

Pathways

Price £ 2.00 (Free to members)

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

Focus on Vitamin Supplements

In Pathways no. 9 we considered Mineral Supplements. In this issue we take a look at Vitamins. Are they really necessary? See page 10.

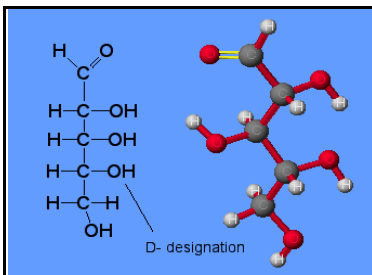


ME and Carbon Monoxide Safety..

Autumn will soon give way to winter, when many ME/CFS patients see more intense symptoms.



For a few the symptoms may not be due to ME/CFS. Read how to avoid these hazards and how in the past canaries helped miners. See page 13.



ME and Ribose

We discuss supplementing with Ribose to reduce rebound fatigue. Over in the States and Australia it is big business. Is it useful?

See pages 4,5 and 6

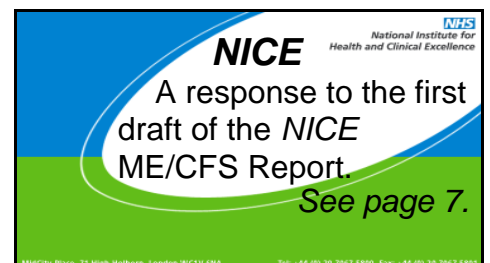


Afternoon Tea in Armthorpe

September 14th 2006 was a bright sunny day. Ideal in fact, for the tea and coffee morning held in Jan & Bob Fox's garden in Armthorpe. Much-needed funds were being raised for Leger M.E. A steady stream of visitors not only enjoyed the tea, coffee, biscuits and cakes on offer, but the garden as well. Along with a well supported raffle (all prizes generously donated) Leger M.E. funds benefited by £77 which will be used to support the Counselling service. Many thanks to everyone who took part. Bob & Jan.

Horse Stories:

A Case of Fluoride Poisoning in Horses See page 17.



LEGER-ME CHRISTMAS PARTY

This will take place as in previous years at the Church Hall, Denton Green Lane (Off Brecks Lane), Kirk Sandall, Doncaster on Sunday 10th December 1.00 p.m.—4.00 p.m. We expect all the usual attractions will be there including Santa and our resident J & J Duo. Dan Dylan will add a little Magic and Circus Sparkle to the event. Please see the flyer for details or contact the helpline.

Members' Announcements

Telephone Problems.

Due to problems with the cable company, I have moved back to BT. This means that the email address starting mvys03487 is no longer operational, please use mike@leger.me.uk. The telephone number of incoming calls is 01302 787353. All previous numbers are non operational. A number of messages have apparently been lost because BT put a message-box on the line and the exchange without my agreement. This meant that in many cases the 'phone didn't even ring at my home. Please do not leave a message unless you hear the Leger ME announcement. Preferably, email me on mike@leger.me.uk because I check my emails far more frequently than the 'phone.

Christmas Party.

This will take place as in previous years at the Church Hall, Denton Green Lane (Off Brecks Lane), Kirk Sandall, Doncaster on Sunday 10th December 1.00 p.m.—4.00 p.m. We expect all the usual attractions will be there including Santa and our resident J & J Duo. Dan Dylan will add a little Magic and Circus Sparkle to the event. Please see the flyer for details or contact the helpline

Membership

As a result of a decision from the AGM, the minimum donation for membership will rise to £8 from April 2007. The main reason for this is the cost insurance and other costs incurred in providing extended services. Any donations paid prior to this date will be at the old rate.

Pathways

The recent increase in costs of postal charges has worked to our benefit for a change. The limiting factor for the size of Pathways was the 60g limit for the lowest rate of 2nd class post which allowed 8 sheets of paper to be sent. This has now been increased to 100g, which means we can send out far more pages and other items. The next issue of Pathways is due in February 2007.

Meetings

We will not be organising any more formal meetings until the Spring. There will be 'drop in' sessions as the Redmond Centre on the 4th Friday afternoon of the month at the Redmond Centre, except of course, December. We will however be on the helpline as usual to deal with any problems that may arise over the holidays. Mike or Sally will arrange any appointments as necessary when required.

Linking UP

Hope everybody's okay! It is hard to believe that Linking Up has been running now for a two full years. As we go into the winter of 2006 we have 26 members which isn't bad but could be better, and it is my hope that some of you reading this who are not yet members may consider joining in the new year. It takes me time and effort to collate, print off and send out the updates four times a year, so please help me by keeping me informed of any changes to your contact details or whether you are still an active member or not. In addition, let me know if you wish to add extra details, for example your email address. Please continue to make fresh contacts, especially with new members, you'll make their day and yours! With all good wishes for a peaceful Christmas and a happy and healthy New Year. *Carolyn.*

Counselling Service

The Counselling Service is taking a well earned Christmas break. We will be resuming the service in the new year, when there will be more places available. The Counselling contact-line number is 07962 907053. Please leave your name and telephone number then Sally will ring back, or ring Mike at Leger ME on 01302 787353 if you feel you need to contact us over the Christmas period. Special thanks to Bob and Jan for fundraising for us to help with the running costs of the service.

On the Horizon

A Magic Show organised by John Turner around Easter and a new Treatment Review Service.

Merry Christmas and Happy New Year to all our readers...Mike.

You Write

Christine writes: *My mum has relied on a drug called Mianserin for a number of years. I have been told it has been removed from prescription. Do you know why, what class of drug this is and if it has been removed for good, and if there is an alternative that may have a similar effect?*

Mianserin is a tricyclic type anti depressant, and there are alternatives. This drug reduces patients' white blood-cell count. (leucopenia, agranulocytosis and aplastic anaemia). Blood counts were always supposed to be done every four weeks on patients receiving this drug. If they went too low, they would be susceptible to infections and cancer in a similar way to AIDS or chemotherapy patients. I never found that this was done in practice. In practice even a small dose affected many patients blood-counts, and there was always a short odds gamble with risk versus benefit trade off. The only advantage it has over amitriptyline is fewer side effects (e.g. dry mouth, blurred vision etc.), but the blood problems associated with this drug make it unattractive to many pharmacists and doctors now that better products are available. Personally I would advise anyone with ME/CFS to avoid it, if possible, as there are safer drugs with fewer side effects available now e.g. nortriptyline.

I have checked at the time of writing (November 2006) with a local pharmacy chain in Doncaster, and it is still available to meet prescriptions and has not been recalled. However I would not be surprised if it were withdrawn. The drugs policies of Primary Care Trusts and Hospitals are becoming increasingly individual and cautious, and vary widely from area to area. My opinion is that mianserin should not be given to patients except as a last resort, or if a patient is already stabilised on it with no significant side effects. It certainly should not be used outside a hospital clinic, and only then with regular blood-counts. If it were withdrawn, it might be possible to obtain it from the manufacturers on a 'Named Patient Basis' as with thalidomide (the infamous baby deformer). *Mike.*

Dave from SWAN Writes. *The National Coalition Against the Welfare Reform Bill will lobby Parliament and hold a Rally in London 4th December 2006 11.00 a.m. to 5.00 p.m. The Rally will be opposite the St Stephens Entrance to Parliament. From there we want groups and individuals to go and lobby their MPs, and challenge them about their position on the Welfare Reform Bill and let the Government know that we oppose the current Bill. These reforms are the most significant in sixty years, in many ways redefining the relationship of the state to disabled people claiming benefits. If passed, the Bill will bring in a form of US-style workfare, it will see disabled people threatened with the loss of benefits and possibly forced into unsuitable work or medical treatments, a massive intervention by the state into an individuals personal health on top of abolishing housing benefit in the private rented sector. In the present Bill, even when someone is unable to see, unable to hear, unable to stand, unable to dress, even incontinent of bowels four times a month, they will not be exempt for the provisions of the Bill! see <http://www.indymedia.org.uk/en/regions/>*

The Welfare Reform Bill was mentioned in the Queens Speech on the State Opening of Parliament on the 16th November. The issue that Dave is concerned about is abolition of Incapacity Benefit in favour of two new benefits 'May work again' and 'May not work again' which I have detailed in Pathways previously. Details of the proposals seem to be difficult to obtain, and some feel that there may be a media blackout. At this point in time all we have are proposals, and that's all they are until they receive the Royal Assent. I'm sure that we will hear more about this in the new year.

When Incapacity Benefit replaced Invalidity Benefit in the mid 90's there were similar concerns. It turned out to be a fairer system in one sense. If a claimant had a disbelieving G.P., then the DWP would be able to override the G.P.'s decision. There were teething problems, and on the whole I found that there was the odd refusal, but people usually won on appeal. My concern is which of the new benefits people will be moved to, and how this will be decided. Certainly some people with ME/CFS would welcome an opportunity to try to do something useful with their time which the current ICB rules are not friendly to. Whatever the new Bill says, it has still got to be implemented and interpreted. As with ICB what Parliament originally intended may not be interpreted in the same way by civil servants. It will certainly take 12 –18 months to roll out. Watch this space –*Mike.*

Anne Writes: *I wonder if you have heard about a new product from the States. A friend of mine in the USA has just sent me some information which has been published in some medical papers. "They have just completed trials and all were successful using a product called Ribose or D Ribose, it was used for ME, Fibromyalgia and CFS. You need to take 5 grams, 3 times a day, then after 2 weeks you can drop down to 5 grams twice a day. They are seeing results in 2 weeks and one man saw a difference in less than a week. It is reasonably priced. I just wondered if you have heard of it and what you think.*

Yes, I know about Ribose. It is a type of sugar used for athletes as an energy source particularly in the cycling community. Dr. Myhill has been using it for the past 18 months. It's along the lines of what I've featured in Pathways about mitochondrial issues. I contacted Dr. Myhill and asked if she could supply anyone apart from her patients. She is unable to supply nutritional supplements prepared in her practice to non-patients unless their medical practitioner (this can be your GP or any other medical doctor whom you have consulted) writes to her and requests that a supply be made. This is a standard letter she sends :

Dear Dr.,

I have recently received a request from your patient for one of the nutritional preparations I dispense from my practice. In order to get round any bureaucratic regulations I would need a written record of your prescription for such preparations as Myhill's Magic Minerals, analar grade magnesium sulphate for nebulisers, D-ribose, acetyl-L-carnitine or mineral drops for each of your patients. This can be in the form of an e-mail (easier) or a letter. When sending your prescription letter with the patient's details, please indicate what you are recommending and for how long you want me to supply that patient under that prescription – say, for one year, or "1 pack x 5", or "for life", or "indefinitely" (e.g. MMMs). Please, kindly advise your patients that they need to contact my office directly to find out the price of the supplement(s) and the carriage costs, as payment is required before dispensing.

Dr Myhill firmly tells me that that ribose can help patients with ME/CFS. I know of two people who have tried it. In one it had no effect, and in the other it reduced the rebound recovery time from a matter of days to several hours. It is sold in the UK to the cycling hobbyist market as an energy-promoter similar to glucose is e.g. in Lucozade or Dextrosol. The raw powder usually costs around £60 per 500g and can be bought in capsules. Dr. Myhill charges about £30 per 500g. There is a whole range of 'sport' confectionery based around ribose on sale in the States and Australia. Although ribose is used for a medical purpose, there is no product licence, it is classed as a food supplement. I do however think its use needs caution, and certainly should be supervised by a doctor. On the following pages I have reproduced a data sheet from an Australian government website.

Date and Oat Bars

Healthier cake bars for a delicious tea-time festive treat. Makes 12. Ready in 1 hour, plus cooling time

PER SERVING:- Calories: 275, carbohydrates 36g, saturated fat 8g, added sugar 6g.

INGREDIENTS:- 175g pitted dates, chopped, 75g soft brown sugar, 75g porridge oats, 25g sunflower seeds, 200g plain flour; sifted, 175g butter; melted, 2 tbsp golden syrup.



Preheat the oven to 150C/130C Fan/Gas 2. Line a 18 cm shallow square tin with baking paper. Put the dates in a small saucepan with 25g sugar and 4 tablespoons water. Cover and simmer, stirring occasionally, for 5 minutes, or until the dates are soft and the liquid has been absorbed. Turn into a bowl to cool. Mix the oats, remaining sugar, sunflower seeds and flour in a large bowl. Melt the butter in a small pan with the golden syrup, then mix with the oats. Spread half in the base of the tin, pressing lightly, then spread the dates on top. Cover evenly with the rest of the oats. Bake for 45 minutes. Mark into 12 bars while warm and leave in the tin to cool.

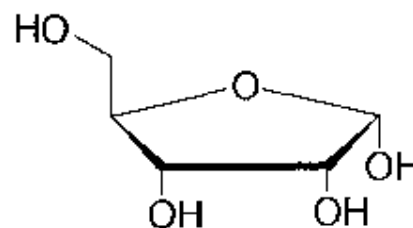
If something stronger than tea would be good, then Cockburn's Special Reserve Port with mellow rich flavours of raisins and cherries works well with dates and oats

Ribose Data Sheet (from the Australian Government Website)

RIBOSE is a carbohydrate naturally found in all cells of the body. Physical stress can increase the loss of nucleotides (such as ATP, ADP and AMP) from the heart and skeletal muscles. Ribose metabolizes into 5-phosphoribosyl-1-pyrophosphate (PRPP), which is a rate limiting substance used in the synthesis of nucleotides.

TRADE NAMES Ribose Power (Champion Nutrition), Ribomax Ribose (Natural Balance), Ribose Fuel (Twinlab), Rx-Energy Ribose (Nutritional Dynamics) and Mega Ribose Fuel (Twinlab).

DESCRIPTION D-ribose is a naturally-occurring five-carbon sugar found in all living cells, as well as in RNA-containing viruses. It is not an essential nutrient, since it can be made in the body from other substances, such as glucose. D-ribose, however, is very essential for life. Some of the most important biological molecules contain D-ribose, including ATP (adenosine triphosphate), all the nucleotides and nucleotide coenzymes and all forms of RNA (ribonucleic acid). D-ribose, in the form of ribonucleoside diphosphates, is converted to deoxyribonucleoside diphosphates, precursor molecules for DNA. D-ribose in RNA and D-deoxyribose in DNA may be considered genetic sugars. Since D-ribose is ubiquitous in living matter, it is ingested in our diets. Such nutritional substances as brewers yeast are rich in RNA and are thus rich sources of D-ribose. Some recent research suggests that supraphysiological amounts of this sugar may have cardioprotective effects, particularly for the ischaemic heart. D-ribose is a sweet, solid, water-soluble substance that is also known as alpha-D-ribofuranoside. L-ribose does not have biological activity. D-ribose is sometimes referred to as just ribose. Supplemental D-ribose is produced from the fermentation of corn syrup. D-ribose has the following structural formula:

**ACTIONS AND PHARMACOLOGY**

ACTIONS Supplemental D-ribose may have metabolic cardioprotective activity. It may also enhance de novo purine biosynthesis.

MECHANISM OF ACTION Following a cardiac ischaemic event, ATP levels in the heart decline rapidly and are slow to rebound. 5-Phosphoribosyl-1-pyrophosphate (PRPP) is a key intermediate in the de novo and salvage pathways of purine nucleotide formation, as well as a key intermediate in synthesis of pyrimidine nucleotides. PRPP is the biochemically-activated form of D-ribose and is synthesized from D-ribose-5-phosphate, which is produced in the oxidative pentose phosphate pathway (PPP). The limiting step in the PPP is the glucose-6-phosphate dehydrogenase (G-6-PD) reaction. The G-6-PD reaction can be bypassed with D-ribose. In supraphysiological amounts, D-ribose may serve as a precursor to PRPP, which then allows for de novo synthesis of purine nucleotides, including ATP. D-ribose infusion has been shown to significantly enhance the recovery of energy levels in the post-ischaemic myocardium in animal models.

PHARMACOKINETICS About 88% to 100% of an oral dose of D-ribose, up to 200 milligrams per kilogram per hour, is absorbed from the small intestine, from whence it is distributed to various tissues of the body, including cardiac muscle and skeletal muscle. Very little first-pass metabolism occurs in the liver. Following transport into cells, D-ribose is phosphorylated to D-ribose-5-phosphate. D-ribose-5-phosphate is metabolized via a number of pathways, including the pentose phosphate pathway and glycolytic pathway. Its metabolism is complex. It is also metabolized to PRPP, which is the precursor to purine nucleotides, as well as L-histidine and pyrimidine nucleotides. Those receiving very high doses of D-ribose excrete a small fraction of the administered dose unchanged in the urine.

INDICATIONS AND USAGE D-ribose may have some protective effects in cardiac ischaemia. Claims that it is an effective "energizer" and exercise-performance enhancer are not substantiated.

by credible evidence. D-ribose may also be beneficial in some rare genetic diseases, such as adenylosuccinase deficiency and myoadenylate deaminase deficiency.

RESEARCH SUMMARY In a study of 20 men (aged 45 to 69 years) with documented severe coronary artery disease and a history of angina induced by normal daily activities, 60 grams of ribose (in four doses of 15 grams each) were tested against placebo. Treated subjects exhibited improvement as measured electrocardiographically, and time to onset of moderate angina (during exercise testing) increased significantly in those ribose-treated subjects. There was no significant electrocardiograph improvement in the placebo group, and there was no significant difference between the groups in time to onset of moderate angina. The authors concluded: "In patients with CAD, administration of ribose by mouth for three days improved the heart's tolerance to ischemia. The presumed effects on cardiac energy metabolism offer new possibilities for adjunctive medical treatment of myocardial ischemia."

Claims that supplemental ribose is an energy booster and exercise/athletic-performance enhancer are unfounded. Studies sometimes cited in support of these claims fall far short of being substantiating. It has been shown that administration of ribose in patients with myoadenylate deaminase deficiency disease can reduce cramping and stiffness caused by exercise. On the other hand, in a double-blind, placebo-controlled crossover trial of ribose in McArdle's disease, 60 grams of ribose daily for seven days failed to improve exercise tolerance in these subjects. Finally, there is one case report of a patient with adenylosuccinate deficiency whose neurological symptoms (behaviour and seizure frequency) improved with supplemental D-ribose.

CONTRAINDICATIONS, PRECAUTIONS, ADVERSE REACTIONS

CONTRAINDICATIONS None known.

PRECAUTIONS Pregnant women and nursing mothers should avoid supplemental D-ribose. Supplemental D-ribose may cause hypoglycaemia and elevation in uric acid levels. Those with gout should avoid supplemental D-ribose, and those with elevated uric acid levels and hypoglycaemics should exercise extreme caution in its use. Those with diabetes should also exercise extreme caution in its use. And those diabetics who decide to try D-ribose must be under a physician's supervision and have their blood glucose levels closely monitored and their antidiabetic medications appropriately adjusted, if necessary.

ADVERSE REACTIONS Reported adverse reactions include hypoglycaemia, hyperuricemia, hyperuricosuria, diarrhea, nausea and headache.

INTERACTIONS Antidiabetic drugs: D-ribose may cause hypoglycaemia. Diabetics who use D-ribose must have their blood glucose levels closely monitored and their antidiabetic medicines appropriately adjusted, if necessary.

OVERDOSAGE No reports of overdosage.

DOSAGE AND ADMINISTRATION No typical dosage. Most experimental studies with ribose used very high doses, usually about 60 grams daily.

HOW SUPPLIED Capsules — 500 mg, Powder, and Tablets — 500 mg, 1000 mg

*Claim from a manufacturer ...***Fibromyalgia and Muscle Health**

"Researchers now believe that muscle and energy challenges may be a result of a deficiency of substances needed for the production of ATP. In addition, many times these individuals have low-oxygen conditions in their muscles. Ribose can be of substantial benefit in the production of ATP and related compounds in low-oxygen conditions. It has even been awarded a patent for the treatment of fibromyalgia." So what about ME/CFS ? .. You tell us. - Mike

Comments about draft NICE Guidelines of 26 09 06 for ME/CFS. by M. Valentine.

Being the Leader of the Leger ME Support group in Doncaster, I have experience of over 500 cases, mainly Moderate and Severe. I suffered from ME/CFS 14+ years. I have also studied the NICE guidelines for Depression and Alzheimers.

When the CMO's report was published an number of years ago we hoped that it would end all the controversy about ME/CFS. Well sort of. We have a new network of NHS clinics, BUT being NHS they have to work to 'evidence based practice'. The trouble is that the 'evidence' does not comply with NHS requirements. NICE (National Institute of Clinical Excellence) is a government body set up to research best economic practice for the NHS. Everyone will have heard of their controversial recommendations about denying expensive life saving cancer treatments. Their recommendations about Alzheimers treatment are just as controversial. As far as a ME/CFS is concerned, it's just as bad. The bulk of the 'evidence' that they have considered is based on Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) studies, which may be effective in mild cases, but certainly do not have any impact in moderate or severe cases as anyone in the ME/CFS world knows. The main problem is that most of the expertise is within the research and private sector. The remit of NICE excludes evidence from these areas as well as foreign studies. I have reviewed the draft and offer the following comments. Please see the NICE Website for further information.

Aetiology (Disease origin). Through experience and involvement with patients, I have concluded that there could be as many as six subtypes of presentation in CME/CFS. Very often the boundaries are blurred, and the main features may vary.

Subtype	Main Features	Prognosis
Pure Chronic Fatigue Syndrome	Psychiatric or mental health.	Good if mental health issues can be cleared.
Depressed Immune Function	Recurring infections.	Poor.
Dysfunctional Immune Function	Multiple Chemical Sensitivity and other auto immune issues.	Poor, can progress to Arthritis or Lupus.
True ME as 1955 Royal Free Hospital experience (Ramsay)	Neurological damage. Allied to Post Polio Syndrome. IBS.	Poor
Post Viral Fatigue Syndrome	Fatigue, Myalgia.	Severe 1-2 years, good after 4-5 years. Recovery often partial.
Fybromyalgia Syndrome	Myalgia	Poor

Recent Gene Expression Studies have identified as least two subtypes. This really should be acknowledged, if only for financial implications because insidious onset has a poor prognosis.

Grading. Severe and Very Severe are should be classed separately as the indication for interventions are different.

Screening Tests (1. 2. 2. 2). The following tests which are not commonly carried out within the NHS frequently produce out of reference range results. Erythrocyte magnesium, NAD, SodASE, and Mitochondrial Profile.

Envelope Theory (1. 3. 1. 10). Go and ask the Patients ! Almost all patients and private doctors I have dealt with acknowledge and find it one of the main management strategies. Most patients find out by experience. Rebounds, where are a worsening of problems which occurs after an activity (cf osteoarthritis). This may happen immediately in new cases, but may be delayed many days in veteran cases. Very often as patients improve, they recover more quickly from rebounds. One case involving a child of 14 took six months to recover.

Complete Bed Rest (1. 3. 1. 10). In the very early stages, possibly before diagnosis, complete rest is mandatory especially if an active severe infection is present and may also be mandatory for longer in some severe cases.

Graded Exercise Therapy (1. 3. 1. 14). The research presentations that I've reviewed only deals with Mild cases. My personal experience is that many Moderate or severe cases drop out early in a programme, mainly due to rebound issues.

Sleep Issues (1. 3. 2. 1). I agree with sleep hygiene techniques, but the evidence I've seen only deals with Mild cases. Almost all patients I deal with are in the Moderate to Severe grades and have a diurnal variation. This is often reflected in late production of cortisol studies. They fall into three classes,

a) Early day. The early day patients tend to be waking early in the day, and at some later time in the day become lethargic and drowsy.

b) Late day. The late day patients experience a morning stiffness similar to that in arthritis, and 'turn on' later in the day as is seen with some Parkinson's Patients. If these patients are forced to be active in a morning, they become drowsy and lethargic and may sleep uncontrollably. In patients where the severity is variable, the degree of disturbance is related to the ME/CFS intensity.

c) Shifted sleep phase. This occurs mainly in early in a case or in paediatric cases. Typically the sleep phase is delayed 4-6 hours, but may be as much as 12 hours in children.

Sleep problems usually improve as the patient recovers, and are a manifestation of the disease.

Pharmacological interventions are very often for social reasons rather than in the patient's interest.

Thyroid Hormones (1. 3. 4. 4). While conservative medical opinion dictates that thyroid hormone should not be give to euthyroid patients, there is a group of doctors and patients who strongly disagree with this. Most ME/CFS patients have T4 levels within the lower quartile of the reference interval. My experience is that thyroid supplementation does have a beneficial effect, providing it does not send the T4 out of the reference interval. My suspicion is that the T4 lower reference interval for ME/CFS patients should be 8 pm/l rather than the current 12 pm/l. Many ME/CFS patients have a reduced body temperature, which may suggest they are hypothyroid contrary to lab findings. Thyroid supplementation has also caused resolution of parallel depression in some cases. Armour thyroid is popular with some private doctors. The use of raw thyroid was abandoned many years ago. Use of this product very often leads to abnormal T3:T4 ratios.

Gut fermentation (1. 3. 4. 5). Gut fermentation is a major issue with many ME/CFS patients and is easily treated, if present. It can be easily checked by standard lab tests and even recreational alcohol detection devices. Levels returned vary from 5-15 mm/l. This test is one of the earliest performed by private doctors, and is treated with antifungals like nystatin.

Melatonin (1. 3. 4. 7). Many private patients find melatonin of benefit. It is freely available abroad. No pharmaceutical company is interested in seeking a product licence because it cannot be patented. This should not be a bar to NHS patients.

Tricyclics (1. 3. 4. 8). Amitriptyline is the most popular with many clinicians. However anticholinergic side effects very often limit its use. My experience is that Nortriptyline is just as effective with fewer side effects.

Hydrocortisone (1. 3. 4. 9). Small does of hydrocortisone may be useful, as some immunosuppressants have a beneficial effect in some patients and reduce the effect of a rebound.

Nutrition Issues (1. 3. 5). Many ME/CFS patients can identify new individual food intolerances coinciding with ME/CFS onset. If an issue, avoidance can have a dramatic effect on recovery. Research (e.g. Behan, Puri) has shown that omega 3 & 6 fatty acids have a beneficial effect in some cases of ME/CFS. Although these products are available on the NHS, there are not licensed for ME/CFS. They are very often prescribed privately.

Vitamins & Minerals (1. 3. 6. 3). B12 given by subcutaneous injection helps many patients, despite apparently-normal blood chemistry. Most of the experience with this drug is in the USA and private sector. When vitamin deficiency tests are carried out, mainly in the private sector, specific abnormalities are often found mainly with Q10, NAD, Magnesium and Zinc. Many patients are aware of this and choose to supplement themselves with A - Z multivitamin available from health shops or pharmacies with beneficial results. This approach is popular with the private sector. *Mike*

I sent a copy to Bryan Ashworth who is a private health practitioner. His comments were

"Isn't it sad that after so many years there are still many problems?"

1. *Melatonin we have found that a number of people have side effects and we no longer recommend it.*
2. *We have not found a solution to sleep problems - called by John Richardson "night owl syndrome" and as in most aspects of the illness sufferers have to build it into their management routines.*
3. *Omega 3,6,9 is available from health food stores (Holland and Barrett) at a reasonable price. It does seem to help and the product is easy to obtain.*
4. *Nutrition - we concentrate on this because it is proven to help. Fruit and green vegetables are obvious. We do not believe that the concentration on organic is justified - it is expensive and in many cases the claims that a product is organic cannot be sustained.*
5. *Vit B12 - we agree with you and have experience of many who have been helped. It does need to be monitored quite carefully."*

Christmas Poems from the SoME Poetry Website.

Many people find writing poetry gives consolation. Christmas can be a stressful time for many people with ME/CFS

Alone at Christmas

Alone at Christmas
 No, I had not thought so soon Lord.
 Maybe in some far distant time when old
 and gnarled.
 Death had robbed me of my loved ones,
 And death was near.
 Not now...

Yet in the dusk, beside the flickering candle
 flames,
 Before the crib.
 I feel you here with me,
 And I with you.

So many families will forget you Lord,
 Your special day.
 Not I this Christmas,
 Thank you Lord.

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Christmas Is Coming

Christmas is coming,
 The goose is getting fat.
 But I'd rather have my health back,
 Than any of that.
 Presents round the tree,
 Gifts for me and you.
 But I'd rather have my health back,
 Than anything new.
 Turkey on the table,
 "Another brussels sprout"
 But I'd rather have my health back,
 And go without.
 Santa down the chimney,
 Carols on TV.
 But I'd rather have my health back,
 If it's up to me.
 Christmas can be wonderful,
 Good times, good fun, good cheer,
 But I rather have my health back.
 THIS YEAR !

© Vicky Gifford

Vitamin Supplements & ME/CFS.

(Please read in conjunction with the feature on mineral supplements in Pathways No. 9)

Earlier on this year, a meeting was convened in Sheffield on nutritional issues, with local support groups, staff from the Sheffield Clinic, dieticians, nutritionists and other health professionals. One outcome was that vitamin supplements had a rôle to play in the management of ME/CFS but there was disagreement on what how and when to use food supplements, so no overall consensus was reached. One dietician from Leeds was quite adamant that vitamin supplements should only be given in proven deficiency following a diagnosis and lab test, and then only if there were problems in getting a balanced diet. This is the NHS 'evidence-based approach'. One private nutritionist said he could substantially improve people's health in several months using vitamins and minerals.

At the meeting we were shown a sheet about ME/CFS from the British Dietetic Association written by Sue Luscombe. You can find it on www.bda.uk.com. Here is an extract from what she wrote:

Diets to help recovery.

The body needs a balance of healthy foods to ensure optimum health. Eat regular meals and snacks. Foods to choose include:

Bread, other cereals including rice and pasta and potato; eat these at every meal.

Fruit and vegetables; aim to eat five or more portions a day.

Meat, fish and alternatives-such as chicken, fish, egg, nuts, Quorn, beans, pulses, soya alternatives. Include these at two meals throughout the day

Milk and milk products including cheese and yoghurts

There are many diets, (such as the anti candida diet), that claim to improve CFS/ME symptoms. However, there is very little scientific evidence to support these claims. Such diets can be very restrictive and can create a lot more work and effort for the sufferer and their carers. Care needs to be taken that the diet remains healthy, nutritionally adequate, and there is no unwanted weight loss or gain. Also, consideration must be taken that benefits outweigh extra demands on the sufferer and carers.

Weight changes and concerns

It is common for there to be weight changes in those with CFS/ME. Weight increase may result from a much reduced activity level, when appetite remains unchanged. Typically, exercising can make muscle pain worse, so restricting the ability to be active. To counteract a lower activity level, choose healthy foods with a good intake of fruit and vegetables (5+ portions). Energy-dense, (high fat/sugar) foods such as biscuits, chocolate, cake, crisps and sugary drinks need to be kept to a minimum. Weight loss can occur if the appetite is poor and nausea is present or if it is difficult to buy and prepare foods due to fatigue. To help minimise this, eat regularly. Try small, quick and easy meals and nourishing snacks such as beans or egg on toast or a bowl of vegetable soup.

Food allergy and intolerance.

CFS/ME may affect or be affected by the immune system, but exactly how is unknown. The number of those affected by food allergy or sensitivity is unknown, but likely to be relatively few. Some sufferers report that symptoms do improve by excluding certain foods such as milk and/or wheat. Your doctor can refer you to a dietician if you would like further advice on food allergy or hypersensitivity. See also the BDA food fact sheet on food allergy and intolerance.

What about supplements?

Further research is urgently needed in this area. There are many nutritional supplements, including vitamins, minerals and essential fatty acids, (omega 3), and co-enzymes claiming to help tiredness. Some are very expensive and contain mega-doses of the active ingredient. Large doses of some vitamins, for instance Vitamin A and B6, can be harmful. If you are concerned about nutritional intake, keep to a multivitamin and mineral supplement, with no more than 100% of recommended daily intake.

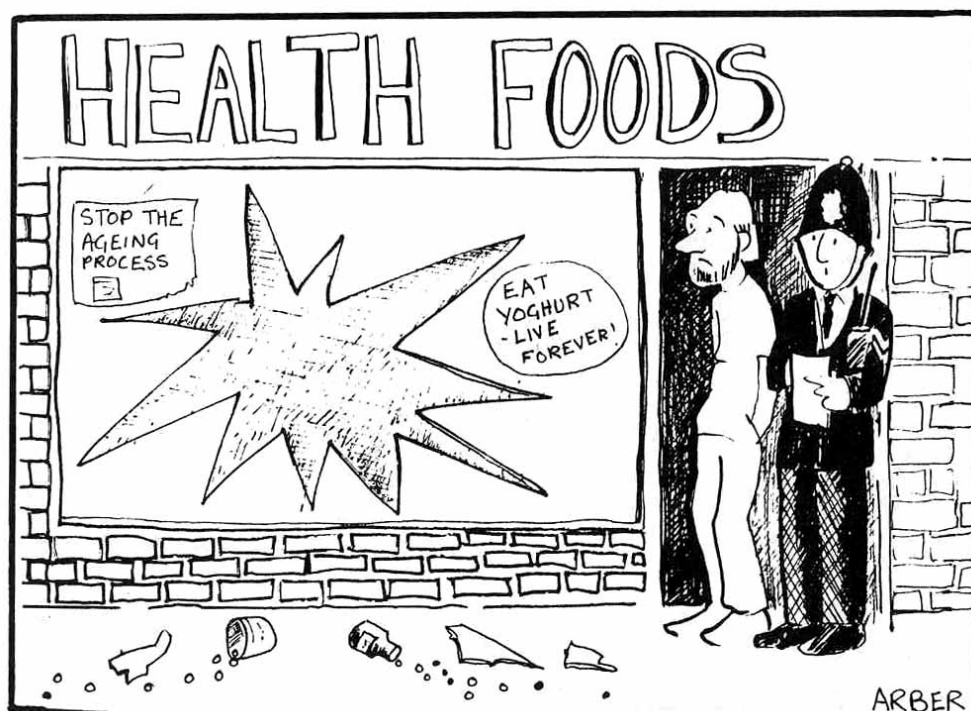
Vitamin Insurance or Assurance ?

My own view is that when people are ill, there will be some deficiency somewhere, but it is impractical and expensive to do the necessary tests. Private doctors treating ME do rely heavily on food supplements when treating their patients. In theory anyone receiving a properly balanced diet should not need to take food supplements. Most people with ME/CFS turn out to have some deficiency or other either due to disease or to obtaining a balanced diet due to practical problems with preparing food, cooking and shopping. From my experience the main problems I've come across are with B1, B2, B3, B6 and B12. Since the costs of most multivitamin and mineral supplements is between £2-3 a month it is cost effective to take a general comprehensive A - Z supplement rather than single individual supplements. Most of the products are similar, and there is very little difference between products. I view this as an early intervention in ME/CFS which the patients can do themselves. Although there may be a placebo effect component, my experience is most sufferers benefit to some degree or other. There are labs like Biolab and other private laboratories that offer analysis for deficiencies. Hair analysis is a popular private option. Personally I believe this a waste of money unless recommended by a health professional.

Over the page I have chosen four multivitamin products to compare, these are the ones I have access to. The Biocare product is recommended by private doctors and other health practitioners. It is a high-dosage product, at many times the recommended daily amount. I personally have found it to make a difference. If I take a lower dose supermarket product like the other three I find my ME/CFS is worse. A high dose

product is available on the NHS, but only in special circumstances. There is really nothing to choose between the Sanatogen and Co-op brands. Thoughtfully, the Co-op have Braille embossed on their label. The Centrum product contains synthetic azo/coal tar dyes. E110 is Sunset Yellow, and has been associated with hypersensitivity reactions in children and allergies. Such dyes are totally unnecessary, and do not contribute to the effectiveness of the product. The reason is possibly for patient or proprietary reasons. This could be a problem as about 30% of ME/CFS patients have allergies or substance sensitivity.

There are some people who advocate mega dosing. The best example is of Ascorbic Acid, vitamin C. Although the RDA is 60 mg some suppliers sell it as a powder or 500mg tablets. Overdosing with vitamin C may cause mild diarrhoea. That may cause partial starvation, with electrolyte and fluid loss. This may give some temporary relief by depressing the immune system but is not recommended. Megadosing with one of the B vitamins may cause deficiency of the others. Vitamin A is toxic above 5000 units daily. The best example of that was polar explorer Anderson who got vitamin A poisoning due to eating dog livers. A 1000 ug injection of B12 which is given by some private doctors acts as a drug rather than a vitamin. Although the dose is high it usually has no side effects but very often causes concern to many doctors not familiar with its use in ME/CFS. Like many interventions for ME/CFS it only works in about 30% of patients.



"IN A CASE LIKE THIS SIR. WE PLAY A WAITING GAME - SEE WHICH OF THE LOCAL VILLAINS LIVE TO A HUNDRED THEN WE SWOOP IN AND NICK 'EM."



Popular Brands of Multivitamins Compared.

(Based on manufactures carton information and data sheets)

Vitamin	Biocare MV + Minerals	Sanatogen Gold A - Z	Centrium Select 50 +	Co-op Total MV & Min.	Recommended Daily Amount	Essential For Health
A	2000 µg	800 µg	800 µg	800 µg	800 µg	Antioxidant , eyes, skin
B1 Thiamine	25 mg	1.4 mg	2.1 mg	1.4 mg	104 mg	Energy,, brain function
B2 Riboflavin	25 mg	1.6 mg	2.4 mg	1.6 mg	1.6 mg	Energy, skin, hair, nails
B3 Niacin	50 mg	18 mg	18 mg	18 mg	18 mg	Energy, nerves
B5 Pantothenic acid	100 mg	6 mg	6 mg	6 mg	6 mg	Energy, nerves
B6 Pyridoxine	25 mg	2 mg	3 mg	2 mg	2 mg	Energy, immunity
B9 Folic Acid	400 µg	200 µg	300 µg	200 µg	200 µg	Blood, nerves. heart
B12 Cyanocobalamine	30 µg	100 µg	3 µg	1 µg	1 µg	Blood, nerves, liver
C Ascorbic Acid	243 mg	60 mg	120 mg	60 mg	60 mg	Antioxidant, skin bones, teeth (ageing), Immunity
D Calciferol	250 iu	5 µg	5 µg	5 µg	5 µg	Bones, teeth
E α-Tocopherol	75 iu	10 mg	12 µg	10 mg	10 mg	Skin, immunity
H Biotin	35 µg	150 µg	150 µg	150 µg	150 µg	skin, protein energy
K Phylloquinine		30 µg	30 µg	20 µg		Bones, teeth, blood clotting
Inositol	12 mg					
Lutin		275 µg	1 mg			
PABA	10 mg					
Minerals	Mg, Zn, K, Ca, Mn, Mo, Se, Cr, I	Ca, P, Fe, Mg, Zn, I, Cu, Cl, Mn. Mo, P, Se, Cr	Ca, P, Fe, Mg, Zn, I, Cu, Mn, K, Cl, Cr, Mo, Se	Ca, P, Fr, Mn, Zn, I, K, Cu, Cr, Mn, Se, Mo, Cl		see Pathways no 9
Excipients	Natural	Natural	Synthetic, natural	Synthetic natural,		Makers' bulking agents
Added Dyes		Mineral Iron Oxide Titanium	E 110, E129, E 132, E171	Mineral, Iron Oxide.		Iron oxides are relatively safe. E numbers have . sensitivity issues
Allergy Caution	From Soya		Issue Azo dyes (synthetic)	Nitrate		
Comment	High dosage under professional supervision	Ethical— Safe doses	. Synthetic dyes hyper-sensitivity issues.	Ethical— Safe doses		

Carbon Monoxide Safety Issues and ME/CFS

When the news first broke of the recent Corfu tragedy, which resulted in the death of two children aged 6 and 7, and the severe poisoning of their father and his partner, carbon monoxide (CO) immediately sprang to my mind before anyone had any definite information. Every year in the U.K. more than 50 people die from carbon monoxide (CO) poisoning caused by gas appliances and flues that have not been properly installed or maintained, whilst many others also suffer ill health. Over the years, I have come across of two cases of ME/CFS patients experiencing an apparent deterioration in their health which turned out to be carbon monoxide poisoning. Fortunately neither cases were fatal. One was the result of a faulty gas appliance, the other of a coal fire. With the winter rapidly approaching I thought it would be a good idea to explore the subject of carbon monoxide.

What Is Carbon Monoxide. Carbon monoxide is a colourless, odourless, tasteless, toxic gas that has the molecular formula CO. The molecule consists of a carbon atom that is triple-bonded to an oxygen atom. Carbon monoxide is produced by the incomplete combustion of the fossil fuels gas, oil, coal and wood used in boilers, engines, oil burners, gas fires, water heaters, solid fuel appliances and open fires. Carbon monoxide is a commercially important chemical. It is also formed in many chemical reactions and in the thermal or incomplete decomposition of many organic materials. Dangerous amounts of CO can accumulate when as a result of poor installation, poor maintenance or failure or damage to an appliance in service, the fuel is not burned properly, or when rooms are poorly ventilated and the Carbon monoxide is unable to escape. Having no smell, taste or colour, in today's world of improved insulation and double glazing it has become increasingly important to have good ventilation, maintain all appliances regularly and to have absolutely reliable detector alarms installed giving both a visual and audible warning immediately there is a build up of CO to dangerous levels. With NO SMELL, TASTE or COLOUR, CO detectors are the only way to alert you to increasingly dangerous levels of CO before tragedy strikes.

What are the effects of carbon monoxide? Carbon monoxide poisons by entering the lungs via the normal breathing mechanism and displacing oxygen from the bloodstream. Interruption of the normal supply of oxygen puts at risk the functions of the heart, brain and other vital organs of the body.

Concentration ppm (parts per million)	Inhalation time and toxic effects developed
50 (0.05%)	Maximum Safety level as specified by the Health and Safety Executive
200 (0.2%)	Slight headache within 2-3 hours. Fatigue
400 (0.4%)	Frontal headache within 1-2 hours, becoming widespread in 3 hours
800 (0.8%)	Dizziness, nausea, convulsions within 45 minutes, insensible in 2 hours
1000 (1%)	Fatal

The above information is for a healthy adult. Persons suffering from heart or respiratory health problems, infants and small children, unborn children, expectant mothers and pets can be affected by CO poisoning more quickly than others in the household and may be the first to show symptoms. You are particularly at risk when you are asleep because you cannot recognise the early symptoms of CO poisoning. These include tiredness, drowsiness, headaches, giddiness, nausea, vomiting, pains in the chest, breathlessness, stomach pains, erratic behaviour and visual problems. These symptoms can mimic many common ailments and may easily be confused as with ME/CFS, flu, or simple tiredness. If you or your family experience the above symptoms and you believe CO may be involved you must seek urgent medical advice. Your doctor will need to test you for a blood or breath sample. Be aware, CO quickly leaves the blood and tests may be inaccurate if taken more than four hours after exposure has ceased.

Why is Carbon Monoxide so Dangerous ?



Carbon monoxide (CO) is produced whenever carbon-containing substances are heated or burned in an insufficient supply of oxygen. In a plentiful supply of oxygen relatively harmless Carbon dioxide (CO₂) would be produced. CO is a chemical curiosity. It contains trivalent carbon as opposed to the normal quadravalency, and trivalent oxygen, as opposed to the normal divalency. It's structural formula has two normal covalent bonds shown as a dash and a dative covalent bond, as shown by an arrow. As a consequence the molecule has a dipole moment, one side being positive with respect to the opposite side. This causes it to react with metals to produce carbonyls. Normally oxygen taken out of the air by the lungs converts deoxyhaemoglobin inside the red blood cells to oxyhaemoglobin (which is the oxygen carrier). In the tissues carbon dioxide replaces the oxygen and is recycled to the lungs as we breathe out. The oxygen take-up and release depends on a loose reversible chemical bond to the iron atom in haemoglobin. Once in the blood, carbon monoxide latches tightly onto haemoglobin about 240 times more strongly than oxygen's attraction. Even worse, once carboxyhaemoglobin (CHb), forms, the remaining haemoglobin molecules that carry oxygen are less likely to give up this vital gas to the tissues that need it. Most people normally have at most only a few percent of their haemoglobin as CHb. Smokers have much more than non smokers, and those who live or work in environments polluted by tobacco smoke are likely to have even higher levels of CHb than smokers themselves. As levels rise to 10% or more, symptoms of poisoning start to appear. At first, they are vague and non specific - headache, dizziness, weakness, nausea - and easily mistaken for a touch of the flu. As CHb levels rise, victims may experience shortness of breath, rapid heart beat, difficulty concentrating, confusion, visual problems, chest or abdominal pain and muscle cramps. The most severe cases of CO poisoning result in loss of consciousness and death

Safety First

- 1) DO NOT use poorly-maintained appliances that burn gas or other fossil fuels. Have all appliances serviced regularly by a trained, reputable and preferably registered engineer and make sure chimneys and flues are clean and not blocked. Do not take short cuts with gas appliances.
- 2) Fit a carbon monoxide alarm that meets British or European Standards.
- 3) Never use unflued appliances in small closed-up rooms.
- 4) Do not use gas appliances if they produce yellow flames or brown staining around, or on appliances and deposit soot on walls and fireclay radiants (apart from flue less fires). Pilot lights that frequently blow out or increased condensation inside windows can be warning signs.
- 5) Fit an extractor fan in your kitchen.. A kitchen full of cooking fumes is dangerous.
- 6) For work on all appliances always employ a qualified, reputable and preferably registered engineer.
- 7) For work on gas appliances always employ suitably qualified engineer who is registered with the Council for Registered Gas Installers (CORGI).




HSE Gas Safety Advice Line 0800 300 363 (Freephone service)
Transco Gas Emergency (24 hours) 0800 111 999 (Freephone Service)

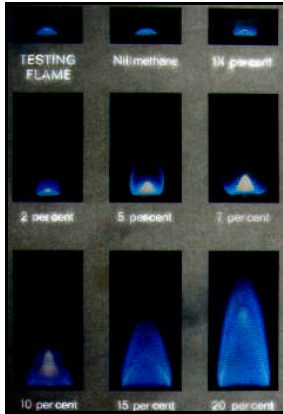
CO is a national and international problem. CO-Gas Safety, Consumer Safety International, CO Awareness and the Dominic Rodgers Trust are joining forces for CO AWARENESS DAY on 5th December. CO Awareness Day will start with a Press Conference at 10 a.m. at the House of Commons. The aim of the day is to raise awareness of the dangers of accidental carbon monoxide poisoning and how to prevent being affected. Attendees include CO victims who have themselves been poisoned by carbon monoxide and those who have lost friends and loved ones to this silent and preventable killer.

For more details please email office@co-gassafety.co.uk

Know the Symptoms of CO Poisoning...

Physical symptoms of CO poisoning vary, depending on the amount of CO in the bloodstream. The higher the concentration, the greater the danger.

Mild Exposure <ul style="list-style-type: none"> ▲ Slight headache ▲ Nausea ▲ Vomiting ▲ Fatigue ▲ Flu-like symptoms 	
Medium Exposure <ul style="list-style-type: none"> ▲ Severe headache ▲ Drowsiness ▲ Confusion ▲ Rapid heart rate 	
Severe Exposure <ul style="list-style-type: none"> ▲ Unconsciousness ▲ Convulsions ▲ Cardiac/respiratory failure ▲ Death 	



Manufacturers' literature showing how the Davy Lamp flame varied with methane level. Carbon monoxide burns with a pink flame, but miners would be dead at those levels.



Poisonous Gas in Coal Mines

When Davy invented the safety lamp in 1815, apart from a light that would not cause explosions, he produced a device to test the air. If the flame went out, there was no oxygen (blackdamp). The flame shape and colour indicated the amount of methane (firedamp), but not carbon monoxide. The 1911

Mines & Quarries Act required canaries to be kept at mines for the purpose of gas testing. Most mines usually kept about a dozen birds. This is still a legal requirement under the Act and has never been withdrawn in spite of more modern and accurate equipment being available. Birds have air sacs in lungs, and breathe about ten times quicker than we do. They are more efficient at extracting gases from the air, and so are more sensitive to toxic gas, showing ill effects before humans do.

The history of any coal mining area will turn up case after case of carbon monoxide poisoning. In the majority of cases the cause is 'after damp', the residual gases after an explosion or fire. Usually this was caused by fossil methane (firedamp) leaking from workings mixing with a limited supply of air and inevitably producing carbon

monoxide due to incomplete combustion. Other sources were underground diesel engines used to haul coal wagons and underground fires. Many of the bodies of miners recovered from such catastrophes showed, like the children in Corfu, no sign of injury except a pink skin colouration. *Photos Pete Davies*



Two versions of the Davy safety Lamp. Left an early model. Middle Davy Right two more recent examples formerly used at Bentley Colliery. The example at left carries the names of the 42 miners killed, along with 5 pit ponies, in a disaster at Bentley 20th November 1931.



Following an incident, rescue teams would take canaries underground in small 6 inch square cages with a single perch. There was no bottom in the cage to allow any gases from the floor to pass through. If the canary fell off its perch, that was an alarm to evacuate as quickly as possible, with the canary of course.



It was not until the 1960s-70s that portable testing equipment became available. These comprised of Dragger tubes, where the air sample was pumped through glass by a rubber bulb. The tubes contained a chemical which changed colour in the presence of Carbon monoxide and other dangerous gases. Since then, more modern electronic equipment has become available.

Following a fire incident in the 1970s at Creswell colliery, a 'self rescue device' for carbon monoxide was developed and was carried for personal protection. It was a mouthpiece containing a filter, though which air was drawn. Any carbon monoxide was converted to carbon dioxide by chemical action, a bit like the action of car catalytic converters.



This is a domestic CO alarm on my wall at home which shows the CO levels. It has only sounded 3 times. A count of 49

was when a new gas fire was installed. The CO came from the smoking protective oil on the heat exchanger. A count of 1 was recorded when my nephew burned some toast and when someone smoked a cigarette. All three also set off my smoke alarm.

Smoking and Carbon Monoxide

During World War I, it was typical for tobacco products to be included in military rations. Following the WWII war, cigarette-smoking was advertised as part of a glamorous, carefree lifestyle, and became socially acceptable for women. However in the 1930s, Nazi medical and military leaders grew concerned with the possibility that tobacco might be hazardous to human health and their scientists were the first to confirm this link. In the 1950s and 1960s, the medical community along with various governmental bodies, began a campaign to reduce the degree of smoking by showing how it damaged public health. Although tobacco smoking in many regions of the world has dropped dramatically in recent years, worldwide tobacco production is still growing. Smoking rates continue to remain relatively high in some Asian countries



Smokers have been found to have quite high levels of carbon monoxide in their blood, long after they have finished lighting up their chosen cigarette. CO increases risk of a blood clot. It is thought that through this mechanism smoking increases the risk of having an ischaemic stroke or heart attack. All too often, especially in winter the flu-like symptoms that are early warning signs of carbon monoxide poisoning are mistakenly attributed to a viral infection, and victims are sent home or back to work to breathe yet more of the deadly gas. Babies and small children (including unborn children), those with chronic heart or lung diseases and the elderly are especially sensitive to the harmful effects of carbon monoxide and are among those who are least likely to respond appropriately to the first signs of trouble. Although it had long been assumed that those who survive carbon monoxide poisoning suffer no lasting effects, studies in recent years have documented permanent problems that may not show up for weeks or months after an apparent recovery in a large minority of victims. They can experience long-lasting, even permanent, neurological and psychological damage that disrupts careers and families and destroys lives.

Drifting tobacco smoke (passive smoking) already kills more people than motor vehicle accidents, all crimes, AIDS, illegal drugs, etc. In other words, people are statistically more likely to die as a result of drifting tobacco smoke than by a car, gun, or the AIDS virus.

Carbon Monoxide from Internal Combustion Engines

It is well known that internal combustion engines produce carbon monoxide. If an engine is being used at full power output, e.g. at full throttle then level of CO is at a minimum. However there is a quirk in design of petrol engines that in order for them to idle or tick over a richer mixture of air/fuel is required, with its consequential increase in carbon monoxide output. For this reason engines should not run in a confined space e.g. garage. Matters are even worse, certainly in cars where heavy use of the choke is needed to start and warm up an engine.

Most modern cars have lean burn engines, and an electronic engine management system controlling fuel injection, timing and taking feedback from the exhaust gases, engine temperature and air flow which make cars cleaner. However, a catalytic converter is mandatory to convert remaining traces of CO to CO₂. Catalytic converters convert carbon monoxide and unburned hydrocarbons into water and carbon dioxide, both of which are common and relatively harmless.



Horse Stories by Elizabeth McDonagh

I've never had anything to do with horses unless you count a seaside donkey. But when I heard that horses on a farm in Colorado, USA, had been diagnosed with 'chronic fluoride poisoning' I had to find out more. Last February the horses' owner, Cathy Justus, sent me her story in what finally amounted to a hundred pages of email.



Cathy and her husband Wayne, a gifted artist who paints pictures of cowboys and the American civil war, met at High School. After their marriage, they successfully bred quality 'Quarter Horses'. The breed is one of the most popular in America and originated by crossing the mustang ponies of the Indians with imported pedigree European horses.



Birds Hoof profile

After a move to Pagosa Springs in Colorado the Justuses bought *Belle*, a pregnant mare with a filly foal (*Bird*) at foot. Things went well for a while and, in 1982 and 1983, *Belle* presented them with two beautiful fillies, one of which, *Baby Doe*, became Cathy's great favourite. Then things began to go badly wrong.

All the horses developed strange illnesses. Problems included colic and chronic coughs, misshapen hooves, lethargy, neurological problems, crooked legs, lameness, soft tissue hardening, hard lumps on bones, thyroid problems, skin problems, kidney problems, reproductive problems and chronic abscesses. In 1990 *Belle*, once again in foal, was taken to California for foaling and re-breeding. Cathy and Wayne received a call from the vet that all was not well and that the mare should be put down. On autopsy, *Belle's* foal was found to be grossly abnormal.

Health problems among the horses continued but tended to improve when they were taken away from home and during one cold winter when they drank snow-melt rather than piped water.

Baby doe had two foals which were born with deformed legs, one of which was 'cryptorchid*'. For fifteen years, vets were at a loss to give any explanation for the horses' symptoms, to which *Baby doe* finally succumbed. Cathy and Wayne suspected the local water supply which was fluoridated but this idea was ridiculed. They themselves drank only distilled water. Eventually Cathy found a laboratory able to test for fluoride and veterinarian Lennart Krook of Cornell University was able to give a diagnosis which was 'chronic fluoride poisoning from drinking the city water'. A few months later the local water board voted unanimously to cease the fluoridation.



Birds deformed legs

My full article 'Cathy's Horses' was published in Namaste, Volume 9 Issue 2, and has been reproduced as a leaflet by National Pure Water Association. Recently, Cathy sent me another horse story related by her friend. I would like to share it with you.

"Just up the road from my home is a field, with two horses in it. From a distance, each looks like every other horse. But if you stop your car, or are walking by, you will notice something quite amazing. Looking into the eyes of one horse will disclose that he is blind. His owner has chosen not to have him put down, but has given him a good home. If nearby and listening, you will hear a sound. It comes from the smaller horse in the field. Attached to her halter is a small bell. It lets her blind friend know where she is so he can follow her.

As you stand and watch these two friends, you'll see how she is always checking on him, and that he will listen for her bell and slowly walk to where she is, trusting that she will not lead him astray. When she returns to the shelter of the barn each evening, she stops occasionally and looks back, making sure her friend isn't too far behind to hear the bell.

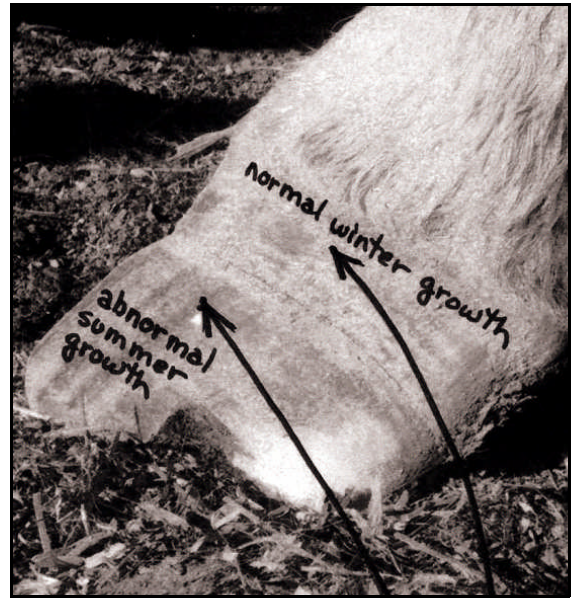
We too have others in our lives to help us when we are in need. Sometimes we are the blind horse being guided by the little ringing bell of a friend. Other times we are the guide horse, helping others to see.

Good friends are like this; you don't always see them but you know they are always there. Please listen for my bell and I'll listen for yours. Be kinder than necessary, for everyone you meet is fighting some kind of battle."

* 'cryptorchid' means born with only one testicle.

Sheffield M.E. Conference.

I have just received a copy of the Sheffield Group newsletter which contains a full report of the Sheffield Conference held on the 14th October. Myself and about half a dozen members attended what was one of the most brilliantly organized meetings I've been to. The transcript make interesting reading, and contains much valuable information. I feel would be of benefit to our members. However the cost of printing a general mailing would be prohibitive. I can print off a copy at cost if anyone wishes. It can be accessed on the Sheffield Group Website. Please go to www.leger.me.uk, and click on the 'ME Links' button. Click on the 'Sheffield ME Group' button, and you will be taken to their website. Click in the 'Annual Conference Report' button to view the pdf file. —Mike.



Baby Does abnormal hoof growth Image show normal winter growth and abnormal summer growth. During the winter of 2003/4 the horses choose to eat the snow rather than fluoridated tap water.



Crashed for Christmas

I may be "crashed for Christmas",
I may be stuck in bed.
And Santa may be playing,
With a hammer in my head.

I may be "crashed for Christmas",
I may not feel too hot.
And opening my presents,
May take all the strength I've got.

I may be "crashed for Christmas",
I may not be much fun.
The Christmas tree, the decorations,
None of it is done.

I may be "crashed for Christmas",
I may not be awake.
For Queenie's speech, the James
Bond film,
Or eating Christmas cake.

© Vicky Gifford

CFS's Genetic Component: Study Clarifies Predisposition to Syndrome

By Rick Weiss, Washington Post

An intense studies of people with CFS has strengthened the idea that the s actually a collection of five or more conditions with varying genetic and environmental causes. But though the syndrome comes in many variants, the new work also points to an important common feature: The brains and immune systems of affected people do not respond normally to physical and psychological stresses. The researchers predicted that continued clarification of the precise genes and hormones involved will lead to better diagnostic tests and therapies for the ailment, which may affect close to 1 million Americans.

The new findings come from the largest clinical trial ever to focus on people with the syndrome, a debilitating condition accompanied by unexplained extreme fatigue, memory and concentration problems, sleep disorders and chronic pain. Taking a multidisciplinary approach that agency officials said represents the future of public health, the CDC recruited 20 physicians, molecular biologists, epidemiologists, computational biologists even physicists and mathematicians to collaborate in an effort to tease apart the syndrome. The results, published in more than a dozen reports and commentaries in the April issue of the journal *Pharmacogenomics* suggest that many cases have links to a handful of brain and immune system related genes that either harbour small mutations or are working abnormally for other reasons. That finding strengthens the case that some people are born with a predisposition to the condition. But those genetic links remain weak and incomplete, researchers conceded, leaving most of the syndrome's roots hidden in a fog of poorly understood physiological, neurological, psychological and behavioural factors. Chronic fatigue syndrome is very heterogeneous. It will take time to identify all the biological pathways involved, but the growing evidence of genetic links should put to rest the idea that the syndrome is a made-up diagnosis for "a bunch of hysterical, upper-class white women."

The new study involved 227 residents of Wichita, Kan., who spent two full days in a hospital undergoing a series of blood tests, hormone studies, psychological exams and sleep studies. About 25% met the formal definition of chronic fatigue syndrome. A similar number proportion had chronic fatigue but did not rank as having the full-blown syndrome, in many cases because their fatigue was not severe enough. A third group met all of the requirements of the syndrome but also had melancholic depression, which does not fit the current diagnostic guidelines for chronic fatigue syndrome. And a fourth control group was healthy. The CDC made blood-test results and other data available to researchers, who performed a wide variety of analyses. In one set of studies the activity levels of 20,000 genes known to be involved in the body's response to such stresses as infections, injuries or emotional trauma were studied. Several hundred were found to be over or under active in various subgroups of fatigued patients. Most of those correlations were weak -that is, the gene expression patterns alone could not accurately distinguish those whose symptoms had been diagnosed as the syndrome from those whose symptoms had not. But in one analysis, the activity of just 26 genes did accurately predict which of six categories of chronic fatigue a patient had on the basis of symptoms and other clinical tests. That is a powerful hint that those genes, many of them involved in immune system regulation, the adrenal gland and the brain's hypothalamus and pituitary gland, which are involved in the body's response to stress -- may hold clues to the disease variants.

In other analyses, involving 50 genes that some people inherit with seemingly minor "misspellings," five of the 500 genetic glitches that were tracked repeatedly correlated with an apparent susceptibility to chronic fatigue. Those five include genes that affect levels of serotonin the neurotransmitter whose levels are tweaked by many antidepressant drugs and glutamate, a chemical that excites certain brain pathways in response to stress. The specific implications remain uncertain for now, said Vernon, a CDC molecular biologist. "But everybody's finding the same five genes to be involved, which is pretty cool." Several other studies on the Wichita samples found abnormal levels of various hormones relating to stress and mood additional evidence that chronic fatigue syndrome patients are genetically and neurologically "wired" to respond to stress abnormally. It is already known that the brain can literally rewire itself, breaking old connections between neurons while building new ones in response to various physical or emotional events. Chronic fatigue syndrome may be the result of a bad rewiring job, she said, in people genetically predisposed to handle stress poorly.

Some alternative, globally sourced, breakfast ideas by Elizabeth McDonagh

Many ME people are intolerant of wheat and may also be intolerant of spelt, an ancient type of wheat which dates back to Roman times. Sometimes oats and/or rye can cause problems. Rice is usually O.K. but can become a bit boring. It's worth trying some grains and other starchy foods which are not related to wheat. Buckwheat, in spite of its name, is one of these. It is of the rhubarb family and is particularly good for making the kind of pancakes which are popular in Brittany and also in Russia.

If you want to make porridge you could try making it with millet. The result is slightly bitter to the taste but you can get used to it. Quinoa (pronounced 'keenwa') is a grain used by the Peruvians which also makes an acceptable porridge. My brother-in-law makes quinoa porridge in a saucepan on top of the stove and mixes into it nuts and seeds ground in a small coffee-grinder. I soon swapped my mortar and pestle for a similar machine which, in seconds, deals with the seeds and nuts for my wheat-free alternative to muesli "Seedy Breakfast". Here's the recipe which may be altered at will. Just assemble in a cereal bowl.

2 tablespoons unsweetened stewed apple
2 tablespoons orange (or cranberry or pineapple) juice
1 dessertspoon raisins
1 dessertspoon lecithin
1 heaped tablespoon ground seeds and nuts
A good dollop of yoghurt or soya yoghurt

Hazelnuts, almonds, brazils, macadamias and cashews are good. Peanuts are cheaper but don't taste so nice and may carry moulds. Seeds to use are sunflower, pumpkin, pinenuts and linseeds which can be used without grinding. Hemp seeds are a favourite of mine for flavour. They are very hard so grinding is essential. Seeds and nuts supply vegetable protein, minerals including magnesium and omega 3 fatty acids.



C H R I S T M A S

The bells of waiting Advent ring,
The Tortoise stove is lit again
And lamp-oil light across the night
Has caught the streaks of winter rain
In many a stained-glass window sheen
From Crimson Lake to Hooker's Green.

The holly in the windy hedge
And round the Manor House the yew
Will soon be stripped to deck the ledge,
The altar, font and arch and pew,
So that villagers can say
'The Church looks nice' on Christmas Day.

Provincial public houses blaze
And Corporation tramcars clang,
On lighted tenements I gaze
Where paper decorations hang,
And bunting in the red Town Hall
Says 'Merry Christmas to you all'.

And London shops on Christmas Eve
Are strung with silver bells and flowers
As hurrying clerks the City leave
To pigeon-haunted classic towers,
And marbled clouds go scudding by
The many-steepled London sky.

And girls in slacks remember Dad,
And oafish louts remember Mum,
And sleepless children's hearts are glad,
And Christmas-morning bells say 'Come!'
Even to shining ones who dwell
Safe in the Dorchester Hotel.

And is it true? And is it true,
This most tremendous tale of all,
Seen in a stained-glass window's hue,
A Baby in an ox's stall?
The Maker of the stars and sea
Become a Child on earth for me?

And is it true? For if it is,
No loving fingers tying strings
Around those tissue fripperies,
The sweet and silly Christmas things,
Bath salts and inexpensive scent
And hideous tie so kindly meant,

No love that in a family dwells,
No carolling in frosty air,
Nor all the steeple-shaking bells
Can with this single Truth compare...
That God was Man in Palestine
And lives today in Bread and Wine.

John Betjeman

Adverse Drug Reactions and ME/CFS

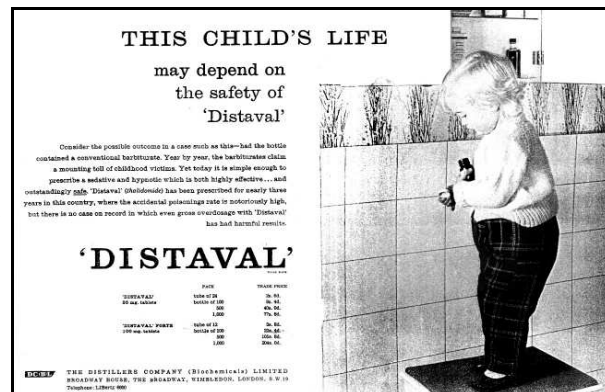
Everyone will have heard about the six men who volunteered to be guinea pigs to test a new drug, and the adverse effect it caused. The most well known disaster was thalidomide, and more recently Vioxx. The thalidomide disaster caused a radical rethink on drug safety and testing at the time, a bit like the Shipman murders the implications from it are still being actioned today on health professionals. There are two types of adverse drug reaction. The first type are the predictable ones, the best example is amitriptyline causing a dry mouth. It is predictable from experience or theory. The second type are unpredictable, or bizarre, e.g. thalidomide. The reason why thalidomide deforming babies was missed was because it only caused problems in white rabbits and humans, and not in rodents or other experimental animals. Strangely enough thalidomide may have a future as an anti-angiogenesis drug which stops blood vessels growing for cancer treatment and other disorders.

In order to weed out potential serious side effects, the Yellow Card scheme was introduced by the Committee for the Safety of Medicines/Medicines and the Healthcare Regulatory Agency. In the early days only doctors could report a problem, but later the scheme was extended to all health professionals. Recently a patient-reporting version has been produced for members of the public to use. Not every adverse reaction should be reported. Well known reactions e.g. dry mouth to tricyclics do not need to be reported because the problem is well known or not serious. The sort of reactions to report are:

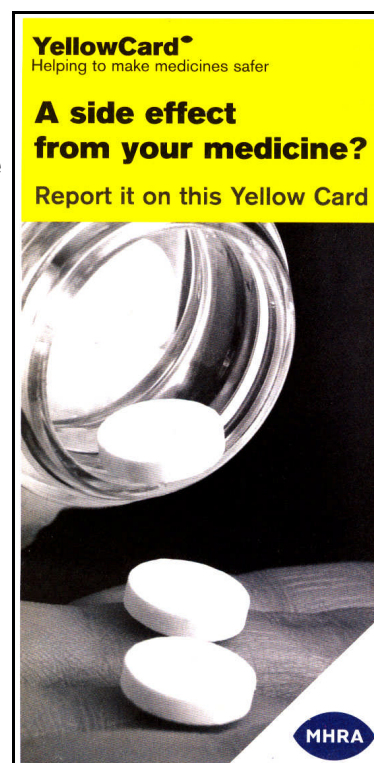
- All suspected reactions to new drugs or drugs under surveillance (Black triangle).
- All suspected reactions to herbal products, supplements and nutraceuticals.
- All suspected reactions occurring in children.
- All serious reactions suspected to established drugs.

It is estimated that around 6% of all hospital admissions are due to adverse reactions, and experienced by 30% of patients. People with ME/CFS are more sensitive to drugs, and so I am reasonably certain that there should be more reports coming from the ME/CFS sector. However it may be the people are not aware of what is a reaction, and what is part of the disease process. Very often it is difficult for healthcare staff to tell the difference between the two. If anyone suspects an adverse reaction I (Mike) as a health professional can give guidance and report it in the way your doctor or another health professional can. Immediate advice can be obtained from NHS Direct. If there is any doubt about the issue it should be reported anyway as it is better than a potential problem being missed. Adverse drug reactions on yellow cards are exempt from the Data Protection Act. If I report the reaction, I do not have to give the patient's name. However a self reported incident requires full personal details. No doctor will prejudice a patient for reporting a reaction as it is in their best interests and important for the safety of his and other patients.

The sort of things I've come across in the past with ME/CFS members are angio-oedema, a potentially fatal swelling of the mouth and throat from herbal sleeping tablets, allergic rashes when different brand medicines have been substituted and induced egg allergies from vaccinations. What certainly should be reported is the triggering of ME/CFS after any treatment e.g. by flu or hepatitis vaccination. If you haven't done so report it now because it is never too late and it will certainly raise the profile of ME/CFS! -Mike



A infamous trade advertisement for 'Distaval' aka thalidomide which was withdrawn from the market in November 1960. As least 8000 children in 46 countries were born without arms, legs, ear, eyes. many died at birth.



The self reporting version of a yellow card which can be found in doctors surgeries and other places. We keep a small stock of these for helpline callers.

North of Doncaster *Personal Comment by Trevor Wainwright***“Celebrity Patrons?”**

Bit of a grumble this issue, about the so called Celebrity Patrons. Yes you see their names at the top of letterheads, and their grinning faces on websites but are they really bothered?

The latest to Join Tymes Trust, Barbara Windsor referring to her illness as trivial, bet she never had ME in the first place, something else more like, but something recoverable from. Esther Rantzen with the sad eyes and catch in her voice said by Yvette Cooper MP to be ideal for pleading the cause of lost puppies but not ME. There for the cameras, doing nothing else but always there for her other causes, where has she been lately? David Puttnam in another newspaper at the behest of AfME promoting ME supposedly, but talking about his lifestyle and his retreat in Ireland, yes I bet those on benefit, struggling to make ends meet were really comforted.

Clare Francis again appealing for funds for AfME to commence funding:

“As one of Action for M.E.'s supporters, I am writing to you to tell you about our latest campaign to promote biomedical research into M.E. with the following words:-

Early this month we are bringing together international researchers from a broad range of specialisms for a Research Summit on M.E. Neurologists, immunologists and physiologists feature prominently among those who are attending. The event will allow researchers to develop suggestions for biomedical pilot studies - projects which will have a real chance of being developed into quality research proposals for submission to the Medical Research Council. “We need your help to make it happen.

We need funds to kick start these pilot studies. We need funds to maintain our campaign for more research into the possible causes, treatments, and potential cures for M.E. We need whatever money you can afford to give.”

Yes she is once again writing to members including past members, but what does she think others have been doing since 1997. She wrote once before begging for money for AfME, a real bleeding heart affair, how AfME needed the money, how had it not been for AfME there would not have been the CMO's Working Group, the 'All Party Parliamentary Group on ME', utter tosh, AfME were against the events that led to them, events organised and supported by the ordinary people.

Dr Anne McIntyre herself hailed the ForT Lobby at the House of Lords against the Royal Colleges' Report on ME as the event that started it all. I was there, and the week before was called upon at a meeting in Huddersfield to speak about the Lobby while Anne arrived, and when she did, she spoke about ME, ending with her support for the ForT Lobby.

Lastly there is, I suppose, the Duchess of Kent, often it is said, referred to as Princess Pushy. Probably the only thing she pushed nowadays is the port across the royal table. But then again how could she identify with the lower orders, 'last orders' maybe.

Celebrity Patrons, do we really need them? They get on about how we would not have managed without their groups. We haven't done too badly. It is also a shame that the groups ride on our backs. Every time we get something in the paper there's a main group add on.

Well, enough doom and gloom, SoME Poetry the ME Poetry site looks set to grow. In the early days of my involvement with ME I contributed my poems to the site Chronic Times hosted by Leeds ME sufferer, Hope Raven. Sadly, the site is no more, but our paths crossed again recently and she has given her kind permission for poems from Chronic Times to be added to SoME Poetry, a task I am looking forward to, hopefully during my Christmas break from work. And finally speaking of Christmas, just time to wish all at Leger ME a Merry Christmas and an even better New Year.