Pathways

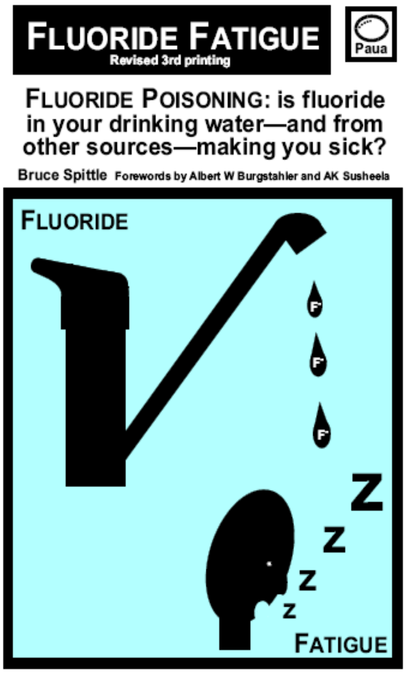
Price £ 2.50 (Free to members)

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

More on Employment and Support Allowance

Over the past few weeks there has been much financial turmoil in the news, and a financial depression seems to be looming. For the Government, unemployment spells double trouble. Firstly, tax income from jobs is lost and secondly they have to fund the extra unemployment benefits via the DWP. The rates of basic rate Employment and Support Allowance (ESA) is the same as Jobseekers' Allowance. Anyone who qualifies for the Support Group (cf. Incapacity Benefit) will of course receive extra funding. There is no doubt that the DWP are tremendously under pressure to reduce costs, and will be scrutinising ESA claims. In the last Pathways, I introduced the new system. In this issue I take a closer look, and provide a toolkit strategy to help members deal with the claims process. The ESA will at some point apply to all members under pension age. The Government documentation suggests that 'Work Gives You Health'. *See page 17*

Arbeit Macht Frei, the gates at Dachau concentration camp. The translation roughly is:' Work Makes You Free'. A parallel ?



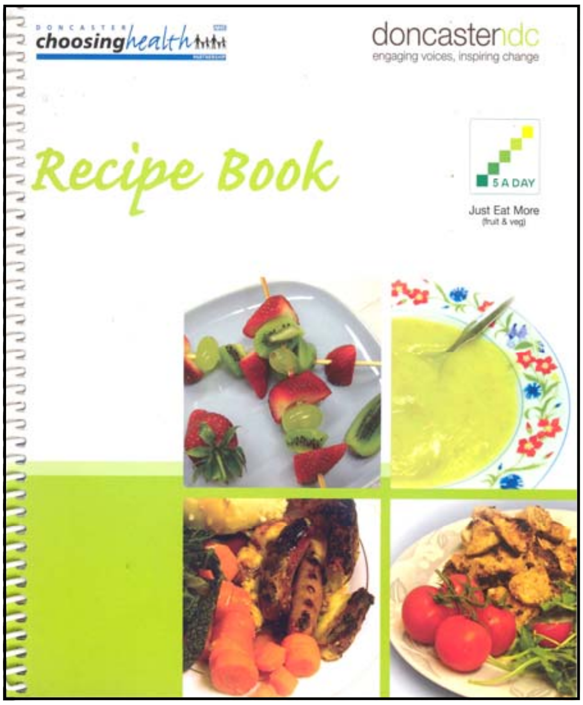
FLUORIDE FATIGUE
Revised 3rd printing

Paua

FLUORIDE POISONING: is fluoride in your drinking water—and from other sources—making you sick?

Bruce Spittle Forewords by Albert W Burgstahler and AK Susheela

Fluoride Fatigue reviewed
see page 13



DONCASTER choosinghealth

doncasterldc
engaging voices, inspiring change

Recipe Book

5 A DAY
Just Eat More (fruit & veg)

Doncaster Health recipe book reviewed
see page 6

A topical seasonal feature: **Chocolate and Health**
see page 8

Also in this issue

You Write

Doris Writes: The organisers bringing the Judicial Review of the NICE Guidelines on CFS/ME would be grateful if you could advise me whether your group supports the need for a Judicial Review of this guideline. Could you please let me have answers to the following questions:
1) Does your group support the need for a Judicial Review of the NICE Guideline on CFS/ME?
2) Approximately how many members does your group have?

1) We do support the need for a Judicial Review of the NICE Guideline on CFS/ME, but we have reservations about the NICE remit, which we believe is too narrow. We do however think they are more useful for mild cases; but for moderate or severe cases quite useless. Most of the CBT GET research does not take into account the 7 Kerr subtypes. Most diseases have subtypes e.g. MS & Diabetes, for which different approaches are needed according to subtype, and a 'one size fits all' approach is inappropriate as is the case with ME/CFS. Many of the nutritional approaches which we know work for some have been ignored. There is no acknowledgement of the complications or interactions with other conditions. For example if a previously stable diabetic gets ME/CFS, the diabetes can induce many management difficulties.
2) The Leger ME has 86 fully paid up members and 95 clients at the time of writing Mike.

Isabel Writes: I listened to a radio programme on Radio 4, which effectively said that being on benefits like ICB and ESA would be detrimental to health. Is this true ? Also it said that contrary to political opinion most of the people on state benefits are really struggling ??

The latter question is easy to answer. People on state benefits receive the minimum to exist, you only have to look around and share experiences around the group to see this, and this is what the Government intends. The second question is, that, yes, it is right. In order to stay healthy, the human body needs to do things. Physically, if we are not active, our bones & joints 'waste' losing mass. If gravity is removed, as for spacemen, as they spend time in space weightless, doing little mechanical work, their bones start to react to not doing any work by losing calcium, and thinning, as in osteoporosis, and this limits their time in space. Bedbound people, after several weeks lose bone mass, and also muscle. Humans are like caged animals in a way, and they need mental stimulation and communication to stay healthy and avoid depression. Any responsible zoo keeper or pet owner will tell you this. Lack of activity leads to a higher incidence of diabetes, heart disease, skeletal/ muscular problems and mental health problems. It is well known that people in wheelchairs are more prone to heart attacks, for example. It is also known that physically stressful activity gives some protection against heart attacks. With ME, there are no easy options, and much trading off in pacing strategies is needed. Even for normal healthy people, pumping iron or gyms are not needed for health. With ME and ESA, apart from grade 4 cases, doing nothing is not an option. Training e.g. counselling or computer classes, or treatments will possibly be the normal 'Work Related Activities' that our

members will do. Even pain management and pacing should count. I have listed (from their website) a range of activities that the DWP say you can do while claiming ESA. However, as I always say with the DWP, don't tell them, unless they ask you. AND the goal posts will move —Mike

Work which you can still do whilst claiming ESA includes:	**Work related-activities may include may include such things as:.**
• Work as a councillor; • Work as a disability member of an appeal tribunal or as a member of the Disability Living Allowance Advisory Board; • Domestic tasks in your own home or that of a relative you are caring for; • Work during an emergency or to prevent serious damage to property or livestock; • Voluntary work (working for nowt); • Permitted work (protected job placing).	• Work trials • Voluntary work • Permitted work • Preparation for self-employment • Condition management programmes • NHS Expert Patients Programmes • Basic skills programmes • Activities to stabilise health conditions (including mental health problems) for example use of cognitive behavioural therapy or treatment.

Helen Writes: I have been reading your site today and would really, REALLY, appreciate your advice. Both my sister and I have recently been diagnosed with ME after 6 years on my part of struggling to get an accurate diagnosis and years of being sent away with thousands of painkillers. I have claimed for DLA at least 3/4 times over the last 5 years each time being refused for the first claim and the appeal. I HATE THE DWP!!! I am now yet again awaiting an appeal. It has now been 14/15 weeks and I am still looking at least another 12. Its not as big a problem for me as I have incapacity benefit and my partner is working every hour God sends to keep our heads above water. However this isn't the case for my sister who had a full time job until "soldiering on" which finally put her completely out of action a few months ago. Her husband is self employed and they are rapidly getting into a dire financial situation. They have defaulted on mortgage payments and are struggling BIGTIME!! My sister's condition is very severe and she is wheelchair-bound and can't do anything for herself. Despite this she is still waiting for the claim to be sorted. The DWP have said they have enough info and the claim is with the decision maker, and then a week later they are waiting for info or the doctor hasn't replied etc.

Funnily enough the exact same excuses they used to cock up my claim as well!! It's really not fair. She is REALLY ill and the stress and money trouble is making her ten times worse. To top it all off, because she isn't "in receipt of" DLA and mobility it makes getting other things more difficult as well! She can't have a powered chair as she doesn't have ramps and she can't have ramps without a letter from a consultant who she has to wait another 3 weeks to see and then there's the wait for the paperwork and the work to be booked and carried out! She is stuck in the house on her own and can't get out anywhere. Despite an occupational therapist visiting her and assessing her and seeing for himself that she is clearly unwell and immobile! No... They still need medical evidence.

I am so sick of fighting with everyone; the DWP, GP's and the unhelpful occupational therapist. Why should we be disbelieved while some idiot 'jobsworth' sits at a desk and mulls over a form. The whole situation is really stressing me out! I have been applying and being refused for 5 years and I am well used to it by now but my sis is desperately in need of help and no one will give either her or me any at all! We have sent letters to MPs and everybody else we can think of! The system is completely stupid! Please have you got any ideas? Do you know of anybody who can help or of any avenues I can pursue next? I would....we would be EXTREMELY grateful! Thank you very much.

Your experience is typical, and all we can do is work around the system. The difficulty is that there is no quick fix, and we have to work with the DWP system we have, with all its shortcomings and so on. Most of the problems can be fixed - but it takes time and effort. If you are in the Doncaster or a nearby area, I can make an appointment to see you a the Redmond Centre - and look into your *issues OR I can point you in the right direction. The problem is you need someone to help you locally as a welfare nights advisor. Most areas have someone somewhere - but the problem is finding them, and very often they are not easy to access.*

I prefer to work with a strategy of getting it right first as far DWP forms go. Many of the refusals are due to forms being filled in incorrectly by members themselves or submitted with weak evidence.

1) You need a diagnosis from a doctor backed up by a hospital, an ME clinic or other clinical evidence.
2) You need to proven track record of ongoing consultation, observation or treatment. This means seeing your NHS doctor regularly, at least once a year. Private practitioners carry little weight.
3) Use a welfare rights service, don't do the forms yourself. Always be truthful and accurate, and don't supply irrelevant information. Leger ME members have resources, checklists, and local information about where to go for help. Some organisations are better than others in certain circumstances.
4) Draft out your form first, then have someone with a working knowledge of the system check it out. Don't use a relative or friend. We provide Leger ME members with proformers and information, and they very often bring draft forms to our welfare rights clinics to be checked out .
5) Copy everything sent to the DWP. If you are given a refusal, ask for a copy of all the evidence they have used. Appeal and use a advocate or welfare rights advisor. During inquests into benefit refusals, in most cases I can quickly spot the reason for refusal. In about 80% of cases, following the above procedure would have avoided the frustration and stress. The remainder are cases of maladministration, mistakes and disbelieving doctors, almost all are winnable eventually..—Mike.

Irene Writes: Did you know that Dr Chaudhuri, a consultant neurologist in ME/CFS at the Essex Centre of Neurological Sciences, carries out post mortem examinations of former ME/CFS patients. I understand that frustrations are encountered from his exciting research in that he is unable to publish photos of what he has found without permission of subjects due to tissue archival law. Because a disease can be defined by its pathology, looking at tissue will determine if there is evidence of something being different from controls of normal patients. He examines the pathology of people with ME post mortem, and was able to investigate relevant tissue from the first person known to have died from ME, finding both inflammation and cell death in Sophia Miraz's brain and spinal fluid. At the 'Invest in ME Conference', 2007, Dr Chaudhuri explained that intervention can be different depending on the stage of the disease. His research into the spinal cord of ME/CFS has shown increased levels of Corpora Amylacea. Their function is to dispose of products of stressful metabolic events throughout life and they are not found in normal patients under 40. They are found, however, in patients under 40 with Downs Syndrome. He details that there is not a specific pathological signature but changes he has observed so far represent two ends of a spectrum. He is quite clear that the observed pathological changes are well recognised in neurological disorders but not present in psychiatric conditions so would support the WHO classification of ME as being neurological. There are demonstrable pathological changes in the brain and spinal cord. Further neurological investigations should provide further evidence. Dr Chaudhuri is working to develop an autopsy protocol that would allow for further investigation of ME/CFS patients who have died.

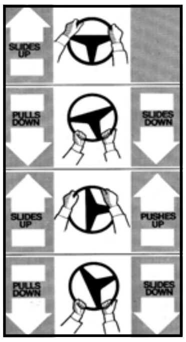
Corpora amylacea, also known as amyloids, is the accumulation of dense amounts of calcified materials that are protein-based in nature. Corpora amylacea normally affect men who are 60+, very often causes no problems unless they obstruct something like a prostrate gland. In a Motor Neurone Disease research project, the densities of Corpora amylacea in the grey matter of the anterior horn spinal chord were significantly reduced in the spinal cord sections in the motor neurone disease patients group, but only where few motor neurones remained. It is highly probable that they arise from neurons, and have two parts, one mobile and one static, the second most likely remaining in the periphery of the spinal cord for prolonged periods. The problem with all this research is that after someone dies, we can say 'Oh yes, the poor guy really did suffer from ME'. But what is the use—and how can it help patients now. I've known about this issue for many years. The newer MRI machines are capable of picking these up, but we will have to wait for a research project and funding whenever that arrives. Mike

Carolyn Writes: Yesterday when I arrived at the doc's surgery I walked up to Reception as usual to say I'd arrived. "Hi, (gave full name) and I've a 4 o 'clock appt with Dr. Timmins. The receptionist's response with a bright smile was "Sign yourself in". Vague look from patient followed. She continued with a nod in the direction, "over there on the wall". I looked where she was signalling to see a screen! I don't know what my expression must have been but something like my eyes rolled round and I muttered "oh for goodness sake", and silently thanked God I could work a computer, as I took myself over to the screen where I duly followed the finger touch instructions to sign myself, - date of birth, sex, etc., and it eventually told me my appt was 4 pm with Dr. Timmins and, to please take a seat. NO, my head was thinking, he's never downstairs, as I made my way back to reception looking around the room for any signs that might say the doc was now downstairs. Suddenly, from behind reception came the same bright voice said "did it work", yes, I said but surely he isn't down here, "no, you go upstairs, came back". "Doesn't work that well" I flung at her as I went through the door to the staircase.

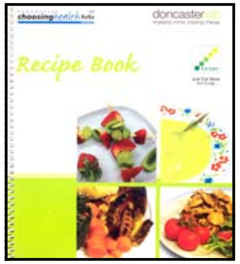
I walked up the stairs thinking how mean the receptionist's attitude was considering how many people wouldn't have a clue how to work 'the screen'. How daunting technology can be for older people who have no knowledge of it and what a rotten way to begin a visit to the doctors, that is when you already are feeling ill and probably less confident than usual. (I was actually off balance yesterday and to look at, and use, a monitor was the last thing I needed to be doing, even though I had no worries about the thing itself.) SO, having got upstairs I looked into the waiting room to see chairs, all neatly lined up in rows. "Oh," I said, to no one in particular, "we're in rows now". I took a chair on the front row not wanting to cram past others all spaced out on the further back rows. I was thoroughly irritated by the whole scenario by this time but what happened next put the finishing touches to it. Suddenly I heard 'beep' everyone looked up nearly to the ceiling where a moving sign had flashed up the full name of the person to go into the doctor, which doctor they were seeing and which room the doctor was in...........The full name at the top in red lights was.......MINE! So now the whole room now knows my name, who I'm seeing, and where I'll be.

I was feeling quite poorly and needed to concentrate when in with the doctor, so I decided to shelve my fuming thoughts on all that had happened until later. It is now the morning of the next day and I've had time to think things over. Firstly, I suspect all receptionists will soon be redundant. Secondly, it is the most people-and patient-impersonal and unfriendly set up you could wish for. Thirdly, I truly object to the rows of seats situation in the waiting rooms both downstairs and upstairs. I know why it has been done.............how else would you spot your name up in flashing moving lights............BUT, when seating was all around the rooms and people sat facing people and children had room to play with the now disappeared toys that used to be provided in a big box on the floor, people spoke, people chatted with each other, patients communicated. Yesterday there was just a silent air of gloom in the room. There is one other thing in this newly renovated and ruined home for doctors, staff, and hapless patients..........wooden/laminate flooring has been put in everywhere. Wonder when we'll all be coming out with sprained ankles .....Very, very, old and losing-the-plot patient of Bolton!

Andrew writes: Issue 13 of Pathways contained an item about advanced driving & I was surprised to see the old 'pull-push' steering method being promoted. I am a driving expert, having studied it for 40 years and with a record and awards to show for it. The police and the IAM no longer require this method of using the steering wheel. The practice dates back many decades to a time when cars were quite different but unfortunately there are plenty of drivers who refuse to accept changes or who will not admit to being wrong. There is NO evidence to show that it is smoother or safer and it would be very unusual to see a good driver using it. In fact, it gives less control, particularly for right-handed drivers (the majority).



Some interesting points. The push-pull technique was introduced in the days of low geared purely mechanical steering, now power steering is the norm. For disabled driving, the push pull technique induces good posture, reducing stress and fatigue, but may increase fatigue by creating more movement. MEs have arm and shoulder weakness or stiffness and have their own individual way of coping. I also think that any change in change in technique a person uses is likely to go with an increased risk of an accident. Whatever technique you use, you must keep control of the wheel. Are there any ROSPA or AA members out there with any views ? Mike.



Recipe Review: The Doncaster IDC Recipe Book As part tof the Choosing Health campaign, Doncaster PCT intends to promote healthy eating with this recipe book, which has been developed locally by New Deal for Communities, in partnership with the Department of Nutrition and Dietetics at DRI. The book contains a guide and tips on health eating and cooking, shopping on a budget and cooking for one, menu planning and fun ways to present food. There is also information on what you need, hygiene, safety and much more. We decided to test three recopies just to see how well they worked. You give them a try. !

Recipe	Ingredients	Method
Tuna Rice and Peppers Serves 4	110 g (4 oz) brown rice 4 assorted peppers, halved and deseeded 200 g (7 oz) can of tuna in brine, drained and flaked 325 g (11½ oz) can of sweetcorn, drained 50 g (2 oz) mature Cheddar cheese, grated, plus ½ extra tbsp for topping 1 bunch fresh basil leaves, shredded, plus a few whole leaves to garnish 2 tbsp dry white breadcrumbs	1. Cook the rice according to packet instructions (you do NOT need to add any salt) until tender and drain well. 2. Meanwhile, preheat the grill to medium. Arrange the peppers on the grill rack, cut sides down. Grill for 5 minutes, turn the peppers over and cook for a further 4-5 minutes. 3. Combine the rice in a large bowl with the tuna and sweetcorn. Gently fold in the grated cheese, basil leaves and pepper to taste. 4. Divide the mixture equally between the pepper halves. Mix the breadcrumbs and extra cheese and sprinkle over each pepper. 5. Return the peppers to the grill for 4-5 minutes, until hot and golden brown, then serve immediately with a crisp salad.
Beany Cottage Pie Serves 2-3	225 g (8 oz) minced beef or turkey 450 g (1 lb) potatoes ½ onion, finely chopped 300 ml (½ pint) of boiling water Beef stock cube Pinch mixed herbs 2 tsp tomato sauce 1 tsp brown or Worcester sauce Baked beans, small can Pepper	1. Preheat the oven to 190°C, 375°F, or Gas Mark 5. 2. Peel the potatoes and boil in the pan until tender. Drain and mash. 3. Place the mince in saucepan and brown over a high heat, stirring continuously. 4. Reduce the heat and add the chopped onion. Continue to fry for a further 10 minutes. 5. Dissolve the stock cube in boiling water pour over the mince then add herbs, sauces, baked beans and pepper. 6. Place the meat mixture in the base of a casserole dish. Top with mashed potato and level the surface with a spoon. 7. Bake uncovered for 20-30 minutes. 8. Serve with vegetables or salad. (The baked beans may be replaced with chick peas or lentils)
Cheese Crusted Scones Makes 8-10	175 g (6 oz) self-raising flour 60 g (3 oz) grated Cheddar cheese 1 large egg 25 g (1 oz) margarine 30 ml (2 tbsp) milk 1 tsp mustard powder	1. Preheat the oven to 220°C, 435°F, or Gas Mark 7. 2. Put the flour into a bowl, add the mustard powder and mix. 3. Add the margarine and rub it in with your fingertips until the mixture looks like breadcrumbs. 4. Mix in nearly all the grated cheese (leaving about 1 tbsp). 5. Beat the egg with 2 tbsp of milk and add it to the ingredients to make a soft dough (if it seems a little dry, add a little extra milk). 6. Roll the dough out on a floured surface to a thickness of about 1/2 inch (11/4 cm). 7. Using a 21/2 inch (6 cm) fluted cutter, cut out the scones. 8. Place on a greased baking sheet and sprinkle grated cheese on top of each scone. 9. Bake on a high shelf for 15-20 minutes.

The book is part of the local Strategy is to try and empower everyone to make better choices of food for health reasons. The Doncaster approach is to go for the whole family with the recipe book. When I asked Carolyn to review the recipes for Pathways, she pointed out that important nutritional information is missing from the book, which of course, we always show in Pathways recipes. So I decided to make health estimates based on the ingredients lists and apply a traffic light system.

Recipe	Ingredients	Calories	Carbs	Fat	Saturated Fat	Sodium
Tuna Rice and Peppers Serves 4	110 g (4 oz) brown rice 4 assorted peppers, halved and deseeded 200 g (7 oz) can of tuna in brine, drained and flaked ●s 325 g (11½ oz) can of sweetcorn, drained 50 g (2 oz) mature Cheddar cheese, grated, plus ½ extra tbsp for topping ●f 1 bunch fresh basil leaves, shredded, plus a few whole leaves to garnish 2 tbsp dry white breadcrumbs	🔴	🔴	🟡	🟢	🟡
Beany Cottage Pie Serves 2-3	225 g (8 oz) minced beef or turkey 450 g (1 lb) potatoes ½ onion, finely chopped 300 ml (½ pint) of boiling water Beef stock cube ●s Pinch mixed herbs 2 tsp tomato sauce 1 tsp brown or Worcestershire sauce Beans, small can ●s Pepper	🟡	🔴	🟡	🟡	🔴
Cheese Crusted Scones Makes 8-10	175 g (6 oz) self-raising flour 60 g (3 oz) grated strong Cheddar cheese ●f 1 large egg 25 g (1 oz) margarine ●m 30 ml (2 tbsp) milk 1 tsp mustard powder	🟢	🟡	🟡	🔴	🟢

●m Margarine contains high levels of saturated fats. Unsaturated vegetable oils would be a better choice.
●f Substituting a lower fat cheese than Cheddar would be a healthier choice
●s Processed food contains high levels of added salt. Alternatives are available.

One recipe, a stir fry, uses ingredients which are expensive, and would possibly be outside most people's budget, and may be cheaper from a Chinese takeaway.

A lot of money has been spent on the preparation of this book, especially with the colour format. On the whole, I do question if the contents have been properly thought out, and I question if it is making good use of public money.

If your shopping doesn't have traffic light colours you can still tell the levels by using this handy card. Remember the label shows you the amount of total sugars, so although some products may be high for sugars they can be healthier choices if they contain lots of fruit. You can tell by checking the ingredients list.

Food Shopping Card

Check how much fat, sugar and salt is in your food

	Sugars	Fat	Saturates	Salt
What is HIGH per100g	Over 15g	Over 20g	Over 5g	Over 1.5g
What is MEDIUM per100g	Between 5g and 15g	Between 3g and 20g	Between 1.5g and 5g	Between 0.3g and 1.5g
What is LOW per100g	5g and below	3g and below	1.5g and below	0.3g and below

Remember that the amount you eat of a particular food affects how much sugars, fat, saturates and salt you will get from it.

This is a aid memoire card from the Food Standards Agency designed to help show how the traffic light system helps in healthy food choices

Chocolate and Health.

Chocolate is made from the seeds of the tropical cacao tree found tropical South America, Central America and Mexico, as was known to the Maya and Aztecs. The seeds of the cacao tree have an intense bitter taste, and must be fermented to develop the flavour. After fermentation, the beans are dried, roasted and shelled. The result is two fractions, cocoa solids and cocoa butter. The first chocolate house opened in London in 1657. In 1689, noted physician and collector Hans Sloane developed a milk chocolate drink in Jamaica which was initially used by apothecaries, but later sold to the Cadbury brothers. In the 1700s, mechanical mills were created that squeezed out cocoa butter, which helped to create hard, durable chocolate. It was not until the arrival of the Industrial Revolution that these mills were scaled up; paving the way for companies to begin advertising this new invention and eventually to sell many of the chocolate treats we see today.

Unusually the Cocoa bean pods grown from the trunk of the tree, not the branches.

Types of chocolate

Pure chocolate is mainly solids and cocoa butter.
Unsweetened chocolate is pure chocolate, which is ground, roasted chocolate beans,
Sweet chocolate is sugar with chocolate solids and cocoa butter.
Milk chocolate contains milk powder or condensed milk powder with chocolate solids and cocoa butter.
Dark chocolate is produced by adding fat and sugar.
White chocolate is formed from a mixture of sugar, cocoa butter, and milk solids without cocoa solids.

While chocolate is regularly eaten for pleasure, there are claims which include anticancer, brain-stimulator, cough-preventer and antidiarrhoeal effects. As an aphrodisiac is it as yet unproven? However, eating large quantities of any energy rich food such as chocolate increases risk of obesity. Chocolate contains a variety of substances, some of which have an effect on body chemistry. Theobromine is believed to cause mood-elevating effect, and is toxic to many animals because of insufficient capacity to metabolize theobromine, which is not prominent in white chocolate. The Tryptophan present is an essential amino acid and precursor to serotonin. The phenethylamine content is sometimes described as a 'love chemical; but does not reach the brain in significant amounts. Caffeine is present only in very small amounts. Chocolate contains about 33% saturated fat.

Coca butter melts just below body temperature, and is sometimes presented as chocolate fountain to serve dessert fondue.

Chocolate tips. Dark chocolate has a stronger taste than milk chocolate, so you shouldn't need so much to fix your craving. Also, it has less sugar and fat, and it's packed with healthy antioxidants. If you like your chocolate bar to have a filling, choose fruit rather than nuts, because fruit is lower in calories and fat than nuts. For example, choose chocolate-coated cherries, raspberries or cranberries rather than chocolate-coated brazil nuts or peanuts. Chocolate coated pretzels are another lower fat alternative. Try out low-fat chocolate alternatives such as low-fat chocolate yogurt and mousse, or low calorie chocolate drinks and chocolate sorbet. Try fun/bite size chocolates, it might help you to control the amount you eat. Eat slowly; let the chocolate melt in your mouth and savour the flavour. Store your chocolate in the fridge and it will take even longer to melt in your mouth. Try to save chocolate treats for after a meal, when you will naturally be less hungry. Decide how much you are going to eat and put the rest of the chocolate away, out of reach. This should help prevent you from having 'just one more piece' and snaffling the whole lot before you realise it! *Mike*

News from Fairlawns (Sheffield ME/CFS Clinic)

I attended a meeting of the CFS/ME Local Patient Involvement Group (LPIG) at Fairlawns on the 24/10/08. The purpose of the meeting is for ‘us’ (user groups) to give feedback to the clinic administration. I represent the Doncaster Area, along with patients and other local group leaders. What has to be understood is that the NHS-run clinic is the only accessible NHS specialist ME/CFS service for Doncaster, and as with many NHS services, it is limited by funding, and we are all aware of it’s shortcomings. This page is intended to give Pathways readers my digest of some of issues discussed.

Since its inception four years ago, well over 1000 people have passed through the clinic’s doors and certainly I’ve seen a difference in terms of less disbelieving doctor issues in Doncaster since it opened for business. While the staff mainly work within the NICE guidelines, they are keen to create their local customisations based on their own experience and that of their patients. To extend this, Anne Nichol is considering organising a meeting early in 2009 with reference to ’Improving the CFS/ME Service’. It is expected that they will invite former users of their service to a meeting in Fairlawns or ask for feedback via mail or email. At this point in time, details are not known and the meeting will take place before the next issue of Pathways is due, so I will email or give details at group meetings when decisions have been made.

I raised the issue about Employment and Support Allowance, at the recent meeting we had with the DWP in Doncaster on DLA. I pointed out that ESA claimants would have to attend five work-based interviews, which would scrutinise their possibility of any type of work-related activity. It was accepted that the Sheffield ME Clinic would be ideally placed to make some resource, information or advice, as yet unidentified, available to their patients. With the new system, there are likely to be more adverse decisions made by the DWP, than the current unacceptable levels. I also pointed out the daily activity/symptom diaries were possibly a way forward for ESA and DLA, but at present we have no indication of exactly what sort of information is being sought or how it is best presented.

The Sheffield ME clinic is a business, and books have to be kept. Part of the information they keep is about what they do, and what they achieve. Each patient they see, as with any other health related service, has a record, which is known as the MDS or Minimum Data Set. The MDS is a national NHS agreed standard used by all the NHS ME/CFS clinics. I have expressed concern, at previous meetings, about shortcomings in recording certain types of information. The key thing is that the way ME/CFS starts, (the mode of onset, sudden or gradual), is a good predictor of what is likely to happen in the long term. Other coexisting illness (co-morbidities) and complications (e.g. depression or IBS) are not recorded, nor are details of pain (the ’M’ in ME). For example many patients have asthma or skin problems, and this is another predictor of the way ME/CFS will go. Furthermore, outcome, e.g. success or failure, is not followed up in sufficient detail, especially in the long term, 5 years or longer. The whole issue is that collection of this sort of data in the long term would enable better targeting of resources, and more cost effective decisions to be made. I also believe that this would put into context NICE-advocated strategies like CBT and GET. This issue will be carried over to the next meeting.

Phillip Burns attended the meeting, as a guest. He is the Regional Representative for the National Collaborative, which is the next tier up from local representation in the NHS. He is also involved with ME North East in the Tyne/Tees area. He brought up the issue about the MDS, telling us that there is much debate about problems with data collections and analysis nationally. He also told us about the National Collaborative merger with the NHS/CFS/ME network, and about questions raised about the viability of a single national body co-ordinating NHS clinical practice for ME/CFS.

I very often come home from these meetings feeling frustrated and ask myself “*Is it worth is getting involved?*” Certainly, the clinic exists because of campaigning by groups like ourselves around six years ago. I feel that the total benefits for people with ME/CFS as a result of my attending these meetings are greater than if I spent that time helping individual members.—*Mike.*

Group Meeting 15th July 2008: Speaker: Dr L Swinburne.

Dr. Swinburne ran a private ME/CFS clinic in Leeds until about 15 years ago, and is now retired. The meeting was entitled 'Back to Basics'. Rather than having a formal presentation, we opted for a question and answer session for specific questions members have sent in.

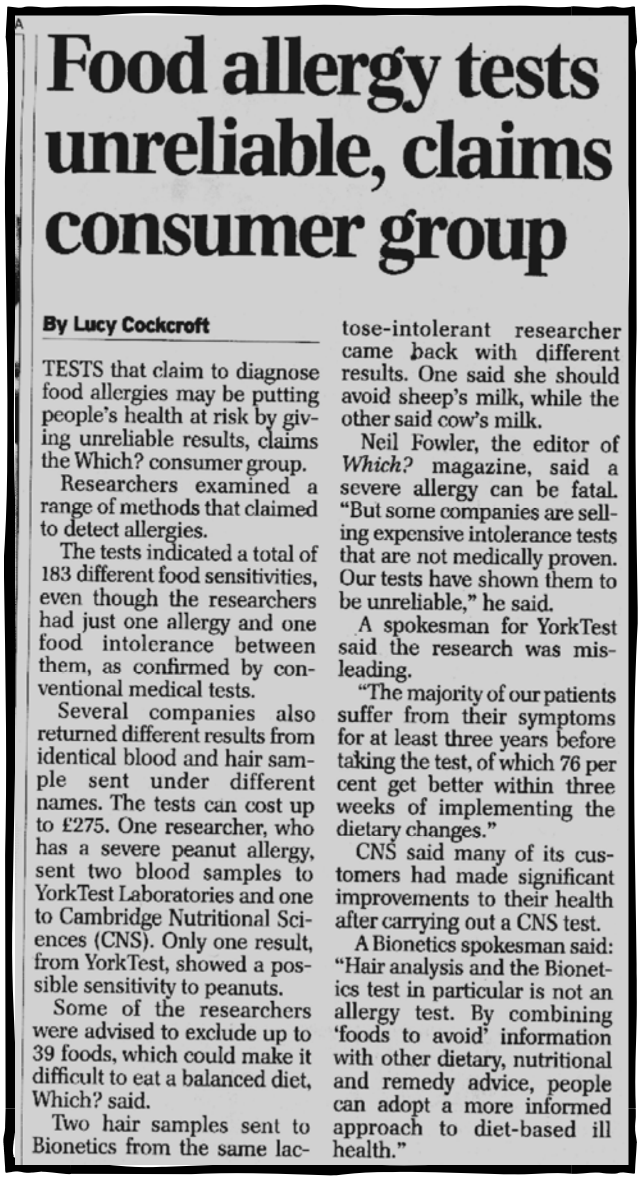
1) ***What are your experiences with ME/CFS ?***
I was associated with the late Dr Melvyn Ramsay, who was the first doctor to coin the name M E. In the early days it was known as Ramsay Syndrome. I was associated with him and carried out research. Later I started the private ME clinic which I held in Leeds for a number of years, prior to retirement. *(This has been covered in Pathways no. 4,. See group website.)*

2) ***What about welfare rights issues ?***
Welfare rights and state benefit issues have always been a problem with ME. Providing reports for employers and now the DWP was one of the most frustrating and unsatisfying aspects of my former practice. Not much has changed over the years, but at least now we have the NICE guidelines, the CMO reports, the Sheffield Clinic and of course, the local ME groups.

3) ***What are your thoughts about B12 injections ?***
B12 helps many ME/CFS patients. The dose needs to be far more frequent, than for B12 deficiency. More is unknown than is known about biochemical pathways. If it works, continue to use it. There are no known adverse reactions, except those from the process of injecting. There are several interesting research findings that suggest 'new metabolic pathways', but nothing is really proven beyond doubt to NICE standards which require a 60% majority of positive results level. If it works, use it. (*There is a nitric oxide /peroxynitryl theory which I intend to feature in Pathways at some future time. Mike*)

4) ***What about Vitamin D ?***
The same applies to Vitamin D2, although it is far better to get exposure to sunlight than to take a supplement. (*There was a discussion about media reports advocating D2 for pain control. Mike)*

5) ***What do you think about food-sensitivity testing ?***
Paying for your own food allergy tests is a waste of money, as they are unreliable. For ME/CFS there are sensitivities, but they tend to change, come and go with time. There is very little point in allergy testing. If you are careful and keep a record of what you react to, you can avoid it. *(See newspaper clipping)*



Food allergy tests unreliable, claims consumer group

By Lucy Cockcroft

TESTS that claim to diagnose food allergies may be putting people's health at risk by giving unreliable results, claims the Which? consumer group.

Researchers examined a range of methods that claimed to detect allergies.

The tests indicated a total of 183 different food sensitivities, even though the researchers had just one allergy and one food intolerance between them, as confirmed by conventional medical tests.

Several companies also returned different results from identical blood and hair sample sent under different names. The tests can cost up to £275. One researcher, who has a severe peanut allergy, sent two blood samples to YorkTest Laboratories and one to Cambridge Nutritional Sciences (CNS). Only one result, from YorkTest, showed a possible sensitivity to peanuts.

Some of the researchers were advised to exclude up to 39 foods, which could make it difficult to eat a balanced diet, Which? said.

Two hair samples sent to Bionetics from the same lactose-intolerant researcher came back with different results. One said she should avoid sheep's milk, while the other said cow's milk.

Neil Fowler, the editor of *Which?* magazine, said a severe allergy can be fatal. "But some companies are selling expensive intolerance tests that are not medically proven. Our tests have shown them to be unreliable," he said.

A spokesman for YorkTest said the research was misleading.

"The majority of our patients suffer from their symptoms for at least three years before taking the test, of which 76 per cent get better within three weeks of implementing the dietary changes."

CNS said many of its customers had made significant improvements to their health after carrying out a CNS test.

A Bionetics spokesman said: "Hair analysis and the Bionetics test in particular is not an allergy test. By combining 'foods to avoid' information with other dietary, nutritional and remedy advice, people can adopt a more informed approach to diet-based ill health."

6) ***What are your thoughts about blanket food supplements ?***
This is an option, but my preferred route is to treat specific issues. The RDA (recommended daily amount) information on various packs of Cod Liver Oil (EPA, Vitamins A & D) can be misleading and could lead to an overdose, particularly vitamin A. (*During case review sessions, I check for this. Mike).*

7) ***Do you have any thoughts on special diets ?***
Unless food allergies or other medical conditions dictate otherwise, the best diet is a well balanced diet and keep your weight within ideal limits. Glycaemic eating, a strategy to reduce the amount of raw sugar in a diet helped many of my patients. (See *Pathways 11, and over page)*

8) ***What are your thoughts about Statin-type drugs promoted for controlling cholesterol. Four group members had experienced severe adverse reactions to simvastatin prescribed for high cholesterol as a precaution against heart attacks and strokes ?***
Statin-type drugs as not good news for ME/CFS patients as they interfere with the B3 pathways which are usually compromised in ME/CFS. From the medical literature. the expected incidence is 1:100,000 but Mike tells me that from Leger ME members' experience the rate is at least 4%. ME kills around 1 person per year in the UK, whereas the five year risk of a stroke or heart attack has to be around 10% before a statin is prescribed. There are other drugs like Maxepa (preferred) and fibrate class drugs which can work just as well. *(One lady was relieved to find she was on Atrovastatin, possibly one of the best statins with the least potential for side effects for ME, and preferred by doctors at DRI. It is however four times more expensive that simvastatin. Another member had reported that her G.P. practice has changed its patients from Atrovastatin, prescriptions on economic grounds, without prior consent or explanation.*

9) ***What are you thoughts about Dr. Myhill's Clinic?***
Dr. Swinburne said she was glad that Dr. Myhill had taken a lead in pioneering ME treatments. Her own similar research-project had to be terminated due to the death of her colleague.
(*Some members had brought in Dr. Myhill's reports which Dr. Swinburne reviewed privately -Mike.)*.

The sugars in fruit are absorbed at different rates; Glucose is the most rapid—glycaemic INDEX 138. Fructose, the slowest, with an index of 30, has more staying power. Sucrose breaks down to equal amounts of glucose and fructose, and is halfway with a index of 86. Starches are converted to glucose, often very quickly, but this depends on the type of food and how it is cooked as you will see from the Glycaemic index table over the page. The starred fruits are the most useful. in giving slow release of energy as part of a meal or snack.

FREE SUGAR CONTENT of FRUIT *(Dr. Swinburne)*

FRUIT	Fructose (GI 30)	Sucrose (GI 86)	Glucose (GI 138)
Dates*	1.4	3.4	1.7
Grapes*	6.5	0.5	6.5
Apples*.	5.9	2.2	1.8
Pears*	5.6	1.11.	2
Cherries*	5.1	0.2	6.1
Gooseberries	3.9	1.2	3.2
Currants	3.6	0.9	3.3
Cantaloupe*	2.6	5.8	2.6
Blueberry	3.2	0.2	2.3
Blackberry	2.7	0.4	2.4
Banana*	2.6	7.0	6.0
Orange	2.5	3.2	2.4
Grapefruit	2.2	2.4	2.1
Strawberries	2.1	1.1	2.0
Raspberries	2.0	1.5	1.8
Tangerines	1.2	5.0	1.1
Plums	1.2	5.2	2.2
Peaches	1.1	4.6	0.9
Apricots	0.4	5.7	1.1

Glycaemic Index of Foods *(Dr. L Swinburne)*

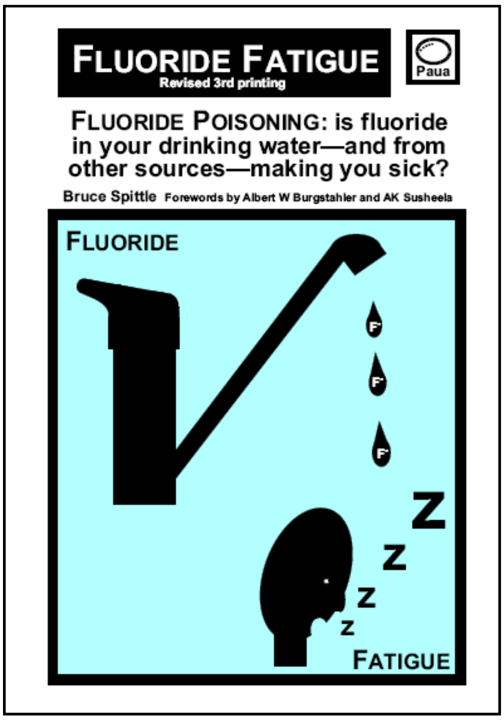
In the following table each food type is compared with white bread, which is set at a Glycaemic Index of 100. Foods which are slowly digested release energy slowly. The lower the figure, the more the food will help you to control your energy levels.

Wholemeal or whole grain or just brown? Foods which contain a good proportion of whole cereal grains and vegetables in which the plant cells remain intact, have a lower Glycaemic Index than those in which the grain has been milled into smaller or smaller particles or flour.

Dried legumes		**Cereals**	
Baked beans	60	White bread	100
Butter beans	52	Wholemeal bread	99
Haricot beans	45	Barley flour bread	96
Soya beans	22	Rye crisp bread	95
Chick peas	49	50% bulgur bread	83
Dried green peas	56	75% bulgur bread	69
Red lentils	43	50% barley bread	66
Fruit		Bulgur (cracked wheat)	62
Banana	79	Wholemeal rye	58
Raisins	97	Barley	39
Cherry	32		
Grapefruit	36	**Cereal products**	
Orange	66	Buckwheat	74
Orange juice	67	Millet	103
Apples	53	Rice, brown	96
Pear	47	Rice, White	83
Peach	40	Spaghetti (whole-wheat)	61
Plum	34	Spaghetti (white)	66
Dates	35	Sweet corn	87
Sugars		**Breakfast cereals**	
Fructose	30	All-bran	73
Glucose	138	Corn-flakes	119
Honey	126	Muesli	96
Maltose	152	Shredded Wheat	97
Sucrose	86	Porridge oats	85
Dairy products		Weetabix	87
Ice cream	52		
Skimmed milk	46	**Biscuits**	
Yoghurt	52	Digestive	82
Whole milk	49	Oatmeal	79
Vegetables		Water biscuits	91
Frozen peas	74	Rich tea	90
Potato (new boiled)	81	Pumpernickel	50
Potato (baked, jacket)	135	Rye bread	50
Sweet potato (yam)	70		

Fluoride Fatigue – A new book by Dr Bruce Spittle,

Reviewed by Elizabeth McDonough



Sometime around 1995, when I was just getting over M.E., a friend gave me a copy of Dr George Waldbott's book *Fluoridation: The Great Dilemma*. Waldbott, an American allergy specialist, had written the book in collaboration with Albert W Burgstahler PhD, a chemistry professor at the University of Kansas, and H Lewis McKinney Professor of the History of Science at the same university. The book was published, in 1978, by Coronado Press Inc. and explains clearly why Waldbott objected to artificial water fluoridation which was being advocated as a means of combating childhood tooth decay. What struck me most forcefully was the list of Symptoms of Chronic Fluoride Toxicity in the Appendix on page 393. The symptoms were many and varied and were the same as the symptoms of ME!

This year I was privileged to attend the 28th Conference of the International Society for Fluoride Research (ISFR) in Toronto (7th – 10th August 2008). A simple, but striking, presentation at that Conference was given by Dr Bruce Spittle, who compared Dr George Waldbott's List of Symptoms with the symptoms of one of his own patients.

Bruce Spittle, from, New Zealand, has had a distinguished career in medicine and psychiatry. His book entitled, FLUORIDE FATIGUE: Fluoride Poisoning: is fluoride in drinking water - and from other sources - making you sick? (3rd revised printing) was available at the Conference.

Dr Spittle is convinced that drinking water with fluoride at one part per million makes some people – and animals – ill. Within the pages of his slim paperback, he explains the mechanisms behind the fatigue and other symptoms of chronic fluoride toxicity, and the research, which has influenced his understanding of the syndrome. The book is illustrated, well-referenced and indexed. It is dedicated to "all those who have struggled, in the face of criticism, to see an end to the irrational policy of fluoridating water supplies."

Waldbott's co-author, Dr Albert W Burgstahler, who also attended the Conference, has said: "Those who deny reality and persist in discounting sensitivity to fluoride in drinking water are like ostriches with their heads in the sand. They would do well to read what Dr Spittle has reported and stop continuing to promote and be misled by scientifically indefensible claims that do not hold up under scrutiny."
The electronic version of Dr Spittle's book is FREE to download at –
www.pauapress.com/fluoride/files

Fluoride appears to be something that is best avoided, especially by people with ME. It is found in appreciable amounts in tea, fish, some wines and fruit juices, toothpaste and toiletries, mouthwash, dental treatments, many medicines, anaesthetics and non-stick pans. Water supplied by Yorkshire Water does not have added fluoride but some areas to the south of Doncaster are supplied by other water companies and may have fluoride added to achieve a fluoride ion concentration of 1 part per million. You can contact your water company to check the fluoride level in your water. Below 0.3 ppm is O.K. The American Dental Association has conceded that baby formula should not be mixed with fluoridated water because of the risk of mottling and staining (*dental fluorosis*) in a child's permanent teeth.

For further information on fluoride and fluoridation, take a look at the websites:
www.npwa.org and www.fluoridealert.org

THE EARTHQUAKES: When you rearrange the letters: becomes THAT QUEER SHAKE

Group Meeting 19th September 2008: DLA (Disability Living Allowance) & ME. Speaker Sandra Lavery

We all squeezed into the small meeting room at the Redmond Centre to hear Sandra Lavery (Customer Relations Manager, Leeds DBC), and a Decision Maker (DM), whose job it is to asses applications and recommend awards. Although the DM's name was made known to the attendees of he meeting, for privacy, I am not recording it in Pathways. Sandra's office deals with the new DLA applications from our area for the first three months, after which they become the responsibility of Warbeck House in Blackpool. We invited Sandra because she has been to see us in Doncaster many times in the past, and has always provided us with constructive advice and help with individual cases. Sandra gave us a resumé of information, which is available from the DWP and other welfare rights organisations. Many of our group members receive DLA, around £65 a week, and is the major ME/CFS issue we can help with. However, the obstacles are the 40+ page DLA1 claim form, obtaining favourable reports from GP's and DWP doctors, and a system that is not ME-friendly. Consequently, DLA refusal is the major issue we help with. The main reason we invited Sandra was to clarify a number of common issues, and hopefully help members get it right on first application, thus reducing the need for appeals and tribunals. Sandra said that the present system has been introduced in the late early 1990's by public demand, after customer dissatisfaction of the previous mobility awards being based in an isolated visiting doctors opinion and not taking into account any other evidence. It is known that 75% of all DLA applications fail at the first attempt. However, for our members the rates are better. About 50% get a first time award, and over 90% eventually succeed after the appeal process.

So the first question I asked was about if they had quotas or targets to give or refuse awards. A firm "NO, we assess each case on it's individual circumstances" was the response. All the decision-makers are trained to the same standard, and, given a particular set of circumstances, should come to be same decision. There is ongoing training and supervision as with any other commercial organisation. The next part of the discussion centred around the filling in of the DLA1 form. We were advised to plan our responses, before starting the form. I explained that we do offer members blank photocopies of selected form pages, and we have a good guide from the Sheffield ME group specific to ME/CFS. We recently had a member who chose to type her DLA form answer on plain paper does it affect the applications? The answer was "As long as we have the information, it doesn't matter if it is from the form completion service, e-form, paper form typed, on paper, as long as we have the right information we will make a decision." (The member who did this subsequently got the expected award). In practice for ME/CFS I have found that DWP form-completion has many shortcomings, and I always recommend a local personal service like SYCIL or D*i*AL. I explained that I frequently find that DIY form fill-outs and lack of expert advice are the main causes of refusal. I also explained that, if asked, I will check out members DLA forms at the Redmond Centre.

One member asked if it is possible to get DLA for ME/CFS without a diagnosis as they had a hostile GP. The response from the DM was that for ME/CFS cases, without a diagnosis or support from a registered doctor or hospital, really there was not enough evidence to substantiate a claim. I clarified the issue to the member, by recommending that they change their GP as they were a known hostile practice. We then talked about section 3 of the form, and the mobility part. I asked if there was a cut off in the 'how far can you walk' box. There is a belief that if you put in more than 30 metres, the remainder of that section is ignored. The DM said that there was no absolute cut off, and any decision they made for the mobility component was balanced against the remainder of the form and not just based on that section alone. The mobility section needs a diagnosis to justify any Mobility Award with reference to Commissioners' decisions. The question was asked as to whether DLA is just awarded for a single condition or the overall case. The DM said that everything is taken into account, and all relevant health and welfare issue should be disclosed. One complaint may not be enough to get anything, but a combination of two or more might.

There have been several specific issues that have caused problems for members. Basically most DLA claimants will have had a ICB/IB50 medical. Based on historical information provided by the examining doctor on IB85 form several members have been refused DLA. Although an ICB medical will give a successful Incapacity Benefit award, the contents of the IB85 have been detrimental to a DLA claim, as the contents are not usually disclosed to the claimant and are only usually revealed when a refusal is made, and a full set of papers requested. The DM said that basically an IB85 is not used in isolation to make a decision - it is part of all the information that is drawn together to make up a picture of an average 24 hours for the individual. My experience however differed.

There is nothing that clearly allows for average 24 hours in the DLA application form. I asked how we could get around this. We were advised to give additional information in terms of a daily diary or activities where possible. After a discussion we have taken this on board, and Helen Butler, a welfare rights worker from SYCIL, also present at the meeting, has given us information. Using this, we have produced an additional diary form, copies of which are available from the Leger ME office.

I also said that I had noticed a reduction in home visits by DWP-appointed doctors, also called Examining Medical Practitioners (EMP). A few years ago, an EMP visit was almost inevitable, but now it is the exception. We were told that the DWP had reduced the use of EMPs because it had turned out not to be ‘best practice’, but was now only used when evidence was queried or absent. I also pointed out that several members had gone to tribunal without an EMP report, and the tribunal had ordered an EMP report, subjecting the member to a second unnecessary tribunal. This issue was glossed over. I strongly suspect that there are some official guidelines somewhere about this not to be made public.

I asked about partial applications. In the old form, the mobility and care components could be claimed for and assessed separately. If someone, say, had Mobility Allowance, and became in need of personal care, would it be possible just to claim the care component. The answer was that once a review is triggered, the DM will review all the claim, even though there may be an unexpired award left. Even a query, enquiry from another DWP office or any other information a DM received could trigger a review. Once this happens, an enhanced award is possible, but at the same some, a reduced award or complete refusal could happen. I mentioned the case of one member who had high care, and on renewal was awarded middle rate care. She had subsequently lost everything, including the Mobility. This had gone to tribunal and been won, but it took, four years. Another member quoted a similar ongoing case.

There was silence from the DWP employees there. I strongly suspect that there is a ’jobsworth’ culture, within the DWP, and when an error is made, they tend to stick together and not admit wrongdoing. Usually such cases end up going to tribunal, and I have on record several apology letters from government departments, including one from John Major (Prime Minister at the time). As a consequence of this, I very often advise members not to query DLA awards, and accept them unless there are exceptional circumstances or other strong medical evidence is available or likely to turn up. Usually DLA awards for ME/CFS are short term, being 1,2 or 3 years, and the strategy is to wait until a renewal form is received and then only submit the form about 2 months before the old award expires to avoid the risk of losing money.

There were a number of personal issues raised by members at that meeting, and six DLA forms were issued to members for new claims. This has kept me busy for the last few weeks. We were advised that some of our website information was outdated, which we will deal with this after the November Pathways. There is one final twist to the afternoon. The DM was an ME/CFS sufferer, this not being made known to the members. A private consultation followed as happens with other Leger ME members. My parting enquiry was, how can we make your job easier. The answer that came back was that they need to know everything, but the 24 daily activity diary/ report is the most useful from their point of view. So.. That will be standard helpline guidance from now on. *Mike*

Sheffield ME Group Annual Conference

This years Sheffield ME conference was based around four workshops**.**

The “Managing CFS/ME” Workshop

This Workshop was presented by Mark Adams of Sheffield NHS CFS/ME Clinic, and focused on looking at the different aspects of ME-management. His strategy is to take control of physical and mental activities. The system starts by asking questions, what the approach is right now, roles of carers, and is there a need that can be supported. Emotional impacts are considered, as changes in the way people live can be achieved by controlling mood, emotions and thinking. Hopefully getting the right approach empowers ME/CFS sufferers to control their lives. He believes that there are three cornerstones of his practice, Activity Management; Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT). Pacing is paramount, as too much too soon can be harmful. During the session, issues regarding popular misconceptions e.g. GET being exercises in the gym are quelled. GET can mean any form of movement in it’s smallest form, standing up from a bed or a chair, or even a short walk. Focusing on the plusses, results are enhanced confidence, and an understanding of the importance of taking control of your life, at whatever level. Issues raised were about NHS waiting times and referrals by GPs. Private therapy is expensive

The “Laughter” Workshop

This Workshop was presented by Jo Eadie, an ME sufferer and a facilitator for the Laughter Network. Laughter is a good leveller and breaks down barriers. It reduces people’s stress and tension, relaxing the entire body. Some say that “Laughter is the best medicine, indeed; let’s laugh more!” Most of the participants left the session exhausted with sore ribs, but relaxed.

The “Role of Fatty Acids in ME/CFS” Workshop

This Workshop was presented by Dr. Nina Bailey, a nutritionist scientist working for Igennus, the makers of VegEPA. A technical presentation explained that people with ME/CFS have an impaired ability to make omega-3 and omega-6 long chain polyunsaturated fatty acids due to the inhibition of the enzyme delta-6-desaturase. This results in disturbances of cell membrane function. Brains contain about 70% lipids. It is believed that depletions of long chain fatty acids in the cell membrane affect the membrane’s fluidity, thus compromising brain function, affecting memory, concentration and learning. It is well known among ME/CFS sufferers that fish oils can help clear ‘brain fog’. Issues raised included that the Government recommends we eat 2 portions of fish per week, one white and one oily, but does not take account of the toxic effects of mercury & dioxin in some fish. Most of the omega-3 components are removed from Tuna in the canning process. Herring and Mackerel are rich in Omega-3 & EPA ·Top predators of the food chain tend to accumulate pollutants and chemicals. A prime example quoted was Cod.

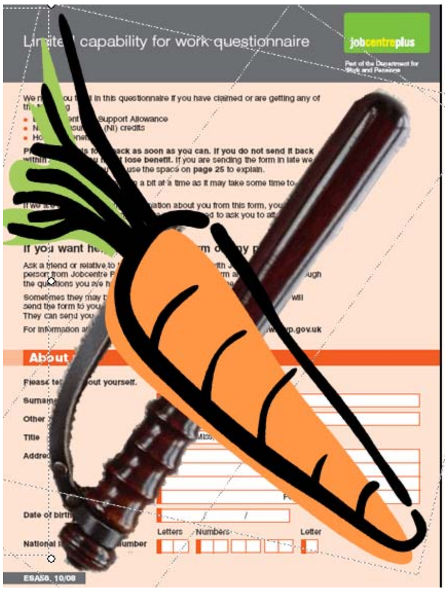
The “Creative Writing” Workshop

This workshop was hosted by Berlie Doherty, who is Sheffield M.E. Group Patron. She is published in many forms of writing including novels, story books, poems and plays. She encouraged us to use all the experiences of the senses when writing, expressing what we see, hear ,smell, touch & taste. To our inner most thoughts and feelings we should add a touch of imagination and artistic license. She focused on enhancing the reality of a story by using the present, rather than the past tense. This enhances the experience of the reader, like being in the audience of a play as opposed to watching it on TV.

As usual Ute and her team had used their creativity to produce something different…so we all look forward to finding out what they come up with next year ...*Mike*

Did you know that A DECIMAL POINT: When you rearrange the letters: becomes I’M A DOT IN PLACE ?

Employment and Support Allowance: A Strategy for Dealing with Interviews, Questionnaires and Medicals.



On Monday 27th October Employment and Support Allowance Started (ESA). It is designed to replace Income Support and Incapacity Benefit in one. Because it is a completely new benefit we have no experience in dealing with issues arising, and consequently the only guidance we can offer is guesswork based on our experience with DLA, ICB and information from the DWP. With ICB there was first an IB50 form which gave warning that a summons for a medical at Crossgates House would eventually follow. The first member received a summons to a Work Based Interview (WBI) on the 1st November. The letter contains veiled threats that your benefit would stop if you didn't attend without good reason and ignores all previous and present benefits, even DLA and previous ICB decisions. Such a letter causes anxiety and ME is made worse by that type of thing. The WBI is actually a assessment of a persons ability to return to work, and is carried out by a Health Professional, who could be a doctor, nurse or physiotherapist.

Support Group First work-focused interview.
The first assessment is to decide if someone is going to be capable of ever returning to work. A medical assessment and examination may be involved. It is a mini ESA 50. From the DWP paperwork it is only foreseeable way people will qualify for grade 3 ME/CFS is a 30 meter walking test as applied in DLA. So unless you have other coexisting conditions, are terminally ill or severely mentally ill, you will be deemed assessed as being able to work at some point in the future. Those ill enough to qualify will be left alone, until some other new benefit or check is introduced. I have no doubt the knowledge of ME/CFS on the part of assessors will be minimal or none existent.

Limited capability for work-related activity assessment will be carried out at the same time. This looks at whether it is reasonable for the claimant to undertake any work-related activity. If a claimant gets 15 points from any one of 46 descriptors that apply to them, they will be put into the 'support group', and will not be expected to engage in work related activity, although they can volunteer to do so. Those in the 'work-related activity group' will have to undertake a variety of work-related activities as a condition of continued entitlement to ESA.

A Strategy for Dealing with the ESA issues.

1) First decide what grade your illness is from the table. You need to choose the worst part of your day. Ignore periods of remission or good periods. Choose the grade that best describes your circumstances. There are no hard and fast rules. If you suffer from another major co-existing illness like Arthritis, Diabetes or Cardiovascular Heart disease asthma, multiple chemical sensitivity, OR are receiving hospital treatment or specialist clinic like mental health or pain control OR are using medical appliances or prosthetics, choose a higher grade.
2) Learn as much as you can about ME/CFS and how it applies to you. We have a table which should help you to fill out a ESA 50, and/or questions that will be asked.
3) Work out your chances of recovery from the table on the following pages.
4) Prepare for the interview. A summary of questions and topics, with possibly defensive answers is on the following pages.
5) Get help from a welfare rights advisor; don't fill out the ESA form yourself without advice. Do not attend any Medical or Interview without a chaperone.

At the time of writing (early November 2008) this is the best information we have. As experience is gained, we be able to update guidance. The tables on the following pages are for ME/CFS guidance only—please not use them as the final authoritative word. With experience, our guidance will change..

Summary of the assessment. *(from DWP literature)*

Jargon Buster: Healthcare Professionals (HCPs) trained in the principles of Disability Analysis (DA). in their training and in performing Work Focused Health Related Assessments (WFHRA)

An overall summary of the report should be cover:

- What the claimant enjoys
- Functional limitations
- Health beliefs
- Other things that prevent work
- Future aspirations
- What the claimant feels is needed for health and return to work

If there were no further additional management of the claimant's condition, what is likely to happen?

- Become more significant
- Improve
- Fluctuate
- Be severe
- Be enduring
- Unable to predict

An example case:

A lady enjoys her role caring for children, and would like to consider work perhaps in the future when the children she cares for are all at school. Enjoys painting and drawing in her spare time. She has never gained any formal qualifications, but has considered the possibility of trying to obtain the necessary qualifications to allow her to pursue child minding as a career or would like to further develop her interest in art, perhaps through night school classes. She feels her mental health condition causes her problems with concentration and dealing with the public in busy places. She feels she would be unable to return to her previous job as a shop assistant due to her mental health condition. She feels her medical problems may be helped by different medication or some form of counselling or anxiety management. She also feels it would help her back to work if she could have help with her childcare responsibilities while she studied for her qualifications. She thinks that she would be overwhelmed with significant responsibility at work

The opinion must be based on the claimant's current overall condition, drawn from information obtained . Health and workplace interventions that may assist a return to work include any reasonable health and workplace interventions that may assist in a return to work, must avoid being too specific or prescriptive in this area as they are not in possession of all the clinical information. The opinion is based on such should be suggestions only. It is the responsibility of the PA and claimant to agree a management plan together. It is still the responsibility of the clinician involved in the intervention (e.g. physiotherapist) to make the final decision as to the suitability of this intervention for the person. The HCP should provide fairly general advice such as:

- Improved understanding of the condition
- Health interventions
- Psychological support
- Expert Patient Programme
- Physical exercise
- Condition Management Programme (CMP)
- Physiotherapy
- Occupational Therapy

Possible work place adoptions :
- Buddy systems
- Flexible working hours
- Working in a quiet environment
- Working on the ground floor
- Provision of lifting aids
- Ergonomic assessment
- Suitable toileting facilities
- Working from home
- Transport such as taxi to work

The many issues such as how to get to work and get around in work, as well as workplace adaptations and specific aspects of work organisation should be considered. Any suggestions must be consistent. The HCP is asked to give an opinion regarding return to work.

Within 6 months OR More than 6 months

This is not a prognosis of the medical condition or work related activity; but an opinion. Most ME's are likely to be within the 'more than 6 months' category.

Leger ME's ME/CFS grading system based on the Findlay and NICE systems

Grade	Type	Ability of Patient	%	DLA usually awarded	Daily Personal Minimal Care	Quality Home Life	Quality Leisure Time	Work Ability
0	Normal	Lives a 'normal' life.		None	Normal	Normal	Normal	Full time
1	Mild	Mobile and self caring and able to manage light domestic and work tasks, with difficulty	25-33%	Low Rate Mobility	Can cope with Personal care, but rationed.	Trade off against work.	May be severely rationed	Part time
2	Moderate	Reduced mobility and restricted in all activities of daily living, often having peaks and troughs of ability, dependent on degree of symptoms. Usually stopped work or limited capacity, requiring many rest periods.	50–60%	High Rate Mobility Low Rate Care	Rationed personal Care	Rationed	Often Minimal	Some possible in protected environment or maybe from home in certain cases.
3	Severe	Will be able to carry out minimal daily tasks, i.e. face-washing, cleaning teeth, has severe cognitive difficulties and is wheelchair dependent for mobility. Often unable to leave the house except rarely.	25%	High Mobility Middle Rate Care	Many need intervention from others. Personal Care and meals	Minimal	Some but severely restricted	Occasional voluntary when and if able with support and protected environment.
4	Very Severe	Unable to mobilize or carry out any daily task for themselves. Bed-ridden the majority of the time.	1-2%	High Mobility High Rate Care	Needs intervention from others 24/7	Zero	Zero	None

The chances of recovery based on Leger ME Experience

History	Most Common Outcome
Child or Young adult acute onset	Expect Peak at around 12-18 months, full recovery possible in 3-5 years, but may not be complete.
Middle age Adult, acute onset	Expect peak at 2 years, and slow, partial or incomplete recovery.
Older acute onset	Expect peak at 2 years, with incomplete recovery influenced by age.
Insidious Onset	Expect the condition will become chronic with poor chance of full recovery.
Long established ME/CFS or duration > 4 years	Chronic, lifelong, may be periods of remission or relapse
Pre-existing atopic disease history e.g. multiple allergies, asthma, psoriasis eczema	Expect partial recovery after 2 years, with the condition becoming chronic, and following the peaks and troughs of the atopic disease.
Later life or age-related conditions cardiovascular, arthritis, diabetes.	Expect partial recovery, and chronic common shared symptoms more severe than would be expected for the simple age-related condition.

The National Association's literature describes short-term ME, which ,provided there is full recovery within a year, indicates that recovery will be complete. However, we have never seen this at Leger ME.

ESA 50 Descriptors *(figures in brackets are possible points based on our experience of ICB)*

ESA 50	***ME/CFS issues***	***Grade 1***	***Grade 2***	***Grade 3***	***Grade 4***
Walking.	Pain, dizziness tremor, rebound, cognitive, confusion.		*<200 metres (6)* *<100 metres (9)*	*<50 metres (15)*	*<50 metres (15) (with no steps)*
Standing and sitting.	Pain, dizziness stiffness discomfort. muscular weakness		Sit <30 minutes (6)	Sit <30 minutes (6) Sit < 10 min. discomfort	Sit or stand < 10 minutes(15) Can't rise or move
Bending or kneeling.	Pain, stiffness, discomfort, dizziness need to lean or hold.			Cannot bend or kneel without help (6)	Cannot bend (15) Cannot bend kneel or squat (9).
Reaching.	Pain, muscle weakness, limited movements, involuntary jerks			Put on hat (9) Above head(6)	Top pocket (15) Behind Back (15)
Picking up and moving things.	Clumsiness, manual dexterity, weakness tremor, fasciculation, myoclonus		Light bulky object (6)	Litre liquid(9)	Pint liquid (15)
Manual dexterity.	Clumsiness, manual dexterity, weakness tremor, fasciculation, myoclonus		Pour 1 pint or pickup coin 1 hand (6)	Keyboard. mouse or buttons.(9)	Tap, coin or book (15)
Speech.	Pausing mid sentence, forgetting or can't find right word, talk out of context		Stranger some difficulty (6)	Strangers great difficulty (9)	Cannot speak or be understood by strangers(15)
Hearing.	Hyperacusis, competing noise, concentration		Loud voice busy street (6)	Loud voice busy street (6)	Normal voice quiet room(9)
Vision.	Photophobia, eye fatigue quickly, loses ability to focus, glasses don't help		Close print (15)	Close print (15) Photophobia (15)	Photophobia (15)
Continence	Leaking, wearing pads		Bladder 1 month (6)	Bladder 1 week(15) Bowel occasionally(9) No control(15)	Bowel occasionally (9) No control(15)
Remaining conscious.	Drowsy in a morning. sleep during day. absences	2x in 6 months(6)	1 weekly (15) 1 month (9)	1 weekly (15) 1 month (9)	1 weekly (15) 1 month (9) 2x in 6 months
Learning or comprehension, completion of tasks.	Attentions span limited Confusion, without awareness, aphasia				Cant set alarm clock(15) or learn(25)
Awareness of hazard.	Concentration span limited. Inappropriate automaton action		Can be managed (6)	Needs supervision (9)	Reduced awareness (15)
Memory and concentration.	Sleeps morning Sleeps during day Short-terms memory issues		Self Managed(6)	Supervision(9)	Verbal prompting (15)
Execution of tasks.	Fatigue limits ability to complete tasks. Many be a good activity window		1.5x as long (6)	2x as long (9) 1.5x as long (6)	Cannot complete (15)
Initiating and sustaining personal action.	Fatigue issue. Many avoid activities. Early morning stiffness (EMS) and later fatigue kicks in		Verbal prompting sometimes(6)	Verbal prompting: sometimes(6) mostly(9)	Verbal prompting always(15)
Coping with routine change.	EMS. Not easy to learn new behaviours, disruptions	minor changes (6)	expected changes (9)	expected minor changes (15)	expected changes (15)
Getting about to expected place supervised.	Anxiety, dizziness, fatigue if driven		Frequently with supervision	Supervision: all time(15) Mostly (9)	Cannot(15) supervision (15)
Coping with social situations. (Anxiety)	Fatigue, pacing strategies don't address, Anxiety, phobia. concentration		Frequently (6)	Mostly(9)	Precluded (15) Mostly(9)
Behaviour with other people.	Usually depressive, and phobic. tends to be irritated.			Over-reacts(6)	Over-reacts(6)
Dealing with other people.	Anxiety, poor self-confidence, aphasia, distress		May misinterpret (6)	Significant distress (9)	Significant distress (9)

Question	**Topics to be Discussed**	**Defensive Response**
1) How do you see your future, from a health and work point of view?	Acquiring new skills, training/retraining, voluntary work, or education. Previous job changing occupation. Exploring beliefs about work, health beliefs, general acceptance, coping with illness	Work aggravated ME. unreliability, health and safety issues.
2a) What activities do you currently enjoy, what may help your health and work prospects?	General activities (housework, family, childcare), socialising, services, hobbies (those no longer pursued), gardening, use of computers. particular subjects, leisure time, sports. voluntary, permitted work, charity activities, education	Don't (hobbies could work). Health problems limitations are persistent. Most people with ME stop socialising & hobbies first.
2b) What activities would you like to do in the future, that may help your health and work prospects?	What activities would you like to do in the future, that may help your health and work prospects? New hobbies or interests, but may also include discussion about acquiring new skills, training/retraining, voluntary work and education.	Would like to get back to a full normal life, tradeoffs have to be made. The biggest stressor is pressure from work.
3) What activities would you like to do, that may help your health and work prospects?	Rehabilitation, including symptom or health improvement. Practical support such as help with childcare, transport or housing issues Careers advice. Financial support such as help with travel costs or help with dealing with debt. Access to work-related equipment	There are no options as there is no cure or control for my condition.
4a) What impact do you feel your health has on your daily life?	Getting about and self care, Communication ,Social interaction. Ability to manage their own affairs, diet and nutrition. pain on mobilising, and driving limited to local driving now. Mental health limits them socially. Don't like crowds and get panicky in busy places. They feel anxious about meeting new people and only feel comfortable in their own environment.	DLA mobility because of limitations. Devastating, Short term memory, Aphasia Morning stiffness, Daytime sleeping or drowsiness Pain. Substance sensitivity
4b) Do you receive any help or support from other people with regard to your daily life?	Support received, psychosocial aspects, managing a household, or actual physical support. Help with bodily functions, or perhaps emotional support such as prompting. supported housing, level/ type of support they require. Alarms are provided, shopping, provision of meals, help with finances, mail etc.	Use of a carer. paid or unpaid A current DLA award says you can't care for yourself and may need help from another. Mental health issues
4c) What sort of caring of responsibilities do you have?	Caring for oneself, children or older relatives .	Self care is first priority, then balance responsibilities. Caring is work.
5a) What impact do you feel your medication has on your daily life?	Is it helpful, or makes things worse? (e.g. relief of pain after taking pain killers) including how long the medication takes to work and how long it lasts for. Side effects and reduction	No cure, palliation only. Pain killers, antidepressants, sleeping tablets may cause dizziness or drowsiness
5b) What impact do you feel your overall treatment has on your daily life?	Assessment of treatment, physiotherapy, osteopathy, cognitive behavioural therapy, and counselling as well as complementary and alternative treatment. Positive and negative impacts	For grade 1, CBT and GET may help, but are unrealistic for grades 2+ as they are hazardous. Pacing works.
6) Are you trying other ways to help yourself get better or move towards work?	Lifestyle modification, complementary or alternative therapies. Life style modifications, dietary changes, regular exercise and cessation of smoking . Complementary or alternative therapies may include homeopathy, acupuncture, aromatherapy, reflexology or massage. OTC medications. Expert Patient Programmes.	Yes, but they are not working nor are they a cure. Lifestyle modification is a pacing or coping strategy
7) What other help that you have had in the past or are currently awaiting that would help get you back into work?	Treatment and investigations (past treatments, current, future). appointments pending, management plans, specialist, referrals, educational needs assessment , physiotherapy, complementary therapy, hydrotherapy, psychological therapy.	No current treatments is NOT a acceptable answer. Abstention is pacing Medicines, therapists &. special clinics
8) Do you feel that you have the right support that you need to help you find work? .	Equipment or transport. practical support, Communication. internet access or computer use. Social support, household managing, responsibilities. Volunteering and confidence building, retraining, work trials and work placements.	No, because there is no cure or support. Work made my condition worse, and would do if I returned.
9a) Is there anything that would help you to move towards work, or work related activity?	Equipment, workplace solutions: i.e. adaptations to suit specific needs, training, flexible hours, re-training, considering alternative work, Communication, specialist employment support. Counselling.	The NHS, NICE or the government are only giving lip service to the condition. Urgently need better services
9b) Is there anything that would help you to return to your most recent job?	Reasons for leaving previous employment, changes enabling to remain at work. If the claimant felt that changes could have been made, discuss what they would have been	**A cure !!**

North of Doncaster

Personal comment by Trevor Wainwright)

Well following on from the last issue what were the poems and how did they come about? The first poem was called HIV

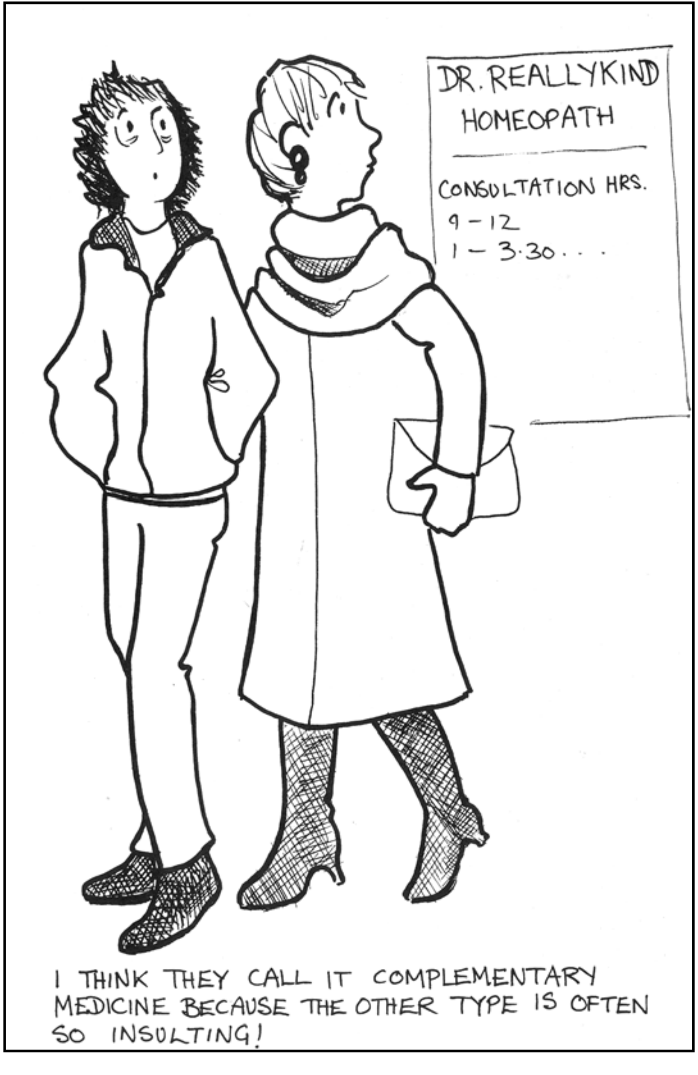
ME (Formerly HIV)

ME is living in me, it's under my skin,
I'm losing weight; I'm going so thin.
Boy can it fight and punch from the right.
By day and by night I get such a fright.
Do I give in? Let it take over my skin.
No! I can fight, isn't that right?
And with all my might yes I will fight

This was the poem that started it all, read in public, adapted there and then on the night depicting so vividly my own daughter's experience and the helplessness I felt and my daughter's own bravery in trying to fight the illness. Yes I knew and had visual proof that ME sufferers did lose weight. This was backed up by a couple who told a similar story, almost a carbon copy of mine. I owe a great debt to SB, the person who wrote it and allowed it to be adapted because as time went on more and more people began to identify with it, making the original opinion

The poem captures so well the sufferer's determination to hang on in there, meet the illness face to face and fight it within ones personal limits. It also caused controversy when adapted when it was said by one local group that ME sufferers did not lose weight. Personal experience of my daughters illness knows this is not so, this was proved when at a following meeting of the same group a couple told so vividly their daughters story for which ME could have been written. So, what were the comments and who were they from? Publishing the book initially I was putting it together at the Yorkshire Arts Circus when Ian Clayton stopped by asking what I was doing. On having a look at the book he said it was excellent; when I asked for a comment to use he said "A bonny little book". Dr Derek Pheby would be sent a copy and he would refer to it as "A splendid book of poems on a touchy subject". My friend and then local councillor Brian Hazell, who often spoke up for the underdog, said of it "the voice of the people", Yvette Cooper MP and first ever secretary of the APPG said of it: "this book sums up the authentic voice of those suffering with ME". Jane Colby would take the poems and read some of them at one of her talks and said of the book, "A time for speaking says Trevor Wainwright in this excellent book of poems, quite right".

There was a further twist to the tale when it was decided by the chair to use the registered charity number of the research project on the front cover, "not allowed without permission", I said, "and what if it folds". "It'll be ok" she said and went ahead with it. Yes the research stopped with the death of Dr Coyle (Dr. Swinburne's research partner) and there we were with a load of info and poetry books all no good because somebody knew better. So the chair and her colleague had to get busy with Tippex and remove mention of the number, as for the books, I simply changed the cover. It was different but they still sold, and were later added to by other poems which would form a powerful awareness exhibit, admired by many that visited it wherever it was, and when MERSC was set up the poems then went under MERSC's name. A far cry from those early days and the narrow minded who did not think they should see the light of day. So what of the ME /AIDS Parallel. I'm saving that for the next issue along with a previous article The Wesseley.



Anagrams

THE EYES: !
When you rearrange the letters:
THEY SEE