



Pathways

Price £ 2.50 (Free to members)

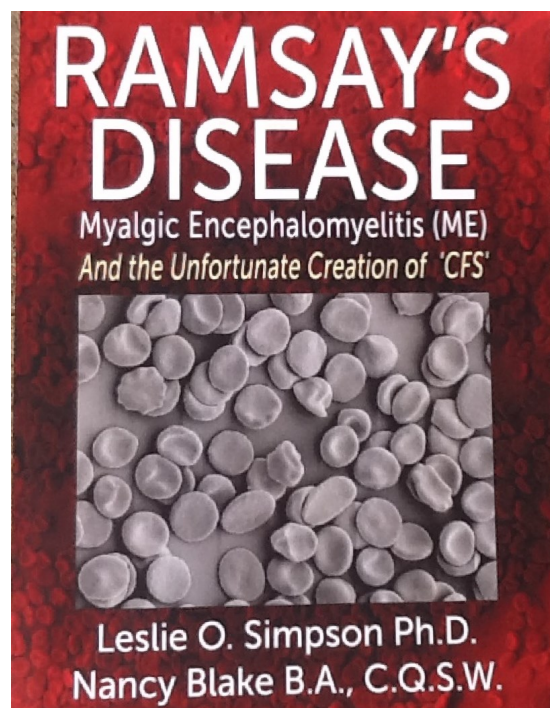
The newsletter of Leger ME/CFS Supporting Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Good and bad news regarding the room hire charge.

I attended another meeting at the Redmond Centre on the 15th of August to discuss the room hire charge threat. Now the dust has settled and things are becoming more clear.

The situation as it appears to me is that the outgoing Mayor of Doncaster steam-rolled a blanket £10/hour room charge for all DMBC users. It was voted in by the DMBC council. The circumstances of the vote are unclear and a number of questions about the integrity of the process remain. At the protest discussion meeting in March there were local councillors who kept quiet and did not really disclose their interests to the meeting as a whole, having been involved with the vote. It also turns out that the manager in overall charge of the community centres was not consulted beforehand, so that a fair balanced assessment could not be made before the decision was taken. What is more clear now is that the Mayor at that time didn't get re-elected and this raises questions about whether this was a political attempt to gain credibility for the re-election campaign. It is also quite clear that my letters to a local MP and his intervention have had some influence. These have been published in the two most recent editions of Pathways.

A hand-out given to us at the meeting was emailed to all registered internet members. The net outcome is that there will be a charge of £5 per hour for the use of the centre for our meetings. At a group meeting called shortly after the original announcement, it was agreed to raise the annual subscription to £15 per year to cover these increased costs. With the current level of group activity this is sustainable. Even better is the news that we have a monthly allocation of free photocopying and internet access at the centre. This will be particularly useful for 1 to 1s, form filling and welfare rights issues. As it is the intention of the DWP to increase the use of internet-based administration of claims, access to the internet will be welcomed by the 40% of members who do not have home internet access. As far as extra charges to members go — at the current level of demand we can fund one 1:1 session per member per year.—Mike



Questions on PIP answered: See page 12

Book Review: See page 9

You Write:

Malcolm writes: I will be transferring from Contribution Based (CB) Employment and Support Allowance (ESA) to Income Based (IB) in September, and have already completed all the necessary paperwork, and it has been processed. When I spoke to the DWP today about it though, they informed me that my money will decrease a bit in September due to the change. Whilst on CB ESA, I have been given an extra transition 'top-up' with every payment due to moving to it from Incapacity Benefit, so there was no change in my income because of the change, but they said that this extra bit will stop in September, because transferring from CB ESA to IB ESA is classed as a 'change in circumstances' even though nothing else at all in my circumstances has changed! They said there is nothing that I can do about this. This means that from September I will get about £10 less per week, which is a lot to me. Is this correct and is there anything that I can do about it? I guess I am hoping that my housing benefit will go up if this happens, so maybe I wouldn't be any worse off, but am not sure if it will, as I think I may possibly be getting max amount of that anyway. Any thoughts or info greatly appreciated.

What you say is right, and that is the system. There may be a few minor premiums you may qualify for but I would expect nothing. With the CB ESA you will get an income tax-style form from the DWP wanting to know all your financial details (usually an ESA 1, 2 or 3 form). There may be a review of housing benefit or council tax benefit which will work in your favour. However we are not experts on some income based benefits and really the only people to tell you things like that are the DWP themselves.

When the Government decided to cut welfare rights the intention was to cut income to people like you. If it were still possible I would have suggested applying for DLA as many Pathways readers do get a small amount extra from this benefit. However, the Government has brought in Personal Independence Payment (PIP) in DLA's place with the intention of cutting payments by around 40% overall nationally. As I see it, the only real option is to apply for PIP. It is a new benefit and I don't know how they are treating people with ME/CFS. Things are very much up in the air, and an important consideration depends on the 20-50 metres rules as described in last month's Pathways. This week, I've got the first PIP form I've seen which a member has asked me to help her fill out. The questions are very similar to those in the old DLA form. It would be reasonable to say that if you got 15 points from your ESA 50 for mobilising and standing, and/or some points in the mental health section there may be a chance you would qualify. The only people who can tell you would be the DWP and to find that out you would have to apply. You should find it worthwhile to read about further issues regarding PIP in this edition of Pathways.

Susan writes: Can you explain why on hot warm days I feel terrible, but I am better on cooler days?

The weather affects many of us, and over the years I've noticed that most group members are affected in the same way at the same time. Here are some of my observations:

Thunderstorms: Many members report increased pain especially headaches. It's due to some relationship between the air pressure change in such storms and the drop in light levels.

Hot Sunny Weather: Most people with ME/CFS are best around 21 degrees centigrade. Any higher temperatures tend to increase fatigue very markedly. It is thought that this may be caused in some way by partial dehydration and problems with inappropriate antidiuretic hormone secretion by the pituitary gland caused by the disease process. A temporary fix found by many members is to drink small amounts of pure water frequently in order to replace fluid lost which also reduces fatigue for a while.

Anticyclonic weather: A 'high' on the weather chart causes many members to have better days- possibly because the air pressure is high and stable.

Atlantic depressions: These tend to be short-lived 'lows' on the weather map and lead to fluctuating air pressure. Most members report their worst problems when a cold front passes over the area.

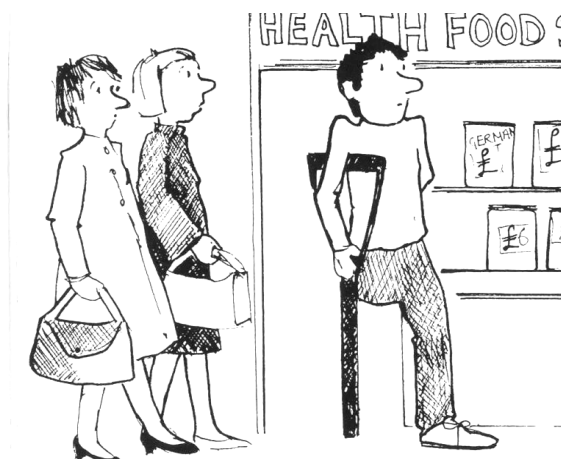
George writes: I've just been through what the Sheffield NHS ME/CFS clinic have to offer i.e. Pacing, CBT & GET. They tell me that there are no other treatment options. My own doctor tells me that there is nothing further he can do. I feel very angry and let down. Is there anything I can do?

I frequently get asked this sort question; Fairlawns and your doctor are both wrong. There is no doubt that most people get a little better over the years, but I've never known anyone with ME/CFS return to their former state of health. The achievable reality is that if you can get the pacing right and get the symptom control right then you will get to the point where ME/CFS only minimally affects your life.

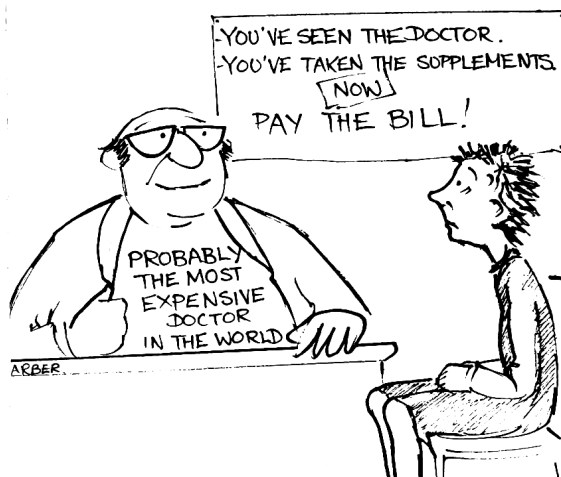
The first thing to do is get the pacing right—that can do a lot, but is not easily achieved. The next thing is look at your overall health. Get your weight right if possible. Energy used follows a square law, so losing weight will pay dividends in that the energy gained far exceeds what might be expected from the weight lost. Get your diet right and avoid junk food. Pack in smoking if you indulge. Smoking is one of the worst things you can do with ME/CFS. After that, look at symptom control for the main ME/CFS problems e.g. sleep & pain. There is plenty of information and treatment available within the NHS. If you suffer from another chronic condition e.g. asthma or diabetes—get that under control because that can make the ME/CFS problems worse if left untreated..

One question I frequently ask is: "How much are you prepared to spend on private treatment?" Most of the expertise in ME/CFS management is within the private sector. There are about thirty private doctors allied to The British Society for Ecological Medicine, who have expertise in treating ME/CFS. The lead is Dr. Sarah Myhill. Her website contains a lot of information and also she has a book which can be downloaded free which contains much useful information. While she offers various tests online, I don't advise using this service except under the guidance of a doctor otherwise you could end up spending a lot of money and gaining very little. There is one test worth thinking about if you have benefit problems or needs to prove that you have a problem and that is the mitochondochondrial function test. On average private patients have not do much change out if £500 from the first consultation with a private doctor. However, the other side of the coin is that you can try most of the treatments recommended for under £200. Each private doctor has their own individual forté, and it is worth talking to group members about their experiences before you commit to spending money.

Many of the private treatments could be available from the NHS, but you would most likely need a very understanding doctor and one prepared to work with you and think outside the box. Generally I find that there is no one treatment that helps everyone and you have to be prepared to try out all the options by trial and error. I find generally that at most one will get worthwhile benefit from one in every three or four treatment tried. Many of the private doctors keep their practice strategies confidential and unlike the NHS, they do not publish their strategies. One exception is Dr. Myhill, who is more open about her strategies. I have included an extract from Dr. Myhill's book in the following pages that may help you find a way forward. You can download the book for yourself free of charge from her website.



HE'S RECOVERED FROM HIS M.E.
- BUT THE TREATMENT COST HIM
AN ARM AND A LEG.



LIZZIE'S DOCTOR SOMETIMES FRUSTRATED
HER ATTEMPTS TO FORGET HOW MUCH HER
TREATMENT WAS COSTING.

Useful medical tests for investigating the patient who presents with chronic fatigue by Dr. S. Myhill.

One of the things I really dislike about the Medical Profession is their power over patients. The main two ways in which they use that power is firstly by controlling the availability of tests and secondly through the power of prescription. My website www.drmyhill.co.uk allows patients to order any test they see fit. The test result comes to me as the referring practitioner; I can interpret it and write to their GP with recommendations (copy to patient). Secondly, most of my treatments do not require prescription drugs and so are available to all. I can also recommend a local ecologically-trained physician who can advise further if necessary.

There is no simple test currently available to diagnose CFS because CFS is not a diagnosis – it is a symptom. Blood tests serve to exclude other diagnoses and can be used to try to identify the underlying causes. Doctors can sometimes be very naughty – they do the routine tests which all come back as normal then turn round and tell their patient that nothing is wrong with them. I believe that the reason so many medical tests are negative in the case of CFS patients is because doctors are looking in the wrong place and asking the wrong questions. The major pathology is inside cells, i.e. in mitochondria. Although cells (and therefore organs) look fine, they do not function properly. It is a bit like having a car with a flat battery – an X-ray MRI scan of a car would come back completely normal – but you try and start it and nothing would work!

However, I now believe a major player in CFS is mitochondrial failure. The paper published by Dr Norman Booth, Dr John McLaren-Howard and me clearly shows that in moderate and severe ME there is a close correlation between mitochondrial function and the level of fatigue. The package of tests show where the biochemical lesion lies and what has to be put in place to correct it. Having said that, various routine blood tests have a place in investigating a patient with fatigue and so let's review them first.

Firstly exclude macroscopical pathology

Most patients, by the time they get to see me, have had all the routine tests done. These tests largely test for macroscopic pathology such as major organ failure (anaemia, heart disease, cancer, liver failure, kidney failure and some gut problems). They do not test for minor organ failures (such as partial thyroid gland failure, partial adrenal gland failure, mild liver damage, poor ability to detox). None of these tests look for poor function of the brain or brain damage, nutritional tests are often absent or limited, hormone tests are usually incomplete and there are virtually no tests of energy delivery. Having said that, there are often mild abnormalities in standard tests which may not have been picked up on by the GP or consultant, but which are clinically important for the CFS sufferer. Results are given by a figure and there should also be a reference range next to this figure – that tells you if you are inside or outside the reference range. This reference range often varies from one lab to another.

The basic tests that most doctors do for their patients with chronic fatigue are:

- Haematology (full blood count – red cells, white cells and platelets)
- Inflammation in the blood – ESR, C reactive protein, plasma viscosity.
- Biochemistry (liver and kidney function)
- Blood sugar level
- Urine testing (for infection or kidney damage)

Faecal occult bloods (looking for bleeding from the gut)

Thyroid stimulating hormone (only looks for primary thyroid failure – most thyroid problems in CFS are secondary to poor pituitary function)

Ferritin (iron), B12, folic acid and calcium

Perhaps a serum magnesium test– which is a completely useless test! This is because serum levels are maintained at the expense of levels inside cells. Serum magnesium is just an ITU (Intensive Therapy Unit) test!

Autoantibody tests for autoimmunity.

Common abnormalities that can be shown by routine tests

The mild abnormalities I always look for in CFS in the above tests are:

Low or low normal white cell count – can be a sign of poor immune function which most commonly is secondary to nutritional deficiencies, such as low zinc, low magnesium, low B vitamins, and low essential fatty acids.

Low or low normal platelet count – can be a sign of toxic stress

Low MCV (mean corpuscular volume) suggesting iron or copper deficiency. Low iron is suggestive of Hypochlorhydria, in which case other mineral deficiencies are also likely.

High MCV suggesting B12, folic acid or Hypothyroidism

A high blood sugar or a low blood sugar suggests there may be a tendency to (a pre-diabetic tendency). A normal blood sugar tells you very little! Normal ranges of blood glucose have been changed because so many people now have carbohydrate intolerance. A normal blood sugar should be between 4-6mmol/l. High blood sugar is now associated with toxic stress because chemicals cause insulin resistance.

Low potassium. Potassium varies according to diet! Low potassium means there is a lack of vegetables in the diet. Bananas may be rich in potassium but they are high glycaemic index, so beware!

High normal bilirubin – may be Gilbert's syndrome suggesting poor ability to detoxify.

High normal or abnormal liver enzymes – suggesting liver damage, usually from chemicals, or poor nutritional status.

High urea or creatinine suggesting dehydration

Low urea or creatinine suggesting low protein diet

Low glomerular filtration rate suggesting poor kidney function – could be due to allergy or toxic damage but may indicate poor mitochondrial function.

A TSH tells you very little about thyroid status! It is essential to see the actual level of thyroid hormones in the blood.

Low levels of B12 can be due to Hypochlorhydria or Malabsorption

High uric acid can point to poor Antioxidant status. See Gout.

Raised cholesterol could mean low levels of vitamin D or hypothyroidism.

Low levels of calcium likely to mean low levels of vitamin D.

Here are the routine tests which I nearly always do initially and which have important implications for management

1. Mitochondrial function profile – this is a batch of tests to identify the mitochondrial problem. This test has important implication for treatment; this test includes:

- **ATP profiles** – looks at levels of ATP, how well energy is released from ATP, the rate of production of ATP from ADP and movement of ATP and ADP across mitochondrial membranes (translocator protein function - could be blocked by toxins or pH changes). Also

gives us an objective measure of the level of disability.

- **Plasma cell-free DNA** – a measurement of cell damage and antioxidant status in CFS
- **Red cell NAD levels** – a measure of the efficiency of Krebs's citric acid cycle. Levels can be corrected with niacinamide 500mgs daily and acetyl L carnitine.
- **Co-enzyme Q10 levels** – the most important antioxidant inside mitochondria. In CFS levels are nearly always deficient
- **Superoxide dismutase (SODase)** – three types measured, indicates levels of zinc, copper and manganese, also gene studies to give an indication of toxic damage. SODase is a major antioxidant in all cells. Glutathione and glutathione peroxidase studies are also included (indicates selenium status).
- **Red cell magnesium** – done as part of the ATP profile or can be done separately.

2. *Thyroid function profile (free T4, Free T3 and TSH).*

More esoteric tests which have implications for management:

- ♦ **Microrespirometry** - looks in detail at ADP to ATP conversion (see sample result on p. 27)
- ♦ **Further investigation of poor translocator protein function** *Translocator protein studies*
- ♦ **Cardiolipin studies looks at the structure of mitochondrial membranes**
- ♦ **Calcium studies** – calcium levels inside cells often too high.
- ♦ **Adrenal stress profile** – salivary levels of cortisol and DHEA over 24 hours
- ♦ **Salivary Melatonin levels** – it is common to get poor melatonin production and therefore poor sleep in CFS. This is a further reflection of the inadequate HPA axis in CFS.
- ♦ **Lactate dehydrogenase studies** – if there is evidence of cell damage, this indicates where the damage is coming from e.g. liver or muscle.
- ♦ **Red cell Carbonic anhydrase** – indicates hyperventilation

When gut symptoms suggest tests

Gut fermentation test – to look for evidence of fermentation by bacteria or yeast. Irritable bowel syndrome may be caused by food allergy or gut dysbiosis. Low levels of short chain fatty acids can mean insufficient probiotics in the gut.

Salivary VEGF test for hypochlorhydria – if there are symptoms of poor digestion or “too much acid”.

Urine hydrogen sulphide test – some people ferment food to produce hydrogen sulphide and this can inhibit mitochondrial function.

Parasitology at the London School of Hygiene and Tropical Medicine – detects worms, amoebae, giardia, blastocystis hominis.

Comprehensive Digestive Stool Analysis – ability to digest and gut flora. Parasitology can also be done as part of this test.

Short chain polypeptides – if the result is abnormal, it suggests leaky gut syndrome.

Early morning **Short chain fatty acids and/or tests of Fructose intolerance** – indicate a tendency to Hypoglycaemia

Looking for toxic stress

- ♦ **Fat biopsy** for **pesticides** and/or for **volatile organic compounds** (VOCs). A fat biopsy is very easy to do – easier than a blood test! A green needle and 10ml syringe is used – the

green needle is pushed into buttock fat, suction applied with the syringe, then needle withdrawn. The amount of fat inside the bore of the needle is sufficient to do the test.

- ♦ Sauna sweat test.
- ♦ **Kelmer test** (urine test) for mercury load – anybody with mercury fillings will have mercury on board – the question is how much? How hard does one have to work to get rid?
- ♦ Translocator protein **studies**.
- ♦ **DNA adducts** – looks to see if toxins have stuck onto DNA – if so, this is a pre-cancerous condition. This is a useful test to work out how much damage has been done to the body as a result of toxic stress and therefore how much work has to be put into a detox regime. If abnormal then it should be repeated following a detox regime to make sure there are improvements.

Looking for sensitivity to chemicals

- ♦ **Lymphocyte sensitivity** test for chemicals, heavy metals, silicones, VOCs. This is helpful if you suspect that you are reacting to one/ some/all of those substances, in other words you are sensitive to them. I often use this where there is a silicone implant to help decide if it should be removed. Where there is sensitivity, there will be toxicity, and vice versa. Indeed, multiple chemical sensitivity is usually triggered by toxicity. More recently John McLaren-Howard has developed similar tests to diagnose electrical sensitivity.

Evidence of damage to cells

- ♦ **Plasma cell-free DNA** – this is nearly always abnormal in CFS and can be for any one of the following reasons:
- There is poor antioxidant status (see **Co-enzyme Q10, SODase**),

There is on-going toxic stress (such as from pesticides, volatile organic compounds, heavy metals etc.),

There is immune activation (as for example in acute infection),

There is very poor mitochondrial function (see mitochondrial function) score but the patient is forced to do some muscular activity just in order to live.

The patient is not pacing well – i.e. pushing too hard and this is resulting in cell damage.

However some people who are very disabled have no choice – just the energy required to exist will cause tissue damage. So people with the worst mitochondrial function score often have high cell free DNAs even though they are doing almost nothing.



This can be investigated further with LDH studies, which tells us where the damage is coming from.

Welfare Rights Issues: ATOS loses monopoly from the Benefits & Work Website

Atos healthcare is to lose its long-held monopoly stranglehold on work capability assessments (open access) from next Summer. The news comes as the DWP revealed that a high percentage of sampled Atos reports had achieved only a 'C' grade in a recent audit. Atos has been the only provider of work-capability assessment medicals for Employment and Support Allowance and of its forerunner, the all work test for Incapacity Benefit, since DWP medical services were outsourced. Campaigners have long argued that the assessments carried out by Atos were not of an acceptable standard but, up until now, the DWP have always defended Atos as if they were of the same department. Now, however, the government has decided that Atos is not up to standard and that an improvement plan has to be put into place. Measures include retraining and re-evaluating all Atos health professionals, bringing in a third party to assess Atos' own audits of its work and engaging Price Waterhouse Coopers to provide advice on improving quality assurance.

ATOS PHYSIO'S EVIDENCE OF NO VALUE

Atos could be in even more difficulties following an upper tribunal decision that the opinion of an Atos health professional who is a physiotherapist was of "no probative value whatsoever" where it concerned a claimant who had a mental, rather than physical, health condition. The case involved a claimant who had been placed in the WRAG but had appealed to be placed in the support group. The claimant's mental health conditions included depression and bouts of uncontrollable rage. The judge stated that:

"I can only express my surprise that in a case where the only issue was the mental health of the claimant and its effect in relation to the mental health descriptors, the report was prepared by a physiotherapist following a 15 minute interview. It is plainly important that questions of mental health should be assessed by a disability analyst with appropriate mental health qualifications if their opinion is to be of any evidential value. Even then tribunals should beware of placing too much weight on such reports, based as they are on a very short interview with a claimant and without access to medical records. "

Although the decision, which was highlighted on the 'Rightsnet' discussion forum for welfare rights workers, relates to ESA, there is no logical reason why similar arguments cannot be employed in relation to PIP, where a very similar points-based system is in place. This could pose a massive problem for Atos whose successful bid for the PIP medical assessment contract stated that they would be using the following health professionals, 933 physiotherapists, 373 nurses, 75 occupational therapists and only 19 doctors. There seems little doubt that the DWP will appeal the decision. Meanwhile, however, we'll be updating our ESA appeals guide in the near future to take account of this decision – and to look at the potential advantages and risks of using it in your own appeal.

I have seen all the issues raised in recent multiple press reports, and from my own experience, can confirm that most Leger ME members have been affected in some way by the issues reported. Personally, I don't trust Atos, simply because of the problems that they cause Leger ME members which I end up having to deal with. The relationship between Atos and the DWP is very intimate and very often I find that when I raise issues on behalf of members the DWP contradict, DWP just wash their hands of the situation and pass the case onto the Tribunals service. This is not new; the problem has been around for many years and has led to the group practice strategy for members who are helped with their DWP forms. One of the biggest considerations is presenting as much evidence from as wide a range of sources as possible simply to mitigate problems caused by the DWP partnership with ATOS.

Regarding the reports about some GPs' refusing to give support letters: GPs for most cases are not in a position to give the sort of information the DWP requires, nor is the local ME/CFS clinic. In fact the DBD 370 enquiry forms that many GPs are sent are usually the key document in refusal cases. The problems are caused simply because the form does not ask the right sort of questions and the GP can't answer them. Please don't forget that if you are a paid up Leger ME member you have access to the 'Benefit and Work Guides'.

Book Review by Sandy Nye, Ohio, USA.

Ramsay's Disease: Myalgic Encephalomyelitis (ME) and the Unfortunate Creation of 'CFS'

Published by Lifelight Publishing; released in March 2013. UK Price: 19.99 213 pages

Authors: Leslie O. Simpson, Ph.D. and Nancy Blake, B.A., CQSW, UKCP Accredited

Dr. Simpson makes his dedication to Dr. A. Melvin Ramsay who has cited the denials to recognise the unique epidemiological pattern of ME. The referral to Ramsay's Disease in the title is used to separate those who suffer from ME from other more inclusive diagnoses.

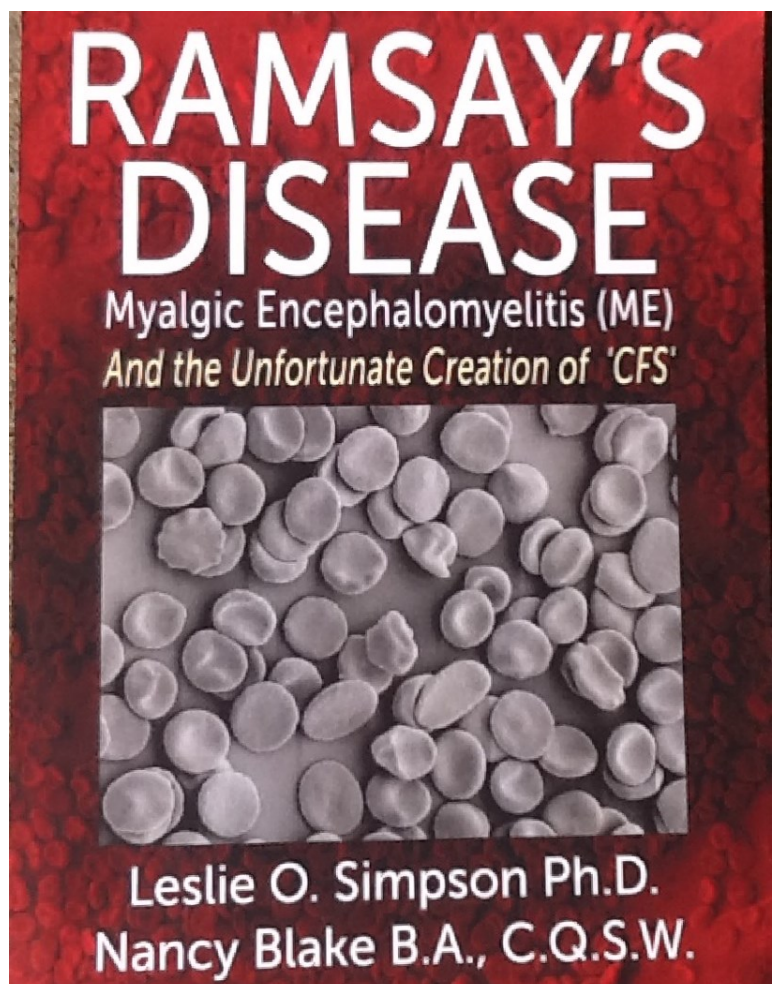
Nancy Blake makes her dedication to those people who supported her in her participation in the writing of the book; plus the many people who helped her over the years in her challenges of living with ME and now virtual recovery.

Nancy Blake's own story begins with two chronological CV-like outlines entitled "Life before ME" and "Life with ME." She then expands on the first signs of becoming ill with ME (1986) and the various trials and tribulations experienced along the way. Being a Neurolinguistic Psychotherapist, she includes many detailed analytical explanations of her feelings as well as how misinformed and unfair are those who assign various flippant evaluations of ME. Her contributions to these sections are almost like she is recalling her history "before" and "with" in conversational form. She frequently takes on, specifically, the psychiatric community that weighs in on the condition of ME.... as they see it.

On the cover of the book is a picture of Nancy's own irregularly-shaped red blood cells. Dr. Simpson, a hemorheologist, has performed years of research relative to the impact of non-deformable erythrocytes on ME. His consensus is that the high proportion of these irregularly-shaped red blood cells interferes with their microcirculation, resulting in oxygen deficiency in muscles, the endocrine system, and cognitive brain functioning and could support a diagnosis of ME if found to exist in a persistent state.

Dr. Simpson includes his own quite lengthy reviews of a number of books about ME that have been produced over the years and read by ME sufferers. Some of these books are written by physicians and some are by non-physicians.

Another chapter in the book is a historical background of ME; Pre-ME, ME and Post-ME. This chapter is pretty heavy reading, but worthwhile if you can tolerate all the contradictory theories and labelling. This section is also written by Dr. Simpson, but with some contributions from Nancy Blake. In the Pre-ME section, he begins with a report of an outbreak of symptoms as early as 1934 in Los Angeles. He goes on to include locations of other "outbreaks" worldwide and describes the varied onsets of symptoms.



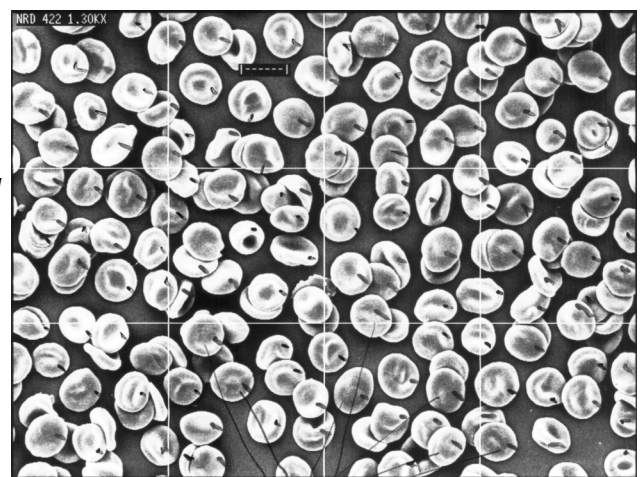
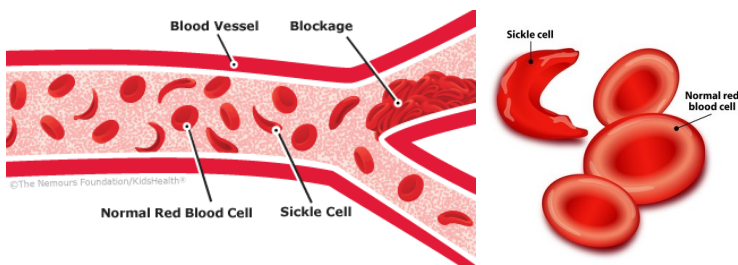
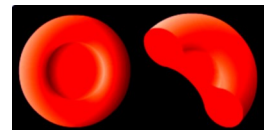
Dr. Simpson also conveys the origin of the unfortunate creation, in 1988, of the widely-used term of "CFS" in the United States; and the back and forth assessments of the condition there. He goes onto a discussion of CFS versus ME, 1997 through 2007. Australian and Canadian Guidelines are covered as well as the British Chief Medical Officer's Working Group. The history is extensive, inclusive of controversies and disputed opinions. A brief, but interesting, mention is made concerning relationships to many commonly-known chronic disorders and the blood flow issue.

The overall purpose of the book appears to be to section out Ramsay's Disease (ME) away from all other designations and labels. It also repeatedly affirms the necessity of rest, virtual laziness, for at least six months; the chances for recovery are still better if this is strictly adhered to when the illness first makes itself known. Supplementing a healthy diet with fish oil, genuine EPO (evening primrose oil), Vitamin B12 as hydroxocobalamin, and pentoxifylline (Trental) is also recommended. For those ME patients who have high values of flat cells in their blood, a state he references various times throughout, he also suggests evening primrose oil and that the patient control his/her own daily patterns of activity (basically, the pacing we all know). Finally, avoid all arguments because the stress can worsen blood flow problems; if the rate of capillary blood flow cannot meet the metabolic needs of secreting glands, the result may be body-wide dysfunction, with oxygen delivery rate reduced, along with energy output and lactic acid production, perhaps accompanied by pain. When/if remission is achieved, it does not indicate cure; danger of a relapse still remains and lifestyle situations should continue to be considered.

Recommendations in this book are also included for doctors, psychotherapists and public policy. There are many references as to how ME sufferers are dealt with in the UK, pertaining to being validated and receiving needed assistance. The authors have certainly put in a lot of time in the production of this book, including massive amounts of research.

Les Simpson is no stranger to the Doncaster ME Group. Back in 1993-4, Les visited us in Doncaster. Blood samples were sent from some group members to Otago University in New Zealand to research a possible micro vascular explanation of ME/CFS

Capillaries are the smallest of blood vessels, but are important because they are the postman of a body cell's needs, delivering oxygen & food and taking away waste products. Oxygen is carried in blood by red blood cells. There is a problem in that some capillaries are very-narrow, being smaller than a red blood cell. Red blood cells have a way around this: They are dough nut shaped they are 'toroid' or 'a toroid' or 'toroidal'. So as they go through capillaries they can squeeze their way through. The cells become flatter as they give up their oxygen. Dr. Simpson's research suggests that people with FMS/ME/CFS have smaller capillary beds than the normal population. In periods of fatigue, the red blood cells change shape, becoming cup or disc shaped which impedes the blood's flow causing miniature clots and bruising. There is a parallel with this in some African races. Sickle-cell anaemia is an inherited genetic condition in which the red cells become sickle-shaped. They clog up capillaries causing blockages, pain and irritating nerve endings. However Simpson's research has never been carried forward—so we have a possible explanation, but the jury is still out.



A micrograph of blood showing flat blood cells.

Recipe Corner: Autumn vegetable soup with cheesy toasts

Serves 4

Preparation time: 10-15 minutes

Cooking time 15-20 minutes

Ingredients

- 1 leek, chopped quite small
- 2 carrots, chopped quite small
- 1 garlic clove, finely chopped
- 1 potato, chopped quite small
- 1 tbsp finely chopped fresh rosemary
- ½ tsp sugar
- 410g can chickpeas, drained and rinsed
- 3 tbsp chopped fresh parsley
- 2 x 400g cans chopped Italian tomatoes
- 425ml/¾ pint vegetable stock

For the toasts

- 8 slices of baguette, cut on the diagonal
- 1 garlic clove, cut in half
- 50g Edam, finely grated

Method

1. Put the vegetables into a large saucepan with the garlic, rosemary, stock and sugar. Season well, stir, and bring to a simmer and cover. Cook gently for 15 minutes or until the vegetables are just tender.
2. Preheat the grill to high. Whizz the tomatoes in a food processor or blender until smooth, then tip into the vegetables with the chickpeas and parsley. Gently heat through, stirring now and then. For the toasts: rub both sides of the bread with the garlic. Grill on one side until golden, turn the bread over, cover with Edam and grill until its bubbling. Serve at once with the piping hot soup. (Note: Remember you can buy baguettes and freeze them until the day of use. Then just defrost them and cook in oven at 190° for about 15mins. Also you can buy garlic butter and just spread that on before cooking if you prefer).



Nutritional values per serving

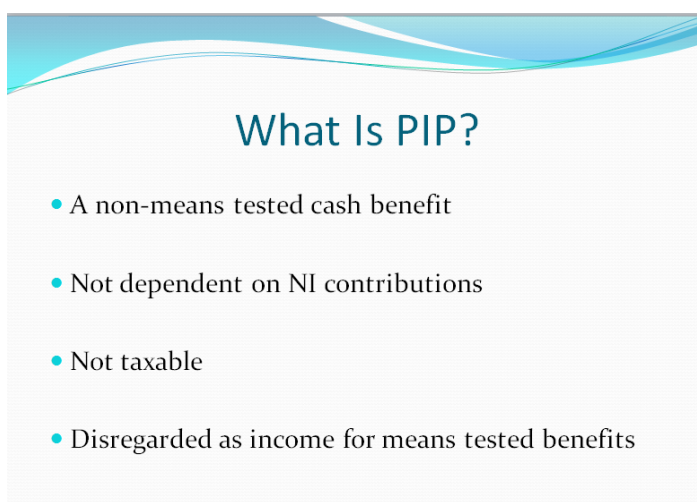
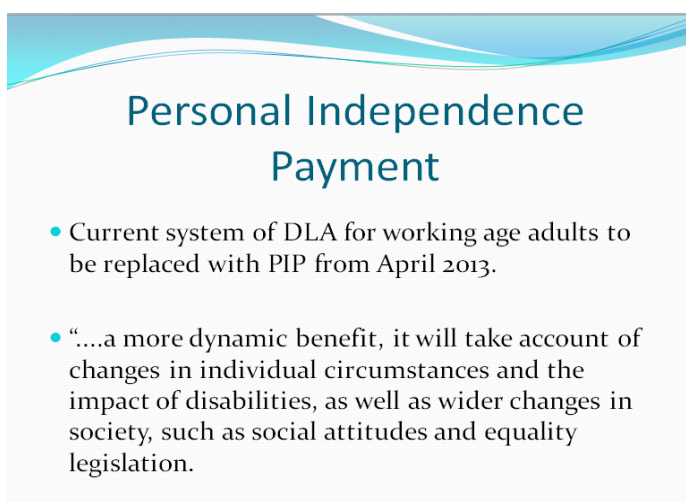
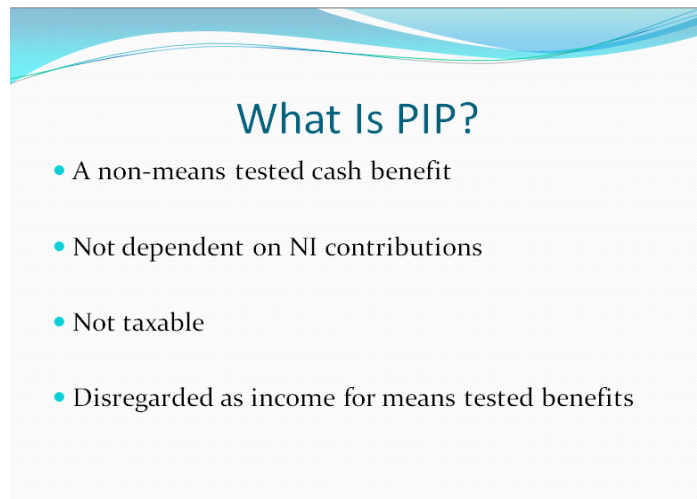
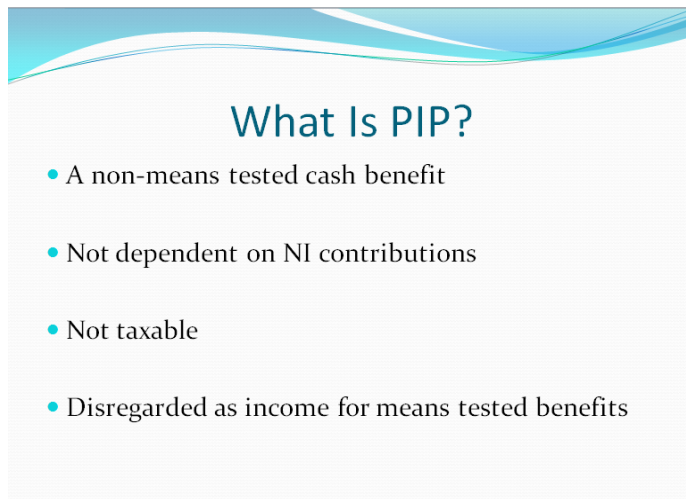
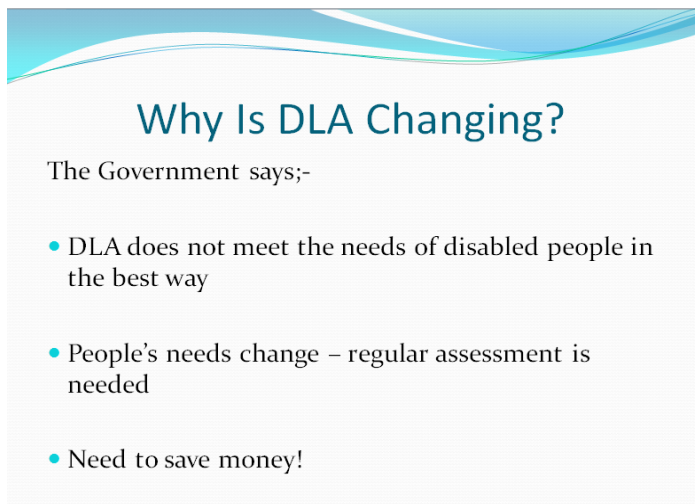
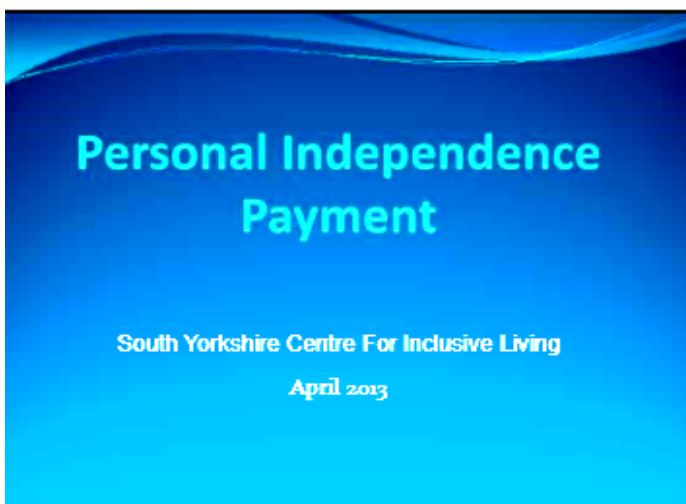
Kcals: 343
 Protein: 17g
 Carbohydrates: 56g
 Fat: 7g of which saturates 2g
 Fibre: 8g
 Sugar: 1g
 Salt: 2.2g



Personal Independence Payment (PIP) Presentation Slides by Helen Butler, SYCIL

I think by now everyone should be aware about PIP replacing DLA. I've received many questions from members—so at the August meeting I asked Helen Butler from *South Yorkshire Centre for Inclusive Living* to come and I've used the presentation on PIP which follows as we saw it.

At the time of writing only one Leger ME member had received a PIP form. So this is something new to us. I suspect that the strategy where Leger ME can help will be similar to how we deal with DLA and ESA. It is also certain that with a new benefit there will be plenty of anomalies and mistakes made by the DWP and its contractors. As with all Welfare Rights matters, our strongest advice is not to do it yourself but seek help from a welfare rights organisation. Leger ME members have access to *Benefit & Work Guides* as well as the session we organised at the Redmond Centre. Further details are available via the Leger ME help desk.





Claiming For The First Time?

- 0 – 15 Children – will still claim DLA
- 16 – 64 **Adults aged 16 – 64 will claim PIP**
- 65+ 65 and over – will still claim Attendance Allowance

Getting DLA Already?

- Aged 65 or over?  Stay On DLA (on 8th April 2013)

Getting DLA Already?

- From October 2013
(DLA due for renewal
After 24th February 2014)
Change of Circumstances
Child reaching age 16.  PIP
 - From October 2015
(Indefinite award of DLA)  PIP
- Must make a claim for PIP – no automatic transfer to PIP!

Personal Independence Payment

- Two components;-
Daily Living
Mobility
- Each component has 2 rates;-
Standard & Enhanced

Amount of Benefit

- **Daily Living**
- Standard Rate = £53.00 = middle rate care DLA
- Enhanced Rate = £79.15 = high rate care DLA
- **Mobility**
- Standard Rate = £21.00 = low rate mobility DLA
- Enhanced Rate = £55.25 = high rate mobility DLA

Non-Disability Rules

- 3 months backwards / 9 months forwards test
- Habitual Residence Test will apply
- 2 years residence out of the last 3 years
- Terminally ill – passported to enhanced rate of daily living component

The Claims Process

- Need to register the claim by phone
- “Telling your story” questionnaires
- Face-to-face assessments for most people

Features of PIP

- Takes account of aids / adaptations
“normally worn or used” or those which the claimant could reasonably be expected to wear or use.

General Principles

- People must be able to carry out the descriptors “reliably”.
- Safely – in a manner unlikely to cause harm to themselves or to another person either during or after completion of the activity.
- To an acceptable standard.
- Repeatedly – as often as the activity being assessed is reasonably required to be completed.
- In a reasonable time period.

PIP Thresholds

- | | |
|---------------------------|---------------------------|
| • Daily Living Component | • Mobility Component |
| • Standard Rate 8 Points | • Standard Rate 8 Points |
| • Enhanced Rate 12 Points | • Enhanced Rate 12 Points |
| • From Activities 1 - 10 | • From Activities 11 - 12 |

Variable Conditions

- If one descriptor in an activity applies for more than 50% of the time, then that descriptor should be chosen.
- If more than one descriptor in an activity for more than 50% of the time, then the descriptor chosen should be the one with the highest points score.
- Where one single descriptor in an activity is not satisfied for more than 50% of the time, but a number of different descriptors in that activity when added together, are satisfied for more than 50% of the time, the descriptor satisfied for the highest proportion of the time should be selected.

Daily Living Component

1. Preparing Food & Drink
2. Taking Nutrition
3. Managing Therapy / Monitoring A Health Condition
4. Washing & Bathing
5. Managing Toilet Needs / Incontinence
6. Dressing & Undressing

Daily Living Component

7. Communicating Verbally
8. Reading & Understanding Signs, Symbols & Words
9. Engaging With Other People Face To Face
10. Making Budgeting Decisions

Mobility Component

11. Planning & Following A Journey
12. Moving Around

Passporting

- Passporting Arrangements Mostly Mirror DLA. Eg.
- Premiums in IS/JSA/HB/WTC
- Non-Dependent Deductions
- Carers Allowance
- Motability

Appeals

- New Rules Cover **All** Benefit Appeals;-
- Mandatory Revision Before Appeal
- Appeals Go Straight To HMCTS
- Time Limits To Respond Once They Have Received Appeals From HMCTS
- (From October 2014)

Personal Independence Payment (PIP) Points Scores**DAILY LIVING ACTIVITIES****1. Preparing food.**

- a. Can prepare and cook a simple meal unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal. **2 points.**
- c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave. **2 points.**
- d. Needs prompting to be able to either prepare or cook a simple meal. **2 points.**
- e. Needs supervision or assistance to either prepare or cook a simple meal. **4 points.**
- f. Cannot prepare and cook food. **8 points.**

2. Taking nutrition.

- a. Can take nutrition unaided. **0 points.**
- b. Needs –
 - (i) to use an aid or appliance to be able to take nutrition; or
 - (ii) supervision to be able to take nutrition; or
 - (iii) assistance to be able to cut up food. **2 points.**
- c. Needs a therapeutic source to be able to take nutrition. **2 points.**
- d. Needs prompting to be able to take nutrition. **4 points.**
- e. Needs assistance to be able to manage a therapeutic source to take nutrition. **6 points.**
- f. Cannot convey food and drink to their mouth and needs another person to do so. **10 points.**

3. Managing therapy or monitoring a health condition.

- a. Either –
 - (i) does not receive medication or therapy or need to monitor a health condition; or
 - (ii) can manage medication or therapy or monitor a health condition unaided. **0 points.**
- b. Needs either –
 - (i) to use an aid or appliance to be able to manage medication; or
 - (ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition. **1 point.**
- c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. **2 points.**
- d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. **4 points.**
- e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. **6 points.**
- f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. **8 points.**

4. Washing and bathing.

- a. Can wash and bathe unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to wash or bathe. **2 points.**
- c. Needs supervision or prompting to be able to wash or bathe. **2 points.**
- d. Needs assistance to be able to wash either their hair or body below the waist. **2 points.**
- e. Needs assistance to be able to get in or out of a bath or shower. **3 points.**
- f. Needs assistance to be able to wash their body between the shoulders and waist. **4 points.**
- g. Cannot wash and bathe at all and needs another person to wash their entire body. **8 points.**

5. Managing toilet needs or incontinence.

- a. Can manage toilet needs or incontinence unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. **2 points.**
- c. Needs supervision or prompting to be able to manage toilet needs. **2 points.**
- d. Needs assistance to be able to manage toilet needs. **4 points.**
- e. Needs assistance to be able to manage incontinence of either bladder or bowel. **6 points.**
- f. Needs assistance to be able to manage incontinence of both bladder and bowel. **8 points.**

6. Dressing and undressing.

- a. Can dress and undress unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to dress or undress. **2 points.**
- c. Needs either –
 - (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or
 - (ii) prompting or assistance to be able to select appropriate clothing. **2 points.**
- d. Needs assistance to be able to dress or undress their lower body. **2 points.**
- e. Needs assistance to be able to dress or undress their upper body. **4 points.**
- f. Cannot dress or undress at all. **8 points.**

7. Communicating verbally.

- a. Can express and understand verbal information unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to speak or hear. **2 points.**
- c. Needs communication support to be able to express or understand complex verbal information. **4 points.**
- d. Needs communication support to be able to express or understand basic verbal information. **8 points.**
- e. Cannot express or understand verbal information at all even with communication support. **12 points.**

8. Reading and understanding signs, symbols and words.

- a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. **0 points.**
- b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. **2 points.**
- c. Needs prompting to be able to read or understand complex written information. **2 points.**
- d. Needs prompting to be able to read or understand basic written information. **4 points.**
- e. Cannot read or understand signs, symbols or words at all. **8 points.**

9. Engaging with other people face to face.

- a. Can engage with other people unaided. **0 points.**
- b. Needs prompting to be able to engage with other people. **2 points.**
- c. Needs social support to be able to engage with other people. **4 points.**
- d. Cannot engage with other people due to such engagement causing either –
 - (i) overwhelming psychological distress to the claimant; or
 - (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. **8 points.**

10. Making budgeting decisions.

- a. Can manage complex budgeting decisions unaided. **0 points.**
- b. Needs prompting or assistance to be able to make complex budgeting decisions. **2 points.**
- c. Needs prompting or assistance to be able to make simple budgeting decisions. **4 points.**
- d. Cannot make any budgeting decisions at all. **6 points.**

MOBILITY ACTIVITIES**1. Planning and following journeys.**

- a. Can plan and follow the route of a journey unaided. **0 points.**
- b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. **4 points.**
- c. Cannot plan the route of a journey. **8 points.**
- d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. **10 points.**
- e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. **10 points.**
- f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. **12 points.**

2. Moving around.

- a. Can stand and then move more than 200 metres, either aided or unaided. **0 points.**
- b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. **4 points.**
- c. Can stand and then move unaided more than 20 metres but no more than 50 metres. **8 points.**
- d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. **10 points.**
- e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. **12 points.**
- f. Cannot, either aided or unaided, –
 - (i) stand; or (ii) move more than 1 metre. **12 points.**

Personal Independence Payment (PIP) daily living component points scores

To get an award of the daily living component, you need to score **8 points** for the standard rate or **12 points** for the enhanced rate. For daily living, the points need to be scored from **activities 1-9** below. You can only score one set of points from each activity, if two or more apply from the same activity only the highest will count.

So, for example, if 4d. Needs assistance to groom. (2 points) and 4g. Needs assistance to bathe. (4 points) both apply you will receive only the 4 points for the 'Bathing and grooming' activity. These can then be added to points for other activities, such as 'Dressing and undressing'

Personal Independence Payment (PIP) Mobility Component Points Scores

To get an award of the mobility component you need to score **8 points** for the standard rate OR **12 points** for the enhanced rate. For mobility, the points need to be scored from **mobility activities 1-2** above. As with daily living above, you only score the highest points that apply to you from each activity, but you can add points from activities 10 and 11 together to reach your final total.

ADDITIONAL

Variable and fluctuating conditions Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore the descriptor choice should be based on consideration of a 12 month period. Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in the 12 month period.

The following rules apply:

If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen. If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time. Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days – for example, descriptor 'B' is satisfied on 40 per cent of days and descriptor 'C' on 30 per cent of days – the descriptor satisfied for the highest proportion of the time should be selected.

Awaiting treatment If someone is awaiting treatment or further intervention it can be difficult to accurately predict its level of success or whether it will even occur. Descriptor choices should therefore be based on the likely continuing impact of the health condition or impairment as if any treatment or further intervention has not occurred.

Reliably, in a timely fashion, repeatedly and safely. An individual must be able to complete an activity descriptor reliably, in a timely fashion, repeatedly and safely; and where indicated, using aids and appliances or with support from another person (or, for activity 10, a support dog). Otherwise they should be considered unable to complete the activity described at that level.

Reliably means to a reasonable standard.

In a timely fashion means in less than twice the time it would take for an individual without any impairment.

Repeatedly means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

Safely means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

Risk and Safety When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event may occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur.

Aids and appliances The assessment will take some account of aids and appliances which are used in everyday life. In this context: **Aids** are devices that help a performance of a function, for example, walking sticks or spectacles.

Appliances are devices that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs. The assessment will take into account aids and appliances that individuals normally use and low cost, commonly available ones which someone with their impairment might reasonably be expected to use, even if they are not normally used.

Individuals who use or could reasonably be expected to use aids to carry out an activity will generally receive a higher scoring descriptor than those who can carry out the activity unaided.

Support dogs We recognise that guide, hearing and dual sensory dogs are not 'aids' but have attempted to ensure that the descriptors capture the additional barriers and costs of needing such a dog where they are required to enable individuals to follow a journey safely.

Support from other people The assessment will take into account where individuals need the support of another person or persons to carry out an activity – including where that person has to carry out the activity for them in its entirety. The criteria refer to three types of support:

Assistance is support that requires the presence and physical intervention of another person i.e. actually doing some or the entire task in question. This specifically excludes non-physical intervention such as prompting or supervision which is defined below. To apply, this only needs to be required for part of the activity.

Prompting is support provided by reminding or encouraging an individual to undertake or complete a task but not physically helping them. To apply, this only needs to be required for part of the activity.

Supervision is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the individual. There must be evidence that any risk would be likely to occur in the absence of such supervision. To apply, this must be required for the full duration of the activity.

Unaided Within the assessment criteria, the ability to perform an activity 'unaided' means without either the use of aids or appliances or assistance/prompting/supervision from another person.

Epilepsy. Epilepsy is a marked example of a fluctuating condition where an individual can have no functional limitation one minute and considerable limitation the next. Assessment should be based on the impact this causes. Key to assessing individuals with epilepsy is the consideration of risk. Within each activity, the relevant descriptor should apply to a person with epilepsy if there is evidence that a serious adverse event is likely to occur if the person carried out the activity in that descriptor. It is essential to consider the likely effects of any seizure – type and frequency of fit, associated behaviour, the post-ictal phase and whether there is likely to be sufficient warning to mitigate any risk of danger.

How does the claim process work? From the DWP website**1) Making a claim.**

The telephone number to start the claim is 0800 917 2222. Claimants (or those supporting them) phone DWP to make a claim to PIP. This involves an identity check and some basic questions. Paper claims won't normally be used, and on line claims will not be available before 2014. Additional support, such as provision of alternative formats will be available. DWP then send claimants a form where they can explain how their disability affects them.

Several members have been through this process and it is basically a telephone interview.

2) Telling your story.

Claimant completes the 'How your disability affects you' form to explain how their condition affects their daily life, both on good and bad days and over a range of activities. Supporting evidence can be sent with this form, which they return to DWP by post.

Leger ME has an emailable

able drafting form to help with this stage. There is also a 'Benefit and Work Guide' available to Leger ME members for this stage.

3) Assessment

Claim details, forms and supporting evidence are passed to the health professional. Most people are asked to attend a face-to-face consultation unless a decision can be reached on the basis of written evidence. Home visits are available when necessary and claimants can take someone along for support. The consultation provides the opportunity for the claimant to explain their support needs in their own words. The health professional reviews the claim against a set of clear descriptors to assess the challenges faced by the individual and provides advice for the DWP Decision Maker to consider.

The main concern I have here is the face-to-face medical. Locally it will be the same people who administer ESA medicals (Atos). I have no confidence in this organisation to do the job correctly, so as with ESA the standard precautions and advice apply. The main issue is to take advice before a visit and always take someone with you. If you have no-one to accompany you contact the help desk, and we will do our best to find you someone.

4) Decision

A DWP Decision Maker uses all the information in the claim form, from the health professional and anything else that has been provided. They make a reasoned decision on entitlement, including the level and length of award.

This is the crunch time. If you think that the decision is wrong seek help.

5) Disputes

Any dispute will start with a GL24 form being submitted to the DWP. As with all benefit refusals, Leger ME will hold an inquest to try to establish as to why the claim was refused. The pathway is a review by the DWP, and then the case is passed to the tribunals service as with other DWP disputes.

As Helen explained, the benefit is new, and it will be at least twelve months before the case law can be tested and any anomalies clarified. I strongly suspect that as with DLA, the criteria for any award will be based on a commissioner's retrospective decision or ruling as it is at present.

Out and About: The Norfolk Broads

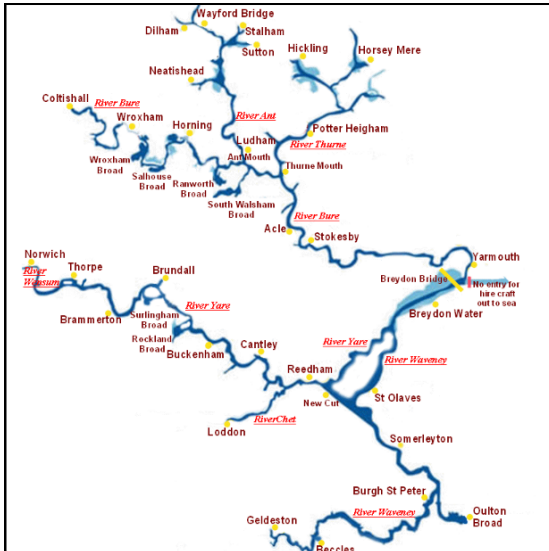
The Norfolk Broads are about a four hour drive from Doncaster—so really they are only worthwhile visiting if you are staying around the East Norfolk area.

The Norfolk Broads are a series of rivers and broads (lakes), most of which are navigable. In prehistoric times, the land was excavated for peat by the ancient Britons.

With the geography of the area, once the first few meters

were mined to a depth of about the height of a man the pit would fill with water. In those days

there were no pumps or easy means to remove the water—so the only way to carry on mining was to expand sideways. Consequently the result was a series of relatively shallow ponds or lakes. Altogether the of the Norfolk Broads totals 303 kilometres, most of this is in the County of Norfolk, and just over 200 square kilometres of these waterways are navigable, covering seven rivers and 63 Broads. The depth of these waterways is usually less than 4 metres deep. Thirteen of the broads are completely navigable whilst three others have channels open to navigation running through them. The Broads range from small ponds through the large areas such as Hickling, Barton and Breydon. The majority are located in the northern half of Broadland which encompass the Rivers, Bure, Ant and Thurne. Central and Southern parts of Broadland encompass the Rivers Waveney, Yare and Chet, however all the waterways are tidal but the effect of the tide decreases the further away from the coast until reaches upstream from Barton Broad are almost non tidal. All the Broads are either on or situated adjacent to the rivers.



and Chet, however all the waterways are tidal but the effect of the tide decreases the further away from the coast until reaches upstream from Barton Broad are almost non tidal. All the Broads are either on or situated adjacent to the rivers.

For our visit we chose to go on a tour with Broads Tours at Wroxham and our boat for the afternoon was the Queen of the Broads. A number of tours are available departing in the main part of the day. We chose the two hour tour to go to Wroxham and Salhouse broads and go towards Horning Reach. The first thing we did on arriving at Wroxham was to book. Dogs are allowed, so we booked. If you are taking a wheelchair advance booking advisable. As we found out later people in wheelchairs are boarded first, the boat having a specific wheelchair lift. We chose to wait in a café just around the corner from the booking office.

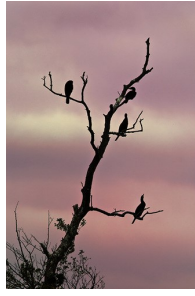


After a short wait we boarded the 'Queen of the Broad'. After leaving the quayside and a bit of clever manoeuvring by our captain we found our way onto the main river. Looking back, we could see Wroxham bridge. We made way through the outskirts of Wroxham into the open country. There were plenty of 'private mooring' signs. Every property adjacent to the river had its own boat mooring, with the bigger houses each having a private dock.

We passed a thatched house called 'Heronby', built in 1907, which was once owned by George Formby, a well-known early twentieth-century entertainer. Not long after we rounded the next



bend we found how the house got its name. About 50



yards away from the bank we saw herons perched on a dead tree. Apparently unlike ducks, their feathers are not waterproof so have to be dried in the air. We then turned right into Wroxham broad. Wroxham broad is the home of the local sailing club and there were many sailing boats moored there.



We returned to the main river. We were overtaken by a red boat with a big ice cream cone stuck on the front.



On the way to Salhouse Broad we passed a Heron fisherman ready to pounce and a floating JCB doing repairs to a windmill. Turning into Salhouse Broad we saw many



boats parked up rear end facing towards the shore and the ice cream boat that had zoomed past us earlier on,



busy plying his trade to the occupant of a boat anchored in the middle of the broad. We then re-joined the main river towards Horning Reach. We turned around and on the way back we passed a tour boat with a squirrel mascot at the head. The captain told us an interesting story about a boat captain, squirrel and a mobile phone. I'm not going to spoil the tale – you'll have to go the two Broads yourself!



North of Doncaster

(Personal thoughts by Trevor Wainwright)

How do you see Four Wheel Drive vehicle owners? I'll bet for some of you it's not very complimentary, me included. Well now what would you say to a group of Four Wheel Drive vehicle owners who broke the mould.

Having left the Red Cross for personal reasons, I was looking for something else to do preferably something run entirely by volunteers, with no salaried staff or management. An opportunity came when I saw an article asking for volunteers to join West Yorkshire 4 x 4 Volunteers

Formed in 2011 as a Group of Volunteers they are ordinary people formed to assist the local community in times of need. The West Yorkshire 4 x 4 Volunteer Group is, as the name suggests a volunteer group who use privately owned and maintained 4 x 4 vehicles to assist the local community in times of need. They are currently setting up agreements with similar neighbouring groups in order to expand their capabilities in times of major emergency.

As the name suggests, they support communities within the West Yorkshire County boundaries. They can call on over 30 volunteer drivers who are supported by a number of back-room volunteers, and we are always on the lookout for new members to join us and allow us to support our users to the maximum possible effectiveness.

The Group evolved from the original but now defunct Humber and Yorkshire 4x4 Response Group and as such many members have experience in assisting during major emergencies such as the flooding both locally and nationally during the summer of 2007 and the bitter winter weather of 2010 and 2011.

As such the Group offers assistance as required by our user services, principally Category 1 and Category 2 responders, such as Police, Ambulance, Doctors and Local Authorities via the Local Resilience Forums set up by the Civil Contingencies Act (2004). This is often in extraordinary circumstances or extremes of weather, such as heavy snow or flooding. They also attend shows and local events to assist in engaging with the people in their local communities to raise the awareness of the group, what they do and to ensure they maintain good relationships with those they volunteer their time for. Such tasks can include:

- Recovering people and or animals in the event of flooding, and other adverse conditions
- Taking a doctor on his rounds in the snow
- Taking Key Workers to their place of work
- Delivering supplies, meals on wheels, etc.
- Recovering people from flooded areas and taking them to a place of safety
- Assisting with road closures
- Marshalling and vehicle recovery at events

Clouds Community Counselling Service Ltd.



Need to talk? We will listen

Free confidential counselling service

Client Telephone Line **07962 907053**

Ring for an appointment

Appointments available at

Dunsville Community Centre, Stainforth and Moorends

Clouds Counsellors are members of BACP and are bound by its Ethical Framework for Good Practice in Counselling and Psychotherapy and subject to Professional Conduct Procedure for the time being in force.

Would they want a 2 Wheel Drive Vehicle Owner I thought, as it turned out they would, they would need us for double crewing of 4 WD's which would prevent using two drivers and a 4WD being laid up.

We could also be used to transport equipment to the scene of operations and transporting any persons from the scene of operations to a further place of safety. We could also be used to staff the control room at Cleckheaton, so I joined. Having completed the initial training I am now ready to answer the call, by sending my availability when responder status is in Stand By. So next time you see on TV floods that are in West Yorkshire, I could be there, or still part of it in the control room. –Trev

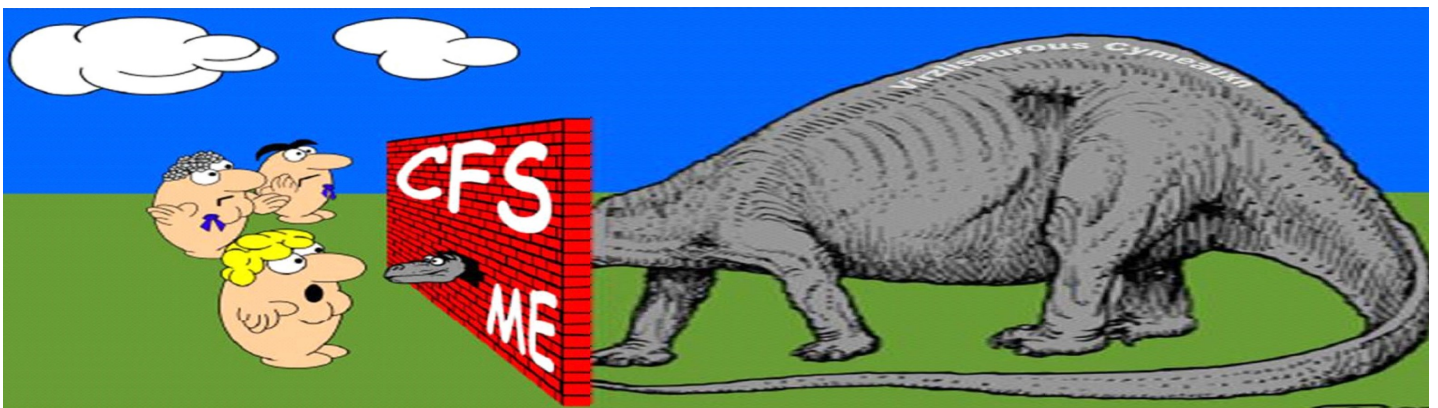


Above. A Land Rover—the classic 4 x 4 derived form the wartime jeep.

Right top. Personal Equipment- Warm Clothing, sleeping bag, flask and food.

Right Centre. 4 x 4 group in action. Mirfield July 2012

Right bottom. Mytholmroyd June 2012



"Although Dinosaurs went extinct 65 million years ago, there are still some living fossils around today."