Price £ 2.00 (Free to members)

Pathways

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

The Leger ME Christmas Party

On Sunday 12th December we held our annual Christmas party at the Church Hall in Kirk Sandall. It was a lovely afternoon and the party was enjoyed by over forty people, including many children. We were delighted with the volume of people who attended and also with their sincere compliments following the party. It was nice to know that all the hard work had been very much appreciated. The three hours flew by and we did not have chance to do all that we had planned. However, Jason compered a game of prize bingo, a Christmas quiz and organised lots of fun games for the children. Justine, our daughter, entertained us once again with her lovely singing and Sophie Beckett, my cousin's daughter delighted us with her keyboard skills. We held a tombola stall, which proved to be very popular and a visit from Santa concluded the party, much to the thrill of the children. We would like to thank everyone who contributed towards the impressive buffet, including Selma Tebbs (my mum), Joan Bowker (Jasons mum) for all her lovely home baking, Christine Shackleton, Linda Kirby, to name but a few. We would also like to thank Tesco's for their generous £10 gift voucher, which we put towards buying presents for the children. Thank you to everyone who contributed in some way towards the party and we hope to see everyone again next year. *Ann Bowker.*

Summer Canal Cruise, Sunday 24th July.

We have booked the restored canal barge 'Ethel' for the day. The boat is operated by the Ethel Trust for community groups like ourselves. There are full disabled facilities. The boat does about 6 mph flat out. The ride itself is smooth, and there is no perception of motion. The day will start at 10 am, and will be divided into two trips of approximately three hours, morning & afternoon. Bookings will be taken for either or both trips. A mini-bus will be provided if necessary. Numbers are limited, so please book early to avoid disappointment. The cost will be £10 per person and will include refreshments midway. Please contact Mike on 01302 787353 or mike@leger.me.uk for further details or to reserve a place.

Linking Up – 6 months on *by Carolyn Byrom.*

As we are now in our 6th month of the Linking Up contact service I am pleased to say that so far we have fifteen members. However, because I feel sure that a number of you are still wondering about it, and maybe not too sure whether to join up or not, I thought I'd tell you how things are going with my local group over here in Greater Manchester, which has also been running a similar service over the past two years or so.

It has gone from strength to strength, and now has many members. From time to time some of the members have written short articles on their experiences in meeting up with others in the group via telephone/email/letter, and of the difference it has made in their lives. Their stories have appeared in their group newsletter, which I'm sure has been a great encouragement for others to join. Some of the Linking Up members have become such good friends that, when well enough, they visit each other in their homes, as well as keeping in regular touch by telephone/email/letter etc.

From time to time a group of them meet for an evening out in a local quiet bar somewhere central in town where there is good access for them. And believe me age is no barrier, there are people of between 18 to over 60 gathered together, and we all mix in fine. During the winter months a small group has started a cinema outing club, and go each month to see a film together. These are a few of the things that have sprung from the existence of the Linking Up service in my area.

If you have been thinking about joining Linking Up and would like to do so, then look out for the Application Forms I'll be sending out for <u>you under separate cover</u> arriving a few days after you receive Pathways No. 3. In the envelope will also be an addressed return envelope for your use – all it will need is the stamp.

Remember we are able to "***provide*** the linking up service" but, it is up to you all to then to decide upon any social getting together outside of the Linking Up via telephone/email/letter etc. Also, we would love to have any feedback you wish to give.

Hoping everyone is keeping as well as possible and trundling on nicely through winter, Carolyn.

I noticed at the Christmas Party that a number of Linking-Up members congregated together and were getting acquainted. - Mike

Clarification of Leger ME Membership & AGM Issues.

<u>Membership</u>. A member is someone who has financially contributed the minimum donation (Currently £6) to LME. A Member has voting rights at meetings and may join the link-up scheme. A Client is someone registered with us who uses services without making a contribution.

<u>Pathways Entitlement.</u> Pathways will be posted to members only. Non members who register with us are entitled to receive one Pathways issue only. After this edition, this rule will be strictly applied. Reprints will be charged at £2, however the Pathways content will be available on <u>www.leger.me.uk</u> as an HTML Web page or in Adobe Portable Document Format (.pdf) file which can be printed by the surfer on their own printer.

<u>End Of Financial Year.</u> This will be the 31st March. The AGM is to be held in mid-September.

Report of the CFS/ME Stakeholders Conference

held at Rotherham Courtyard Hotel, Rotherham on 16th December 2004.

This full-day conference, organised by Sheffield South West NHS Primary Care Trust, was entitled:-

"Developing a Specialist Clinical Service for South Yorkshire and North Derbyshire".

A wide range of disciplines and establishments were represented by the delegates, who included GPs, consultants in rheumatology, infectious diseases, paediatrics and clinical psychology; clinical psychologists, physiotherapists, occupational therapists, a homeopath and a number of NHS executives. ME groups from Doncaster, Sheffield and Rotherham had also sent representatives.

The topic was introduced by Gwyneth De Lacey (Clinical Champion for CFS/ME for South Yorkshire and North Derbyshire) and Jan Appelbee, (Lead Commissioner, Sheffield South West Primary Care Trust). They gave feedback from the "National CFS/ME Collaborative". This Department of Health (DOH) initiative held a two-day event during which issues of treatment of ME patients within the NHS were considered. The DOH will fund multidisciplinary teams in specialist centres throughout the UK, will supply training for team members and will operate a website.

Sheffield was granted funding and work began in April 2004. An exploratory event was held in July and two Sheffield Teams (for adults and children) were set up in October. Further funding has been secured so that, from April 2005, the Teams will cover the Primary Care Trusts for Sheffield (4 PCTs), Doncaster (3), Barnsley, Rotherham, Chesterfield, North Eastern Derbyshire, and High Peak and Dales. Staffing appointments have been made and much developmental work is under way. This includes staff training, budgeting and methods of monitoring. There are many uncertainties but it is expected that the clinical service will be phased in from this year. Guidance on best practice is expected from the National Institute for Clinical Excellence but this may not be forthcoming until 2007.

Sue Pemberton, Consultant Occupational Therapist and Clinical Champion for CFS/ME in NEW (North East and West) Yorkshire outlined the Leeds model of specialist care for CFS/ME. She said stress has a physiological response. ME/CFS sufferers have a tendency to push themselves. They have high standards and are out-givers of energy. This has to be corrected. People have to commit to change and to self control. A clinical history is taken over $1\frac{1}{2}$ hours, during which the pattern of fatigue is established. There is screening out of other physical disorders (e.g. sleep disorders) and mental health problems. People need different approaches. Every aspect of a person's life is considered and, very gradually, under the control of the patient, graded activity is established. 'Pacing' is one aspect of this, as is stress-management. There is a full-time therapist for CBT. For some patients an eight-week group therapy course is offered. Psychiatric ward inpatients are given two weeks' assessment followed by a six week programme and domiciliary support. This scheme is still under development. Dietetic and benefits advice are also given. Follow-up is valuable.

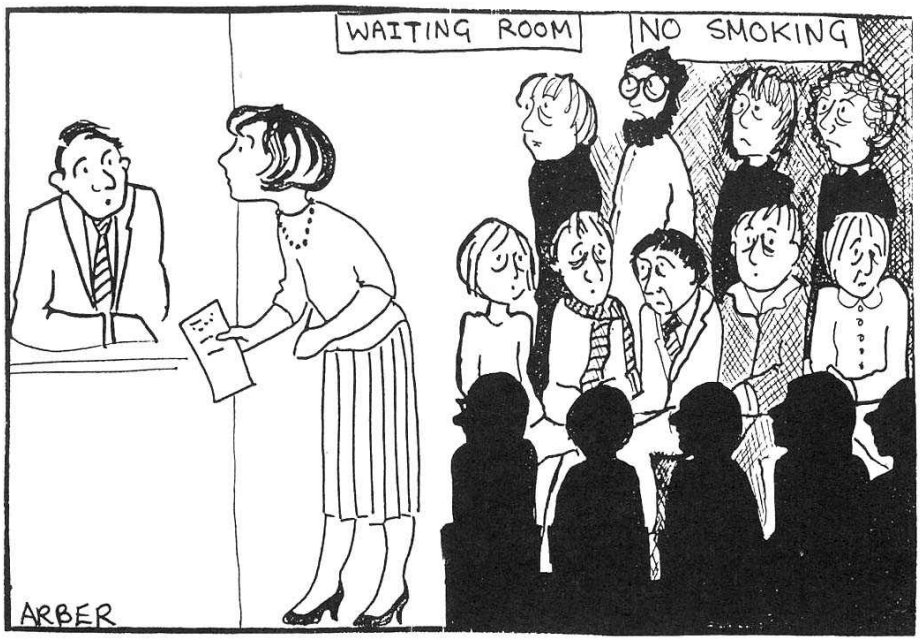
Hazel O'Dowd, Clinical Psychologist and Clinical Champion for CFS/ME in Bristol outlined the difficulties in defining ME/CFS and in establishing the epidemiology of the condition. It is estimated that there are between 2,400 ad 4,800 adult ME/CFS sufferers in the Bristol area which includes Gloucestershire, Avon, Somerset and West Wiltshire. The area is served by four multi-disciplinary teams and one paediatric team. Regional clinics, domiciliary assessments and hospital assessments for inpatients are available.

The impact of the illness on children is serious. ME/CFS is the most common reason for absence from school. Mean school-time lost is one year. 57% of the children are bedridden at some stage and $\frac{1}{3}$ of them obtain no school qualifications. Training has been given to school nurses, health visitors, Education Welfare Officers, home tutors and some school staff. Telephone counsellors are soon to be appointed. The service provided for child and adult patients in the Bristol area is based on cognitive behavioural therapy, life-skills and graded activity. A systematic review of 26 studies of

prognosis (Joyce et al 1997) indicated that 54-94% of children recovered. Less than 10% of adult subjects return to their previous level of function, many remaining significantly impaired.

Mary Jane Willows, Chief Executive Officer for the Association of Young People with ME, said her organisation started with five young people in 1994. It registered as a charity with 350 members in 1996 and has now helped over 3000 young people with ME. AYME works with the DOH, the Department of Education and Skills, and the Royal College of Paediatrics and Child Health. Children with ME had informed Mary Jane's talk. They asked to be listened to, for the reality of their illness to be recognised, to be given information, for the fact that there is no cure to be acknowledged, for appointments to be made at an appropriate time of day, to be afforded the comfort of an easy chair or beanbag on arrival at the clinic, that a facility to dim lights be available, and to be given time to rest.

Mark Adams, (Clinical Network Lead for CFS/ME for South Yorkshire and North Derbyshire and Sheffield South West PCT) spoke on local plans. A pilot phase of the service will operate in Sheffield, to be widened in the next financial year. Accommodation is still being sought. Clinicians will design and set up the service, informed by the stakeholders, to incorporate paediatrics, psychiatry and infectious diseases. Additional staffing, permanent administrative support and a physiotherapist will be appointed. Team building is an essential part of the strategy as is the development of clinical skills. The pilot phase of the service will be reviewed using stakeholder feedback and adaptations will be incorporated as necessary.



The final session was in pre-arranged discussion groups. Delegates were asked to consider what they had learned during the day, and what implications this had for the clinical teams in terms of referral protocols, interventions to be offered, follow-up and ongoing support, communication and training.

My impression was that ME/CFS is currently generating a lot of work within the NHS. The emphasis still tends towards the psychiatric field and I expect the therapies offered will chiefly be the 'evidence-based' strategies of cognitive behavioural therapy and pacing. I wonder whether there will be a different approach for the severely affected. It will be interesting to see how the new service develops locally and how ME/CFS patients respond to it.

Elizabeth A McDonagh
January 28th 2005.

The Sheffield Clinic opened for business on the 31st January 2005. It is expected that satellite clinics (including Doncaster) will follow later in the year. Elizabeth and I attended a subsequent meeting with other M.E. group representatives as Stakeholder Representatives.. We hope to have a meeting towards the end of April/May with Mark Adams and representatives from the clinic coming to Doncaster which members can attend. –Mike.

Incapacity Benefit Revamp (Source BBC News)

An Incapacity Benefit overhaul is overdue. The benefit paid to three million sick and disabled people will be overhauled to stop it being a disincentive to get back into work. The payments could be renamed, and there could be new financial penalties on those who refuse actively to seek work. Disability charities have expressed fears that the reforms could make some disabled people poorer. A previous reorganisation of the system prompted rebellion by 65 Labour MPs in 1999, and some backbenchers have voiced concern ahead of the latest package. The Conservatives say ministers are trying to grab headlines and the Liberal Democrats have criticised what they say is a "one-size-fits-all" approach. People whose condition causes them pain or fatigue should not be forced to look for employment The Government's five year plan is expected to try to cut the length of time some people spend on Incapacity Benefit. Officials are worried that somebody claiming the payments for two years is more likely to start drawing their state pension or die than get a job. Prime Minister Tony Blair said "Those who play by the rules get the help, those who don't play by the rules."

They are planning two categories. Firstly, a short term benefit for people who expect to return to work at some point. The plans will mean anybody wanting to claim the benefit will first have to be tested by a Government doctor. The payment could be replaced by a flat rate of £56. Claimants who attend work-focused interviews, rehabilitation schemes and training, will get more money as a reward. Mr Johnson said he wanted to ensure that the "9 out of 10 people" who went on to Incapacity Benefit expecting to be on it for a short period found their way back into work. "What happens at the moment is that if they are on it for a year, they will be on it for eight years, and if they are on it for two years, they will retire or die on Incapacity Benefit." Secondly, one new category will cover the 20% of claimants whom doctors believe are too severely disabled to work again - they will get extra cash.

I agree with Steve Webb, Liberal Democrat work and pensions spokesman who said Labour had "failed to get to grips with this issue". His party wants a new partial capability benefit to allow people to undertake varying amounts of paid work without becoming ineligible for some level of benefit. Jon Knight, from disability charity Leonard Cheshire, said: "People whose condition causes them pain or fatigue should not be forced to look for employment".

Flapjack RECIPE by Ann Bowker)

Ingredients

100g (4oz) butter or margarine
50g (2oz) granulated or Demerara sugar
2 x 15ml spoons (2tbsp) golden syrup ~ 1 tbsp syrup and 1 tbsp honey
150g (6oz) porridge oats /

Method
1. Melt fat, sugar and syrup over low beat, stirring until dissolved.
Remove from heat.
2. Mix in porridge oats. Press into a well greased 8" shallow tin (and line with non stick baking paper).
.3. Bake for 15-20 minutes at 180C, 250F, Gas mark 4, until golden brown.
Mark into bars. Leave to cool before removing from tin.
I have a fan assisted oven and I bake my flapjacks at 150C for 15 mins only.

There have been issues with some members taking on part time jobs which make them worse off. Some people are forced to make a decision after six months to go to full time work or go back on Incapacity Benefit. There is also a trap when if someone works part time, they cannot claim Incapacity Benefit if they become ill again for any reason. My guess is that there will be transitional arrangements for existing claimants, and the new rules will apply to new claimants. I think that most M.E.'s will be in the 20% that qualify for write offs, unable to work again, and will be left alone.

Coproxamol To Be Phased Out

For some time now it has been known that Coproxamol, a popular prescription medicine which is a combination of paracetamol 325 mg and dextropropoxyphene 32.5 mg is no more effective than paracetamol alone. Coproxamol' a medicine used by thousands for conditions such as back pain, will be phased out over the next year or two. Paracetamol is a well known General Sales List medicine. Dextropropoxyphene is an opiate-like pain killer similar to codeine which is a Prescription Only Medcine. It is estimated that 1.7 million GP patients per year receive 7.5 million prescriptions for Coproxamol.

It is believed that Coproxamol accounts for up to 400 deaths by accidental and intentional overdoses each year. It is the second most frequent means of suicide with prescribed medicines in England and Wales. The risk of death associated with Coproxamol overdose seems to be higher than for either tricyclic antidepressants or paracetamol alone.

It is estimated that 1.7 million GP patients per year receive 7.5 million prescriptions for Coproxamol. Patients already receiving Coproxamol should continue to take their prescribed dose until their doctor reviews the prescription. As long as no more than eight tablets a day are taken in divided doses and no other products containing paracetamol are taken at the same time there should be no problem with safety.

I've produced a list of common medicines used for pain control in M.E. in order of estimated of potency. All medicines have side effects and can react adversely is other medicines and medical conditions. Painkillers have a strange effect, in that doubling the dose only raises the pain relief by one level. Some like dihydrocodeine have a switch-off effect whereby they will work at a certain dose, but if the dose is increased no better pain relief is obtained.

Paracetamol is the safest, but only helps some, and if you take it you have to be careful of overdosing because other medicines may contain Paracetamol as a hidden ingredient.
Non Steroidal Anti Inflammatory Medicines (NSAIDs) include ibuprofen and aspirin. There can be problems with stomachs, especially if an ulcer or helicobacter is present and with asthmatics. But ibuprofen in high dosage can provide a high level of pain relief. All these medicines work peripherally (at the site of the inflammation rather than on the central nervous system).
Opiates, contrastingly, work by direct action on the central nervous system. They include e.g. codeine, dihydrocodeine, morphine, and Tramadol. All cause constipation to some extent, which in M.E. can be a problem, especially if IBS (Irritable Bowel Syndrome) is present. Some people take a mild laxative e.g. lactulose to overcome this problem.
Compound tablets i.e. an opiate & NSAID/paracetamol are used to tackle pain from two routes but it does not always achieve the desired results. It can be helpful for severe pain if constipation is a problem. It does allow codeine to be sold over the pharmacy counter with e.g. paracetamol, which would otherwise be a Prescription Only Medicine.
Neuroleptic medicines e.g. gabapentin, valporate and carbimazole have been used when the usual analgesics don't work, but they are usually case-specific.
Calcium channel blockers usually given for circulation problems, in some cases have worked quite well, but have been found purely by accident e.g. verapamil & nifedipine.
Tricyclic Antidepressants in a very low dose are very effective at total pain control in some cases. Amitryptyline in doses as low as 2 mg is the best example. The smallest tablet is 10mg, but even at this dose it doesn't suit some M.E.s because it has anti cholinergic side effects. Some people can have bad reactions to a single 10mg dose.
Over the counter (OTC) painkillers are based on combinations of aspirin, paracetamol and ibuprofen. Codeine is often added to magnify the analgesic effect, but often in too low a dose to have any significant effect. Some contain caffeine, which can stop some people sleeping. I don't recommend that M.E.s use these because they are often branded and more expensive. As most people with M.E. get prescriptions free or have bought prepayment certificates (season tickets), there is very little point in buying OTCs.

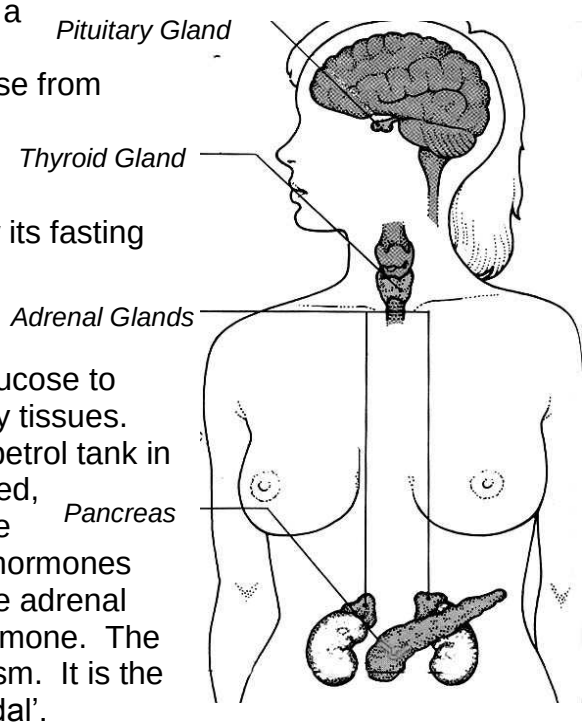
Comparison of Medications used for Pain Relief in M.E.

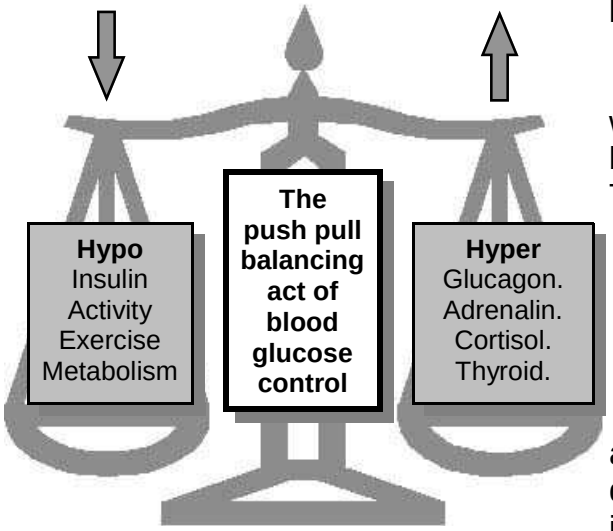
® = Brandname Generic (Unbranded)	Analgesic Medication & Dose	Type	Effectiveness Index (4-6 hr)	Supply	Side Effects ! Cautions
Generic	Codeine 60mg	Opiate	(-4)	POM	Constipation !Alcohol/ Drowsy
	Placebo		0		
Cocodaprin 325/30	Aspirin 650mg + Codeine 60mg	Opiate/ NSAID	9	POM	Constipation ! Asthmatics .! Stomach
Zydol®	Tramadol 100mg	Opiate	15	POM	! Asthmatics !Alcohol/ Drowsy
DF118 Forte	Dihydrocodeine 40mg	Opiate	16	POM	Constipation !Alcohol/ Drowsy
Calpofen®	Ibuprofen 50mg	NSAID	16	P/POM	! Asthmatics
Caprin® generic	Aspirin 600mg	NSAID	24	P/POM	! Asthmatics
Cocodaprin 500/8 Codis 500®	Aspirin 1000mg Codeine 16mg	Opiate/ NSAID	24	P	Constipation ! Asthmatics ! Stomach
Coproxamol generic Distalgesic® Cosalgesic®	Paracetamol 650mg Dextropropoxyphene 65 mg	Opiate/ NSAID	24	POM	Constipation !Alcohol/ Drowsy
Doloxene®	Dextropropoxyphene 130mg	Opiate	27	POM	Constipation !Alcohol/ Drowsy
Cocodamol 500/8 generic	Paracetamol 1g Codeine 8mg	Opiate/ NSAID	33	P	Constipation
Generic Naprosyn®	Naproxen 500mg	NSAID	34	POM	! Asthmatics ! Stomach
Generic	Paracetamol 1g		34	P/GSL	! Liver long term
Generic	Morphine 10mg	Opiate	39	POM	Constipation !Alcohol/ Drowsy
Generic Nurophen®	Ibuprofen 200mg	NSAID	39	P	! Asthmatics ! Stomach
Sopladol®, Tylex® Cocodamol 500/30	Paracetamol 1g Codeine 60mg	Opiate/ NSAID	48	POM	Constipation !Alcohol/ Drowsy
Voltarol® Generic	Diclofenac 50mg	NSAID	77	POM	! Asthmatics ! Stomach
Feldene® Generic	Piroxicam 20mg	NSAID	77	POM	! Asthmatics ! Stomach
Brufen® Generic	Ibuprofen 800mg	NSAID	100	POM	! Asthmatic ! Stomach

This table is based on my experience, and is presented for information only. Bear in mind that most medicines listed are prescription only (POM), and are only available on a doctors prescription. P = Pharmacy Only GSL = General

Glycaemic Control Issues In C.F.S./M.E.

Blood sugar is glucose or dextrose, produced by digestion of food. Table sugar is a chemical combination of glucose and fructose. Glucose is the main fuel of the body and the brain. In a normal healthy person, blood sugar levels are kept within a tight range in the normal range levels. The body, by its regulating mechanism, stimulates the production of glucose from stores in the body if the level falls too low and removes glucose from the blood if the level gets too high. The normal fasting level is about 4 and after about 1 hour following ingestion of food, rises to 7. It falls to just below its fasting value, then rises slightly by which time the next meal is due. The levels are under hormonal control, mainly by insulin which is secreted by the pancreas in response to rising glucose levels. Insulin acts as a bridge allowing glucose to enter cells for conversion to glycogen in the liver and body tissues. Glycogen is a cellular level temporary store a bit like the petrol tank in a car. When glucose levels fall, insulin secretion is stopped, and a different set of hormones comes into play to release glucose from temporary stores, especially the liver. The hormones involved are glucagon from the pancreas, cortisol from the adrenal glands, adrenalin from the adrenal glands and growth hormone. The thyroid glands via thyroxin regulates the level of metabolism. It is the body's 'gas pedal'.





Hyperglycaemia, a major health problem, is caused when the pancreas cannot product enough insulin to balance blood sugar levels, and they rise above normal. This is diabetes. If there is a small shortfall, then glucose levels will rise to about 10 mg/dl. This is Glucose Intolerance, a prediabetic state. It is not called diabetes because of legal implications of diagnosis. A rise above 10 would confirm diabetes. If the loss of insulin is only partial, then the diagnosis is type 2 diabetes, which is controlled by diet and oral medicines, and is usually only found in older people. Type 1 diabetes is where s no insulin available, and requires insulin to be given by injection. The boundaries between all three types are blurred, the exact diagnosis being done by clinical tests. Diabetics with M.E. can up their blood sugar as high as 20+, and partially compensate for M.E., BUT they risk the dangers and consequences of diabetes, especially if gut dysbiosis (Candida) complicates the issue. High blood sugar levels cause drowsiness. About 2% of M.E.'s have diabetes as opposed to 1% of the general population. There are other causes of hyperglycaemia.

Hypoglycaemia ('hypo') is when there blood glucose levels fall below 3 or 4 mg/dl. This is then more important with M.E. It can be caused by adrenal, HPA or thyroid problems, gut dysbiosis, excess activity etc. The mild symptoms usually start off with pallor, tremor or shaking, & weakness. As blood sugar falls, perspiration, a feeling of weakness, rapid heartbeat, hunger, agitation, difficulty in concentrating, irritability and fatigue appear. In severe cases blurred vision, temporary loss of consciousness, confusion, convulsions and coma or even death can result. This problem is common in diabetics who have overdosed on insulin or have not had enough food or exercised too much. The first aid treatment is to give sugar or glucose at 1 tablespoonful. More severe cases may require glucagon or IV glucose to be given by paramedics or in hospital. Diabetics with M.E. can suffer hypos because of blood sugar control issues, or M.E. itself or both. Some M.E./diabetics have a difficult time because it is difficult to identify the cause of the hypo, and if the wrong cause is treated, it can have an adverse effect on the other.

Why Hypoglycaemia In C.F.S./M.E. ?

In M.E. the hypos can occur at blood sugar levels as high as 5 or 6 mg/dl for a number of reasons. In some cases one issue may be present while in others it may be a combination.

Thyroid Hormones. The thyroid gland produces two hormones T4 (thyroxin) and T3 (tri-iodothyronine) which regulate the metabolism. Many M.E. patients have a blood level of T4 of between 9 and 12 pmol/l which is just above the borderline for thyroid deficiency, which starts at 8. Some private sector doctors argue that giving a small dose of T4 to bring the level up to around 18 (ideal) would reduce the level of fatigue. This view is disputed by many doctors mainly on the NHS. For some patients this approach works, but others experience adverse heart problems like arrhythmias or missed beats. In some cases there is 'resistance' to thyroid hormones, because of the low conversion of T4 to the more active T3. My own view is that thyroid hormones (T4,T3 and thyroid extract) can be tried up the equivalent of 100µg of T4 daily under medical supervision, provided that regular thyroid function tests are carried out to monitor the treatment and the extent of thyroid suppression. Dried Kelp (a natural source of iodine) has been tried by one member, and found to helpful as a safer alternative to T4.

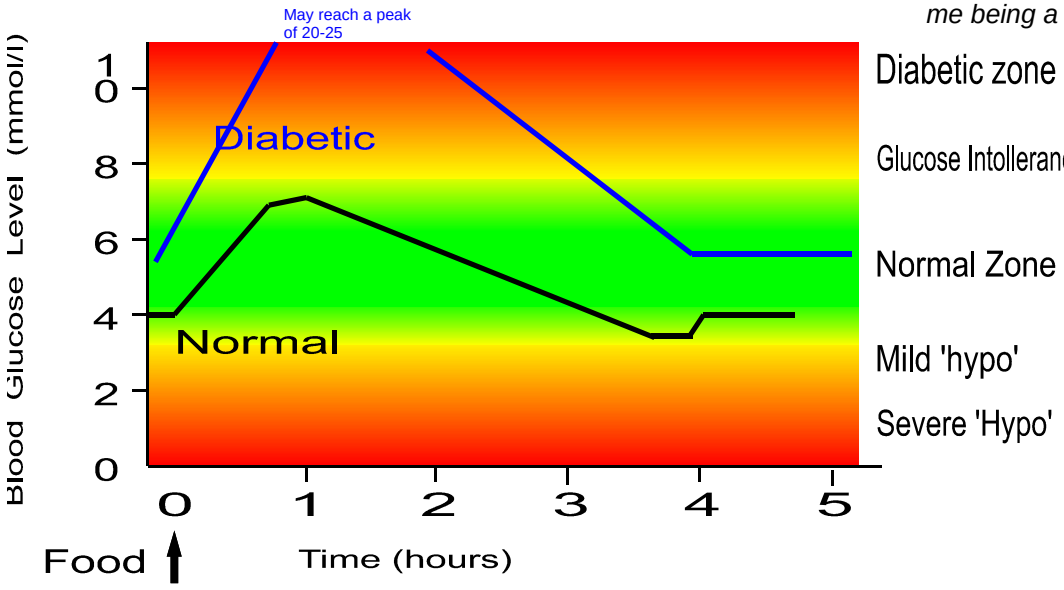
Adrenalin and the HPA (Hypothalamic Pituitary Adrenal) **axis**. The HPA axis when activated prepares the body for action. Adrenalin increases the heart rate, diverts blood to the muscles, and elevates blood sugar levels. This can be thought of as a strategy evolved for our cavemen ancestors to ready them for hunting, fighting or running away from an enemy. In 1992 research by Demitrak in the U.S.A. showed that HPA axis activation is impaired in M.E., however no treatment has been derived from this. It may explain why some M.E.s react badly to stress, and become inpatient very quickly. Possibly low blood flow in the brainstem, a specific abnormality in M.E., may be the problem.

Cortisol is an adrenal hormone which also increases blood sugar levels. It is secreted in response to ACTH (Adrenal Cortico Trophic Hormone) from the pituitary gland. Cortisol suppresses the immune system and raises blood sugar. In some M.E. cases there are disturbances in cortisol production. This should be highest in the morning and lowest in the evening, but some patients have a delayed profile by about six hours. These patients' mornings can be made better by a small dose of hydrocortisone. Research into hydrocortisone treatment for M.E. has been disappointing. The use of hydrocortisone in M.E. is generally limited to certain private doctors as the NHS does not recognise this as a valid treatment. An Adrenal Stress Index and Temporal Adrenal Index test is available privately, which may give an individual indication for hydrocortisone treatment. One doctor believes that hydrocortisone and thyroxin should be given concurrently. Many M.E.s have allergies or MCS (Multiple Chemical Sensitivities). M.E. somehow over-activates the immune system and some believe that disturbances in cortisol production magnify this effect. Treatment with cortisol or one of its analogues may correct part of the problem.

Gut Fermentation, Dysbiosis or Candida. In about of 30% of M.E. patients this is an issue. In M.E., as with some other diseases, disturbances in the immune system allows overgrowth of opportunistic organisms. Particularly prominent is a yeast, Candida, which being a yeast ferments sugar to alcohol. This can be demonstrated by the Gut Fermentation Test. A patient is starved overnight, then given a oral dose of glucose, and one hour later a blood sample is taken. A typical positive result would find alcohol between 5–10 mg/100ml (80 is the legal limit for driving). It is also known as Auto Brewery Syndrome. The fermentation is never clean, and by products can include methanol and propanol which are both toxic. One treatment avoids all raw sugar, eating only food with a low glycaemic index, but it can be controlled by antibiotics such as fluconazole and Nystatin or by diet. If gut fermentation is present, this must be treated before a patient can improve.

Alcohol in alcoholic drink or by gut fermentation has the same effect, lowering blood sugar. One patient suffered from hypoglycaemia, collapsed and was taken to hospital. She was given a glucose drip, but the more sugar that went in, the lower her blood sugar became, baffling doctors. It was the alcohol produced by the Candida that was the problem. Something similar happens if diabetic M.E.s with gut dysbiosis take sugar to correct a hypo.

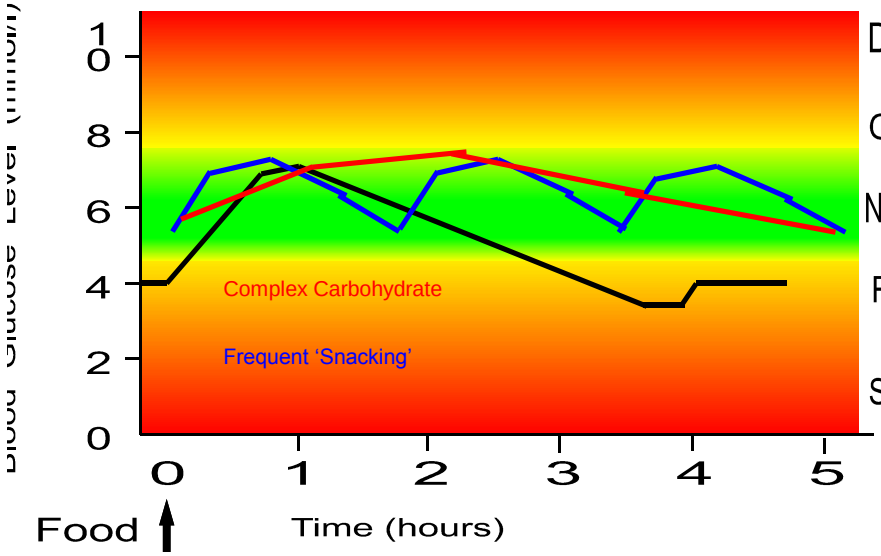
The Normal Blood Suger Response

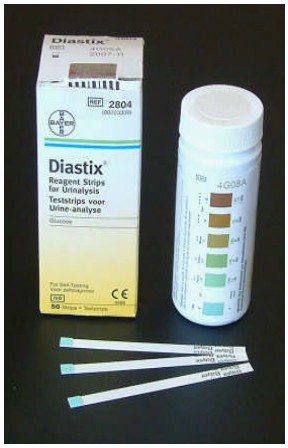


These graphs are what i produced using my glucose meter. The normal curve came from me being a guinea pig at university.

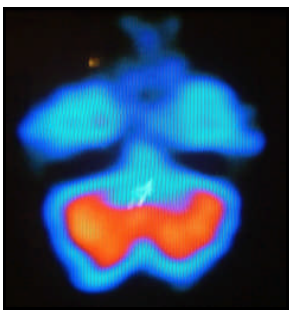
Many diabetics and some M.E. patients use a home Accu-check blood glucose meter.

The M.E. Blood Suger Response

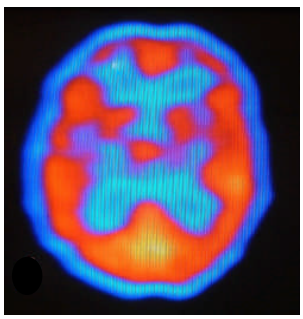




Diastix, although originally for test glucose in urine comes in handy for estimating the sugar content of foods, especially processed food.



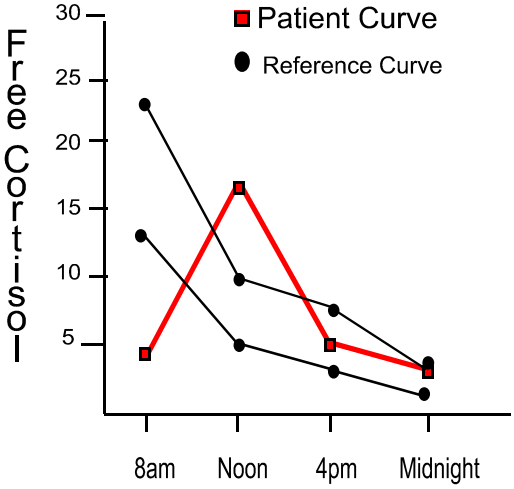
ME Patient



Normal Control

Dr Durval Costa in 1996 carried out ground breaking research use in SPECT scans on CFS/ME patients. He produced evidence that CFS/ME patients have reduced blood flow in the brain stem.

Temporal Adrenal Profile



Dr Mark Demitrack and associates in 1991 published a paper about "Impaired Activation of the Hypothalamic Pituitary Adrenal axis (HPA) in Chronic Fatigue Syndrome". The diagram shows a temporal adrenal profile of free cortisol secretion in a CFS/ME patient. The patient's curve is shifted by about six hours. This coincides with and may explain the fact that most CFS/ME experience fatigue in the morning and are better later in the day.

Dietary Issues and Glycaemic Control. *By Dr. S. Myhill*

Treatment of Hypoglycaemia is to avoid all foods containing sugar and refined carbohydrate. For the established hypoglycaemic it may take many weeks for the liver to regain full control of blood sugar, hence hypoglycaemia may persist for sometime whilst still avoiding sugar and refined carbohydrate. These are withdrawal symptoms and it may take many weeks of a correct diet before these symptoms resolve. This type of addiction is very much like that which the smoker or the heavy drinker suffers from. One needs to switch to a diet which concentrates on eating proteins, fats and complex (and therefore slowly digested) carbohydrates. Initially I suggest doing a high protein high fat diet (e.g. the Atkins diet), but include all vegetables (care with potato), nuts, seeds, etc. Fruit is permitted but rationed, since excessive amount of fruit juices or dried fruits contain too much fruit sugar for the liver to be able to deal with. I suggest one piece of fruit at mealtimes. With time the regime can be relaxed, but a return to excessive sugar and refined carbohydrate and the problem starts again. Many sufferers of hypoglycaemia may need something sweet to eat immediately before and during vigorous exercise, until the body learns to fully adapt. Hypoglycaemia is usually accompanied by micronutrient deficiencies. You should also take nutritional supplements and ideally do some tests, especially of mineral levels, as chromium is a common deficiency.

A Low Glycaemic Index Diet - What To Eat on it. Very often I ask people to do diets with a low glycaemic index. The glycaemic index reflects the ability of foods to raise your blood sugar. The glycaemic index of foods is partly dictated by their carbohydrate content, is partly dependent on food preparation, how large the particles of food are and with which other foods they are eaten. For example, high fibre, large particle, raw food eaten with protein and fat will have a lower glycaemic index than low fibre, cooked food, with small particle (e.g. ground white flour, crisps) which are consumed on their own. Ideally eat foods with as low a reading as possible. The absolute index of common foods is as follows:
No carbohydrates - i.e. hypoglycaemic index of zero - eat as much as you like. Meat, poultry, fish, eggs, oils, butter, margarine
Low glycaemic index - eat ad lib Cream, cheese, Nuts - brazil, peanuts, cashews, walnuts, almonds, hazelnuts, Seeds - sesame, pumpkin, sunflower, pine-nuts, herbs and spices. Salads - lettuce, tomato, peppers, cucumber, radish, parsley, celery. Green vegetables - cabbage, sprouts, cauliflower, kale, kohlrabi, spring greens, asparagus, purple sprouting broccoli. Swede, turnip, rhubarb, and soya
Medium glycaemic index - ration yourself to 2-3 portions daily Vegetables - onion, squash, sweetcorn, Fresh fruit (tart), e.g. apple, citrus, berries, avocado. Pulses - peas, beans, and Milk
High glycaemic index - avoid - asking for trouble! One portion daily sugar, syrup, anything ending in -ose (fructose, glucose, maltose), honey, jam, marmalade, sweets, chocolate, fruit juice. Cereals - wheat, rye, oats, rice, barley. Bread, pasta, pastry, biscuits, oats, porridge, Ryvita, potato, parsnip, crisps, sweet potato. Sweet fruits - banana, peach, grapes, melon, mango. Dried fruit - dates, figs, sultanas.

Easy Yeast-free and-Sugar-free Bread Rolls

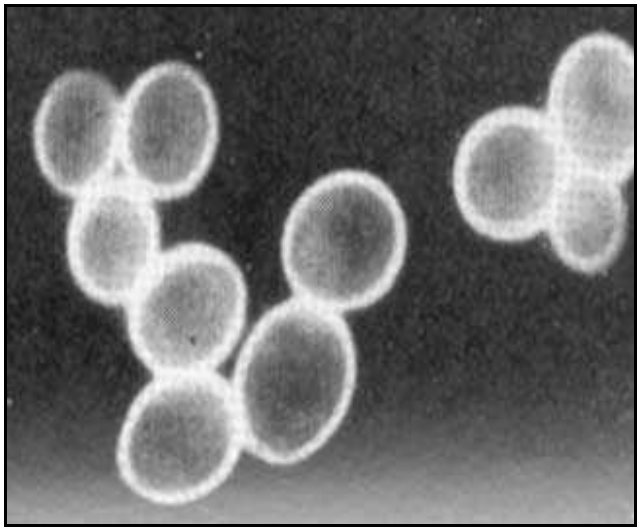
by Elizabeth McDonagh

When very ill and trying to follow an anti-Candida diet I found the following recipe useful. For people with intolerances to any of the ingredients it might be possible to make adaptations e.g. you could use gram (pea) flour instead of wheat flour. Choose a milk-free margarine which suits you or use butter instead. If you are concerned about the level of sodium from the salt and baking powder you could substitute with potassium versions available from pharmacies. Instructions are for the larger quantity. The small quantity makes one round, eight rolls.

Large quantity 24 rolls	Ingredients	Small quantity 8 rolls
$1\frac{1}{2}$ lb	Wholemeal flour (preferably organic)	8 oz
3 oz	Vegetarian margarine	1 oz
$1\frac{1}{2}$ tsp	Salt	$\frac{1}{2}$ tsp
$3\frac{1}{2}$ tsp	Baking powder	$1\frac{1}{4}$ tsp
18 fluid oz	Water	6 fluid oz

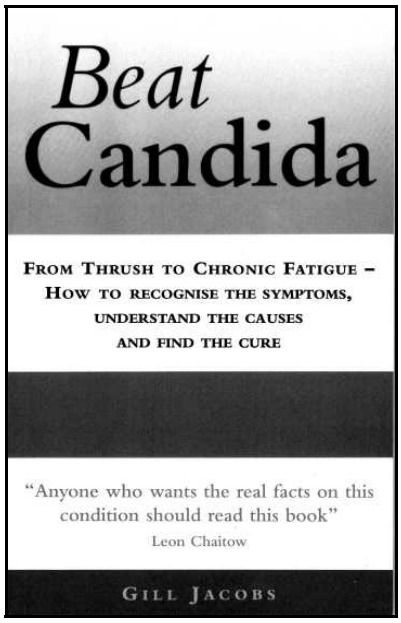
Set oven to 220˚ C/Gas mark 7 and arrange shelves fairly near the top. Oil 2 baking sheets. Rub fat into flour until like fine breadcrumbs. Add salt and baking powder and mix well. Pour in water and mix well. Knead lightly. Divide mixture into three on a floured board. Shape each portion into a flat round ¾ to 1 inch thick. Divide each round into eight triangles. If you want round rolls you can reshape. Place twelve rolls on each tray Bake 30–35 minutes until they loosen from tins and sound hollow when tapped underneath. Cool on a wire rack. When cold, the rolls may be frozen in a polythene bag. I reheat in a 650 watt microwave oven on power level 6. 2 rolls take one minute. However microwave ovens vary so you might have to experiment.

Candida Revisited *by Elizabeth A McDonagh.*



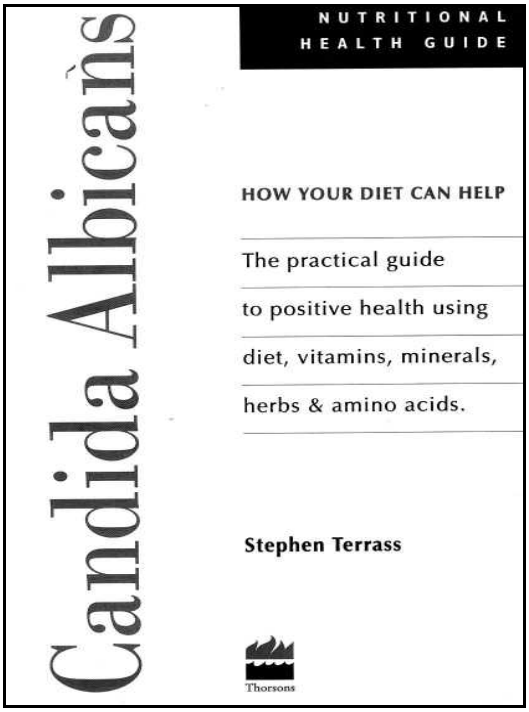
The Yeast Candida albicans

In the last twenty years or so, numerous books have been published on the subject of Candida albicans, a parasitic yeast which lives harmlessly in the digestive tract of every healthy person. The growth of Candida is is normally held in check, mainly by the beneficial bacteria which also inhabit the gut. The theory is that in people with immune dysfunction or when the beneficial bacteria are in short supply, Candida proliferates and, fuelled by sugar, may even penetrate the gut wall, enter the bloodstream and cause chaos all over the body as well as a 'foggy brain'. This theory is not widely accepted by the medical profession. However, some ME sufferers (myself included) believe that a diet against Candida greatly improved their health.



Not the first, but probably the most comprehensive book on Candida "*The Yeast Connection – a medical breakthrough*" by Dr William G Crook, was first published by Vintage Books in America in 1983. Since then the subject has been explored by a number of authors on both sides of the Atlantic. Gill Jacobs is a member of the Council of Management of Action for ME and Chronic Fatigue. Her book "Beat Candida" first published in 1990 carries a foreword by Dr Anne Macintyre. Its 280 pages provide an eminently practical guide to understanding Candida and its links to ME. Readers are led through recognition of the symptoms, understanding of the causes and what to do in order to effect a cure. There are many case-studies. The book ends with a useful appendix on "Information, Support and Advice" which includes a list of practitioners and suppliers of nutrients, natural medications and probiotics.

A more pocket-sized manual is "*Candida Albicans*" by Stephen Terrass, a Canadian nutritionist with a world-wide reputation. Thorsons are the publishers. The book begins with the anatomy and physiology of the digestive system and explains the involvement of the immune system in protection against the harmful effects of Candida. Symptoms, their causes and other illnesses associated with Candidiasis are considered. Terrass then outlines his Candida Control Diet and describes nutritional and herbal remedies which can help. There is a comprehensive bibliography and index.



Pursuing an anti-Candida diet is not easy, especially in the initial stages when die-off of the yeast can cause exacerbation of symptoms. Support of family and friends is vital and consultation with a knowledgeable practitioner is often useful. Progress is not rapid but, after a few months of conscientious application of the programme, many people do find a steady improvement in their overall health.

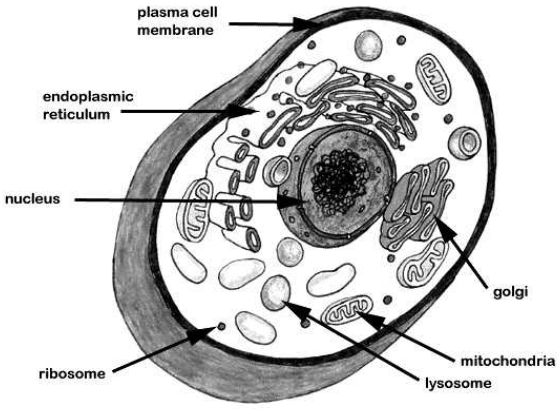
As the symptoms of Candida are similar to those of more serious diseases, it is best to be checked out by a doctor first. Antibiotics like fluconazole are available which are supposed to clear candida in a single dose, but are not always 100% effective and are too toxic to take continuously. Hence the diet has still a major role to play in management and prevention. Mike.

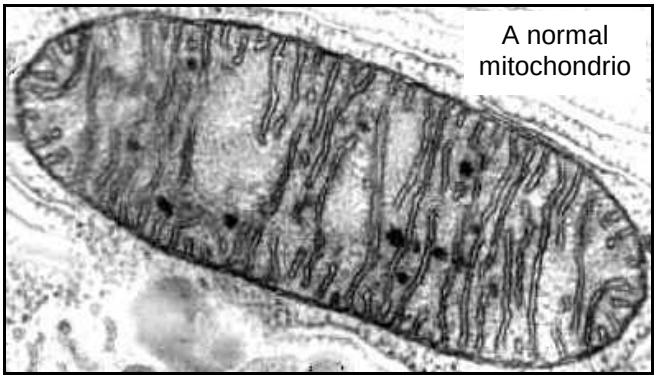
The Mitochondria, Power House of the Cell. A smoking gun ?

For years it has been known that in some CFS/ME patients there are abnormalities in the mitochondria, and increasingly some research is pointing to damaged mitochondria as the cause of CFS/ME in some cases. I have been aware of this for many years. When I last saw Dr. Myhill, she gave me the information presented in the next two pages. It is presented in Pathways as an idea, and is for comment. It does bring together some clinical observations and research. This is certainly the best postulation I've seen, and for me gives answers to many questions. Dr Myhill's paper is technical. What follows is as a way of introduction. It is what biology students are taught.

Animal cells come in all shapes and sizes. Whatever their function, they all need the energy molecule ATP. The organelle within the cell that produces most of the ATP is the *mitochondrion*. Mitochondria (plural) are sausage shaped organelles, with a double membrane. The inner membrane has finger like projections called cristae. It is here that the enzymes are located to produce ATP, the cells energy source. ATP is analogous to electricitry. The fuel can be glucose, amino acids or fatty acids. They are converted into pyruvate, then acetyl coenzyme A. This is like grinding up the coal into small lumps. This then enters the citric acid cycle or Krebs cycle. This is the 'flame' of the fire and the cristae is the fire grate.

The Animal Cell

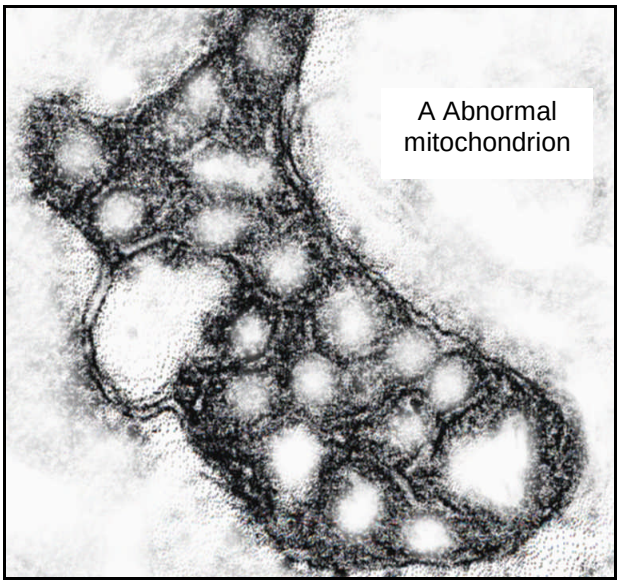




A normal mitochondrio

Mitochondria are unusual in that they contain DNA, independent of the cell nucleus. This does not come from the sperm but the egg, and is passed only from the mother. They contain their own ribosomes for protein synthesis. When they reproduce, they do so by dividing in two like an amoeba, and are not constructed by DNA transcription. They behave like a cell within a cell, and are thought to be evolved from bacteria. Because of this, if a mitochondrion is damaged, the two daughter mitochondria and subsequent generations carry on the damage. There is no equivalent of sexual reproduction to evolve or regenerate the DNA. Like many body tissues, mitochondria are turned over and repleted over a number of days. It is thought that fatigue is caused while they regenerate themselves after damage. The propagation of damaged mitochondria is thought to be the reason for continued M.E.

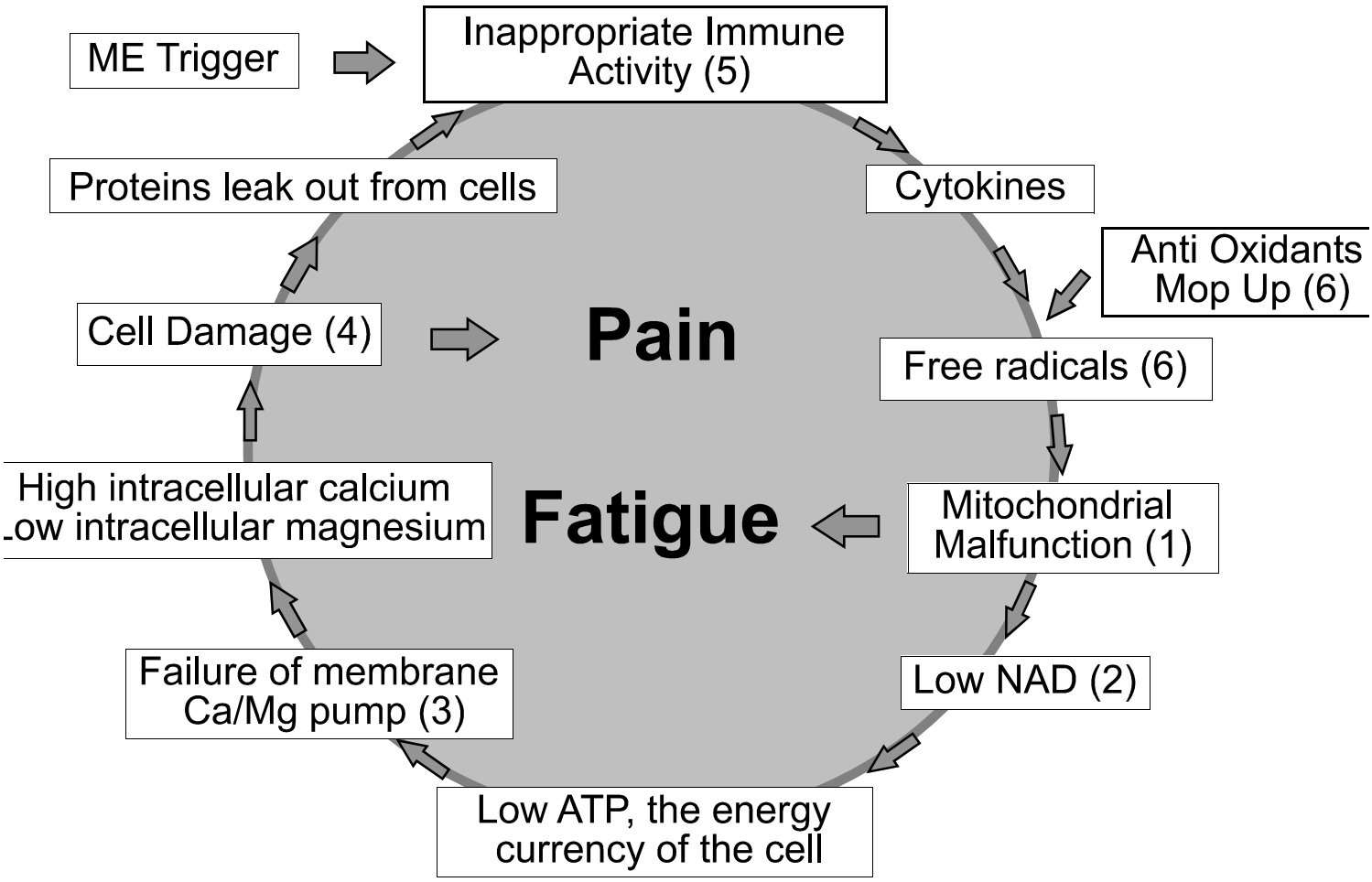
The image on the right is based on a heavily damaged mitochondrion from an M.E. patient. The sausage like shape is distorted beyond recognition. The vacuoles, white areas, are fluid filled with distorted cristae and one is about to rupture the membrane. Organelles like this retain some degree of functionality, but certainly only a fraction of what it should do, as typical with M.E. The images are based on electron microscope images, heavily art-worked for clarity. They are magnified about 40,000 times. An electron microscope is a hundreds of thousands of pounds instrument. Specimens need sophisticated preparation, and this explains why it is not used as a common diagnostic tool. In comparison, a light microscope will cost only £1000, and will only magnify to 600x, too little to view mitochondria.



A Abnormal mitochondrion

A Model for The Biochemical Pathophysiology of Chronic Fatigue Syndrome

By Dr. S. Myhill.



1) Mitochondrial failure may be initiated by direct damage from infections (viruses, bacteria, parasites). It may result from a reflex shut down "hibernation reflex" in response to overwhelming stress, and damage by free radicals. Mitochondria are also "switched off' by raised insulin levels from high carbohydrate diets, by low levels of thyroid hormones especially T3 and/or by long term high cortisol (the stress hormone). In the short term cortisol and adrenaline switch on mitochondria.

2) Poor mitochondrial function results in low levels of NAD. NAD is necessary to make ATP which normally fuels muscles and all cellular metabolic processes.

3) The membrane ion pump which pumps magnesium (Mg) into cells and calcium out of cells fails. This results in calcium (Ca) flooding into cells which is highly damaging to them. This explains why red cell Mg is nearly always low in CFS patients, it is a symptom of failed Ca/Mg pump. Mg supplements are helpful because they reduce the work of the pump by reducing the concentration gradient.

4) Cells are damaged. They may be damaged in many ways such as:
High levels of intracellular calcium. This is particularly damaging to muscle cells because, magnesium deficiency means they are unable to relax. Any muscle contraction will flex a joint and stretch the opposing muscle which is unable to relax, so creating numerous widespread muscle tears. This explains the raised or high normal levels of CPK (creatine phosphokinase) in CFS sufferers.
Direct damage from infections (viruses, bacteria, parasites).
Direct damage from chemicals (pesticides, heavy metals, volatile organic compounds)
Immune damage and free radicals

5) As cells are damaged, proteins leak from them. They are "seen" by the immune system which mounts an inflammatory response against them, partly as a system of repair. This inflammatory response produces cytokines which generate free radicals which further damage mitochondria and cells.

6) Antioxidants "mop up" free radicals and thereby limit the damage caused by them. The important antioxidants are: Superoxide dismutase which is dependent on adequate supplies of copper, manganese and zinc, Glutathione peroxidase which is dependent on adequate supplies of selenium and protein), Vitamins A, C, E, and Vitamin B 12, a scavenger of peroxynitrite.

Implications for a test for CFS

- NAD levels, a symptom of mitochondrial failure.
- Mitochondrial enzyme levels to see if the mitochondria are working normally.
- Intracellular levels of calcium and magnesium. A measure of the Ca/Mg ion pump activity.
- CPK levels, an indication of muscle damage.
- Cytokine levels, an indication of Immune system activity.
- SODase, a measure of antioxidant status.

Evidence of back up the Model

Work done by John McLaren Howard suggests that SODase is the most important enzyme which protects against inadvertent damage by the immune system. Early trial results in six of my CFS sufferers tested at Biolab by John Mclaren Howard showed poor levels of NAD in 6/6, low levels of mitochondrial enzymes in 5/6, low intracellular Mg in 6/6, high intracellular Ca in 4/6 (with one high normal), low SODase in 5/6. All six are currently taking niacinamide 500mgs to improve NAD levels and copper Img am, manganese 5mg at lunch and zinc 30mg at night to improve SODase and I will recheck both NAD and SODase in due course. BUT will they be better clinically? Watch this space.

Implications for Treatment of CFS

a) Identify and avoid substances which trigger immune activity such as infections (viruses, bacteria, parasites), vaccinations, pesticides, radiation (depleted uranium), heavy metals (mercury, lead, cadmium, aluminium etc), foreign bodies (silicone).
b) Take supplements which moderate immune activity such as high dose essential fatty acids and vitamin D3 (sunshine or cholecalciferoI 2,000-4,000 i.u). Identify and avoid substances which cause allergy reactions e.g. foods, inhalants, chemicals and micro-organisms.
c) Avoid drugs especially medical like statins which interfere with selenoproteins and so muscle metabolism, beta blockers which block adrenaline, the Pill and HRT which are immunodisruptive. Avoid social drugs especially alcohol which overloads detox system.
d) Improve antioxidant activity: correct SODase. I use Cu 1mg in the morning, Mn 5mg at midday, Zn 30mgs at night, Se 200mcgms for glutathione, high dose vitamin C (1-10gms daily), A and E.
e) Scavange peroxynitrite with B 12 injections up to 6mgs weekly.
f) Improve mitochondrial function. Use B3 500mgs to improve NAD levels.
g) Stimulate mitochondrial function with low carbohydrate high protein diet, correct thyroid and adrenal function.
h) Reduce the concentration gradient for the Ca/Mg ion pump by giving magnesium supplements and/or Mg injections.
i) Reduce cell damage by careful pacing of physical (muscle) and brain (mental) activity. Do not exercise to the point of getting symptoms because this indicates cell damage which worsens the vicious cycle.
j) Allow time for cells to repair themselves by ensuring a good night's sleep.
k) Reduce toxic stress by avoiding toxins (pesticides, VOCs (volatile organic compounds), heavy metals). Improve detox by taking a good range of micronutrients, high protein diet and sweating regimes like sauna, Turkish baths or hot tubs.

Comment: The lack of a control group is the obvious omission, which would be needed to gain general credibility. The reasons I've published it in Pathways is because I've monitored the research for the last 15 years and there are many oddments of research which back up this model. But really the next stage would be to do a double blind crossover trial in two different centers. I believe one problem that blights research is that ME/CFS has different subtypes, maybe with different disease models, and that is not taken into account in the research I've seen. What I know is that I didn't start to improve until I took nutritional treatment seriously. NHS please note. Mike.

North of Doncaster *Personal Comment by Trevor Wainwright*

The group M. E. Research & Support Castleford goes from strength to strength, launched on October 1st last year, when I thought there was a great need for funding for good quality Research, Awareness & Support projects, so the logical solution was to set up a group dedicated to this. So who to go with? The choice for Secretary was my good friend Joyce Cogan who has good secretarial skills and had experience relevant with the post. The next was a Chair who would fill the role as one of responsibility, not authority, the position was filled by Leger ME's very own Chair, Mike Valentine. His previous experience with other groups makes him the ideal choice. So after the first 3 months of fundraising we have paid out the following as of December 31 2004:

£915.00 to The Chronic Fatigue Syndrome Research Foundation to help with a Gene Expression Study.
£210.00 to The Blue Ribbon for the Awareness of ME Campaign to help continue to make governmental and other groups including the general public aware of the devastating effects of M. E.
£210.00 The Tymes Trust Telephone Helpline to enable them when distraught parents ring asking if they can help say, continue to say “yes we can”.

On a sadder note, Gary Frankum, MERSC’s Patron has now given up campaigning, dismayed by lack of support, particularly from the main groups. He has had enough. He is to remain Patron of MERSC, and I would like to thank him through my column for all he has done for ME. Now one of the groups above The Blue Ribbon for the Awareness of ME Campaign, I have been supporting their work since 1997, so they are this editions feature:

Prisoner Cell Block M.E.

There are no bars to my cell
No locked door to keep me in
Yet I am a prisoner,
To an illness within

M.E. is a life sentence
No release date, remission or parole
Imprisoning my body
And slowly destroying my soul

Alone in silence I suffer grief
At the ignorance and disbelief
Come and visit me if you will
You will see I'm really ill

How I long for a cure
How I long to be free
How I long to be no more
Prisoner Cell Block M.E.

Trevor Wainwright, April 2003

BRAME

Launched in Great Britain on 24 April 1995,.BRAME is run entirely by Tanya and Christine Harrison; a severe sufferer and 24/7 carer. Following the success of BRAME in Britain, in November 1995 Tanya took the campaign to the World Medical Conference on ME/CFS in Brussels. As a result, the idea was taken back to 12 countries around the world, some of which have since initiated the BRAME campaign with enormous success. BRAME has now created a worldwide network and is in contact with 21 countries around the world.

BRAME is an integral and active participant in International ME/CFS Awareness Day on May 12, a time when the universal symbol of the Blue Ribbon, or the BRAME enamel badge, is worn and promoted around the world. As a result of the BRAME meeting in Parliament on 14 May 1998 an All Party Parliamentary Group on ME was set up in the UK Parliament, and the Chief Medical Officer announced in July 1998 the setting up of a Working Group on ME/CFS. Tanya was a patient representative on the Key Group and the report was published on 11th January 2002. Tanya’s response to it can be found on the BRAME website. BRAME is really working in stimulating conversation about ME/CFS, offering an opportunity to educate society in general, creating a greater awareness and understanding of ME/CFS. Its aims and further details can be found in the Blue Leaflet that come with this edition of Pathways.

Contributors of Pathways no. 3 are : Anne Bowker, Joyce Cogan, Trevor Wainwright, Dr. Sarah Myhill, Liz McDonagh & Mike Valentine. Cartoons by Martin Arber from Interaction.