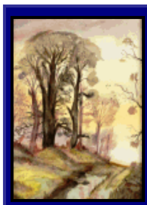
Price £ 2.00 (Free to members)

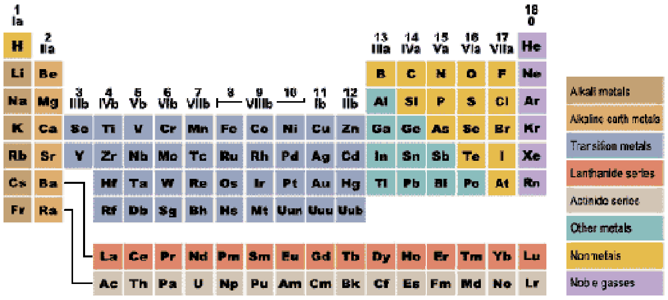


Pathways

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.

Focus on Mineral Elements

Almost every substance under the sun has been tried for its medicinal properties. This issue focuses on various issues around mineral elements.



1 Ia	2 IIa	3 IIIb	4 IVb	5 Vb	6 VIb	7 VIIb	8	9 VIIIb	10	11 Ib	12 IIb	13 IIIa	14 IVa	15 Va	16 VIa	17 VIIa	18 0
H																	He
Li	Be											B	C	N	O	F	Ne
Na	Mg											Al	Si	P	S	Cl	Ar
K	Ca	Sc	Ti	V	Cr	Mn	Fe	Co	Ni	Cu	Zn	Ga	Ge	As	Se	Br	Kr
Rb	Sr	Y	Zr	Nb	Mo	Tc	Ru	Rh	Pd	Ag	Cd	In	Sn	Sb	Te	I	Xe
Cs	Ba		Hf	Ta	W	Re	Os	Ir	Pt	Au	Hg	Tl	Pb	Bi	Po	At	Rn
Fr	Ra		Rf	Db	Sg	Bh	Hs	Mt	Uun	Uuu	Uub						
			La	Ce	Pr	Nd	Pm	Sm	Eu	Gd	Tb	Dy	Ho	Er	Tm	Yb	Lu
			Ac	Th	Pa	U	Np	Pu	Am	Cm	Bk	Cf	Es	Fm	Md	No	Lr

Alkali metals
Alkaline earth metals
Transition metals
Lanthanide series
Actinide series
Other metals
Nonmetals
Noble gasses

The Periodic table of elements as tough in schools.

Following the discovery of Radium by the Curies earlier last century, radium was tried for everything. In the U.S.A., radium salts were even sold in health shops as a health tonic, without the scrutiny given to modern medicines. Very quickly it became apparent that radium was extremely dangerous, because it is radio active, emitting alpha particles, radon gas and other radiation. To some extent radium is a double edged sword, because it was one of the first anticancer treatments that really helped.

Radon is a radioactive gas is responsible for about 20% of lung cancer cases in the UK, and is a definite hazard as is heavier than air, and can accumulate in basements of buildings, especially where the ground rocks contain granite. However, the lesson of history does not seem to have been learnt by some health product suppliers.

Some suppliers of products in the U.S.A. derived from inland sea salt deposits openly advertise their products to contain elements like thorium which emit radon gas, as well as nastier elements like thallium available over the internet. Over there, the product has to be proven dangerous before it can be banned. Fortunately, in this country we have better regulation.

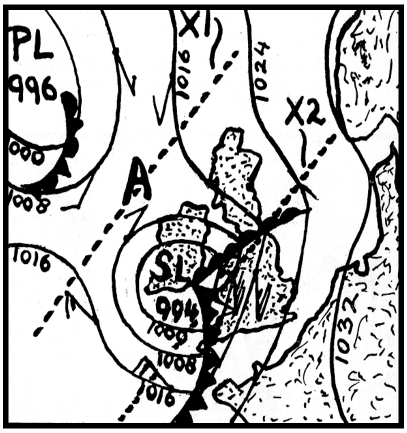
Fluoride and ME. *What health damage fluoride can do and its similarity in relationship to ME. See page 16.*

Recent Meetings at the Sheffield ME Clinic. *How Leger ME represents it's members. See page 9.*

Ham, Potato, Leek and Herb Hotpot. *See page 14.*

SoME Poetry

A new website from Trevor Wainwright. See page 14.

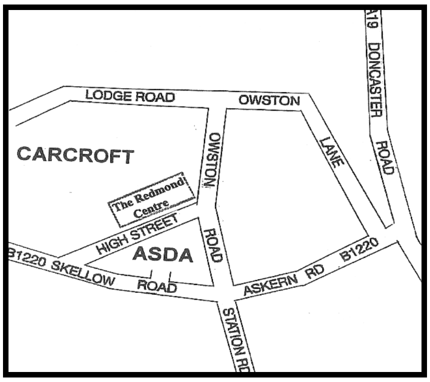


The Weather and ME. *How the weather can affected people with ME. See page 2.*

ME and Lyme Disease. *See page 15.*

Leger ME Members' Announcements

Tea & Coffee afternoon
14th September 2006
12.00 noon until 4.00 pm.
Hosted by Jan & Bob Fox in their home in Armthorpe.
50p only for Tea, Coffee and Biscuits
All proceeds to Leger M.E. Counselling Service.
A social event so come along and bring a friend!
We will be running a raffle as well.



The Redmond Centre High Street
Carcroft Doncaster DN6 DN
Tel: (01302) 724501

Leger ME Meetings*.*

4th Friday in month Redmond Centre 1.30 pm)
Friday 22nd September, 1.30 to 3.30 p.m. Annual General Meeting.
Friday 27th October, 1.30 to 3.30 p.m. Direct payments
Friday 24th November, 1.30 to 3.30 p.m. Incapacity Benefit reform.

Sunday 10th December, Christmas Party. See November Pathways for details.

Redmond Centre Community Group Events

15th September 6.30 - 8.30 pm Beetle Drive, Pie & Pea supper. Tickets from Redmond Centre.

Sheffield Annual M.E. Conference 2006.
Saturday 14 October 2006
1.30 - 4 pm. In the Platinum Suite, Sheffield United Football Ground - Cherry Street entrance

Everything you've always wanted to know about ME/CFS
chaired by Andy Kershaw of BBC Radio Sheffield, our panel will comprise:

Alan Barker, Homeopath
Dr Alan Blair, Consultant Clinical Psychologist
Dr Richard Grunewald, Consultant Neurologist
Anne Nichol, Occupational Therapist and Clinical Services Coordinator for ME/CFS in Sheffield
Dr Alison Wray, Principal Clinical Psychologist, Child Team for ME/CFS
Marcus Windle, Welfare Benefits Advice Worker

Subscriptions. Subscriptions are now due. As a result of the resolution at the last AGM, the financial year will run from the end of April instead of September. Members who paid subscriptions in September will only need to pay £3.50 for the half year until the end of March 2007 to keep their subscription current.

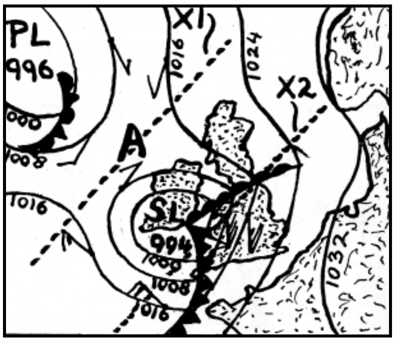
Pathways by email. Some groups are emailing their newsletters with significant cost savings. If anyone would prefer to received their *Pathways* by email, please let me know.

Counselling Service. The service is up and running on Monday afternoons, and is run by Sally who is a diploma-trained counsellor. A special thanks goes to the Redmond Centre for providing a comfortable venue. The counselling itself is in a comfortable private room away from the public side of the centre. There is a private car park and full disabled facilities. At the time of writing there are no spare places available, but if there is enough demand, we will set up another session on Wednesday afternoons. The Counselling line number 07962 907053. Please leave your name and telephone number then Sally will ring back, or ring Mike at Leger ME on 01302 787353. For the time being, the access to the service is restricted to members and their families. This is because the running costs are being funded from within Leger ME. Any donations will be welcome.

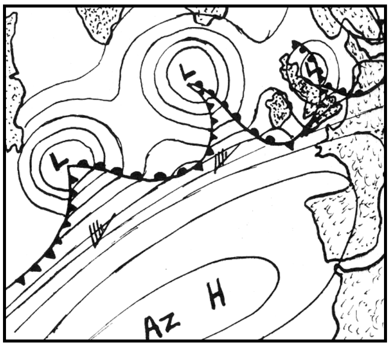
You Write

Carolyn Writes I've noticed that thunderstorms given me a headache and I certainly feel worse when they are around. I've also noticed that I feel wiped out during the recent periods of hot weather. Can weather affect ME ?

There is a classic example of wind affecting health. 'Le Mistral' is a wind that blows in the Rhone Valley in France. When it blows, everyone with arthritic aches and pains tends to have an increase in their symptoms. Here in Doncaster I've noticed that everyone seems to have good and bad periods at the same time, particularly when the weather in under the influence of depressions which cause quite rapid changes in low air pressure often with plenty of wind. This may be because of restricted blood flow in the brain due to ME, where a small change in pressure can make a massive difference. Sometimes this happens in aircraft journeys when the cabin is pressurised. There are reports of good and bad days depending on the wind direction, and also some people report relapses when the wind blows over from certain chemical plants and agricultural establishments. Conversely, anticyclones give stable warm high air pressure, and people are generally better in these periods. Thunderstorms tend to ionise the air, and generally cause darkening of the sky which tends to increase depressive mood. Lightening produces a strong broad spectrum electromagnetic pulse which may affect susceptible people many miles away, and not just in the immediate locality. A lightening strike anywhere in the world can be detected by a phenomenon known as the Beckmann resonance. In the north Scandinavian countries around the artic circle where in winter daylight can be almost non existent, there is a corresponding rise in depression and self harm. Light level affects the pineal gland which secretes melatonin, a sleep-promoting hormone which is disturbed in ME. Heavy thunderstorms tend to clear the air of fine dust and pollen, which may make some people feel better.



Isobars of a depression which makes many ME's feel worse. The depressions pass over the country in a matter of hours.



Trouble brewing. When a series of Atlantic depressions (L) pass over most people in Doncaster feel worse..

Bob writes "After a long wait I have just been received substantial sum of money as back payment of Attendance Allowance (AA). As I am a practising Christian my local Minister says that I should give 10% of this to the church as I do with all my income. Is this right ?"

When a col (space between weather system) or anticyclone (H) dominates the weather is stable, and many people have better periods.

Historically the church was the only source of welfare. It was supported by a 'tithe' or 10% tax imposed on people of the parish who were able to pay. A sort of robbing the rich and giving to the poor. Historically, "tythe" maps were produced, and some still exist, which record everything from which a tithe is due, a bit like the Doomsday Book. The tithes were not always paid in cash, but sometimes in goods or produce. These were stored in the many tithe barns dotted around the country. These days the government does the tithing under the guise of the welfare state. Seriously though, I can't say if is right or wrong. That is a decision you have to make yourself. To try and obtain guidance I talked this issue over with a local hospital chaplain I know. He said:

"Obviously the Attendance Allowance is given according to Bobs needs and circumstances, and is intended to be for his support which is needed because of his disability. Now, its true that if as a church member, that Bob will want to give to the local church, but this has to be according to Bob's ability. After all, more prosperous members will have far more choice in what they can give. Bob has a duty to care for himself and the state is helping him to do this. Tything has a long history and some churches encourage it, but it is voluntary. On a low income this might well be a burden rather than a joy."

Chris writes “I am a worker of Sheffield Welfare Action Network. We are campaigning for positive welfare reform, challenging the Incapacity Benefit cuts. We were contacted recently by a claimant in South Yorkshire who has recently undergone a new "mouse-led", computer-based assessment for Incapacity Benefit. She told us that the assessor was putting information into a computer as she explained the difficulties she has. At no point was she told what was being entered on the computer, and she was not offered a copy of the report which the computer would generate. It was only when she requested a copy of the information that she discovered that the software had "interpreted" her comments in a worrying way, and had effectively put words into her mouth. So although she had told the assessor that after 5 minutes of housework, she had to stop because of the pain, the report states that she can "clean the house in 5 minutes". This is deeply worrying, and is further proof that if the government's IB reforms are implemented, many people will be forced to take part in activities which they are not ready for, or face a cut in benefits. Luckily for this claimant, she qualified for IB despite the inaccuracies in her report, but how many will be denied the benefit based on false information? And why should claimants have to request the information, rather than it being offered?”

100% agree Chris. This can get a little worrying because it’s a sign of things to come, especially with the Incapacity Benefit reforms which are due. Generally our members don’t have problems. We will keep watch over the situation, and take any action that we think is necessary. For the benefit of our readers, my advice for anyone facing the Personal Capability Assessment (PCA) IB50 form is to contact us on the helpline 01302 787353 for assistance. We have information leaflets about this on our Website: www.leger.me.uk. To contact SWAN, use www.swansheffield.org.uk.

Matthew writes “Are B vitamins central nervous system stimulants as such? If a multi vitamin contains the following: B1 - 25 mg, B2 - 25 mg , B3 - 50 mg , B5 - 50 mg , B6 - 6.6 mg , B12 10 mcg, do you reckon there could be any potential problems for an ME brain?”

These are not stimulants. Folic Acid, which is a B vitamin, is missing from the formulation. These doses do not appear to be related to the Recommend Daily Amount (RDA), but I have experience of B vitamins in these doses being OK. Recently the Government has ratified new EC legislation, which effectively limits what can be put into food supplements. You may have seen the unsuccessful ‘Save Our Supplements’ campaign opposing this. Personally, I think that it is a step forward. Just compare these doses you are asking about to the Government recommendations on http://www.eatwell.gov.uk/healthydiet/nutritionessentials/vitaminsandminerals.

There are specific deficiencies common in ME/CFS, which can be tested for and treated. However, this is expensive. If you look on the pharmacy and supermarket shelves, you’ll find that the single supplements are the same price as the multivitamins. My general advice about vitamin/mineral supplements is that unless a doctor directs otherwise, a good quality comprehensive A-Z multivitamin/mineral supplement will give vitamin insurance against deficiency and save money. Most people with ME/CFS that I’ve spoken to find that it makes a difference.

Audrey writes “I am an M.E. sufferer and have been prescribed Simvastatin for high cholesterol. After I started on this medication I have felt worse. In particular my muscle pain levels have increased and the fatigue is worse. I stopped taking these tablets and all the problems stopped. When I restarted, the problems started again. What should I do ?”

You had proven quite clearly to simvastatin is causing you problems. It looks like that you are suffering from the typical side effects of statins. About half of the people who take statins feel tired, and may get muscular aches and pains. I know of one doctor who totally against giving statins to ME patients because while blocking cholesterol production statins block 50% of the coenzyme Q10 in the liver, which in ME/CFS is usually depleted anyway.

Just exactly who to do about it is up to you and your doctor to decide. A product available on the NHS, which your doctor may want to consider, is MaxEPA which could have a beneficial side effect. It is derived from fish oil, and contains EPA, which is clinically proven to help ME/CFS. See our feature on page 12.

Francis Writes I have a friend who has been taking ‘Istem’, and says she feels much better when she takes it. I’ve asked about it at my local health shop who say that they cannot trace it. However a friend has found it on the internet, and tells me that it would cost £75 to get a bottle from the USA. I have been suffering from many years, and I am only basic state benefits. Can you help. ?

‘Istem’ is a trademarked brand, an acronym for ‘Inland Sea Trace Elements and Minerals’ of what is similar to sea salt which can be purchased at almost all supermarkets and grocers. I tried sea salt in the early days of my ME and found it made a difference. I made a lifestyle choice to use it.

Istem is one of an number of products which is derived from prehistoric dried lake salt deposits similar to what is happening today to Great Salt Lake in the Utah in the USA and the Dead Sea. Being inland seas, the composition of the salt is different from that of the oceans and depends on local geography. Istem is mainly magnesium chloride in contrast to sodium chloride in sea water. A magnesium supplement certainly makes a difference in ME. The cheapest form of magnesium is Epsom salts, (magnesium sulphate) which were sold as a mild laxative by Pharmacies in bygone days. The UK supplement manufactures of course have their own versions.

Personally I would not advise anyone to take any products containing ISS internally as they contain many elements which are not necessary, and could be dangerous. The law allows this in the USA where most of these product originate, but would not in the U.K. unless a doctor prescribes ISS products. The table below contains ISS elements based on various merchants’ data.

Element	**Approx Proportion**
Chloride+	69%
Magnesium+	23%
Sulphate+	5.5%
Sodium+, Potassium+, Carbonate+	0.6%
Bromide*	0.3%
Lithium*, Boron+	0.1%
Calcium+, Fluoride*+	0.015%
Selenium+, Nitrogen+, Silicon+, Phosphorus+, Titanium	100 or less ppm
Rubidium, Iodide+, Arsenic *3, Iron, Scandium, Chromium+, Cobalt+, Zinc+, Strontium+, Nickel +, Cadmium *3	10 or less ppm
Copper+, Aluminium, Molybdenum+, Tellurium, Antimony *3, Tungsten, Lead *3, Lanthanum, Barium, Germanium+, Vanadium+, Cerium, Yttrium, Caesium, Bismuth, Mercury *3	1 or less ppm
Tin, Gallium, Uranium *2, Gold, Thallium*, Thorium *2	0.1 or less ppm
Beryllium *3, Thulium, Terbium, Neodymium, Lutetium, Holmium, Gadolinium, Europium, Erbium, Praseodymium.	0.02 or less ppm
Thulium, Terbium, Neodymium, Lutetium, Holmium, Gadolinium, Europium, Erbium, Praseodymium, Ytterbium, Niobium, Platinum, Tantalum	0.01 or less ppm

ppm = parts per million..
+ Used in the human body
** Used in medicine and has significant toxicity.*
**1 Thallium has no biological role. All forms are extremely toxic. The effects are cumulative and they can be absorbed though the skin and affects the nervous system.*
**2 Has no biological role. It is a radioactive emitter of alpha particles and radon gas which is responsible for about 20% of lung cancer cases.*
**3 All compounds are highly toxic, its compounds cause severe liver damage.*

Doctors highlight risks of buying drugs from online pharmacies for ME/CFS.

adapted from a feature by Jeremy Laurance, 11/8/06 in The Independent.

A woman who bought drugs on the internet and took them for four years went blind as a result, doctors say. The case highlights the dangers of the multimillion-pound international market in prescription medicines available from online pharmacies across the globe. The easy availability of drugs has allowed many people to bypass their doctors and self-prescribe medicines which they hope will boost their energy, improve their sex life or help them lose weight. The 64-year-old woman from Sunderland diagnosed herself with chronic fatigue syndrome and, on the advice of a neighbour, bought oral steroids from an online pharmacy in Thailand. She later complained of loss of vision and doctors at Sunderland Eye Infirmary found cataracts in both eyes and signs of glaucoma (high pressure), both side effects of steroid use. Dr Philip Severn and Dr Scott Fraser, consultant ophthalmologists, writing in The Lancet, warn colleagues to watch for patients who may have bought drugs online. "Some of the drug therapies can be counterfeit and contain a concoction of compounds that bear little resemblance to the drug named on the bottle," they say. "Even if the patient receives the actual drug, there are many problems with this unchecked availability, including interactions with coexisting treatment, side effects and the lack of careful medical monitoring."

Popular lifestyle drugs including Viagra for impotence, Reductil for weight loss and Prozac for depression are among the biggest internet sellers. Many internet pharmacies offer online prescriptions allowing patients to consult a doctor by e-mail instead. The British Medical Association is opposed to the practice but it is not against the law. The General Medical Council has successfully prosecuted doctors for inappropriate prescribing and failing to make adequate diagnoses over the internet. Websites based abroad, which may use a ".co.uk" address, are not subject to British jurisdiction, and many sell medicines without a prescription as well as controlled drugs, such as stimulants and opiate-based painkillers.

The Medicines and Healthcare Products Regulatory Agency has warned of the growing problem of counterfeit drugs. Every year, the agency seizes £3m of stolen or faked Viagra, the best-selling internet drug. Dr Fraser said he had heard of the dangers of buying drugs over the internet but it was the first time he had seen the effects. "Most patients aren't going to say if they have bought drugs over the Net," he said. "Buying drugs in this way is a gamble. Even though it was the right drug and it was not a counterfeit, because she wasn't monitored, she suffered the side effects. "I am not saying doctors must be in control of all prescriptions, but with steroids, although they are life-saving drugs, patients must be monitored because of the side effects, which include diabetes, bone loss and eye problems." The woman had cataracts removed from both eyes and will require treatment for glaucoma for the rest of her life, Dr Fraser added.

The Royal Pharmaceutical Society said it was developing a register of approved online pharmacies.
Available on the internet are:

Viagra, made by Pfizer, for impotence. About £50 for four tablets. Most widely sold prescription drug on the internet.

Xenical, made by Roche, for weight loss. About £65 for 85 capsules. Marketed as a potential panacea for the obesity epidemic.

Prozac, made by Eli Lilley, for depression. About £20 for 30 tablets. The best known anti-depressant, with low toxicity compared to older drugs.

Valium, made by Roche, for anxiety. About £50 for 30 tablets. Known as mother's little helper, it is effective but addictive.

Ritalin, made by Novartis, for attention deficit disorder. About £20 for 60 tablets. Abused by students and others to increase concentration.

Lipitor, made by Pfizer, for high cholesterol. About £40 for 30 tablets. The world's best-selling drug - counterfeit versions exist.

Comment: This is one of the reasons that we require new members to have a diagnosis, and advise people to see their doctors on a regular basis. Mike.

Notes on Mineral & Trace Elements Supplements and ME

What are minerals? Minerals are essential nutrients that your body needs in small amounts to work properly. We need them in the form they are found in food. Minerals can be found in varying amounts in a variety of foods such as meat, cereals (including cereal products such as bread), fish, milk and dairy foods, vegetables, fruit (especially dried fruit) and nuts. Minerals are necessary for three main reasons:

- building strong bones and teeth
- controlling body fluids inside and outside cells
- turning the food we eat into energy

What are trace elements? Trace elements are also essential nutrients that your body needs to work properly, but in much smaller amounts than vitamins and minerals. Trace elements are found in small amounts in a variety of foods such as meat, fish, cereals, milk and dairy foods, vegetables and nuts.

Why take supplements ? Mostly as insurance against deficiency. People who are ill, pregnant, or have dietary problems may go short. There is an argument that modern agricultural practice leads to a reduction of minerals and trace elements in the soil and consequently in any food produced. In ME/CFS food supplementation does make a difference in many people who I've met. I've produced a table comparing the contents and average daily dose.

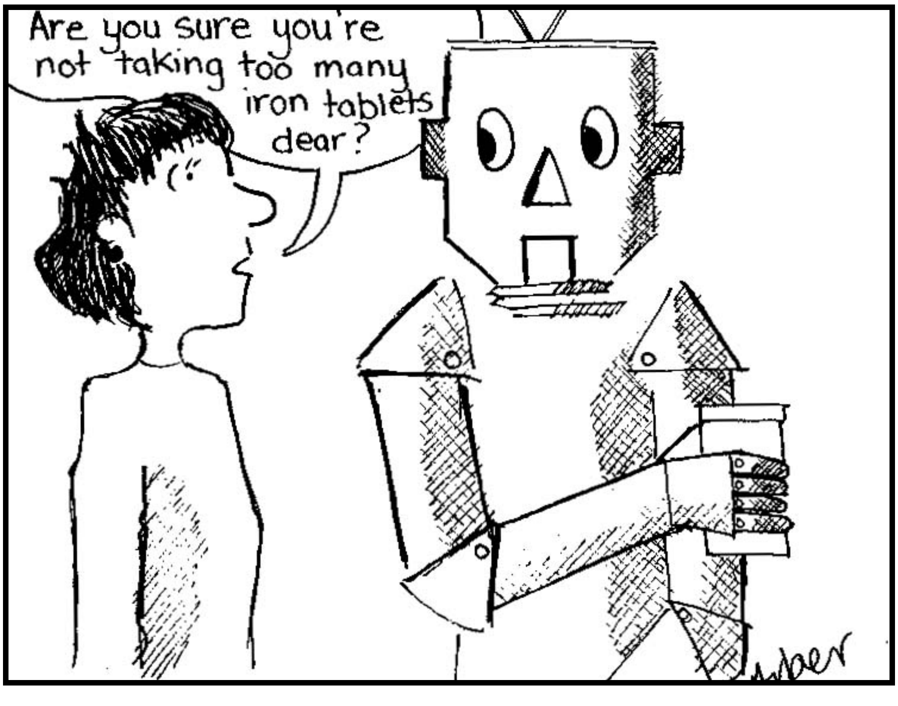
MMM (Myhill's Magic Minerals), MMM is a powder mix of minerals which you make up in water or fruit juice, all essential for human metabolism which increasingly are lacking in modern food supplies. It contains minerals in the correct proportion for human requirements. These amounts are those considered desirable from modern nutrition research and are mostly above the "Recommended Daily Amount". The product is effectively prescription only, supplied by Dr. Myhill to her patients. It can be supplied to anyone if the person's G.P. writes to Dr. Myhill.

BMC (Biocare's Mineral Complex) was originally supplied as Ethanolamine Phosphate Esters (EAP) which is also referred to as vitamin M1 by German physician Dr Hans I Neiper. He considered EAP an important transporter of minerals in the body, and it was supposed to have produced more reliable absorption. Recently-introduced EEC regulations now prohibit EAP variants, and limit mineral and trace elements to their respective salts.

A—Z (A typical A-Z multivitamin product). These are widely available in Pharmacies and supermarkets.

Notes
*1 Silicon cannot be used by the body as an inorganic mineral.
*2 Sulphur is not biologically available as the mineral – it is available in sulphur-containing amino acids in protein and in Glucosamine sulphate or MSM or N acetyl Glucosamine.
*3 phosphorus is plentiful in meat.
*4 Cobalt is necessary to make vitamin B12 – present in good vitamin preparations.

Information derived from Biocare, Pharma Nord, Food Standards Agency, Dr Myhill and Forceval.



Element	**FSA**	**Body use**	**RDA**	**MMM**	**BMC**	**A-Z**
Boron	Trace	for healthy bones		2 mg		
Calcium	Essential	Healthy bones an teeth, normal blood clotting cell membrane permeability and neuromuscular activity	800 mg			100 mg
Chloride		Gastric acid secretion, water balance		60 mgs	trace	
Chromium	Trace	Controls sugar levels		40 ug	100 ug	200 ug
Cobalt	Trace	Component of vitamin B12		*4		
Copper	Trace	Normal red blood cell formation, collagen, fertility, immune function antioxidant enzyme component		0.2 mg	200 ug	2 mg
Fluoride	Trace	Said to strengthen bones & teeth				
Iodine	Trace	Component of thyroxin, regulation of cellular metabolism & energy	150 ug	3 mg		140 ug
Iron	Essential	Haemoglobin in blood oxygen transport. Energy supply enzyme & immune component	14 mg	3 mg		12 mg
Magnesium	Essential	Hormone function , co-factor, bones & teeth important in energy production	300 mg	70 mgs	90 mg	30 mg
Manganese	Trace	Co-factor involved in energy production enzymes and bone & connective tissue production.			3 mg	3 mg
Molybdenum	Trace	Males sexual function. haemoglobin antioxidant enzymes. bone and connective tissue formation		40 ug	150 ug	250 ug
Nickel		Enzyme co factor				
Phosphorus	Essential	Bones & teeth, energy supply and DNA	800 mg	*3		77 mg
Potassium	Essential	Water balance, CO_2 transport, cell membrane, Neuromuscular action		40 mg		4 mg
Selenium	Trace	For the antioxidant enzyme glutathione peroxidase , immune function, normal fertility and cardiovascular system.		40 ug	100 ug	50 ug
Silicon	Trace	Silicon is beneficial for the skin, hair and nails and is a constituent of synovial fluid found in the joints		*1	50u g	
Sodium (salt)	Essential	Water balance, CO_2 transport, cell membrane neuromuscular action				
Strontium		Found in bone		20 mg		
Sulphur	Essential	Liver function, immune, antioxidant		*2		
Vanadium		For healthy bones & teeth promotes normal fertility		10 ug		
Zinc	Trace	Immune function, antioxidant enzyme component nuts, insulin, growth, tasted, fertility and skin	15 mg	6 mg	14 mg	15 mg

NHS Politics: Representation at the Sheffield Clinic.

Liz and I have been regularly attending various meetings at the Sheffield Clinic since 2004 with representatives of the Derbyshire, Rotherham and Sheffield groups, representing the service users. The Sheffield Clinic was formed with money allocated by an initiative following the Chief Medical Officer's Report. Now that the initial funding has been used up, the service has to compete with other services for funding. Thanks to the foresight of Jan Appelbee, Head of Commissioning, this has now been successful for the Sheffield Clinic. However, a number of specialist M.E. services are under threat as a result of the financial crisis in the NHS. In fact one service - the East Herts service for children - has already closed, and Leeds and West Yorkshire CNCC has stopped taking referrals. Its fate will be decided in September.

DLA. Sally and I attended a meeting on 12/7/6 with from representatives from other groups and support agencies. The current situation was reviewed, and it was agreed the Sheffield Clinic needs to support benefit applications and needs to know and understand more about this often difficult issue and who to refer to for expert advice. Also support agency staff require a better knowledge of CFS/ME. Having access to someone with specialist knowledge increases the chances of getting the right award. Forms are long (20+ pages) and intimidating, physically and mentally tiring. and people often need practical help. Some people feel they are cheating if they describe only their worst days. Some do not see their GP regularly; thus the GP cannot support their claim. The secrecy surrounding the decision-making process and the changes in the system (without previous information going out) make people feel very insecure. Any initial letter of refusal contains scant information and complaints are not well managed. Examining Medical Practitioners (EMPs) are not independent and can also be influenced positively as well as negatively by the advocate during the interview depending on the quality of the advocate. We managed to agree a process mapping up to the point of submitting the application. Further meetings are required. The main thought I came home with was Leger ME are doing it right. Every application needs to be supervised by an expert. To date, all Leger ME members' applications have been successful, only one being currently disputed. I made contact with Helen Butler from SYCIL, and we agreed to cooperate on this issue.

Nutrition. Liz and I attended a meeting on 20/7/06 together with invited representatives from other groups and support agencies. We looked at the options. Everyone can do it, most will benefit to some degree and it's free. We have to consider levels of severity and different groupings of people. Overall we need general options for anyone and a service leaflet. Strategies like *eat little and often, dietary clean up, drinking plenty of water, avoid "old wives tales", seeking professional advice and guidance / know where to go to get helpful advice , eat lots of fruit and vegetables and it's not just what you take out of your diet, but also what you put in*. Good quality A-Z supplements for vitamin insurance were discussed, but professionally and ethically we cannot necessarily endorse a multivitamin for all clients. Common issues like malabsorption, candida or gut dysbiosis, blood-sugar imbalance, weight changes, irritable bowel syndrome, food sensitivities, leaky gut, thyroid and metabolic issues were discussed. Obviously a dietary and nutritional assessment, followed by dietary combining and clean-up would be helpful, and a gentle approach to diet optimisation would be suitable for the majority of people. Privately arranged specific tests may be valid and may influence treatment. We agreed to:

- Find out who is in the area and what they can offer, possibly we could develop a resource pack.
- Individuals do need a link worker or coordinator as many clients are mix-and-matching lots of different advice / supplements, without understanding interactions.
- Find out who's out there to help, advise and support with nutrition
- Identify nutritional consultants or clinical nutritionists from the private sector
- Find a dietician with specialist knowledge and /or interest in nutritional issues for ME/CFS
- Ideally get involved from start of a case with signposting and basic advice
- Liaise with support groups for signposting and basic advice
- Look at the CFS/ME service for basic advice and signposting

We will meet again on the 15th September.

Fatty Acids and Oils

Fat has a bad reputation. It is a word associated with obesity, heart disease and many other disease states. However, not all fats are bad fats. The different types of dietary fat fall into three main groups: saturated; mono-unsaturated; and polyunsaturated.

a) Saturated fats are the animal-derived 'hard' fats such as butter, cream, and fat in meat and dairy products. These fats are used in many processed foods. Chemically-speaking, saturated fats are a chain of carbon atoms jointed by single links, which means that the maximum amount of hydrogen is present. These are the fats to reduce in the diet.

b) Olive oil is the best-known example of an oil which contains predominantly monounsaturated fatty acids. Of the unsaturated fats (so-called because extra hydrogen atoms can be inserted chemically) monounsaturated fatty acids (MUFA) are made up of a chain of carbon atoms containing one double bond. They characteristically have a lower melting point than saturated fats and so are generally liquids (oils) rather than solids (fats).

c) A polyunsaturated fatty acid (PUFA) has more than one double bond in the chain. Two to six double bonds can be found in common edible oils. Vegetable oils such as sunflower oil, and the oils from fish contain high levels of polyunsaturates. Polyunsaturated fatty acids are further divided into two sub-groups called omega-6 and omega-3 (sometimes referred to as ω-6 or ω-3 or n-6 and n-3). Both of these groups are essential for good health and normal growth. Since they cannot be manufactured by the human body, they must be supplied in the diet. For this reason, they are often referred to as 'essential fatty acids' (EFAs).

AA Arachidonic Acid 20:4 (n=6)

EPA Eicosapentaenoic 20:5 (3)

Omega 3 and omega 6 fatty acids cannot be inter-converted and both must be present in the diet in a proper balance for good health. Their differences lie in their chemical structure and their roles in the body.

As polyunsaturated fatty acids, both the omega-6 and the omega-3 families have more than one double bond in the carbon chain. All fatty acids in the omega-6 family contain their first double bond between the 6th and 7th carbon atoms (counted from the methyl (CH3) terminal carbon atom and the omega-3 family of fatty acids have their first double bond between the 3rd and 4th carbon atom.

Both families of fatty acids are vital components of membranes and are used by the body in the production of eicosanoids, a vast range of highly bioactive substances (prostaglandins, leukotrienes, lipoxins) but the activity of these metabolites varies. For example, the eicosanoids derived from omega-6 are in general more active (or reactive) than those produced from omega-3 and omega-6 is aggregatory whereas omega-6 is pro-aggregatory.

Basically, the omega-3s have anti-inflammatory benefits and help prevent heart disease, whereas omega-6s lower blood cholesterol and support the skin. Like all fats, EFAs provide energy. Their calorific value is similar to other fats and oils but, unlike saturated fats, they have important health roles. In fact, as their name suggest, they are essential and must be consumed regularly as the body has limited storage for them. They are converted by the body into eicosanoids, leukotrienes and prostaglandins - all of which are needed on a second-by-second basis by most tissue activities in the body.

EFAs are involved in normal physiology, including:

- regulating pressure in the eye, joints, and blood vessels, and mediating immune response
- regulating bodily secretions and their viscosity
- dilating or constricting blood vessels
- regulating collateral circulation
- directing endocrine hormones to their target cells
- regulating smooth muscles and autonomic reflexes
- being primary constituents of cell membranes
- regulating the rate of cell division
- maintaining the fluidity and rigidity of cellular membranes
- regulating the inflow and outflow of substances to and from cells
- transporting oxygen from red blood cells to the tissues
- maintaining proper kidney function and fluid balance
- keeping saturated fats mobile in the blood stream
- preventing blood cells from clumping together (blood clots that can be a cause of heart attack and stroke)
- mediating the release of inflammatory substances from cells that may trigger allergic conditions
- regulating nerve transmission and communication

If the diet is deficient in either omega-6 or omega-3 long-term degenerative illnesses will result. However, because the end product (e.g. .prostaglandin, leukotriene) of EFA metabolism differ slightly but significantly from omega-6 to omega-3, they must be present in balance for optimum health. Both omega-6 and omega-3 fatty acids are essential but the body requires them in a ratio that is not normally achieved by the typical diet of today's industrialised nations.

Experts think that man evolved on a diet which would have had roughly 1-2 times more omega-6 than omega-3, though there is a school of thought which argues for a 1:1 ratio. Currently, average UK intakes are in a ratio of around 8:1 in favour of the omega-6s, while in the US it is around 10:1, and in Australia nearer 12:1. Many individuals within those populations will have an even greater omega-6 to omega-3 imbalance.

The Effamol Marine Trial.

In 1990 a clinical trial was carried out by Behan, Behan & Horrobin (1990) into the effects of high doses of essential fatty acids on the post viral fatigue syndrome. 63 adults took part in a three month double-blind, placebo-controlled trial. The dose was 8 capsules daily containing 36 mg GLA, 17 mg EPA, 11 mg DHA 255 mg linoleic acid, 10 IU vitamin E (antioxidant). The Placebo capsules contained 50 mg linoleic acid, Liquid paraffin (inert oil), 10 IU vitamin E (antioxidant). In consultation with the patient, the doctors assessed the following on a three-point scale, overall condition, fatigue , myalgia, dizziness, poor concentration, & depression. At the one month, 74% active & 23% placebo assessed as improved over baseline. Improvement was much greater in the active group. At three months, 85% active & 17% placebo assessed as improved over baseline. On change-over the placebo group reverted towards baseline state, while the active group showed continued improvement. The first thing noticed was that brain-fog completely vanished. Patients felt something changing for the better in the lower part to the right side at the back of the brain, and had for the first time a feeling of well-being. Relapses became more spaced out, before treatment an average of in the winter months 4-12 per month. Whilst on the treatment it dropped down to 1-3 per 3 months. Relapses were are not so severe, people were able to maintain normal awareness. Patients were also able to communicate whilst in a relapse, something not possible before treatment.

Is Eicosapentaenoic Acid (EPA) a Potential Treatment for ME/CFS ?

I recently attend a Bury and Bolton Group meeting presented by Professor Basant Puri. He is head of the Lipid Neuroscience Group at Imperial College. He detailed a study of ME done in the late 1990's, which gave clear evidence that the chemistry within the brain of ME sufferers is different from normal subjects. The study was done using an in-house customised MRI scanner. Part of the output of the machine is in the form of a graph. ME patients show a much enlarged choline peak. This has been confirmed by two other research teams with similar equipment and age-matched controls.

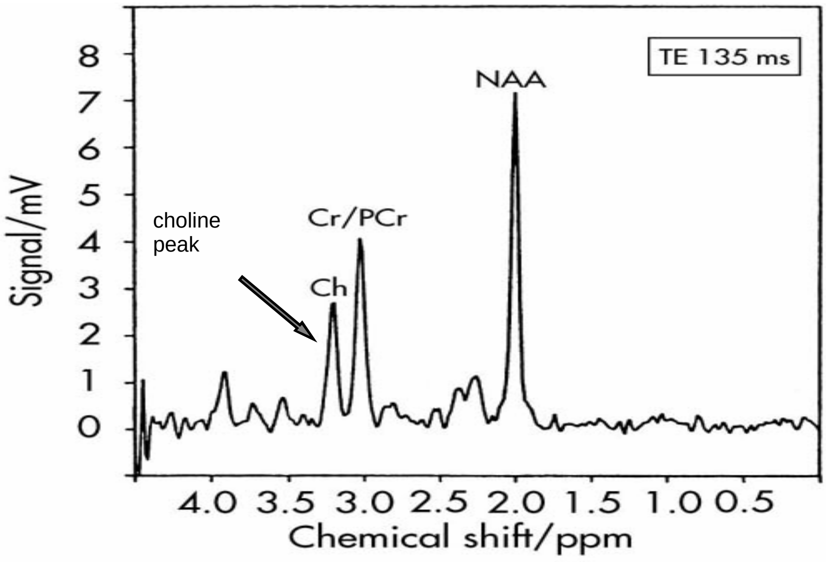
In nervous tissue, the cell walls care composed of triglyceride phospholipids. If the body becomes short of the right kind of fatty acids either because of poor diet or disease, then this could cause the brain to shrink, as seen in recent research, and cause the 'head' problems suffered by ME many patients. The high levels of choline are attributed to it not being able to be used to make phospholipids. If the right sort of fatty acids are given as treatment, then the brain should expand, returning to its normal size with an overall improvement in the patients condition. Professor Puri has observed this in his patients, with a corresponding reduction in brain choline levels.

The body takes fatty acids from food sources and builds them into longer chain units it needs in phospholipids. The most important of these fatty acids are EPA (Eicosapentaenoic Acid), DGLA (Dihomo-gamma-linoleic Acid), and AA (Arachidonic Acid). Even with a good diet it is still possible to be deficient in these most important fatty acids. The Δ-6 desaturase enzyme system can be blocked by such things as cortisol which is produced by the body in response to stress. Viruses also block the enzyme because certain fatty acids like EPA are virocidal. Shortage of some micronutrients such as zinc and selenium can interfere with the building process as can damage caused by caffeine and nicotine from smoking. One way to overcome this is to bypass the block by supplementation.

Ω6 Fatty acids pathway		**Enzyme system**	**Ω3 Fatty acids Pathway**	
Linoleic	18:2	*Δ6-desaturase*	Alpha-linolenic	18:3
Gamma-linolenic	18:3	*elongase*	Octadecatetraenoic	18:4
Dihomogammalinolenic	20:3	*Δ5-desaturase*	Eicosatetraenoic	20:4
Arachidonic	20:4	*elongase*	Eicosapentaenoic	20:5
Adrenic	22:4	*elongase*	Docosapentaenoic	22:5
Tetracosatetraenoic	24:4	*Δ6-desaturase*	Tetracosapentaenoic	24:5
Tetracosapentaenoic	24:5	*β-oxidation*	Tetrahexaenoic	24:6
Docosapentaenoic	22:5		Docosahexaenoic	22:6

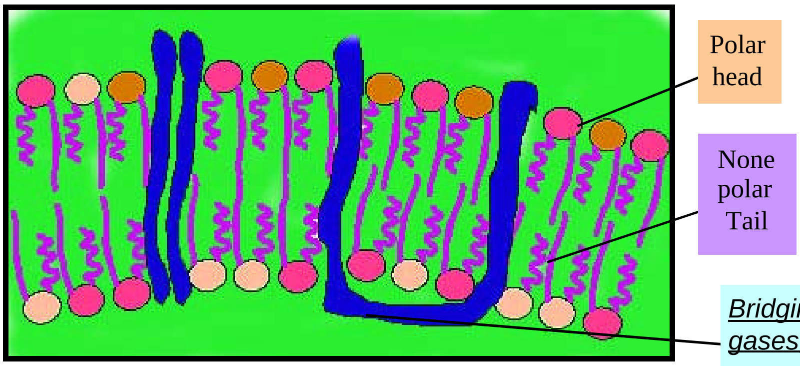
There was brisk activity at the side of the room which I though it might be refreshments, but on closer inspection, I noticed people carrying carrier bags full of something. This turned out to be VegEPA, the product that Dr. Puri had used for his latest trial. The makers had sponsored Dr Puri to talk to the Bolton Group in order to promote their product. I became extremely angry, and left that meeting.

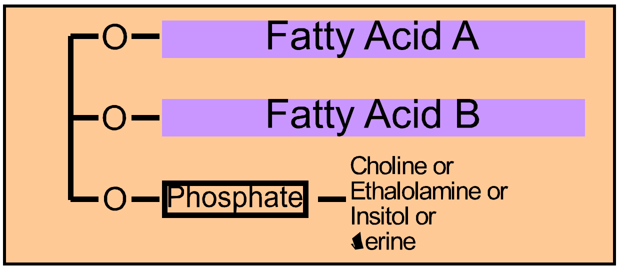
Instead of trying to push EPA treatment for ME/CFS through the system of clinical trials and licensing so that EPA based medicines may be prescribed by the NHS for ME/CFS, he has chosen the easy option to make money. The manufacturers of VegEPA have trademarked and patented their product, and claim a number of unique features, charging an extortionate price, which is fleecing ME sufferers, most of whom are desperate and on state benefits. There is not doubt that EPA works. A number of ME patients in the Bolton Area have been prescribed MaxEPA by their G.P.'s. Although it is not licensed for ME/CFS, some G.P.'s prescribe it for their patients. It is a useful alternative to statins for triglyceride and cholesterol control. I called at a local supermarket and bought a tub of supermarket Cod Liver Oil and Evening Primrose Oil capsules . The price was £1.49. VegEPA retails at £11.95. No doubt that there are other similar products in the well know pharmacy chains. The makers of VegEPA would argue that their product does not contain DHA, because it works against the EPA. Personally, I've seen improvement with Maxepa which does contain DHA.



Above -The tell tale choline peak seen in ME Patients.

Left Prof Puri and his Proton Neuro Spectroscopy MRI Scanner





Bridging proteins bridging act as gates allowing gases, ions and chemicals to pass through

Cells are enclosed in an envelope called the cell membrane. The structural units (bricks) are phospholipids which have two parts, a polar (water-loving) head and nonpolar (water-hating) tail. Part of the natural behaviour of these phospholipids is to form skins. They do this by forming a double layer, with the polar head on the outside and the nonpolar tails on the inside. Not just any fatty acid will do, it has to be the right sort otherwise it will be incorporated into a cell wall and cause damage.

Product	EPA	GLA	DHA	Antioxidant	Daily Dose	Price
Effamol Marine	17 mg	36 mg	11 mg	10 IU Vit E	8	No longer available.
Maxepa	170 mg		115 mg	Vit E	2-4	Prescription product
VegEPA	280 mg	~11 mg (100 mg EPO)	zero claimed	present	2	60 for £11.95
Supermarket Cod Liver Oil and Evening Primrose Oil	55 mg	40 mg	35 mg	10 mg Vit E	1	30 for £1.49

Ham, Potato, Leek and Herb Hotpot

Ingredients:-

1 red onion, peeled and finely chopped.
4 garlic cloves, peeled and finely chopped.
2 small leeks, cleaned and sliced.
225g (8oz) butter
200ml (7oz) white wine.
500ml (18fl oz) fresh ham stock.
450g (1lb) new potatoes, cooked.
550g (1.25lb) cooked ham, cut into chunks.
Sea salt and freshly ground black pepper.
65g (2.5oz) each of chopped fresh basil, parsley, chives and coriander.
French bread (optional).

Method:-

Using about 55g (2oz) of the butter, sauté the onion, garlic and leeks in a large pan, until soft.
Add the white wine, ham stock, potatoes and ham and cook for 5-10 minutes, until everything is nice and hot.
Drain off the liquid, keeping the meat and vegetables warm. Gently simmer the liquid, adding the remaining butter bit by bit, whisking all the time to thicken the sauce. Do not boil.
Put all the ingredients back into the sauce and season.
To finish, add all the chopped fresh herbs. Serve piping hot in bowls with some French bread.

This recipe is adapted from James Martin's grandmothers recipe. For the stock she used the end knuckle of hams left over from the butcher's slicer, and for the meat, the bits around the bones of a carved joint. Whatever you use, the ham must be a good quality, not a sliced, processed ham bought in a packet. James uses a great deal of herbs because the hotpot should be like a thick stew. As the sauce mainly consists of butter, the herbs serve to thicken and flavour it.

James's tip:- If you don't have the time or the inclination to make ham stock yourself, use fresh chicken stock, available in tubs from most supermarkets.

Who ?

Who do I tell that won't run a mile,
Or look on with a conceited smile.
Who do I tell that will understand.
And will offer a helping hand.
Who do I tell in confidence?
Who will not sneer at my diffidence?
Who do I tell who will be kind
And for the Stigma, never mind.
Who do I tell? The problem you see,
Is that I have now got ME.

Trevor Wainwright 1996

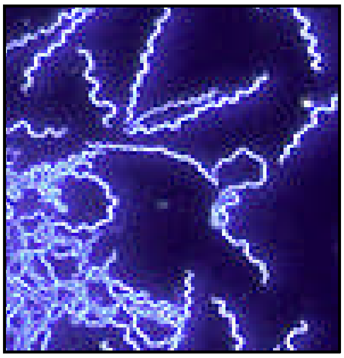
SoME Poetry is an internet Poetry Site depicting the daily struggle to come to terms with and live with the devastating debilitating illness Myalgic Encephalomyelitis Put together by Pathways columnist Trevor Wainwright and Pathways editor Mike Valentine. Comprising the work of 12 poets including one who wishes to remain anonymous, each with their own unique style and experience of ME and life itself with a severe illness, each poem is as individual as its author. One such poem is 'Who' by Trevor Wainwright, written in 1996 as an AIDS Awareness poem it sums up so eloquently the ignorance surrounding ME at the time.
http://somepoetry.me.uk/

Spectroscopic diagnosis in ME/CFS

A May 2006 report from Osaka University, Japan presents some astonishing results, for the researchers claim to have developed a way to diagnose ME/CFS using visible and near-infrared spectroscopy (Sakudo et ai, Biochemical and Biophysical Research Communications 2006). Blood sera from 77 patients and 71 healthy donors were analysed "blind" and the results subjected to principal component analysis (PCA) to examine how sensitive the test was in discriminating between patients and health controls. The PCA model predicted successful discrimination of the masked samples, predicting 54/54 (100%) of healthy donors and 42/45 (93.3%) of ME/CFS patients.
The authors say that their new approach deserves further evaluation as a potential strategy for instrumental diagnosis of CFS. If true, and replicated by other research groups, the findings would be a great advance in the diagnostic armoury for ME/CFS, and - intriguingly - they suggest that unknown factor(s) in blood serum are commonly present in all CFS patients.

ME and Lyme Disease

Lyme disease is an infection caused by the bacterium Borrelia burgdorferi, a member of the spirochaete family. Infection is transmitted by the bite of a tick that usually lives on deer but can infest dogs. The disease is most widely recognized in the US but is also a problem in many parts of Europe, including the heathlands of southern England. Lyme disease is a disease characterized by skin changes, flu-like symptoms, and joint inflammation. It was first described in the community of Old Lyme, Connecticut, in the US in 1975. There are in the region of 500 confirmed cases each year in the UK., but there could be up to 2,000 p.a. Full recovery may not take place in some cases, so the total number of cases will accumulate.



Borrelia burgdorferi magnified about 1000 times

At tick prior to feeding. It's body may swell to the size of a pea. after feeding when full of blood

At the site of the tick bite, a red dot may appear and gradually expand into a reddened area up to 5 mm across; and can expand to cover a large area of the body or pass unnoticed. Symptoms such as fever, headache, lethargy, flu-like symptoms and muscle pains usually develop, followed by a characteristic joint inflammation, with redness and swelling typically affecting the knees and other large joints. The symptoms may vary in severity and may occur in cycles lasting a week or so. Unless the disease is diagnosed and treated, problems may become chronic. There is usually no permanent damage to joints unless septic arthritis is triggered. Complications affecting the heart (such as myocarditis and heart block) or nervous system (such as meningitis) occur in some cases. The Jarisch-Herxheimer reaction may occur. If the spirochete infects the brain it is termed neuroborreliosis where neurological and psychiatric problems occur.. This serious condition needs skilled treatment.

This is a typical skin reaction to a insect or tick bite. This may occur after many hours, and in some cases spread to an area over a foot across. If this happens, immediate hospital treatment is required before the infection can take hold..

If Lyme proceeds to this neurological stage, and this is where the relationship with ME/CFS gets complicated. Neuroborreliosis is a syndrome that shares many features with ME/CFS, and is one of the medical conditions that have to be excluded prior to diagnosis of ME/CFS. However Borreliosis, being an infection can trigger ME/CFS itself, which complicates the issue

Lyme disease in the early stages can be diagnosed by the history of a tick bite and symptoms, and confirmed by blood tests. If diagnosed before joint inflammation occurs, the disease can be quickly cleared up with antibiotic drugs, although this may require aggressive and high dose treatment. Treatment of the complications depends on what problems present themselves.

Further information from www.lymediseaseaction.org.uk, Lyme Disease Action, PO Box 235, Penryn. TR10 8WZ. UK

Comment: I became concerned because some private doctors believe that NHS blood tests are not sufficiently accurate, and may order private tests. This is however disputed by doctors to whom have spoken because of the high incidence of false positives in test results. I very often come across patients who have paid out much money to certain private doctors for expensive antibiotics based on the results of these tests. Observation of these patients over many months reveals no improvement, and some are made worse. This can itself lead to mental health problems as our local ME/CFS clinics have found out, and make these patients reject what is good advice. Fortunately, it is not a big problem on our side of the Pennines. - Mike

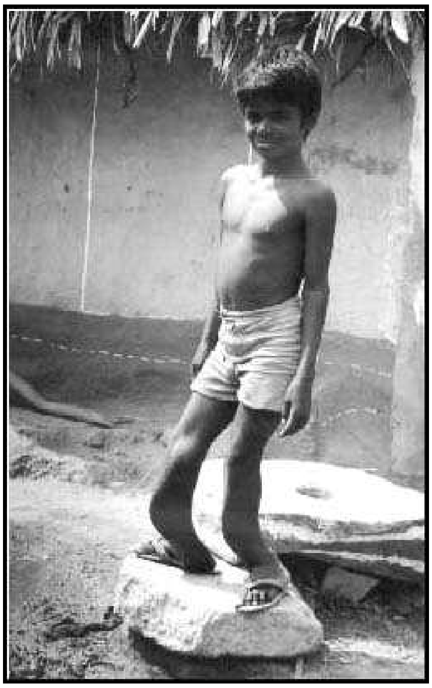
ME and Fluoride' *by Elizabeth McDonagh*

Background. Some time ago I was given a fluoride gel to use by my dentist. Within hours my ME was worse, and I recovered when I stopped using the gel. Because of this I've asked Liz to present this feature. Mike.

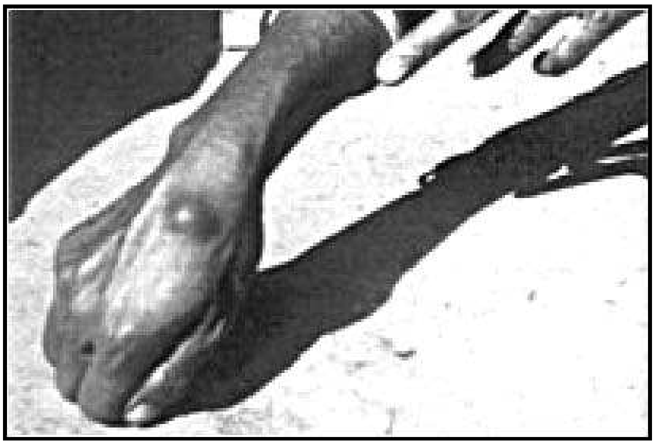
Fluoride' is the anion (negatively charged ion) of the mineral element fluorine. Fluorine is, like chlorine and bromine, a 'halogen' and is one of the most reactive elements in the periodic table of elements. Consequently, fluorine, a greenish yellow gas at normal temperatures and pressures, is never seen in nature (except in a chemistry laboratory). Fluorine is always associated with other elements as, for example, calcium fluoride, magnesium fluoride, sodium fluoride, hexafluorosilicic acid, sulphuryl fluoride etc. In water, such compounds dissociate to a greater or lesser extent to release some free fluoride ions. Since the late 1940s, when experiments began in America, the addition of fluoride to some water supplies has been promoted as a means of strengthening children's teeth. The practice has always been highly controversial. Fluoridation brings the level of fluoride in water to 1 milligramme /litre (1 mg/l) or one part per million (1 ppm) but it has been known since the 1940s that mottling and discolouration of teeth (dental fluorosis) is quite prevalent at 2 ppm and is strongly associated with fluoridation at 1 ppm .[1]

Dental Fluorosis

'A Handbook of Animal Nutrition' from 1949,[2] categorises fluorine (=fluoride) as a 'harmful mineral element' and describes it as 'a cumulative poison'. It has never been shown to be an essential mineral element. Its acute toxicity is recorded as between that of lead and arsenic yet the Drinking Water Inspectorate allows 1500 micrograms (1.5 ppm) maximum in water supplies in contrast to the 50 microgram limits on lead and arsenic Cumulative poisons build up in the body over time when the body's clearance mechanisms are unable to regularly remove all of the intake. In adults, fluoride accumulates mainly in the bones and (often years later) can lead to arthritic pains and fusion of joints, a condition known as crippling skeletal fluorosis. High levels (typically 4 to 11 ppm) of fluoride in Indian water supplies have crippled millions of people in India. Professor Susheela of New Delhi is the Indian Government's adviser on fluoride and fluorosis. She cites irritable bowel conditions, infertility and chronic fatigue as further consequences of excessive fluoride intake.



Skeletal fluorosis



Skeletal fluorosis— bone spurs

Fluorotic skin lesions

In ‘Fluoride-The Great Dilemma’ (1978),[6] George Waldbott lists the major symptoms of “CHRONIC FLUORIDE TOXICITY SYNDROME”. These are:-

Symptom	Chronic Fluoride toxicity Syndrome[6]	ME/CFS Comment
Fatigue	Chronic fatigue not relieved by extra sleep or rest, ’Flu-like symptoms	Common
Neurological	Headaches, Visual disturbances. Tingling sensations in fingers especially) and feet Dizziness. Tendency to lose balance	Sometimes happens.
Mental	Loss of mental acuity and ability to concentrate. Depression. Excessive nervousness	Common except excessive nervousness
Muscular skeletal	Arthritic-like pains in lower back, jaws, neck and limbs Muscular weakness	Common
G.U.	Excessive thirst, Frequent need to urinate. Urinary tract irritation	Rare, but not unknown
G.I.	Mouth sores, IBS (gastro-intestinal disturbances, pain, diarrhoea, constipation, bloating, tenderness). Nausea	Mouth sores usually absent. IBS common.
Skin	Skin rash.	Not part of ME

Members will note that this list largely parallels the symptoms of M.E. One symptom of ME not on the list is food intolerance or ‘allergy’. I believe Waldbott missed this out because he was an allergist, so most of his patients were ‘allergic’ anyway. The addition of fluoride to drinking water gives no control on the total intake of fluoride of any individual as that depends on the amount of tap water drunk and the intake of fluoride from other sources such as, tea, fish, fruit juices, non-stick pans, toothpastes and toiletries etc. It has been claimed that much fluoride can be absorbed trans -dermally through bathing or showering in fluoridated water. Some fifty years ago, the National Academy of Sciences published data claiming up to 80 mg/day of fluoride could be consumed without harm. Forty years later, this was revised to 10-20 mg/day after it was discovered that the original calculations were erroneous.[7]. In 2005, the Opinion of the EU Scientific Panel on Dietetic Products, Nutrition and Allergies was that the Tolerable Upper Intake Level is only around 12 mg/day for an adult male, and less for women and children. [8]

March 22nd 2006 saw the publication of the long-awaited US National Research Council Report *‘Fluoride in Drinking Water’* [9]. This carries a rider. “The safety and effectiveness of fluoridation is outside the scope of this Report and is not evaluated”. However, the Report states that American children drinking water with fluoride levels of 4 ppm (4 mg/l) are at risk of ‘severe dental enamel fluorosis’ and that people drinking water with that level for years have increased risk of bone fractures. The Report recommends that the US Maximum Contaminant Level for fluoride, established by the EPA in 1986 at 4 mg/l, be reduced. Regardless of its disclaimer, this Report must be of tremendous significance to the future of artificial water fluoridation. It emphasises the danger of fluoride in drinking water at 4 mg/l and admits that fluoride has the potential to bring about biochemical changes in body cells. It calls for further research to clarify the effect of fluoride on the brain and the endocrine system (especially the thyroid gland) and acknowledges research evidence of a wide range of adverse effects of fluoride. Dr Elise Bassin’s recently published research [10] estimates that drinking fluoridated water significantly increases the risk of osteosarcoma (bone cancer) in boys between the ages of five and eight. Why is it taking us so long to realise that fluoride is something to be avoided?

1 NHS CRD University of York, *Review on fluoridation of drinking water* 2000
2 Lowe, L.T. *The Student’s Handbook to Animal Nutrition* Littlebury & Co Ltd, Worcester (1949)
3 Gosselin R. E. et al *Clinical Toxicity of Commercial Products* 5th Edn Williams & Wilkins (1984)
4 The Water Supply (Water Quality) Regulations 1989 London HMSO Reprinted 1995
5 Susheela, A *Fluoride Toxicity* International Society for Fluoride Research (1985)
6 Waldbott, George “Fluoridation, The Great Dilemma” Coronado Press 1978
7 Groves, Barry *Fluoride–Drinking Ourselves to Death?* Newleaf (2001) ISBN 0 7171 3274 9
8 Opinion of the EU Scientific Panel on Dietetic Products, Nutrition and Allergies
9 NRC Report *Fluoride in Drinking Water’ 2006*
10 Bassin E.B., Wypij D., Davis R B., and Mittleman M A. Age-specific Fluoride Exposure in Drinking Water and Osteosarcoma (United States) *Cancer Causes and Control*

North of Doncaster *Personal comment by Trevor Wainwright*

I begin my column for this issue with a comment that I made an error in the text of your the last issue of Pathways, Issue 8 with regards to the Invest in ME Conference on May 12th 2006 and the following statement:

After a fight the family got her back home. The daughter died, age 22 when she became unable to take food or drink.

Following publication, I received information that the young woman died at the age of 32, not 22, with a suggestion that I should arrange for this to be corrected. Although not a professional columnist, I thought it only just that I look into the matter so I have visited the Invest in ME website and found the following on the issue, the first reading as such:

After a fight the family got her back home. The daughter died, age 22 when she became unable to take food or drink. I left at this stage so cannot comment on possible topics for further research that will have emerged from this interactive session.

Thus backing up the original article, but a further search came up with:

We heard the heartbreaking story of yet another unnecessary and young death, beautiful young Sophia who could not get a doctor who would treat her disease as something other than psychosomatic, and after a horrific experience of being committed unwillingly to an institution, eventually died last year of what can only be called medical neglect at the young age of 32.

So who is right, perhaps for anyone interested the answer lies with Invest in ME who can be contacted via their website www.investinme.org but first click on the relevant section The ME CONFERENCE 2006 – REVIEW and ask for confirmation.

Well now there is another question, What is happening at Seacroft?, and what of the other so called centres of excellence? Cuts to services have been mooted, which leads to the question. What has happened to the £8 million plus the MRC boasted about that was going to do so much. What has it achieved, and most importantly where has it all gone? Was it just another gravy train that stopped at certain stations just long enough for those on the make to get on. Is it yet another Governmental plot to give money away, make sufferers think they are been thought of and then go away? Well answers and comments to mersc_wy@hotmail.com

Well on to research, and another petition, this time from Di Newman, Organiser of this year's May 12th Peoples Rally. Launched at the Peoples Rally it calls for a Science & Research-based Healthcare Policy in the UK. The Petition will be presented to Parliament on European Day of Disabled People, 3rd December 2006. For those with internet access the petition can be found at www.petition.me.uk and click on "Sign Petition Now", the heading being:

"We believe that there should be a clear Biomedical-Science Based Healthcare Policy for Myalgic Encephalomyelitis in the UK and Clinical Guidance that recognises the multi-system complexity and profoundly debilitating effects of M.E."

All information will be treated in confidence and there are certain fields which one need not fill in. For those not on the internet and or would wish to take the petition further, or simply require more information, it can be obtained from Di at PO Box 775, 42 Elizabeth Court, Peterborough PE1 4WZ. Email: MEpeoplesDayPetition.ME.uk Tel: 01733 552872 or 07742 615 952 and returned by 17th Nov 2006.

Will they take any notice? Maybe one day.