilderness, but willing to help. There are not many who would have done what Anne would have done on that October afternoon, bless her.

This coming April I will be once more in America watch out for my travel stories in future issues.