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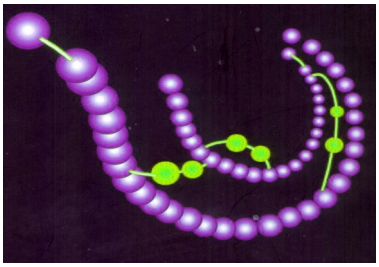
Pathways

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

Later-life health problems and ME/CFS



A diagrammatic representation of the chemical structure of insulin which features as the big player in diabetes management.

Over the past few months there have been quite a number of enquiries about ME/CFS and other chronic problems. All in all they can be summarised as later-life problems such as cancer, arthritis, diabetes and circulatory disorders. While there is not a lot of effective treatment for ME/CFS, many later life conditions can be effectively treated and managed so that they have a minimal effect on quality of life.
Many are life threatening and very often do not reveal themselves until an emergency arises (e.g. heart attack) and if they are not managed properly, the damage is done. When someone with ME/CFS gets Type 2 diabetes there is a temptation to address the ME/CFS because it is having an immediate effect on your life, while the diabetes may not produce any problems for many years. The reality is that the ME/CFS is just a nuisance and the diabetes can be fatal if not managed properly in the early stages. Concern for a patient enquiring on the group helpline prompted me to write the feature *Dealing with Type 2 Diabetes & ME/CFS* which starts on page 13. I will cover other later-life diseases and ME/CFS in future issues.

Viruses 'are not to blame for ME'

Study rules out old theory 'once and for all'

By Tamara Cohen
Science Reporter

THE debilitating condition ME is not caused by viruses, according to a study which claims to dismiss this theory 'once and for all'.

Hopes for a treatment were raised three years ago when researchers sensationally claimed that most cases of the illness – also known as chronic fatigue syndrome – may be triggered by little-known bugs in the blood.

Now experts say the latest study – which involved many of the same US researchers – provides conclusive evidence that this theory was wrong.

The research, at Columbia University in New York, found no evidence that sufferers are infected with the rare viruses XMRV or pMLV, which are distantly related to HIV.

It is believed that the 2009 study suggesting the link, which was published in a prestigious scientific journal, may have been flawed.

Similar studies at King's College London and in the Netherlands have also failed to find evidence of the viruses in the blood of sufferers.

Co-author of the latest study Ian Lipkin, a professor of epidemiology, said: "We went ahead and set up a study to test this thing once and for all and determine whether we could find footprints of these viruses.

"We found no evidence of infection with XMRV and pMLV. These results refute any correlation between these agents and disease." ME, or myalgic encephalomyelitis, affects 250,000 people in Britain and symptoms include extreme fatigue and muscle pain.

Some sufferers become so weak they are bedridden or confined to a wheelchair.

It was dismissed as 'yuppie flu' in the Eighties and the lack of a clear cause led to scepticism it was a genuine illness. It was only properly recognised in 2002 when then chief medical officer Sir Liam Donaldson said ME was a 'debilitating and distressing condition'.

In 2009 'spectacular' findings published in the journal Science pinned 70 per cent of cases on the rare viruses, usually found in mice.

It is now thought these results may have been contaminated and the journal has retracted the research from the Whittemore Peterson Institute in Nevada.

This time researchers took 'extraordinary care' to eliminate contamination in the chemicals used in the study, which tested the blood of 147 ME patients and a similar sized group of healthy volunteers.

Speaking of the findings, published in mBio, the journal of the American Society for Microbiology, Professor Lipkin said: 'We've tested the XMRV/pMLV hypothesis and found it wanting.

'But we are not abandoning the patients. We're not abandoning the science.'

Experts believe there may be a genetic cause for ME, or it may be triggered by a traumatic event or a weakness in the immune system.

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CONDITION WITH NO CURE

- ME costs the economy £100million a year in lost productivity, according to researchers at the University of Bristol
- Most patients wait three years before seeking specialist treatment
- Studies suggest cognitive behaviour therapy and exercise are the most effective treatments, but there is no known cure
- According to the NHS, it usually develops in the early-20s to mid-40s
- Half of those seeking treatment have to give up work due to 'fatigue-related symptoms'
- The first official UK death from ME was recorded in 2006 when a 32-year-old woman died of dehydration brought on by chronic fatigue syndrome

Several members have sent us copies of the Daily Mail of the 18th October. ME/CFS has multiple causes, being viral, bacterial, chemical, environmental & so on. It is effectively immune-system damage or 'scarring', once the original cause has gone. The feature in the Daily Mail produced this headline. As frequently happens, the journalists have angled on first impression rather than putting the matter into context. Many ME/CFS organisations have derided this feature as incorrect. The feature on page 18 from the ME Association, '*The XMRV saga has finally ended',* has firmly put the matter into the correct context.

It's NHS reorganisation time again. Although the Government promised to ring-fence NHS services from financial cutbacks this is far from true. The issue of *Lillybells letter* on page 3 where the GP's are refusing to supply B12 injections and '*All change, everything in the melting pot.*' are example of how cutbacks are affecting members now.

On the lighter side Anne Fisher's feature on *Out and About Around Doncaster II* shows us that in times of austerity you don't have to go far to enjoy the countryside. In *Recipe Corner* on page 19 we feature two diabetic-friendly recipes that are easily prepared. Finally we feature '*Cartoons about life with ME/CFS' by Hans-Michael Sobetzko*

You write

Terry writes: Do you know anything about the Lightning Process because I have read very varied accounts on different websites.

The Lightning Process is promoted by an upmarket glossy branded package product image. It appears to be a belief system involving Counselling & CBT aspects. I've spoken with practitioners and patients with both negative and positive experiences. The signing of a secrecy agreement is required from people accessing the therapy. However, a similar 'contract' is standard practice in the counselling services we use—but these are open and are standard practice with the British Association of Counselling Psychologists' registered practitioners. One counsellor I know takes the view that The Lightning Process is a form of CBT, using the 'Rewind Technique'.

From the feedback I have received what has always concerned me is that patients are programmed to ignore what their bodies are telling in a military like fashion and carry on regardless. I believe that as with CBT, The Lightning process has uses with rehabilitation of Grade 1 cases or those who have almost recovered from ME/CFS. What does concern me is the apparent absence of networking with medical services by practitioners.

Lillybelle writes. Over the years I have had my B12 injections which have made a massive difference to my ME/CFS. A couple of days ago I was told by the head doctor in my practice that I can no longer have B12 injections. It turns out the a couple of the practice nurses brought my case up, as my B12 blood levels are normal. It also turns out that the head doctor has been overruled by his junior partners. Any Idea what is going on and how could I get around this problem?

1) Vitamin B12 injections have never been advocated for treatment of ME/CFS within the National Health Service. They are not listed in the British National Formulary (BNF) or Clinical Knowledge Summary (CKS) for ME/CFS treatment. In fact there is no specific reference to ME/CFS & medicines treatment—only in terms of general symptom control e.g. pain relief or IBS. There is very little credible evidence to justify B12 usage in ME/CFS, unless the bloods tests come back showing deficiency.
2) The NHS is undergoing a massive change. Doctors' practices are now adopting practice policy for treatments or practice formularies. In some cases individual doctors' wishes are being overruled as appears to be the case with your GP. Money is tight—the use of medicines are being audited, and deep questions asked if anything unusual or outside BNF or CKS guidelines is found.
3) Also B12 has no product licence for use in ME/CFS, and many doctors will not prescribe outside these guidelines. This is because they would then not be covered by their professional indemnity insurance if something went wrong. In ME/CFS, B12 works as an antioxidant which requires higher and more frequent dosing than usual use, and is independent of the blood-level results. It is unlikely that you will get anywhere by complaining or even if you changed your GP. However if you went to see a private doctor things would be different, as they have their own rules and standards, as well as working outside the NHS. In the following pages of 'Pathways', we've printed Doctor Myhill's thoughts about this from her website. This might help to resolve your problem.

Gwengi writes: I have severe ME/CFS, and I'm just recovering from breast cancer chemotherapy treatment. I have to take an anti oestrogen drug for the next five years. I would like to try one of the fish oil products to help manage my ME/CFS. Any thoughts about this.?

While you were receiving active treatment for breast cancer, it would have been an unreasonable gamble to take any supplements because they could have worked against the cancer treatment. However there is no reason to avoid supplements once that treatment has stopped. You have to remain cancer free for five years for you to be classed as cured.

I would view an anti oestrogen drug as basically an insurance policy, rather than active treatment, so I think you would be justified in trying fish oil supplements again. I have researched this issue and I can't find anything that says fish oil is contra indicated. I have also come across one paper where it appears that fish oil products may have a mild protective effect against breast cancer. The reference is from Cancer Epidemiology, Biomarkers & Prevention, July 2010 and is entitled Fish oil supplements reduce risk of ductal breast cancer.
Cancer Epidemiol Biomarkers Prev; 19(7); 1696–708. ©2010 AACR.

Sheffield M.E. Group
Helping YOU with ME

Registered Charity 1095416

Annual Conference

24th October 2012
1.00 p.m. to 4.30 p.m. at
The Circle
33 Rockingham Lane Sheffield S1 4FW

Speaker:

Professor Julia Newton
'Standing up for Fatigue'

Light refreshments available Bring your family/friends/carers
A donation of £3 suggested Other information stalls present
For further information call 0114 2536 700

The rationale for using vitamin B12 in CFS *by Dr. S. Myhill*

Since 1982 a programme of treatment has evolved which I believe all chronic fatigue syndrome patients must do as the foundation before proceeding to other treatments. Vitamin B12 by injection I see as an important part of this programme and it is effective for many, regardless of the cause of their Chronic Fatigue Syndrome. Those patients who respond to B12 are not obviously deficient in B12; indeed, blood tests usually show normal levels. The "normal" levels of B12 have been set at those levels necessary to prevent pernicious anaemia - this may not be the same as those levels for optimal biochemical function. B12 has a great many other functions as well as the prevention of pernicious anaemia. However, what is interesting is how B12 is beneficial in so many patients with fatigue, regardless of the cause of their CFS, and suggests that there is a common mechanism of chronic fatigue which B12 is effective at alleviating.

General mechanism by which B12 relieves the symptoms of CFS.

Professor Martin Pall has looked at the biochemical abnormalities in CFS and shown that sufferers have high levels of nitric oxide and its oxidant product peroxynitrite. These substances may be directly responsible for many of the symptoms of CFS and are released in response to stress, whether that is infectious stress, chemical stress or whatever. B12 is important because it is the most powerful scavenger of nitric oxide and will therefore reduce the symptoms of CFS regardless of the cause (Ref: 1-6) Nitric oxide is known to have a detrimental effect on brain-function and pain-sensitivity. Levels are greatly increased by exposure to chemicals such as organophosphates and organic solvents (ref: 7). When sensitive tests of B12 were applied (serum methylmalonic acid and homocysteine) before and after B12 therapy, the following symptoms were noted to be caused by subclinical B12 deficiency: paraesthesia, ataxia, muscle weakness, hallucinations, personality and mood changes, fatigue, sore tongue and diarrhoea (ref: 8).

B12 in fatigue syndromes.

The "foggy brain" with difficulty thinking clearly, poor short term memory and multitasking are often much improved by B12.(ref: 9, 10, 11). Mood and personality changes, so often a feature of patients with chemical poisoning, can be improved by B12 (ref: 12). The physical fatigue and well being are often both improved. A study was carried out as follows:
Twenty eight subjects suffering from non-specific fatigue were evaluated in a double-blind crossover trial of 5 mg of hydroxocobalamin twice weekly for 2 weeks, followed by a 2-week rest period, and then a similar treatment with a matching placebo. The placebo group in the first 2 weeks had a favourable response to the hydroxocobalamin during the second 2 week period with respect to enhanced general well being. Subjects who received hydroxocobalamin in the first 2-week period showed no difference between responses to the active and placebo treatments, which suggests that the effect of vitamin B12 lasted for over 4 weeks. It is noted there was no direct correlation between serum vitamin B12 concentrations and improvement. Whatever the mechanism, the improvement after hydroxocobalamin may be sustained for 4 weeks after stopping the medication (ref: 13).

Practical details.

Vitamin B12 has no known toxicity and B12 surplus to requirement is simply passed out in the urine (which may discolour pink). It is theoretically possible to be allergic to B12 but in the thousands of injections that I have sanctioned this has only ever occurred after several injections and caused local itching, redness and swelling (although the commonest cause of redness and swelling is poor injection technique) in a handful of patients. I usually start with 1/2 mg (500 mcg) daily by subcutaneous injection, then adjust the frequency according to response - some patients will respond straight away, some need several doses before they see improvement. I would do at least a month of injections before giving up. Many of my patients learn to inject themselves - this means they can be independent of their doctors.

What Happens If Your GP Refuses To Give The B12 Injections.

This is a real bore. B12 injections are so helpful that it is pointless progressing on to other things without trying these first. Therefore a way must be found to get this done. First my own patients, I may be able to supply B12 and the GP's practice nurse should be able to inject.

The next possibility is that the GP refuses to have anything to do with B12 injections. In this event either you need to find a local nurse, physiotherapist, health visitor or mid-wife or whoever who can do the injections for you. I am very happy to write a covering letter so that I take clinical responsibility, send that person instructions as to how to inject B12 and I can supply the wherewithal.

The third possibility is that I teach you to inject yourself. This has great advantages because the timing of the B12 depends on your clinical symptoms. Some people know exactly how long the injections last and if they are going through a good phase they last longer, shorter with a bad phase. However, you really need to come and see me so that I can teach you to inject yourself, or alternatively be taught by a competent local practitioner such as a doctor or nurse. Many of my patients do end up injecting themselves simply because this saves the effort of travelling down to their GP's surgery on a regular basis and the risk of picking up nasty infections in the waiting room.

Fourthly I now have a preparation of B12 which delivers 5,000mcgms (i.e. ten times the dose in a ½ml injection) as a sublingual spray, but even with perfect B12 absorption one can only expect 1% to actually get through the gut wall!. The idea of the sublingual spray is that some is absorbed under the tongue. It works well for some people, but many CFS's tell me that the injections are irreplaceable!

What to do if you get better with B12 injections?

A very useful website is B12 Deficiency Patient Support Group. On this page you will find a B12 Signs and Symptoms Assessment Form developed by Dr Joseph Chandy, a GP with many years experience of using vitamin B12 injections.

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Money and ME/CFS

Money- management hints and tips

Money and ME/CFS affect each other: Problems with one make the other one more difficult to manage. It's a double edged sword; you get anxious depressed and then you spend, or you spend too much, which makes you even more anxious. It's a vicious cycle , and is a major problem for a lot of people who have ME/CFS. Keeping track of your finances can be difficult at the best of times. When life gets stressful, paying your bills and managing your money can become even harder. What matters is that you take action as soon as you begin to find it difficult to cope. Many people find opening letters from the bank upsetting. If necessary contact someone to help you go through to go through them., it takes a lot of worry away. Here's a list of things you can check each week to help you keep track of things. Put it up in a place where you can easily see it, such as your fridge, as a reminder. Try to choose a regular time to look at your money and bills each week, maybe with someone who can help, so that things don't pile up and start to feel too big to cope with.

- Know how much money you have - check bank account balances at least monthly and count your cash, before spending.
- Try to stick to the budget. Know exactly how much a month goes out in standard bills. We work out how much money we need for food and clothing, then try to save some for emergencies.
- Get advice - there are many organisations who can provide this or who can help you sort out your finances (e.g. Citizens' Advice).
- Check you have enough money for essentials like food and toiletries

-If you don't, get urgent advice from your local Citizens Advice or social security office.

- Deal with bills - if you can pay, do so. If you can't, contact those you owe and explain your circumstances.
- Collect any money due to you e.g. wages, benefits.
- Review your circumstances - if your income, spending or needs have changed, you may need to tell people you owe money to or who pay you benefits.
- Open your post - it isn't always easy to face bills, but it will help you know where you stand. You could ask someone you trust to do it with you.
- Stay organised - put all important records and documents, e.g. payslips, bank statements, bills, receipts etc. in one place, so that you can find them easily again.
- Deal with issues when you are well. This will often help both your financial situation and ME/CFS when you are not so well.

The true cost of those telephone calls *by Carolyn*

If you want to call a company or Government Department you will often be asked to ring a number beginning with 084 or 087, which cost more than ringing standard landline numbers that begin with 01, 02, or 03. When you use these dearer numbers, the people you call will earn about 2p a minute and you will pay between 1.5p and 13p a minute from a landline and, anything from 12.5p to 41p from a mobile. In addition, there may be a small 'set-up' charge. You can avoid these charges by looking up the high-cost numbers on a website called saynoto0870.com. It lists alternative cheaper numbers. Another tip when calling your bank or credit card provider is to look on the back of the card for a number to be used from abroad – normally beginning +44(0). If you first dial 141, and substitute 0 for the +44, you will be charged the normal UK landline rate.

Another warning: If a firm asks you to call a number beginning 09, be aware that calls can cost up to £1.65 a minute from a landline or £2.55 from a mobile – and some of these numbers are scams (e.g., those offering prizes for fake lotteries). Finally, remember that 0800 numbers are not usually free on mobiles.

For more information, visit ofcom.org.uk (search for 'number crunching') or see fairtelecoms.org.uk.

News from Fairlawns.

The South Yorkshire & North Derbyshire Chronic Fatigue Syndrome/ME Service

I represent the Leger ME group, along with Michèle Young, from Derbyshire ME Support Group and Ute Elliott from Sheffield ME Support Group. Here is a digest of the LPIG meeting held in the 21/9/12

All change, everything in the melting pot.

Currently the Sheffield ME/CFS clinic is funded by the Sheffield & Social Care Foundation Trust via the Long Term Neurological Conditions Service. In effect ME/CFS clinic is part of the same unit that deals with stroke and other brain injuries. At the time of writing the clinic had been under audit and review for the past six weeks. This is all about making the best use of the money available. The results are expected early in the new year. This is in preparation for the new system of G.P.-Based Commissioning— in effect the G.P. would buy services for the patients form the clinic, and the clinic would have to 'sell' it's services. In theory another organisation could set up and bid for the contract to the commissioners. So the fact that the clinic exists counts for nothing and this time next year the staff could be out of a job like Dr Philip Wood and Sue Pemberton at the Leeds ME/ CFS clinic. Sue and Dr. Wood have effectively lost their jobs at the Leeds Clinic where they have worked for many years, after the Clinic's reorganisation along Psychiatric lines. They have set up the Yorkshire ME/CFS clinic based in York to bid for new G.P. based contracts. Watch this space.

Maggie Campbell moves on.

Maggie Campbell was the Senior Commissioning Manager for Sheffield CCG, her role has been administrative—mainly championing for funding for the continued existence of the clinic. She wrote in a email to us"...*I leave my post next week. Can you please pass on my best wishes to the Group and thank them for their help in increasing my understanding of ME and the challenges of living with the condition. Best wishes Maggie"*

Clinic DVD

The Sheffield clinic is producing a DVD to help people with ME/CFS-management and it is in the early 'draft' stages. A number of comments regarding a trial version have been received from various people. They will be implemented into the final version.

Vitamin D

It was interesting to note that at that meeting there were three ME/CFS suffers there, and all had been found to have low Vitamin D levels in their blood. For one lady, being given Vitamin D made a massive difference -which was confirmed by subsequent blood tests. We were shown a hand-out of a general nature about vitamin D from the British Dietetic Association. Disappointingly, although this was discussed, the staff at the clinic are making no recommendations to patients to have their vitamin D levels checked on a routine basis, for deficiency, by their GP. Vitamin D tests are very expensive for the NHS.

Break away Clinic by former Leeds Staff

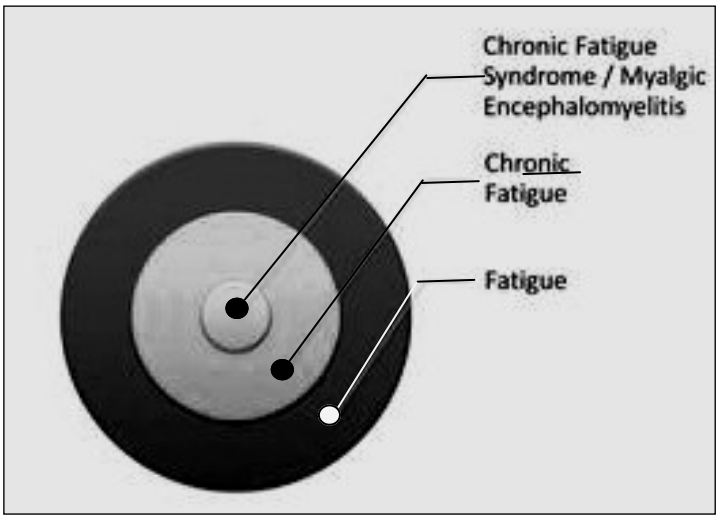
Because of changes in the Leeds ME/CFS clinic, Sue Pemberton, consultant Occupational Therapist and Dr. Philip Wood a Consultant Immunologist & Allergist have set up '*The Yorkshire Fatigue Clinic*' in a strategy to bid for funding from the NHS in competition against what is left of the existing Leeds clinic. They are based in York, and will take private patients.
(We have reproduced literature received from them later in the edition of Pathways –Ed).
I enquired if a similar thing could happen with the Sheffield clinic. The answer was yes—and the meeting moved on to the next agenda item—so who knows ???.

The 'Yorkshire' Fatigue Clinic Patient Information Sheet

What is fatigue?

Fatigue is a common problem. Around 10-25% of people, who go to see their General Practitioner, are suffering from fatigue. It can have a major impact on people's lives and for some people it can significantly reduce their ability to do everyday activities.
Fatigue is different to tiredness. We can all experience tiredness. This happens when we exceed our available energy. This may be because we have been doing more than usual or because our energy levels are lower than normal, for example during an illness or when our sleep is disturbed. General tiredness will normally be improved by rest or by changing the demands on our energy. Fatigue is a state of complete exhaustion that is normally persistent and does not improve with rest. There is a spectrum of severity ranging from mild to very severe.

Why do we get fatigue?



Fatigue is known to be a debilitating symptom of many types of illnesses, for example in conditions such as Multiple Sclerosis, Crohn's disease or depression. This may be because of how a particular health problem affects structures in the body that support energy, such as the nervous system, digestion, or hormones. But it can also be a side effect of the treatments given for many health conditions, such as painkillers or chemotherapy. However, sometimes fatigue can be severe even when there is no obvious reason for this or when problems that have been found, such as hypothyroidism or infection, have been treated.

A large number of people in the population will experience prolonged and disabling fatigue lasting at least one month. Of these, some people will have chronic fatigue where it lasts for over six months. Within the group of people who experience chronic fatigue, some people will have a specific condition, called Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME).

What should I do if I am experiencing fatigue?

Often problems with fatigue will resolve over time. However, if symptoms are continuing then it is important to have appropriate assessment and treatment. Your General Practitioner (Doctor) can perform routine investigations that should show some of the easily identifiable causes for fatigue, such as anaemia, diabetes, infection, liver and thyroid problems.
However, for many people these tests will come back within normal ranges and your doctor may discuss with you whether you meet criteria for CFS/ME and whether specialist assessment and intervention is appropriate. Not everyone who experiences chronic fatigue will have the syndrome, but you can still get help through the rehabilitation strategies the Yorkshire Fatigue Clinic can offer you.
You might find the following resources useful: NHS Choices and NICE Guidelines for CFS/ME

What is the Yorkshire Fatigue Clinic?

The Yorkshire Fatigue Clinic is an assessment and treatment service for people with chronic fatigue, and a specialist service for those with CFS/ME. The clinic was established after over 20 years' experience of working in CFS/ME within the NHS. The founders were involved in setting up the Leeds & West Yorkshire CFS/ME Service which was assessed as having some of the best clinical outcomes in the country and highly rated by patients. The Yorkshire Fatigue Clinic aims to make these specialist skills more available to people with a broader range of fatigue problems and provide a high quality of individualised care. We work with a range of people from those who are rarely able to venture out of the house to those who are managing to work.

What can the Yorkshire Fatigue Clinic offer me?

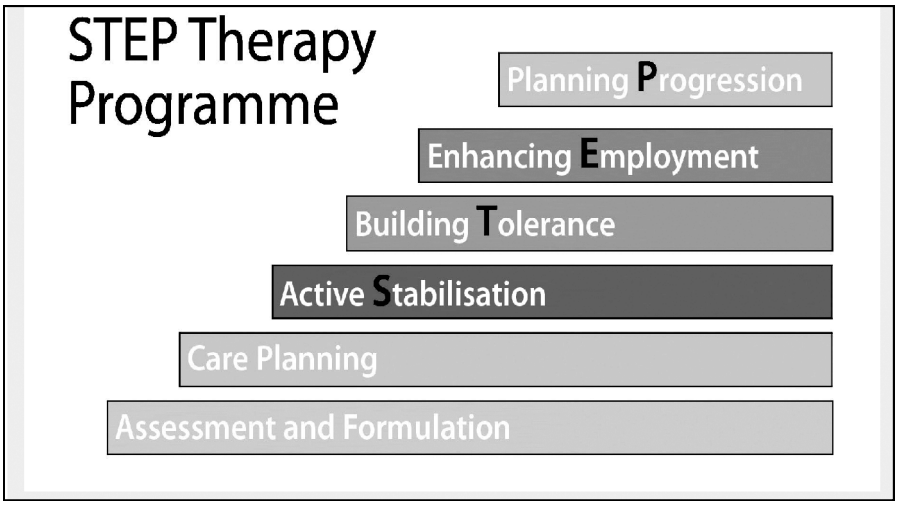
The Yorkshire Fatigue Clinic offers:

Specialist assessment with either a consultant physician or specialist clinician. Fatigue is usually a systemic problem.

This means it affects the functioning of many parts of our body. In addition, CFS/ME is a syndrome, so it causes disruption across a broad range of biological systems, not just physical strength. This can include experiencing pain in muscles and joints, headaches, problems with cognitive processes, such as memory and concentration, sleep, temperature deregulation and many, many more.

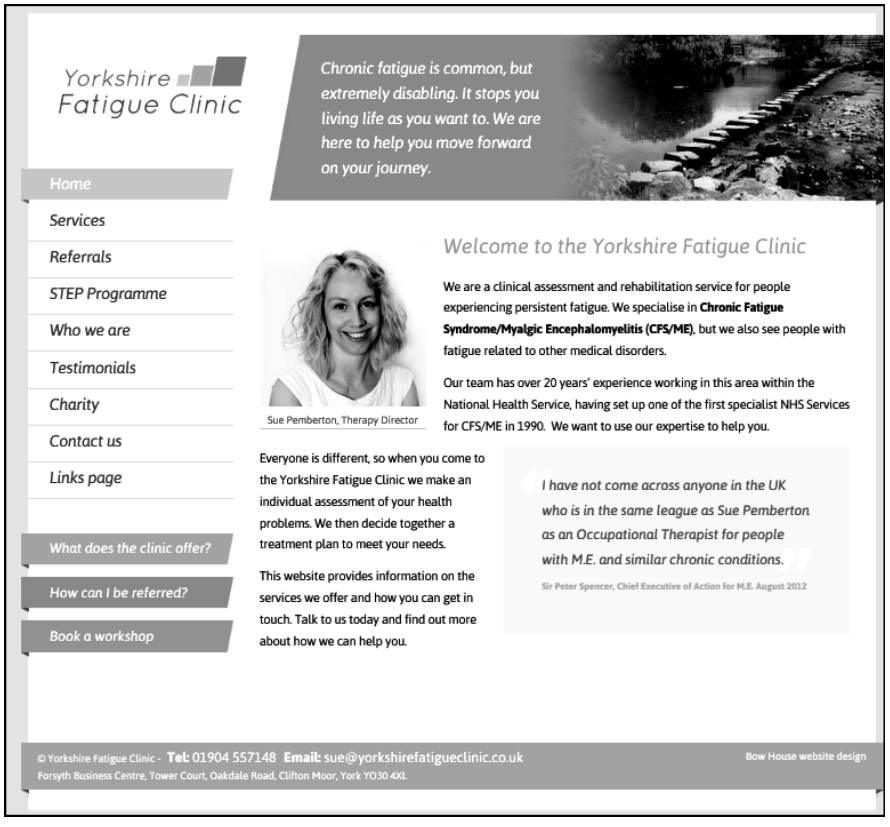
Therefore, an assessment for fatigue will look at the specific symptoms you are experiencing, as well as all the aspects that can have a significant impact upon the way your body produces and uses energy. This can include a wide range of things such as sleep, diet, activity patterns, your emotional wellbeing, and your lifestyle.

Specialist Rehabilitation



There is currently no medication available that eradicates fatigue*. The Yorkshire Fatigue Clinic uses treatment approaches that focus on building your energy resources gradually and addressing factors that can impair physiological processes that support energy, such as sleep patterns, diet and poor quality rest.

The clinic uses the STEP Programme to enable you to actively stabilise your energy supply and then build up your tolerance to activity. This may also identify underlying drivers to your energy usage. There is also specific advice available for people still struggling to maintain employment or hoping to return to work.



How can I find out more about the Yorkshire Fatigue Clinic?

If you would like to know more about the programmes provided at the Yorkshire Fatigue Clinic then look at our website www.yorkshirefatigueclinic.co.uk, or call us on 01904557148 so we can discuss how we can help you. If you want to come along and meet us to find out more you can attend an Introductory Workshop, details are available on our website.

** Certain drugs and supplements may reduce fatigue on an individual basis. Ed.*

Out and About Around Doncaster II

by Anne Fisher

I hope you were able to visit some of the places in the last feature (OUT AND ABOUT) here are a few more you may like to try, I can not guarantee that all these places are suitable for everyone so please use your own judgment if you try them.

ME/CFS ADVICE

If you don't have own scooter or wheelchair then try some of the places listed that loan or hire them. Build up slowly the amount you can do in a day and try somewhere close and only stay out for a short time at first (you can always go back for a second visit). You may need to rest before you go and be prepared to rest afterwards until you know how much you can do. I also recommend that you take a hat, gloves, scarf, blanket and dress warmly as the wind seems to be very chilling even on mild days when sitting in a wheelchair or scooter, my hands suffer the most from holding onto the handles of the scooter. The blanket is also useful for picnics and an afternoon nap if needed.

COASTAL WALK – Scarborough

A visit to Scarborough is always a treat. The whole of the sea front is accessible to chairs of all kinds, with large numbers of cafes and facilities. Some of the Marine Drive is a little bumpy and wet on a windy day, if you are going to attempt the whole of both bays then make sure your batteries are fully charged as I think it is about 3 miles (6 miles return). Parking is available at the North Bay, along the Marine Drive and the South Bay. I have just found this site; *www.scarboroughshopmobility.co.uk*, 01723 369910. If you need to hire a scooter or chair, they are advertising that they are free. I have not used this company so I am unable to recommend them.

NATURE RESERVES. Old Moor RSPB, Wath on Dearne

Parking, refreshments and toilets are available at Old Moor Nature Reserve. The Trans Pennine trail also goes both ways from the car park at the Bird sanctuary but the reserve is fully accessible for a small charge. Wheelchairs can be taken into the bird hides but I like to leave mine outside each hut, (it's good to move the legs a little). There is a lovely café with a lift up to the first floor also disabled toilets are available. Insect repellent is always a good idea when visiting sites with water.

http://www.rspb.org.uk/reserves/guide/d/dearne-oldmoor/accessibility.aspx 01226 751593

OPEN COUNTRYSIDE. Trans Pennine Trail –

This Trail has access at many points with good but rough paths, the following sections are the ones I have been on, but there are many more. The Doncaster Cycling map show the routes available, this can be obtained from DMBC (01302 736000) or the Trans Pennine Trail office (01226 772574).

Sprotbrough to Conisbrough

Parking by the side of the canal is limited, access there can take you towards Doncaster or Conisbrough. The path towards Conisbrough follows the river via the nature reserve. There are some gates but we have only come across one that has been locked and we managed to get round that but with a little difficulty. The path can be rough and muddy in places. You can exit the Trail at Conisbrough close to the Kingswood Dearne Valley Centre (formally the Earth Centre). It may be better to start from here then you can lunch at the Boat inn. There are no official toilets.

Boart Inn Sprotborough

Canal Lock

Canal Bridge

Conisbrough Viaduct was opened in 1909 to trains on and closed in July 1966.

Sustrans have laid a tarmac path across it in 2010, forming a link to the Trans Pennine Trail at its north-western end. With 21 arches, 14 to the north side of its girder span and seven to the south, Conisbrough Viaduct is 1,527 feet in length, built of 15 million bricks sourced locally

Conisbrough to Pastures Lane (1.7 mile) continuing on to Harlington (1.3 mile) or to Pastures lodge for refreshments and toilets (0.4 mile). Parking is available close to the Kingswood Dearne Valley Centre (Earth centre) or Conisbrough Railway Station. Access to the Trail is over the river bridge, again the track can be a little rough or muddy but is very clear. This path is well used by walkers and cyclists.

COUNTRY PARK. – Clumber Park

We always find this a very enjoyable trip out, the parkland is extensive and very pretty. There are places to park free if you don't want to visit the lake area otherwise each car is charged on entry unless you are a member of the National Trust. The main car park is very good but there is also plenty of additional space on the grassed areas. Disabled access is very good to the toilets and café as one would expect in a National Trust site. I have used my scooter to go around the lake (about 3 miles) but some of the paths were rough. Further details are available from 01909 544917 and www.nationaltrust.org.uk/clumber

STATELY HOMES. - Brodsworth Hall

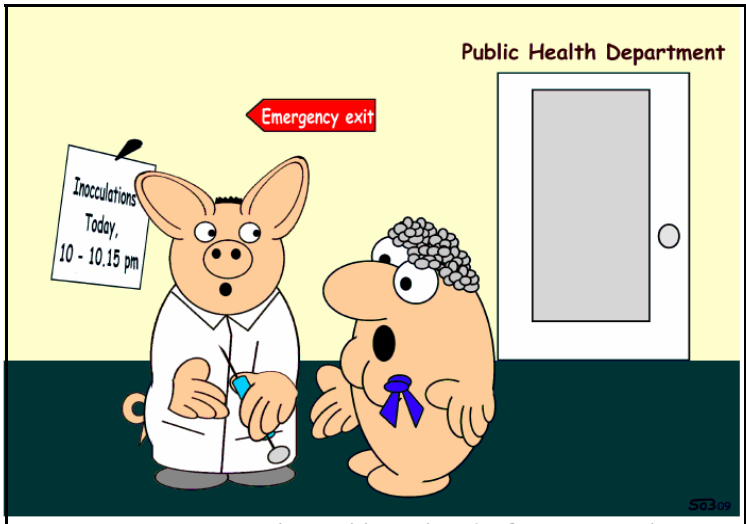
Brodsworth Hall is an English Heritage Property so is free if you are a member. The Hall may be difficult to get around but there is a lift up onto the first floor. We enjoy just visiting the gardens as there are new areas coming into bloom throughout the year as it changes with the seasons. The café and toilets are wheelchair-friendly, and most of the paths are accessible for wheelchairs or scooters but some are quite steep and a few have steps. There is an electric buggy that runs from the car park to the house if you can then manage around the gardens and house without help. A wheelchair can also be loaned from the pay desk. There are special events such as band concerts and the Enchanted Garden event during the Autumn. The house is closed during the winter months but the garden and tea rooms remain open all year (I can recommend the food). I would advise looking on the English Heritage website www.english-heritage.org.uk/brodsworthhall before visiting for opening hours or ring on 01302 722598.

I hope you have as much fun as I have done by being able to go 'Out and About' again. Still more places to visit in the next issue.

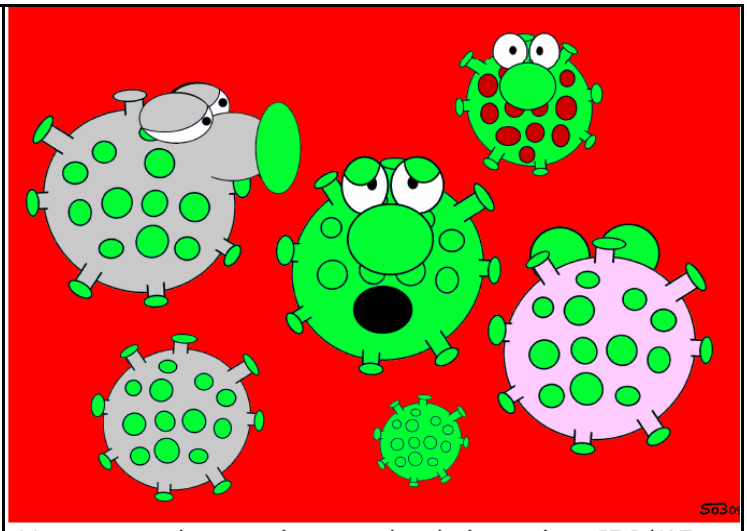
Cartoons about life with CFS

By Hans-Michael Sobetzko

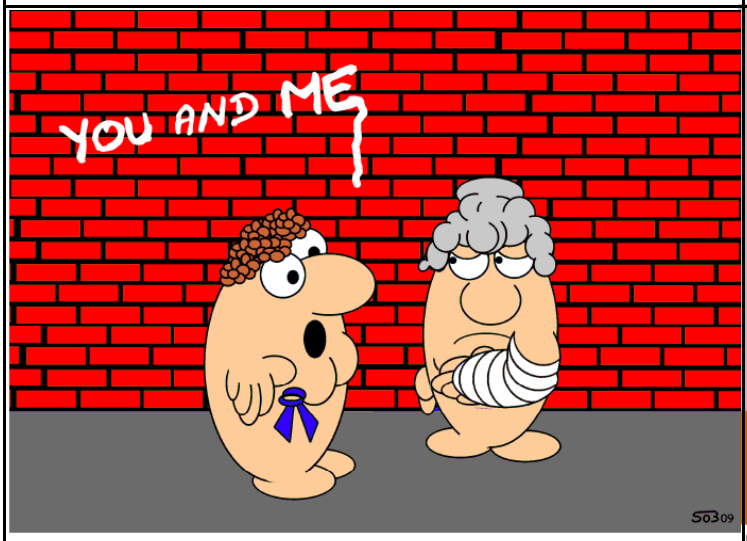
These are from the 2010 Calendar via www.InvestinME.org.uk



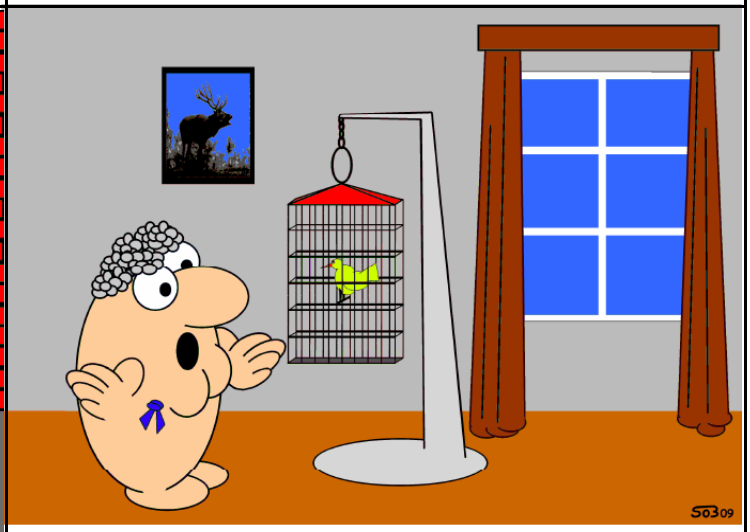
Are you sure you looked like that before your jab?



Hey guys, as long as those medics believe that CFS/ME is a psychiatric disease we can carry on partying!



Well, at least people can see you're ill!



Don't know what you've got to complain about, Polly. At least people can see the cage you live in!

Hells Bells! If only I felt this awake during the day!

Well, no, as far as I know this painting isn't of a sleeping CFS/ME patient.

Dealing with Type 2 Diabetes & ME/CFS.

At the last count there were around 85 members in Leger ME, of which about a dozen are Type 2 diabetics. In pathways No.3 winter 2005 (www.leger.me.uk) I covered Glycaemic Control and the physiology of maintenance, and just touched on diabetes. With this feature I want to cover the practical aspects of type 2 diabetes and ME/CFS management.

Although there are around half a dozen subtypes of diabetes, they can be divided into two main types as far as management goes:

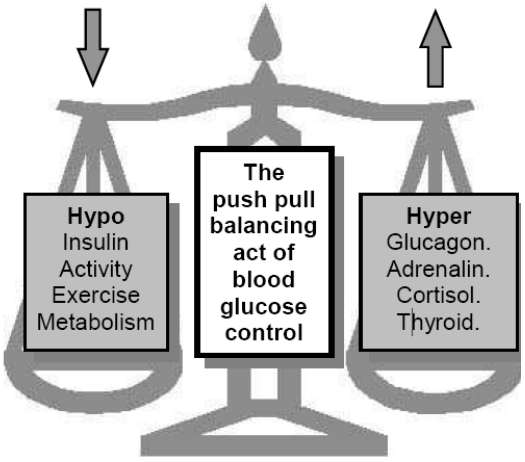
With type 1 diabetes, the usual history is sudden onset as a child in a medical emergency. The beta cells in Islets of Langerhans in the patient's pancreas are damaged in some way, and cannot produce any insulin to control blood sugar levels, so they need daily insulin injections to maintain life. This variant of diabetes is sometimes known as type A or juvenile onset diabetes.

With type 2 diabetes things are more complicated. Onset is gradual, usually occurring in later life being progressive over a period of around ten years. Although there is a loss of blood sugar control, it is partial at first, being able too be controlled by diet in the early stages, then drugs and ultimately insulin if necessary. There may be several mechanisms at work - Firstly the insulin produced by the pancreas in not sufficient or is defective in some way. Secondly there is insulin resistance by the target cells/tissues and is some cases abnormally massive amounts of insulin are produced. In some cases where insulin is used the dose of insulin is many times higher than that of type1 diabetics. Originally Type 2 diabetes was mistakenly referred to as mild or partial diabetes. It is a common question given to medical students as to which type of diabetes is the most serious. The answer is both. Type 2 diabetes is a also known as a 'metabolic syndrome' because alongside blood sugar control problems occur with high blood pressure and high cholesterol. These are serious health problems within their own right, and have to be individually managed as separate conditions.

Many diabetics with ME I've met tend to underestimate just how serious diabetes is, and tend to address ME/CFS mainly because of unpleasant problems –which are in fact a nuisance or irritating, and generally are not life threatening. However type 2 diabetes by comparison is a relatively silent killer, not really producing any unpleasant problems until the later stages maybe 10-20 years down the line. Paul, a nurse I know who specialises in diabetes-care told me

"*I quite often see someone in middle age be sent to our clinic. Apart from an abnormal blood sugar reading, they don't feel ill or consider themselves as having major health problems. It very often comes as quite a shock to change diet, make major lifestyle changes, and take 4-5 lots of medicines or more every days for the rest of their life, even though they don't feel ill."*

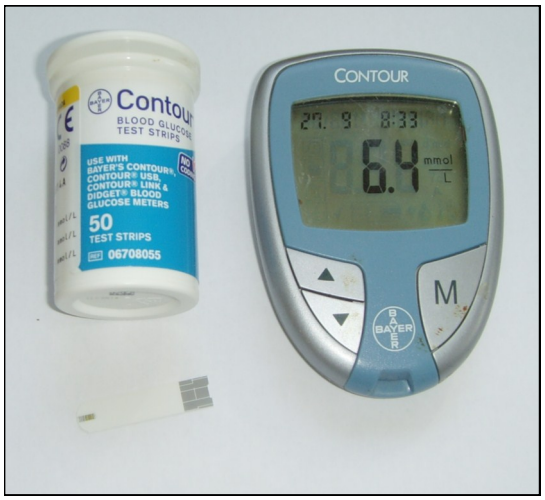
Anyone with diabetes should become a member of Diabetes UK. They have a website – www.diabetes.org.uk and can be contacted on 0845 123 2399. They have produced a 15 point list of Healthcare Essentials, and are really the key to good diabetic management, and are considered a minimum level of healthcare that every person with diabetes deserves and should expect. However, what is gold standard diabetic care may have to be severely traded off against the reality of living ME/CFS –many doctors and nurses who treat diabetes find this difficult to understand and comprehend. At the end of the day the only way to mange diabetes is to learn as much as you can about it. The key on how to achieve good diabetic control is to achieve balance in the various factors that control blood sugar (glucose) levels. The diagram to the right summaries that way balance has to be achieved. You can't pick and choose what you do—it's the balance of the whole management package that counts.



Here are the 15 essential checks and services you should receive. If you aren't getting all the care you need, take this checklist to your diabetes healthcare team and discuss it with them. I've modified & added to it in the light of my experience with group members.

1) Your should have blood glucose levels measured at least once a year. Locally, the HbA1c test is used to asses overall blood glucose control on a three or six monthly basis. It's a bit like an end of term school report, but not really useful for day to day management as it is an over all average, and is very little use day to day. A variety of self test gadgets are available for you to do your own checks. Properly used these will help you test if drugs are missed, if you are getting your diet right and to deal with other diabetic issues. The various suppliers will supply the gadgets free or at very little cost, but the test strips are expensive. Some doctors quite wrongly refuse to supply these on prescription. According to NIHCE GC66, Recommendation 23. Self-monitoring of plasma glucose should be available:-

- to those on insulin treatment
- to those on oral glucose lowering medications (e.g. glicazide or metformin) to provide information on hypoglycaemia
- to assess changes in glucose control resulting from medications and lifestyle changes (applies to ME/CFS)
- to monitor changes during undercurrent illness (applies to ME/CFS)
- to ensure safety during activities, including driving.

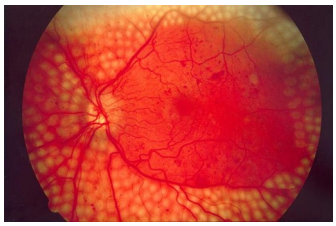


An example of a blood sugar monitor, the type all people with ME/CFS and diabetes should have access to.

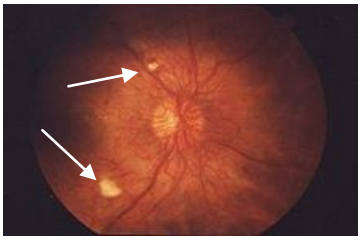
A log book of there readings should be kept, and shown to a diabetic nurse or doctor who is treating you to enable him/her to advise you. ME/CFS itself can cause unexpected hypoglycaemia because HPA axis compensation is lost, and very few doctors are aware of this.
.

2) Have your blood pressure measured and recorded at least once a year, and if necessary treated, and regularly reviewed. This is normally done at a diabetic review by a practice nurse. High blood pressure leads to heart attacks and strokes, and usually shows no symptoms until an emergency arises. Diabetics are prone to these problems and usually the treatment target is 5 - 10 mmHg lower than non-diabetics. Locally a medicine called enalapril is favoured because of evidence of being cardio-protective in diabetics. However, one of the side-effects listed on the data sheet is fatigue, which obviously is a potential problem with ME/CFS. If this is suspected, a trial at a lower dose or alternatives are worth trying with your doctor's or nurse's supervision. What really matters is the numbers are kept within the targets. Don't use one of the home test devices without medical advice or supervision from your diabetic nurse.

3) Have your blood fats (cholesterol) measured every year, keep them to the recommended levels. These are usually checked at diabetic review. If high, statin-type drugs are usually recommended to correct this. However, quite a number of doctors who I know who specialise in ME/CFS don't like statins which, they say, make ME/CFS worse. I have sent in a significant number of yellow cards from LME members reporting issues resembling rhabdomyolysis-type problems which would tend to support their views. Again, what really matters is that the cholesterol numbers are kept in check. A number of members have transferred over to alternatives like fibrates without problems. There are two further issues regarding blood with fats. Firstly, fish oil-type products which are known to be effective in treating ME/CFS e.g. VegEPA, MaxEPA, (Generic EPA oils) affect cholesterol blood tests, but have a favourable cardiovascular protective effect which can cause confusion. Secondly nicotinic acid type medicines have a cholesterol-lowering effect, but also has a beneficial effect on ME/CFS in some cases because of it's relationship to the B3 & NAD pathways.



Left a normal eye image, right 'cotton wool spots' showing where bleeds have occurred in a diabetic patient. These can be avoided with good diabetic control, and treated with laser eye surgery.



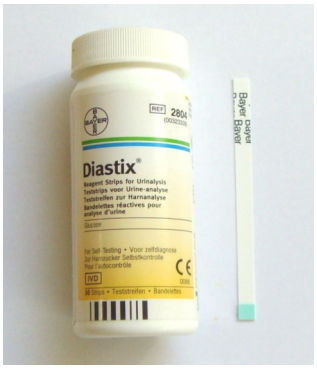
Normal vision

4) Have your eyes screened for signs of retinopathy every year. Using a specialised digital camera, a photo of each eye will be taken and examined by a specialist who will look for any changes or bleeds to your retina (the seeing part at the back of your eye). These can lead to total sight loss, but can be treated with a laser device if caught early enough. The risk of retinopathy is reduced by good diabetic management. The NHS recognise this, and eye tests performed by opticians are free to people with diabetes. A frequent eye examination at least once a year should be part of your on-going diabetic care.

The same view from a patient with diabetic retinopathy

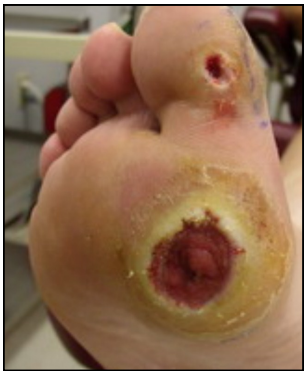
When you hand in a urine sample, it is taken out of sight, and usually the practice nurse will dip it with a 'multistix' type test strip.
The colours mean different things. The two most relevant to diabetics are shown.

5) Have your kidney function monitored annually. You should have two tests for your kidneys: A urine test for protein (a sign of possible kidney problems) and a blood (U&E) test to measure kidney function. There is an increased risk of kidney failure, and should this be an issue the drugs used have to be changed. If you take big quantities of NSAID type painkillers for pain e.g. ibuprofen, this can also have an adverse effect on kidney function.

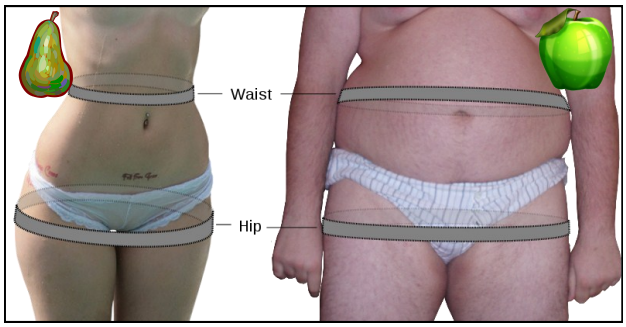


A urine sugar test trip for home use. The reagent pad changes colour according to the level of sugar in urine.
If sugar appears in urine it usually means that diabetic control has been lost. They also are useful for measuring the sugar in bought foods.

6) Have your feet checked – the skin, circulation and nerve supply of your feet should be examined annually. You should be told if you have any risk of foot problems, how serious they are and if you will be referred to a specialist podiatrist or specialist foot clinic. This cause because in diabetics nutrition from the blood cannot enter the cells in your feet even if control is 100%. Healing times can take 3-4 times longer than in a non diabetic and sensation is often lost. Part of the routine foot examination involved ticking of feet with a calibrated hair tool to check for sensation loss – something that diabetic nurses seem to enjoy!



Diabetic are prone foot ulcers, which can take many months to heal. Badly fitting footwear causing poor circulation are very often causal.



It is generally thought that there are more health risks for the apple shape waists. This is calculated by measuring your waist to hip ratio. A ratio of 0.8 or above indicates that you are an apple shape. A ratio of under 0.8 means you are a pear shape. This kind of fat presents many more risks than subcutaneous fat; it decreases insulin sensitivity, raises blood pressure, and decreases levels of 'good' (HDL) cholesterol. These are all key indicators of heart disease risk and diabetes risk. The higher the waist to hip ratio, the higher the risk.

7) Have your weight checked and have your waist measured to see if you need to lose weight. If you are overweight, losing weight will have a positive effect on cholesterol and blood sugar readings, as well as reducing overall fatigue.

8) Get support if you are a smoker including advice and support on how to quit. Having diabetes already puts people at increased risk of heart disease and stroke, and smoking further increases this risk. Smoking has an adverse effect on ME/CFS

9) You should receive care-planning to meet your individual needs – you live with diabetes every day so you should have a say in every aspect of your care. Your yearly care-plan should be agreed as a result of a discussion between you and your diabetes healthcare team, where you talk about your individual needs and set targets. However this has to be taken in context with ME/CFS particularly where exercise in concerned.

10) If necessary, attend an education course to help you understand and manage your diabetes. You should be offered and have the opportunity to attend courses in your local area.

11) Receive paediatric care if you are a child or young person. You should receive care from specialist diabetes paediatric healthcare professionals. When the time comes to leave paediatric care, you should know exactly what to expect so you have a smooth change over to adult health services. This applies equally also to ME/CFS.

12) Receive high quality care if admitted to hospital. If you have to stay in hospital, you should still continue to receive high-quality diabetes care from specialist diabetes healthcare professionals, regardless of whether you have been admitted due to your diabetes or not. You may in hospital be put on a different treatment as a temporary measure e.g. insulin if you are having an operation. Please remember to take a copy of the ME/CFS guidelines for the nursing staff. People with ME/ CFS tend to take longer to recover from anaesthetics and are quite often discharged far too early.

13) Get information and specialist care if you are planning to have a baby as your diabetes control has to be a lot tighter and monitored very closely. You should expect care and support from specialist healthcare professionals at every stage from preconception to post-natal care.

14) See specialist diabetes healthcare professionals to help you manage your diabetes. Diabetes affects different parts of the body and you should have the opportunity to see specialist professionals such as an ophthalmologist, podiatrist or dietician.

15) Get emotional and psychological support. Being diagnosed with diabetes and living with another long term condition like ME/CFS can be very difficult. You should be able to talk about your issues and concerns with specialist healthcare professionals. Don't be put off by the fact you have received less that satisfactory treatment with ME/CFS. ME/CFS is a Cinderella condition, while diabetes is well known and many times more serious.

Strategies for controlling type 2 Diabetes

Food is the first consideration when treating diabetes.

- Food has to be sensible, and restricted in certain ways, and has to be treated in some ways like a medicine or calorie controlled diet, it but doesn't have to be boring. Diabetes UK have plenty of advice & information about food including some very good recipes which are published in Balance, the magazine of Diabetes UK.
- Fad diets relying on a single source of food or low calories diets as with ME/CFS have no place in diabetes management.
- 'Diabetic' foods have no place in diabetes management, and can be harmful. For example diabetic sweets may contain a sugar substitute, Sorbitol, with has all the calories of sugar and is a very strong laxative as many diabetics find out to their costs.
- Using fructose substituting for sugar is a way of cheating the blood sugar readings, but does effectively end up as glucose after a time, and has an adverse effect on blood makeup.
- Fatty liver disease is a problem with diabetics who are overweight and can cause additional fatigue issues. It can also be very dangerous is not addressed. As with diabetes getting the diet & food right is the easiest way to sort it out. Certainly in early case of type 2 diabetes, getting the diet right is paramount, and may be the only intervention needed.
- Herbal and alternative medicines have no place in diabetic treatment, and using them may be detrimental or dangerous.

Medicines. In addition to dieting, medicines may be added if needed. The guidelines tend to change frequently with NHS fashion and different areas have different guidelines. Here is the local consensus.

First Line. Metformin is the medicine of choice. It works by stopping the liver producing glucose from stored glycogen and increasing muscle cell take up of glucose. In addition to helping control blood sugar, it has a protective effect against all diabetic complications. This medicine has been around for many years and the pros & cons about using it are well known. The big problem is GI side effects which may limit its use, which is the biggest complaint on the group helpline. It is recommended to be taken with food for this reason. There is a sustained release version of it available which is supposed to improve its tolerability. However possibly because many people with ME/CFS have IBS type problems this doesn't often work out. There is an oral power available, something which a lot of doctors don't know about. This can be incorporated into food or taken with a drink, which sometimes solves the problem.

Glicazide is the second choice, and has been around for many years. It works by stimulating the pancreas beta cells to product more insulin. However the biggest drawback, as with insulin, is that is causes weight increase, and need to be taken before a meal. As glicazide is a pancreatic stimulant, and over time beta cell function decreases, there is a limit to how much can be given. '*Glicazide can stimulate beta cells to death'* is a statement I hear quite openly from health professionals.

Alpha glycosidase inhibitors work by delaying adsorption of glucose by inhibiting digestion. I have come across an issue is which there may be a problem with people with ME/CFS being as this class of drugs could aggravate the symptoms of irritable bowel syndrome or gut fermentation & causing brain fog.

The next step is usually a combination of both metformin & glicazide, increasing the dose to maximum recommended

Second Line drugs are basically 'new kids' on the block. Not a lot is known about the long term side effects. These tend to used when the above have failed or are unsuitable.

The Glitazones were a family four fold anti-diabetic drugs. They work by magnifying the effect of what insulin remains. Rosiglitazone (Avandia) has been withdrawn UK because of safety concerns, mainly because it caused fluid retention, which in turn caused an unacceptable number of heart attacks. Pioglitazone remains available, mainly as a 'bolt on' therapy to the above two – however some people who prescribe it tell me that they think it has the same risks as with rosiglitazone and so are very reluctant to prescribe it unless there are problems with glicazide or metformin.

More recently the Gliptins have become available. These are thought to work be reducing insulin resistance. They also have a favourable effect of reducing weight by encouraging the body to use fat as an energy source. In some ways they may be a better first line choice than glicazide, but have only been infrequent use for around five years so there is not a lot of long term safety data available. The more recent addition of some *'me to'* Gliptins made by competing manufacturers is tending cloud the overall clinical picture, but I would bet that this is class of drugs will become increasingly important.

A newer class on anti-diabetic drug, known as Incretion Mimetics has appeared. Incretion is a hormone which is produced in the small intestine what stimulates production of insulin from the pancreas. In theory, as these are insulin stimulants, you would expect to have the same limitations as glicazide.
The GLP1 Agonists are injectable drugs, and are claimed to have a favourable effect on weight. They are being closely scrutinised in use. There is a relative new one formulated to need a once a week injection—but again nothing is known about long term safety or long term effectiveness in use.

Third line—when all else fails. About half the people with Type 2 diabetes will need insulin 6-7 years after diagnosis. Insulin therapy is a last resort, mainly because it can only be injected, and has all the issues of weight gain and hypoglycaemia. Even then – sometimes oral medication is added like metformin.

Neuropathic Pain in diabetes and ME/CFS

Here is a list of problems that can be caused by diabetic neuropathy (nerve damage). As ME/CFS is a neurological condition, some diabetic neurological problems/symptoms overlap those of ME/CFS, so, it is difficult to allocate the blame.

Sensory loss	Numbness, Paraesthesias (pins & needles) Contact sensitivity (allodynia), Neurogenic pain
Autonomic dysfunction	Abnormal sweating (gustatory sweating, dry feet, episodic nocturnal sweating)
Cardiovascular dysfunction	Postural hypotension Abnormal cardiovascular reflexes & Sudden death
Gastrointestinal dysfunction	Gastroparesis (reduced motility and delayed emptying) Diarrhoea (rare) & Constipation
Bladder dysfunction	Overfilled bladder leading to abdominal swelling and overflow incontinence Recurrent urinary tract infections
Erectile dysfunction	Failure to achieve erection and ejaculation
Acute painful polyneuropathy	Lancinating pains & Cramps

The XMRV saga has finally ended

Lipkin study – Statement by The ME Association 18/9/12
by Tony Britton on September 19, 2012

Dr Ian Lipkin and his colleagues should be congratulated on the way in which they have co-operated in carrying out a very thorough piece of medical detective work. This has found that there is no link between XMRV (xenotropic murine leukaemia virus-related virus) and pMLV (polytropic murine virus) and ME/CFS. The results come as no surprise given what has happened since researchers at the Whittemore Peterson Institute first linked XMRV to ME/CFS in a paper that was published (but now retracted) in Science back in 2009.

All the initial hype that surrounded the publication in Science meant that people with ME/CFS were led to believe that a causative infection (ie XMRV) had been discovered, along with a diagnostic blood test, and that effective treatment with antiretroviral drugs would then follow. Sadly, all three claims have turned out to be false hopes based on flawed science – with the scientific consensus now being that the original finding was due to laboratory contamination, probably from mouse DNA in the samples. There should now be an apology – firstly from the laboratories who persuaded people to spend large sums of money on useless XMRV tests; secondly from those who influenced people with ME/CFS to put their health at risk by taking antiretroviral drugs.

ME/CFS is a serious neurological illness and there are many promising lines of biomedical research into the cause that need to be pursued, including the role of viral infections.

Contrary to the press headlines that are accompanying this story (see front page) there is already a substantial amount of sound scientific evidence to show that a variety of viral infections (including enteroviruses, glandular fever, hepatitis and parvovirus) can trigger ME/CFS, that persisting viral infection may play a role in some people, and that reactivated viral infection (e.g. Epstein Barr virus and HHV-6/human herpes virus type 6) may also be playing a role. Hopefully, we can return to more pressing research priorities now that the final chapter in the XMRV saga has been written.
Finally, it is encouraging to note that Dr Ian Lipkin is going to continue working in the area of ME/CFS research.
Dr Charles Shepherd, Hon Medical Adviser, The ME Association, September 18th 2012

Recipe Corner

Here are two diabetic friendly recipes for you to try.

Pasta with prawns, peas and mint

Preparation time: 10 minutes Cooking time: 10 minutes

1) Cook the pasta according to packet instructions, add the peas 2 minutes before the end of cooking time. Drain.
2) Meanwhile heat the oil in a non-stick saucepan, add the onion and garlic and fry for 2-3 minutes until they begin to
soften.
3) Add the wine to the pan, bring to the boil and reduce by about a half.
4) Stir in the prawns, crème fraiche, Parmesan and mint and heat through. Season to taste with salt and pepper. Toss the sauce through the pasta and serve garnished with mint leaves.
Nutritional information: Shellfish are a source of cholesterol; however they can be included in your diet as blood cholesterol more affected by the amount of saturated fat in diet and other factors such as weight.

Ingredients

375 g (12 oz) dried pasta shapes
200 g (7 oz) frozen peas
1 tablespoon olive oil
1 onion, sliced
1 garlic clove, crushed
150 ml (¼ pint) dry white wine
200 g (7 oz) cooked tiger prawns
6 tablespoons light creme fraiche
2 tablespoons freshly grated Parmesan cheese
2 tablespoons chopped mint salt and pepper
mint leaves, to garnish

Nutritional data

GI rating: LOW
Kcals-444
Protein - 25 g
Carbohydrate -75 g

Pearl barley salad with griddled chicken

Preparation time: 10 minutes Cooking time: 10 minutes

1) Brush each chicken piece with a little oil. Heat a griddle until hot and cook the chicken for 4-5 minutes on each side until cooked and browned. Cut each breast into 4 slices.
2) Stir the remaining oil into the barley, and add the onion, chilli, coriander, lime rind and juice, and red pepper. Season to taste with salt and pepper and stir to combine.
3) Serve the barley topped with the chicken, garnished with parsley and lime wedges.
Nutritional information: Pearl barley is high in soluble fibre and can be used as a substitute for rice.

Ingredients

4 boneless, skinless chicken breasts
1 tablespoon olive oil
125 g (4oz) pearl barley, cooked to packet instructions
1 red onion, finely chopped
1 red chilli, finely chopped
4 tablespoons chopped coriander leaves
grated rind and juice of 2 limes
1 red pepper, cored, deseeded and finely chopped
salt and pepper

TO GARNISH parsley sprigs lime wedges

Nutritional data

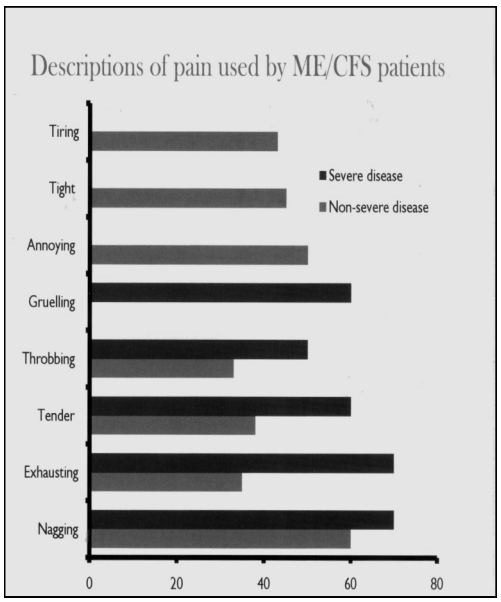
GI rating: LOW
Kcals-274
Protein - 27 g
Carbohydrate - 31 g
Fat- 5 g

Are ME/CFS patients more sensitive to pain? *from BREAKTHROUGH Autumn 2012*

Widespread and persistent pain is common in people with ME/CFS. In surveys, around 80% of patients say that they have severe pain sometimes, much or all of the time, while 84 to 94% of patients in formal research studies report some degree of muscle or joint pain. Also, around one-third of patients say that chronic pain limits or restricts their everyday activities, and that pain is a more disabling day-to -day symptom than fatigue. Despite this, there has been very little scientific investigation of the pain characteristics of ME/CFS patients. One of the very few studies done - part of a PhD studentship at Glasgow Caledonian University - was funded by ME Research UK and published in the Journal of Musculoskeletal Pain. As the results of this investigation showed (see Figure), the patients used words such as 'throbbing', 'aching', 'tender', 'gnawing' and 'burning' to describe their pain experience, while those with more severe illness also used 'exhausting' and 'nagging'.

These descriptions may give clues as to the mechanisms causing pain in ME/CFS; in particular, 'burning' pain is often associated with neuropathic conditions in which the nerves have been damaged. Significantly, ME/CFS patients reported more pain than did patients with rheumatoid arthritis or multiple sclerosis in previous studies, both conditions in which pain is recognised as a major symptom. Fibromyalgia is an illness with overlapping symptoms to ME/CFS, and one concept which has been extensively explored in fibromyalgia research in recent years concerns central sensitization - an increased sensitivity of cells in the spinal cord and the brain to various stimuli, including touch, heat, cold and chemicals. Central sensitization is believed to underlie many chronic pain conditions (see Box), leading to an increased sensitivity to pain, but could it also be a factor in the pain felt by ME/CFS patients?

One of the most active ME/CFS and fibromyalgia research groups in the world is headed by Prof. Jo Nijs at Vrije Universiteit and Artesis University College Antwerp in Belgium. With funding from ME Research UK, he and his colleagues have been investigating immunological response stimuli including mechanical pressure, heat, aerosol inhalation of histamine, and electrical stimulation. Taking the studies as a whole, there was good evidence that ME/CFS patients had a generalised hyperalgesia (an increased sensitivity to pain throughout the body). Furthermore, patients' pain sensitivity increased after stressors, such as harmful heat pain, and following exercise ¬an unusual observation since sensitivity to pain normally decreases in people during physical activity. These findings came as no surprise to the researchers, who say that the presence of central sensitization accords with many of the symptoms of ME/CFS, as well as simply increasing sensitivity to pain.
For example, infections are associated with the illness (see page 4), and immune dysfunctions are characteristic features. Infection is known to trigger the release of the substances promoting inflammation, such as interleukin-I b, which play a role in sensitising peripheral nerves, and infections themselves can activate cells in the spinal cord which enhance the pain response.



Also, the activity of the hypothalamus-pituitary-adrenal (HPA) axis - a major player in the neuroendocrine system that controls reactions to stress and regulates many body processes - is known to be blunted in ME/CFS, and some crucial factors in the HPA axis are involved in pain sensitivity. In particular, low cortisol levels might contribute to (pain) hypersensitivity since cortisol levels are involved in pain inhibition. Finally, the neurocognitive symptoms seen in patients - principally memory and attention-span deficit and associated emotional processes could inhibit central nervous system pathways from the brain downwards, resulting in sensitization of nerve cells in the spinal cord. Indeed, this could explain why psychological therapies designed to help patients manage symptoms and cope better with illness can be helpful in a minority of cases, as some patient surveys and clinical trials have shown.. The group has been undertaking a comparison of the different criteria for myalgic encephalomyelitis and CFS currently in use. They also have a long-standing interest in central sensitization, and have just published a narrative review of its potential relevance in ME/CFS (in the European Journal of Clinical Investigation, February 2012).

After searching the scientific literature, they found a range of experimental studies that had tested patients' responses to therapies. The fact that central sensitization can be found in ME/CFS patients raises the question of treatment strategies to desensitize the central nervous system, making it less sensitive to painful stimuli. Fortunately, over the past few years there has been on-going scientific work to develop targets specifically designed to block or reduce central sensitization. Various centrally acting drugs that have shown promise in animal models include analgesics, serotonin reuptake inhibitor drugs, the serotonin precursor tryptophan, opioids, and NMDA receptor antagonists (a class of anaesthetic). However, some of these agents may not be appropriate for ME/CFS patients.

Likewise, various non-invasive treatment options have been proposed, based on the premise that nerve pathways from the brain downwards could be activated to help inhibit pain. These therapies include trans-cranial magnetic stimulation and transcutaneous electric nerve stimulation, and may also include cognitive techniques or biofeedback to address the emotional aspects of increased pain.

Of course, it is widely recognised that the 'black box' diagnosis of ME/CFS probably contains a variety of different types of patients, and it will be important to identify patients with a clinical picture dominated by central sensitization. The researchers say that these patients could be identified clinically by questioning them regarding hypersensitivity to bright light, sound, smell, hot or cold sensations, pressure, touch, and mechanical loading, whereas widespread sensitivity to pain can be recognised by testing muscle tone at various anatomical locations. Interestingly, the new International Consensus Criteria for ME (Journal of Internal Medicine, 2011) includes several characteristics related to central sensitization.

Since its first description, central sensitization has become an increasingly important concept in pain research. It is known to underlie many pain conditions (from allodynia caused by nerve injury, to headache), and now the review from the Brussels team has shown that it could be involved in ME/CFS as well. In their view, a change in thinking towards studying and treating ME/CFS as a central sensitization disorder appears warranted, particularly as therapeutic interventions become available.

What is 'central sensitization'?

•Nerve impulses can be thought of as messages fired along nerve fibres at great speed. Central sensitization involves an abnormal increase in the firing of nerve cells lying deep within the central nervous system (i.e., the brain and the spinal cord). This leads to an increase in the pain experienced by the person.

• The increased firing (excitability) is typically triggered by a burst of activity in nociceptors (pain receptors) which send nerve signals to the spinal cord and brain.

• The mechanisms involved in central sensitization are complicated. Some are top down (from brain to the periphery), such as when sensory processing is altered in the brain. Others are bottom-up (from periphery to brain), such as when local infections trigger the release of the inflammatory molecules which activate cells in the spinal cord.

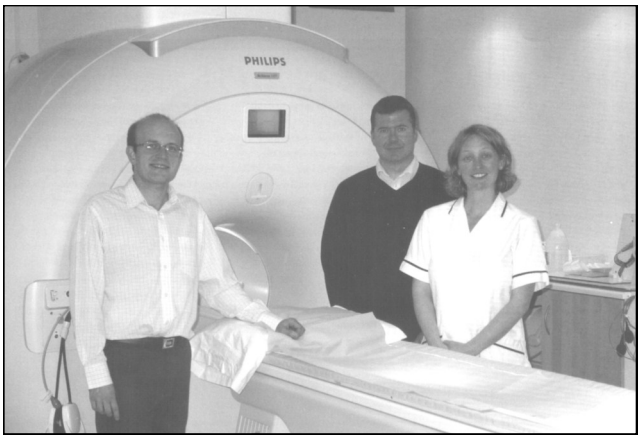
• An example of central sensitization is when a very light touch of the skin (from low threshold sensory fibres) activates nerve cells in the spinal cord or brainstem that normally only respond to harmful stimuli. In this case, the light touch produces pain inappropriately - to the person, the pain feels like it comes from the skin or limb, whereas actually it is a manifestation of abnormal sensory processing in the central nervous system.

• Central sensitization is known to be responsible for tactile allodynia (pain in response to light brushing of the skin) and for the spread of pain hypersensitivity beyond an area of tissue damage so that adjacent non-damaged tissue is tender. The phenomenon can also occur after surgery, contributing to pain on movement or touch; during migraine attacks where brushing hair is often painful; and in some patients with nerve damage where even blowing on the skin produces excruciating burning pain.

Impaired cardiac function in ME/CFS from BREAKTHROUGH Autumn 2012

Some ME/CFS patients experience heart symptoms, most commonly cardiac arrhythmias including tachycardia (racing heart) or palpitations usually associated with autonomic nervous system dysfunction. In fact, for some patients they can be the most frightening aspects of their debilitating illness. In the scientific literature, a few reports have confirmed the existence of abnormalities of cardiac function in some patients. For instance, a study in 2006 found that ME/ CFS patients had relatively short QT intervals (measures of the time of the heart s electrical cycle) compared with healthy people. Also, in 2009, Japanese researchers reported cardiac dysfunction with low cardiac output in some oriental patients, and an echocardiographic study from 2010 found that the ability of the heart to contract was reduced. Overall, however, little formal research has been conducted on the presence of heart abnormalities in ME/CFS patients, and what these might mean for the individual patient.

Since 2008, ME Research UK, in conjunction with the John Richardson Research Group and the Irish ME Trust, has funded Professor Julia Newton of the Institute for Ageing and Health, University of Newcastle to explore some of the mechanisms behind autonomic nervous system abnormalities in a large cohort of ME/CFS patients. She and her colleagues Prof. David Jones and senior physicist Dr Kieren Hollingsworth of the Institute of Cellular Medicine have been using state of the art magnetic resonance techniques to investigate whether autonomic nervous system symptoms (which can be found in around three-quarters of patients) are associated with abnormalities in other major organ systems, something we know to be the case in other illnesses. Their investigations of the heart have been throwing up some intriguing findings. For example, in a previous report (discussed in full in Breakthrough, Spring 2011) they showed that bioenergetic abnormalities could be found both in the muscles of the skeleton and in heart muscle, with a correlation between the two suggesting the existence of linked underlying mechanisms. Also, they found that the hearts of the ME/CFS patients had to work harder during prolonged standing than in healthy people. These findings raised the question of whether abnormalities could be detected in the function of the heart, particularly during the heartbeat.



Dr. Kieran Hollingsworth, Tim Hodgson and Tamsin Gaudie

To investigate these aspects, the team have been using cardiac MRI tagging, a complex technique that has been used previously to examine the function of the heart during the ageing process, in which gradual changes might be expected to occur subclinically (before actual symptoms can be observed). The researchers thought it could be the ideal tool to examine the hearts of ME/ CFS patients for defects that are not yet clinically apparent. The technique allows accurate assessment of myocardial (heart muscle) movement in three dimensions, and gives detailed information about myocardial transmural strain (an indication of the shortening of heart muscle fibres) and torsion (a measure of the twist of the heart during the beat), two events that can be affected by energy deficits before they are obvious clinically.

Their experiment involved 12 women with well-defined ME/CFS and 10 closely matched, sedentary healthy women. Each person underwent cardiac examinations using an MRI scanner for cardiac tagging, and cardiac MRI cine imaging to assess cardiac form and structure, as well as systolic and diastolic function. The group s findings have now been published in the March 2012 issue of the Journal of Internal Medicine (see the box below). The Figure below illustrates one of the main findings the dramatic increase in residual torsion in patients compared with matched, sedentary healthy women. Each person underwent cardiac examinations using an MRI scanner for cardiac tagging, and cardiac MRI cine imaging to assess cardiac form and structure, as well as systolic and diastolic function.

The group s findings have now been published in the March 2012 issue of the Journal of Internal Medicine (see the box below). The Figure below illustrates one of the main findings the dramatic increase in residual torsion in patients compared with controls. This is a measure of the efficiency of the release of torsion and strain during the relaxation phase of the heartbeat. ME/ CFS patients had 200% more residual torsion than the matched controls, indicating that their heart muscle was taking longer to relax.

What did the results show?

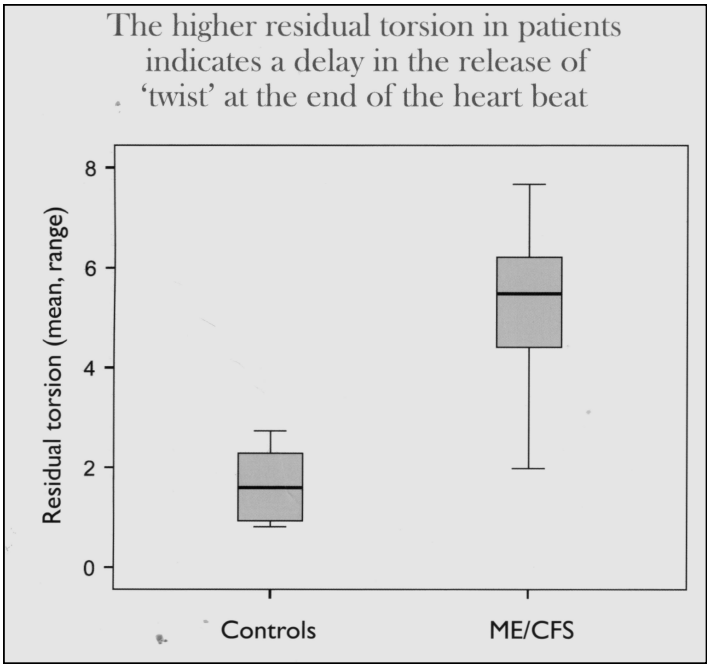
There were no significant differences in resting heart rate or systolic/ diastolic blood pressure between patients and controls.

In the ME/CFS patients, left ventricular mass (the thickness of the heart wall at the ventricle) was substantially reduced (by 23%) compared with controls. After correction for individual body size, the various measures of 'blood pool volume' in the heart were significantly lower in patients than controls:

- stroke volume (the amount of blood pumped by the left ventricle in one contraction) was lower by 26%;
- cardiac output (the output of blood by the heart per minute) was lower by 21%;
- end diastolic volume (the volume of blood in each ventricle at the end of diastole) was lower by 25%.

Intriguingly, residual torsion (at 150% of the end-systolic time) was significantly higher in the patients (see Figure), indicating a delay in the release of torsion ('twist') at the end of the beat.

To put this in context, healthy people have an increase in residual torsion of around 50% between the ages of 22 and 69 years, possibly because ageing affects the lining of the muscle fibres which permit the heart to relax. Why residual torsion is raised even more in people with ME/CFS is unclear, but because the level of torsion was found to be related to end-diastolic volume the researchers speculate that low total blood volume might be involved. In fact, the research team says that its overall findings strongly suggest a marked reduction in the total (central) blood volume in ME/CFS patients since a smaller volume flowing into the heart would lead to a lower amount of blood pumped by the ventricle and a lower cardiac output. This suggestion is not new: low total blood volume and associated autonomic nervous system dysfunction have been proposed as part of the disease process in subgroups of ME/CFS patients in the past. Indeed, one investigation in 2002 found a 9% lower blood volume in ME/CFS patients than in controls. A further study in 2010 showed that the reductions in cardiac output and end-diastolic volume in ME/ CFS could be entirely accounted for by a reduction in the total blood volume, and an accompanying editorial pointed out that the results did not imply heart disease, but rather pointed to circulatory impairment .



So, what can be done or should be done about correcting low cardiac blood volume?
Well, blood volume is known to be affected by relative inactivity, and so may be a reflection of chronic ill-health rather than ME/CFS per se. If this is so, keeping active, such as by pacing, may improve total blood volume. Also, there is anecdotal evidence that ME/CFS patients have had symptomatic improvements with the administration of intravenous fluid as a treatment intervention (although this is not without its drawbacks and risks), and the researchers say that they intend to explore interventions to restore fluid volume in ME/CFS patients. They also point out, however, that ME/ CFS patients may indeed have primary myocardial deficits that are not associated with low total blood volume, and this possibility needs to be explored too.

North of Doncaster

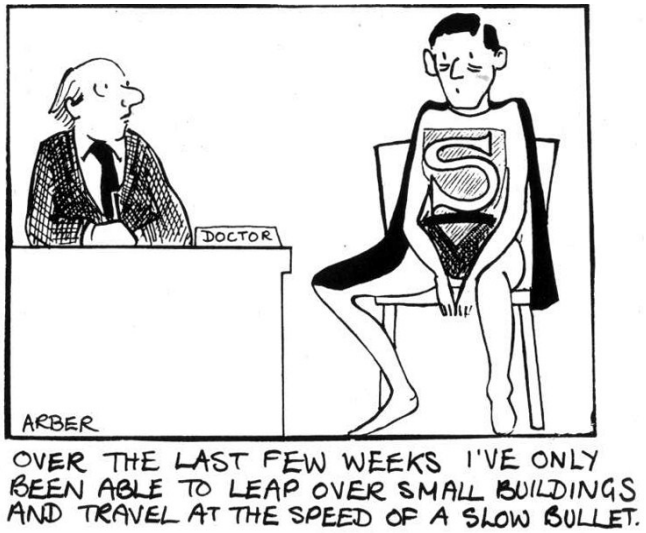
Personal comment on the World of ME/CFS by Trevor Wainwirght

Advocacy and Support Groups, What is the difference? Part 3.

So we come to the last article in where we look further at the attributes of a good leader essential for the success of the group: A truly effective support group leader is one who through experience, awareness, and/or individual personality develops the following characteristics:

Sensitivity to the feelings of individuals: Creating and keeping an atmosphere of trust and respect requires an awareness of how people are responding to both the topics and the opinions and reaction of others. Most people will not speak about their discomfort, hurt feelings, or even anger; instead they will withdraw from the discussion and often from the group. Sensing how people are feeling and understanding how to respond to a particular situation is an important skill.
Sensitivity to the feeling of the group: In any group, the whole is greater than the sum of the parts, and group "chemistry" generally reflects shared feelings of eagerness, restlessness, anger, boredom, enthusiasm, suspicion, or even silliness. Picking up on and responding to the group's dynamic is essential to skilful facilitation.
Ability to listen: One way the group leader learns to sense the feelings of individuals and the group is by careful listening, both to the clear meaning of words and also to their tone and unspoken meaning. In fact, facilitators generally speak less than anyone in the group. Often the facilitator's comments repeat, sum up, or respond directly to what others have said.
Tact: Sometimes the leader must take uncomfortable actions or say awkward things for the good of the group. The ability to do so carefully and kindly is critical. The subject matter of personal health struggles can evoke strong feelings and painful memories and a leader needs particular tact in dealing with emotional situations respectfully and sometimes also firmly.
Commitment to group effort: Sharing duties can occasionally seem frustrating and inefficient, and at such times every leader feels tempted to take on the familiar role of doing it all. However, a genuine conviction about the empowering value of a support group will help the leader resist a dominating role.
A sense of timing: The leader needs to develop a "sixth sense" for when to bring a discussion to a close; when to change the topic; when to cut off someone who has talked too long; when to let the discussion run over the allotted time and when to let the silence continue a little longer.
Flexibility: Group leaders must plan, but they must also be willing to drop those plans in response to the situation. Often the group will take a session in an unforeseen direction or may demand more time to explore a particular topic. The leader needs to be able to evaluate the group's needs and determine how to respond to it. Although every session is important, sometimes a facilitator will decide to omit a topic in favour of giving another fuller treatment.
A sense of humour: As in most human endeavours, even the most serious, a leader's appreciation of life's ironies, ability to laugh at one's self, and to share the laughter of others enhances the experience for everyone.
Resourcefulness and creativity: Each group is as different as the people who make it up. An effective leader needs an overall program and goals but may also alter them to fit changing conditions and opportunities. For example, the leader may call on the talents and experiences of people in the group and the community or members may suggest resources.

As you can see there's more to being a leader than simply being the boss, the question any potential leader must ask themselves is "am I up for it?"



In the next issue:
What happened when ME Awareness Day fell on a Sunday, because next year it does.