

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.



Oilseed Rape

In early May the fields around Doncaster were a sea of yellow. Is this responsible for the sore throats and sniffles everyone suffered ?

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Thyroid Connections and Interesting Books

See page 9



Two Summer Recipes & Hints for summer food safety

Butterfly Trout Fillets, Feta And Melon Salad.

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Fluoridation Issues:

Lecture by Dr Paul Connett in Manchester and how fluoride could affect ME/CFS sufferers. See page 8.

News from the Sheffield NHS CFS/ME Clinic.

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The Importance of the Doctor-Patient Relationship

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Linking Up—The Latest News

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Expert Patients Programme



Doncaster **NHS**
Primary Care Trusts



Help yourself,
you're the expert

There are free, locally-held courses, designed to help people living with long-standing illnesses regain as much control over their well being as possible. People with conditions such as arthritis, heart disease, multiple sclerosis, asthma, diabetes and osteoporosis have all benefited by talking to people who understand, meeting others who live with pain or have similar problems and talking to organisations who can help and support. See page 10

You Write

Carolyn Writes: *Over the last couple of years I've noticed my hair has become horrible and dry. Recently I have been prescribed thyroxin tablets 50 ug daily by my G.P., and since starting on them I've noticed a that my hair has become more normal and how it used to be. Prior to this he has been watching my TSH levels increase over a number of years following a thyroid problem. Is there any connection ?*

Yes. Dry skin and hair are symptoms of decreased thyroid function, and it is to be expected giving you thyroxin would fix the problem. Doctors will keep surveillance on patients who they suspect will eventually suffer from thyroid failure. The good news is that you will find your ME/CFS will improve slightly and you will be exempt from all prescription charges from now on. Thyroid issues and ME are contentious and I will deal with those in Pathways later this year.

Anne Writes: *Regarding taking D-Ribose; at first I really felt there was some benefit in taking it because my head felt much clearer and I did feel as if I had more energy. I began to work a full extra day a week on the strength of this. However, over the last few weeks I have had a bad spell having to take some time off my part time job which I have never had to do before in the 4 years since returning to work. I normally work 15 hours a week + 2 hours administration time, but since being on D-ribose I have worked an extra 8 hours week, far too large an increase with hindsight. I have obviously overdone it because I was feeling better. I am now committed to working the extra 8 hours a week, if I can maintain it, until the middle of July and so could not really give an accurate report on the D-Ribose. However, after this time I will be on holiday for 8 weeks and will trial it again during this time, but this again will probably not give me a true measure because I will be resting more anyway. The best time to trial it properly again would be when I return to my normal 15 hours + 2 in September. I have to admit these hours sometimes stretch my health and I was very foolish to take on the extra hours. The recovery time theory does seem to ring true I have to admit. I think though it has taken longer than six hours, but certainly quicker than I would normally recover. My GP was not really convinced that this product would help ME, but I now have a regular prescription via my own GP.*

I think what Dr Myhill says in the first place still holds true. What d-ribose does is reduce the mitochondria repair time (= 'recovery time') from many days to six hours. So in effect it does not alter the disease process or the consequential ups and downs, but does shorten the recovery time to get back to a base level. So there is an increase in quality of life if you like. You've achieved something that many people haven't and would give their eye teeth for, and this is an effective intervention.

Irene Writes: *Mike don't know if you have seen this on the Yahoo groups, but it was posted on MEActionUK group. One of the Members had been asked by Dr Peter White to post it for him, I think you could say as a right to reply, as the psychiatric involvement was getting a lot of flack at the time. It also shows to me that THEY are looking at our group chats. The bit that interested me most was the saying "if it wasn't for them they would not have discovered that anti depressants don't work for ME."*

The website is www.bartscfsme.org and the posting follows. I'm sure the printing that follows is contentious. 'You write' is for YOUR VIEWS. Let us know what you think.

Psychiatrists and CFS/ME , Professor Peter White, St Bartholomew's Hospital and the London NHS Trust

Why and how are psychiatrists involved in the care of and research into CFS/ME ?

The role of a liaison psychiatrist. A small number of psychiatrists, who practise in general acute hospitals, are specialists in 'Liaison' or 'Liaison/Consultation' psychiatry. This specialty is primarily involved in the assessment and care of people who attend general hospitals. Such patients usually have a significant medical illness, such as cancer, and also have emotional problems adjusting to their illness and treatment, or they have psychiatric illnesses such as a depressive illness .Liaison psychiatrists talk with such patients and their medical teams to help them overcome these emotional or psychiatric problems. Common psychiatric illnesses seen by liaison psychiatrists not only include

depressive and anxiety disorders, but also neuropsychiatric problems such as delirium (a confessional state some times brought on by medicines or infections), dementia, as well as the consequences of substance misuse such as delirium tremens (alcohol withdrawal state). Liaison psychiatrists work with a team of other clinicians, such as clinical psychologists and social workers to provide the best care for their patients.

As part of their role they are often asked by their medical colleagues to assess and help people who suffer from various illnesses which Medicine currently finds difficult to understand and treat. These illnesses commonly are composed of symptoms and disability with no obvious pathology being found. These are sometimes called "functional disorders" on account of the apparent lack of anatomical pathology accompanied by obvious change in the function of the particular organ or bodily system. Examples include irritable bowel syndrome and chronic pain disorders, such as tension headaches or fibromyalgia. Most doctors see CFS/ME as such an illness and thus refer patients.

Their training To qualify as a liaison psychiatrist, a person has to first of all qualify as a doctor (five or six years). A number of liaison psychiatrists do further training (three years) to obtain the physician's qualification of membership of the Royal College of Physicians before they then undergo training as a general psychiatrist (a further six or seven years), and this will include further training specifically in liaison psychiatry (two years). With their membership of the Royal College of Psychiatrists and their Certificate of Specialist Training, they then become a consultant, although such jobs are uncommon with many acute general hospitals not having such a post.

CFS/ME A small group of liaison psychiatrists became interested in CFS/ME and started to specialise in the assessment and care of CFS/ME patients in the 1980s, since these patients otherwise received no care at all. They therefore set up clinics as well as inpatient units to try and help such patients. Have they succeeded?

Liaison psychiatrists lead or co-lead three of the 13 CNCCs in England, and are involved in more LMDTs as well as some services in Northern Ireland and Scotland. They can be particularly helpful in finding out whether a patient is suffering from a psychiatric illness, either as an alternative diagnosis to CFS/ME or as a second problem alongside CFS/ME. They are then in a good position to treat such an illness. Liaison psychiatrists are also able to help people with CFS/ME who also have significant but understandable emotional problems coping with their disability and symptoms. In some clinics liaison psychiatrists work alongside physicians so that the patient can receive care and help for both "mind" and "body". The quote marks are there because liaison psychiatrists fundamentally believe that the mind is not separate from the body but is an integral part; so what is emotional is also physical, but happening physically in the brain and autonomic nervous system. Liaison psychiatrists therefore work alongside physicians and clinical psychologists, as well as occupational therapists and physiotherapists to help patients improve their health.

Research into CFS/ME An even smaller number of liaison psychiatrists around the world are active researchers, trying to achieve a better understanding of what CFS/ME is, its causes, and how best to treat it. What have they achieved? Liaison psychiatrists have either led or been involved in research that has done the following:

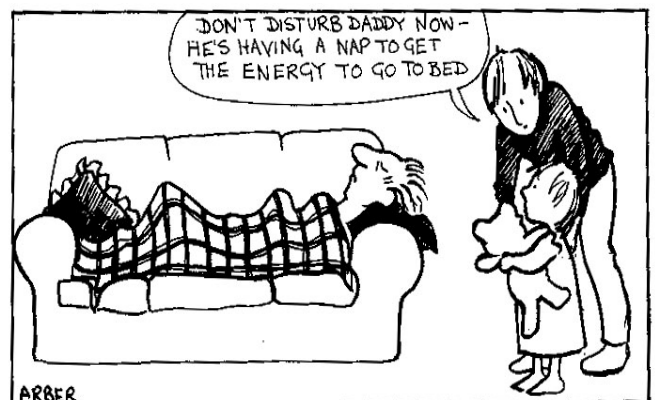
- Established the separateness of CFS/ME from other medical illnesses
- First showed how common it is
- Demonstrated its heterogeneity
- Established the role of certain infections in triggering CFS/ME
- Established that the stress hormone system the hypothalamic pituitary axis is down-regulated in CFS/ME
- Showed that stress has a role to play in some patients
- Provided early evidence that showed sleep is abnormal

Research into treatments Perhaps the most important research carried out by liaison psychiatrists has been into designing and testing treatments. There have been three major achievements that have involved liaison psychiatrists:

- Demonstrating the ability of cognitive behaviour therapy to help patients improve their disability and fatigue
- Demonstrating the ability of graded exercise therapy to help patients improve their disability and fatigue
- Showing that antidepressants do not work

Without this research, there would be no treatments available to patients with CFS/ME that doctors can say have reasonable evidence of helping, with few adverse effects.

Future research Liaison psychiatrists are working with other colleagues to both improve these established treatments and to test them against other treatments (www.pacetrail.org and www.fine-trial.net). We are also involved in research into causes, such as cytokines, genetics, stress, and how these interact with each other to cause the illness.



If I were ever to be unfortunate enough to develop CFS/ME, I would want to be treated by a team which includes a liaison psychiatrist, so that my care was truly holistic and integrated addressing both mind and body equally.

The Importance of the Doctor-Patient Relationship

Your doctor is paid to look after your health. I get very worried when people tell me that they haven't see their doctor in years. There are numerous reasons like "He can't do anything for me". "He does not believe in CFS/ME". "He thinks I'm wasting his time". If for any reason you don't trust your doctor or don't get along with him/her, then change. There is no point in carrying on a relationship that doesn't work. Very often in a practice of several doctors, there may one who is interested in CFS/ME.

Your doctor is not a magician. He cannot cure CFS/ME, but is your gateway to treatment. He can prescribe drugs like antidepressants, pain killers etc. You cannot get access to N.H.S. specialists e.g. the Sheffield CFS/ME clinic without a G.P. referral. You need him for example to get access to the other NHS services like the Pain Control Clinic. Really everyone with CFS/ME should visit their doctor at least every six months. This will enable him to follow your case, and adjust treatments etc. as required.

Another reason you should keep in contact with your doctor is for DSS benefits. When benefits are claimed, the DSS send questionnaires to your doctor without your knowledge. It is important that he knows your problems, especially if benefits are disputed. It is difficult to prove your case without his support. Ideally everyone should attend a specialist Fatigue Clinic as soon as possible after onset, and be seen every year. The economics of the NHS make this a dream rather than a reality.

CFS/MEs very often can suffer other medical conditions, or new conditions may arise. It is important that they are screened for, and checked. They may be more serious than CFS/ME or may just aggravate the fatigue. The important thing is that something is done about it. Here are examples why:-

- One member delayed a thyroid operation because of the fear that it would aggravate her CFS/ME. Eventually, she had the operation and was very much better, but still has CFS/ME
- Another member was diagnosed with bowel cancer, but delayed treatment six months using alternative treatments, being afraid it would affect his CFS/ME. He eventually had the operation, ending up with a colostomy, and eventually died. He would have had a better chance of survival had treatment started earlier.
- One member had bad CFS/ME. No one seemed to be able to help her. She was a regular at a local A&E department. In desperation things like electric shock therapy were tried. Eventually a consultant realized she had high blood pressure, which is not a symptom of CFS/ME. A full clinical investigation revealed a non cancerous kidney tumour. This was operated on successfully, clearing the hypertension and the fatigue.
- A case of Moresch Woltmann (Stiff Person) Syndrome, a rare clinical condition similar to CFS/ME, but unknown to many doctors, was detected after five years only because the person had kept in touch with his doctors.
- Within South Yorkshire recently there have been several cases brought to my attention of lung cancer. Apart from a wheezing, cough (sometimes + blood), unexplained weight loss, shortness of breath and chest pain, these people suffer chronic fatigue. Sometimes a self diagnosis of CFS/ME prevents people seeking early treatment which would have given a good chance for curative treatment. This symptom cluster is recognised by doctors, and further blood tests and investigations would have shown the true cause.

Our policy is that before anyone is accepted for membership they have a diagnosis of ME/CFS from a doctor. It is then the policy that they are encouraged to attend a CFS/ME clinic like Leeds, where they will be checked that the diagnosis **is** CFS/ME, and not something that mimics it. A significant number of patients at the Leeds and Sheffield Fatigue Clinics have alternative or additional diagnoses.

If your doctor is not sure about CFS/ME, you may obtain a summary of the Chief Medical Officer's recommendations regarding ME/CFS by contacting me. *Mike*

Mitochondrial Diseases.

Malaria, is the worlds biggest killer. Although well known historically, the cause of the disease was discovered only after the invention of the microscope, and development of associated medical technology was necessary before ways were found to control the disease. Similarly the discovery of mitochondria had to wait for the electron microscope, and most knowledge of Mitochondrial Disease (MD) dates from 1940. In 1959, the first patient was diagnosed with a mitochondrial disorder. MD include 40+ disorders having a common factor that the mitochondria are unable to completely burn food and oxygen in order to generate energy. Several thousand mitochondria are found in every cell in the body and they are the power houses of the cells, producing adenosine triphosphate (ATP), which is the electricity of the Cell.

Causes: One case of MD in 4000 may be inherited, acquired MD may be caused by auto antibodies, medicines or other toxic substances. Mitochondria have their own DNA (mDNA). Nuclear DNA (nDNA) has two copies of each gene, one from each parent; mDNA contains only genes inherited from the mother. When cells divide, the nDNA is duplicated and there are mechanisms which repair damaged DNA. Mitochondria duplicate in a similar, but separate process. mDNA does not have the same repair mechanisms as nDNA, and defective copies do end up in the new mitochondria. MD becomes apparent once the number of affected mitochondria reaches the 'threshold expression'. Not all of the enzymes and other components necessary for proper mitochondrial function are encoded in the mDNA. Most mitochondrial function is controlled by nDNA instead. Mutations to mitochondrial DNA occur frequently, due to the lack of the error checking capability that nDNA has; mDNA has very limited repair abilities and almost no protective capacity to shield the mitochondria from free radical damage. This explains why mitochondrial disorders often occur spontaneously and relatively often. Sometimes the enzymes that control mitochondrial DNA duplication (and which are encoded for by genes in the nuclear DNA) are defective, causing mDNA mutations to occur at a rapid rate.

Symptoms: In adults, many diseases of aging have defects of mitochondrial function. These include type 2 diabetes, Parkinson's disease, atherosclerotic heart disease, stroke, Alzheimer's disease, and cancer. There are 40+ diseases and symptoms specific to MD. MD may affect one sort or many sorts of cells of the brain, nerves, gut, muscles, kidneys, heart, liver, eyes, ears, or pancreas. The severity of the illness ranges from mild to fatal. Depending on which cells of the body are affected, symptoms might include: lack of energy, poor growth, loss of muscle coordination, muscle weakness, visual and/or hearing problems, developmental delays, learning disabilities, mental retardation, heart, liver, or kidney disease gastrointestinal disorders, severe constipation, respiratory disorders, and diabetes. There may also be increased risk of infection, neurological problems, seizures, thyroid dysfunction, and dementia.

Diagnosis: Like all diseases, MD is diagnosed by history, symptoms, and a physical examination, together with routine lab tests. Further investigations may include various tests: neurological, metabolic, cerebral spinal fluid, MRI, eye, heart, ear and DNA testing. More invasive tests, such as a skin or muscle biopsy, might be performed. Even after a complete investigation a specific diagnosis may not be revealed.

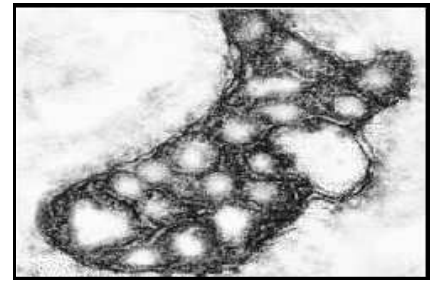
Treatment: MD is not curable. Limiting the damage may be an option for acquired MD, otherwise treatment can only help reduce symptoms, or delay or prevent the progression of the disease. No two people will respond to a particular treatment in a specific way, even if they have the same disease, so treatment is 'try and see'. Nutritional strategies along with occupational and physical treatment may help some patients. Vitamins and supplements reputed to help are Coenzyme Q10, B complex vitamins, thiamine (B1), riboflavin (B2), niacin (B3), B6, foliate, B12, biotin, pantothenic acid, Vitamin E, lipoic acid, selenium, and other antioxidants, and vitamin C. Specific diets may be advised by a doctor or dietitian.

Outlook: After a diagnosis the patient's medical treatment relieves symptoms and delays the progression. The course is unpredictable and may progress quickly, slowly, or be stable for years.

Mitochondrial Disease and ME/CFS Issues.

Anyone researching ME/CFS and mitochondrial diseases will notice that there are many similarities such as the onset of trigger or threshold, multiple variable symptoms and family tendency. Similar treatments are advocated, so could the conditions related ?

Muscle biopsies on ME patients have revealed mitochondrial abnormalities in muscle cells, but since this is an invasive procedure, it can only be carried out in a hospital environment. Other studies indicate that there are abnormalities in the mitochondria of certain white blood cells called neutrophils in some ME/CFS patients. One company has recently started to offer a laboratory test which is available through private doctors treating ME/CFS, which can be derived from a blood sample. The test gives a series of numbers reflecting the condition of various mitochondrial functions. The results I've seen indicate a high degree of correlation between the level of



Above, a micrograph image of a mitochondrion from an M.E. patient, and below is the normal appearance.

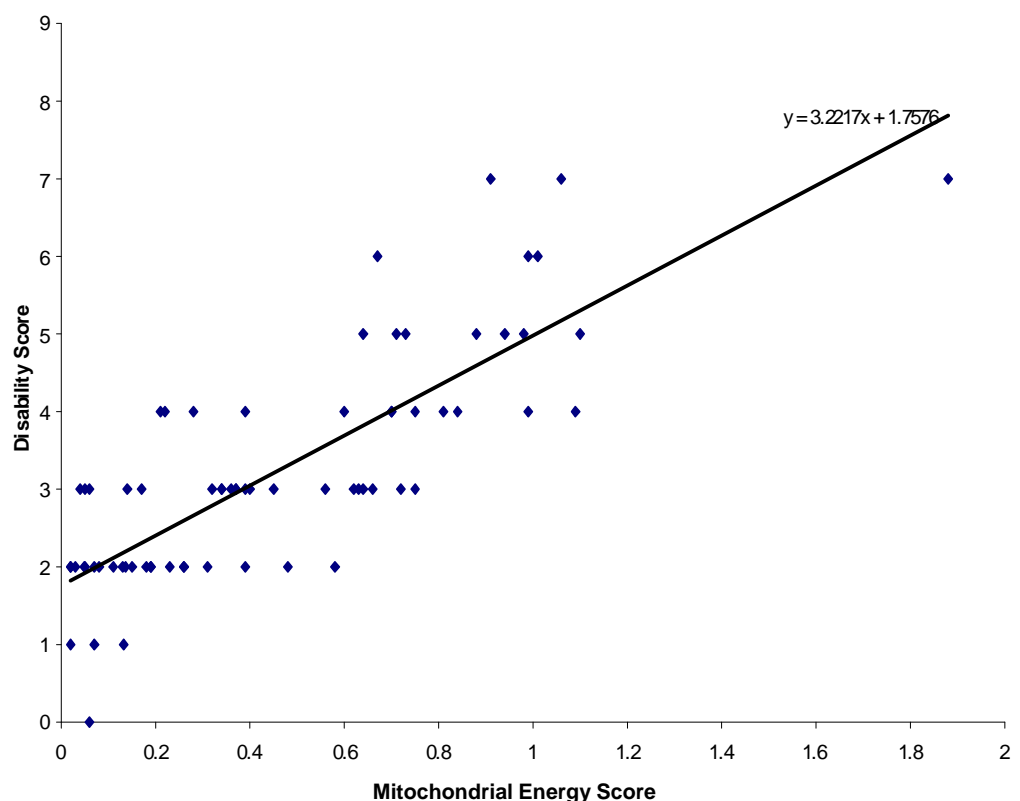


observed fatigue (disability score, Bell scale) and measured abnormalities (energy score). The correlation coefficient (a test for the quality of data) is about 80%, with a 65% variation. I see a number of negative aspects with this test and results.

- 1) The Bell scale of ME/CFS disability is an arbitrary scale, and is based on a qualitative or subjective assessment based on a personal judgement.
- 2) I am not aware of any double blind crossover trials into the use of this technique, which would be the gold standard for the NHS to accept it as evidence based. Private medicine has a different set of criteria based on what the patient pays for, not the NHS.
- 3) There is very little quality assurance, and at the time of writing only one lab is currently offering the test, although I stand to be corrected on this issue.
- 4) The full clinical significance of the test has yet to be established.
- 5) Although the level of correlation appears to be high, it is known that a few patients with CFS/ME return 'normal' results. However, this may be explained by research evidence showing that there are at least two subtypes, one which may not affect the mitochondria. No distinction is usually made in the diagnosis or data used by doctors.

However the test does have positive aspects:

- 1) It provides evidence supporting diagnosis. Although costing several hundred pounds, it provides an accessible test outside the research environment showing ME/CFS patients, for the first time, that something real is wrong.
- 2) It has established a yardstick or a number that can be used to check the progress of disease and responses to treatments.
- 3) It does provide an indication of treatment options for doctors.



Mike.

Meeting Report: The Expert Patients Programme. (25/5/07)

Participants report: *"The EPP course has made me realise that I can have some say over my pain and not let it dictate my life". "I have started swimming again which I never thought I would do, it's given me a new lease of life". "It's just been great to be able to see and speak to people with the same problems". So, we decided to invite Debbie Leyden to address our group meeting.*

At our meeting on 25th May, Expert Patients Programme Co-ordinator for Doncaster PCT, Debbie Leyden, told us the PCT is now offering free courses (called The Expert patient programme) designed to help people with long-term illness to manage their condition on a daily basis. She was accompanied by Sharon Fordham, one of the voluntary tutors for the courses. All the tutors have personal experience of chronic illness and provide good support for participants. They are police-checked and covered by NHS indemnities. They have training and evaluation, including a year of supervision of their work.

The courses are held in a friendly, welcoming atmosphere in a comfortable venue. Currently, courses are held during daytime hours but there is no reason why evening courses should not be held if desired by patients. Groups consist of 8 to 16 people. 12 is usual. People are not encouraged to come with a partner or close friend.

Seventeen million people live with chronic conditions such as ME/CFS, heart disease, stroke, cancer, arthritis, diabetes, and mental illness. The Expert Patients Programme is a self-management programme that has been specifically developed for people living with long-term conditions. Relaxation, fatigue, anger, fear, frustration, communicating with professionals, medication, depression, goal-setting and problem-solving are some of the subjects covered. The aim of the programme is to support people, to increase their confidence, improve their quality of life and enable them to better manage their personal condition.

Course materials are multi-lingual and in large-print format. Each course consists of a weekly 2½ hr session over six weeks. There is a mid-session break and tutors are understanding if people need further rest.

A 'Community Interest Company' runs the courses locally on behalf of the PCT. Plans are under way for an on-line course in the future and possibly for a course for under-eighteens. The next course is at the Sandringham Centre on 12th June with an introductory session on June 5th. Another is planned to take place in Cantley, dates to be announced. Those who complete a course are invited to a feedback and reunion session two to three months after the end of their course. For further information Doncaster Primary Trust can be contacted on 01302 32011 or visit www.expertpatients.nhs.uk - Liz

A poem written by an Expert Patients Programme Course Participant

*For six weeks I've come here each Thursday
To learn what's the best way to cope
With my chronic illness,Parkinson's,
Like Muhammed Ali and the Pope*

*I've learned about drugs and their dosage
And what taking too many will do.
I've got tablets and capsules and pastilles
And pills coloured red, white and blue*

*All the class have a long term illness
Many tutors are afflicted too,
Ours has a turbo charged wheel chair
And laps the car park at a hundred and two*

*Some students have problems in walking
Or have pains in their chest or a joint
Some are depressed and lethargic
And don't want to go on....what's the point?*

*But six weeks of sharing ideas
And suggestions that others have made
Has cheered us all up, restored courage
So that none of us now is afraid*

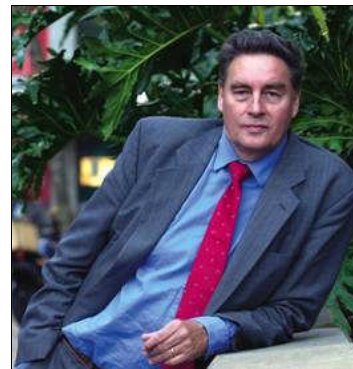
*We can look forward to a future
Far better than our recent past
Thanks to our classmates and tutors
You are all EXPERT PATIENTS, yes, you've passed!*

Anon 13th April 2006

Fluoridation Issues

Lecture by Dr Paul Connett in Manchester

On May 17th, Michael and I were privileged to hear Dr Paul Connett address a meeting in Manchester. Health chiefs in the North West claim that adding fluorosilicic acid to water supplies at 1 part per million (1 milligram per litre) will reduce tooth decay and cause no harm to anyone. They are planning to supply up to seven million people from Cumbria to the Wirrall and from Blackpool to Glossop with fluoridated tap-water.



Dr Connett, who recently retired as Professor of Chemistry at St Lawrence University, Canton, New York, is one of the world's foremost scientific critics of fluoridation. In an hour-long Power Point presentation, he explained why he is so opposed. He said much of the scientific research supporting fluoridation is of poor quality. Fluoride is not an essential element in the body so comparing it to a vitamin or an essential mineral is invalid. Fluoride is very poisonous and 1 ppm cannot be thought of as a small amount. The maximum allowed in water in this country is 1.5 ppm so there is no margin of safety. The American Dental Association recently stated that fluoridated water should not be recommended for mixing baby formula.

Fluoridation gives no control on dose, because that depends on how much tap-water is drunk and on how much fluoride is obtained from other sources. Scientific evidence has shown that excessive fluoride can cause children to have mottled and stained teeth (dental fluorosis) a sign of fluoride poisoning. Fluoride could also cause increased hip fractures and bone cancers, besides having adverse effects on the brain, even lowering children's IQ.

Fluoridation is a medical intervention. Mass-medication contravenes accepted principles of medical ethics and is against Human Rights because under EU Fundamental Human Rights law every individual has the right to accept or reject any medical intervention for any reason and at any stage of their treatment. Dr Connett advised the people of Manchester and district to organise in advance of the 'public consultations' which must be held before fluoridation is implemented. - Liz

Why could fluoridation be an issue in ME/CFS ?

When I witnessed Dr. Connett's presentation, I was considering it from the point of view of CFS/ME. Around ten years ago I was presented with a mouth wash 'Fluorigard' by my dentist. Very quickly I identified this product as making my fatigue worse. My dentist was not prepared to accept this, because to him it was dental heresy.

Dr. Connett specifically told of rats being given 1 ppm fluoride in their water for one year (within the 0.7 to 1.2 ppm range recommended for fluoridation). The exposed rats had kidney damage, brain damage, greater uptake of aluminium into the brain and beta amyloid deposits similar to those found in Alzheimer's disease. There is evidence that under certain conditions fluoride can weaken bone and increase the risk of fractures. However the most worrying part was hearing that fluorides also increase the production of free radicals in the brain through several different biological pathways. These are capable of causing substantial damage. Fluoride accumulates in human pineal gland, and can interfere with melatonin production, which is usually disturbed in ME/CFS. Fluorides can depress thyroid function. In the past sodium fluoride has been used as a means to reduce thyroid activity in patients with hyperthyroidism (an over active thyroid gland) to reduce the overproduction of thyroxine (T4). As many patients with ME/CFS have borderline thyroid function, my concern is that for people with borderline thyroid function, this may cause thyroid deficiency. The doses used were about 2.3 - 4.5 mg of fluoride per day. This dose is currently exceeded by some people, especially those using a high concentration fluoride product like 'Fluorigard'.

Fluoride is a chemical 'spanner in the works', and can activate as well as depress many cellular enzymes through hydrogen bonding. For myself personally, I avoid fluoride products as much as possible. -Mike

Thyroid Connections and Interesting Books

by Elizabeth A McDonagh

Adapted from National Pure Water Association's newsletter *Watershed* Volume 12, Autumn 2006.

There is plenty of evidence that fluoride adversely affects the function of the thyroid gland and those who attended NPWA's last AGM will recall Dr. Barry Durrant Peatfield's interesting talk on precisely that subject. Dr Peatfield's new book *Your Thyroid and How to Keep It Healthy: The Great Thyroid Scandal and How to Survive It* (Paperback) is now available from bookshops and, at a discount, online from Amazon.

The issue of missed diagnosis of thyroid illness was first brought to popular attention in this country by Diana Holmes. Following polio at the age of ten, Diana's health steadily declined until she was unable to function. She was variously (and incorrectly) diagnosed as having anxiety and depression, epilepsy, coeliac disease, polymyalgia rheumatica, M.E., M.S. and myasthenia gravis. Forty years of her life were lost to illness. Finally, she was diagnosed by Dr Peatfield as suffering from 'hypothyroidism and hypoadrenalism', though hospital blood tests had recorded normal thyroid function. Within a few months, Dr Peatfield's recommended treatment had restored Diana to good health. In *Tears Behind Closed Doors*, first published in 1998, Diana related her story and called for re-assessment of the value of hospital blood tests in the diagnosis of thyroid illness. The new 2002 edition of her book is expanded to include a chapter entitled "Artificial Fluoride, The Great Thyroid Antagonist". A call for the official guidelines on diagnosis of thyroid illness to be changed, with the doctor also giving attention to clinical signs and symptoms rather than relying exclusively on the hospital blood test, was made by seven doctors in a letter to the Editor of the British Medical Journal published in BMJ Vol 314: 14 June 1997. One of the authors was a Senior Lecturer at Birmingham Medical School, Dr Gordon Robert Bruce Skinner.

A few years ago, a persistent virus was believed to be responsible for the relatively new illness, M.E. (myalgic encephalopathy). A virologist, Dr Skinner had been consulted by a number of M.E. patients. He discovered that up to 50% of them, classified as euthyroid (within the normal reference range for thyroid hormones) showed clinical signs of hypothyroidism (low thyroid hormone production) and they improved on thyroid hormone replacement. Dr Skinner has written his 'ain book' *Diagnosis and Management of Hypothyroidism* which explains the rationale behind his treatment of thyroid illness and gives a fascinating insight into the life, thought and decision-making processes of one Glaswegian, caring, individualist, football-loving, (and some would say persecuted), physician. Doctor Skinner is currently under a regime of restrictions to his practice imposed by the General Medical Council. On the occasion of a hearing of his case, at the GMC, on June 15th 2006, I was privileged to meet him, a healthy and radiant Diana Holmes and almost forty patients who had turned up in his support.

Twins Donna Roach and Coralie Phillips were there with copies of their book *Hypothyroidism in Childhood and in Adulthood-A personal approach and scientific standpoint*. In it they record their diagnoses of hypo-thyroidism in childhood. Thyroid replacement restored their health but doctors reduced their levels of medication because of fears that it might induce osteoporosis. They soon became ill again and one had to give up work. They were full of gratitude to Dr Skinner who had reassessed their medical needs and made them well again. Other patients had similar stories, many praising the efficacy of 'Armour Thyroid', a porcine-derived thyroid extract.

Tears Behind Closed Doors by Diana Holmes is available from

Namaste Publishing, PO Box 127, Shrewsbury, SY3 7WS

01743 341303. Price £9.95 +p&p

Diagnosis and Management of Hypothyroidism by Doctor G.R.B.Skinner is available from the author at 22, Alcester Road, Moseley, Birmingham. B13 8BE .. 0121 449 8895 The price is £14.95 including p&p.

Hypothyroidism in Childhood and in Adulthood by C Phillips and D Roach is published by Nottingham University Press.

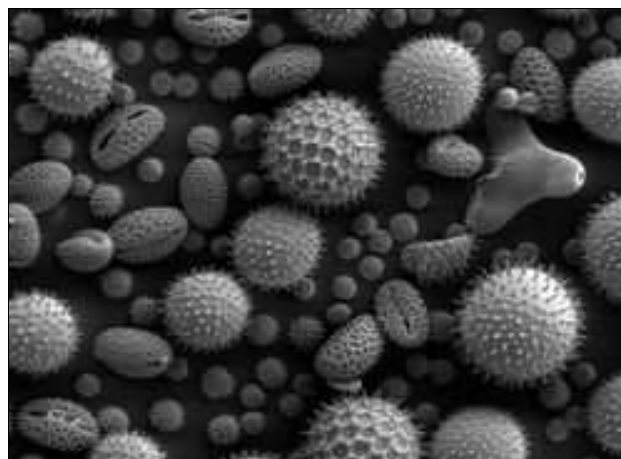
It may be ordered via www.nup.com or from the authors on 01639 641367 at £13.50+p&p.

Seasonal Allergic Rhinitis (Hay Fever) and ME/CFS

With the coming of Spring comes the reproductive imperative. As plants are immobile they need a mechanism to disperse and transport their pollen by the wind which is the main cause of 'hay fever'. Hay fever affects 10-20% (around 6 million people) of the population. It is an allergic response to pollen, which can affect anyone regardless of age, sex or nationality. Hay fever is more common in people aged between eight and twenty-five and research suggests that the allergy can run in the family. Many people with ME/CFS seem to have more than their fair share of atopic problems which are immune system mediated e.g. asthma eczema and allergies. Some people react quite badly because they have an over active immune system, while others are not affected or may even experience a remission, which is usually attributed to a diversion of immune activity from the ME/CFS disease process. This could be because of different ME/CFS subtypes.

At different times of the year different plants release their pollen. Most people are affected between May and July although the season can start as early as March and as late as October. Hay fever is caused by three main phases. Spring hay fever is usually caused by tree pollen, summer problems by grass pollen and in autumn by late-flowering plants and fungal spores. This explains why different sufferers have hay fever at different times of the year. Although Hay fever treatments can ease uncomfortable symptoms, sufferers should also try to protect themselves from any pollens that cause an allergic reaction. To help, here is a list of ten top tips:

- Avoid places that may trigger symptoms - such as long grass, freshly mown grass in gardens or fields, and certain types of trees.
- Keep windows and doors closed when the pollen count is high - early evening and at night time.
- Dry clothes indoors, rather than on a washing line outside.
- Avoid damp areas where mould may be present.
- Be aware of the pollen count - which is broadcast on the weather forecast, radio, TV and the internet.
- If you are using antihistamine tablets then always read the label, to check that they do not cause drowsiness.
- Wear sunglasses when outside, to protect your eyes from the pollen.
- Try applying a thin layer of Vaseline just inside nostrils to trap pollen.
- Avoid smoky environments as these can irritate the allergy and make symptoms worse.
- Always ask your pharmacist to recommend a suitable treatment.



Scanning electron microscope of image of pollen grains from a variety of common plants

Treatments

Antihistamine medicines If antihistamines just blocked the histamine receptors all would be fine. But they also like many other drugs, have other effects. In the brain they can slow down the chemistry which very often manifests itself as drowsiness. How much an individual is affected depends on the dose, other depressant drugs, alcohol and above all the individual. The older antihistamines like chlorpheniramine have a marked sedating effect, but the newer ones like cetirizine are claimed to be 'less sedating', although some individuals will still be affected. There is a standard warning which is printed on over the counter packs and dispensed medicines. *"Warning. may cause drowsiness. If affected do not drive or operate machinery. Avoid alcoholic drink"*. It is up to the individual to decide if they are affected or not. It is recognised that as many as 10% of motorway accidents and 5% of accidents on other roads are caused by 'fatigue' issues. Fatigue caused by drugs will be additional to that caused by ME/CFS. It is an offence to drive when unfit to drive through drink or drugs (section 4, Road Traffic Act 1988). The law makes no distinction between impairment due to illegal drugs and impairment due to medicinal drugs, whether prescribed or purchased over-the-counter. The penalties are the same as for drink driving - disqualification for at least a year, a fine up to £5,000 and up to 6 months imprisonment.

How Antihistamines Work and What Goes Wrong

It is the effect of the pollen on our immune system which causes 'Hay Fever' or 'Seasonal Allergic Rhinitis'. Our immune system, which is responsible for defence against disease, sees pollen as a potential enemy or allergen. What happens is that the lymphocytes which are part of our immune system detect the pollen and remember it as foreign.

If it encounters the same allergen again it responds by making antibodies,

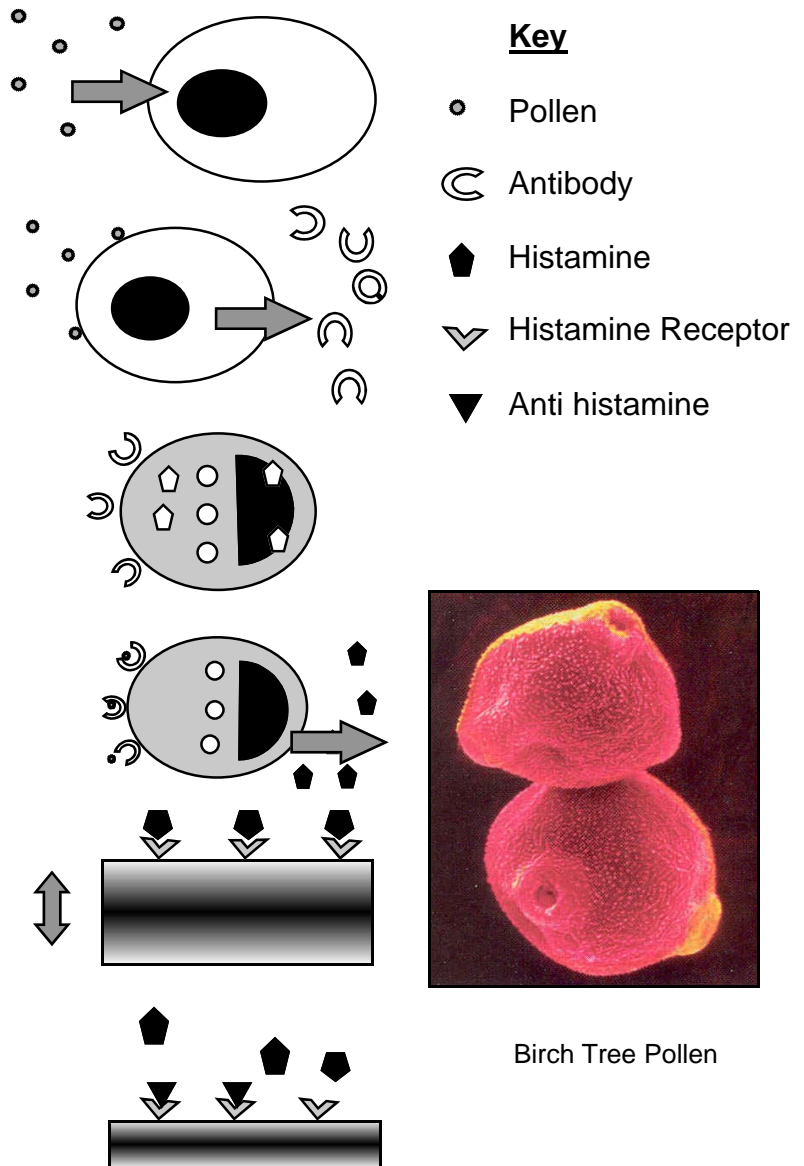
The antibodies then attach to the mast cells which are found throughout the body.

When an allergen comes into contact with the antibodies attached to a mast cell it causes histamine, stored in the mast cell, to be released into the circulation.

Histamine causes changes in the body to try and guard against infection. One of the results is to cause swelling and irritation of the nasal passages and watering of the eyes and nose i.e. a wash out effect.

Part of this process is caused by histamine attaching to receptors ('lock and key') on blood vessels causing them to swell or dilate. This brings more blood into the affected area.

If we can get an antihistamine drug to attach to this receptor in the blood vessel walls and block (mask or plug up) histamine receptor sites, then we have a method by which we can control the symptoms.



Acrivastine is a short-acting antihistamine which must be taken three times a day which above all does not cause drowsiness. There are other antihistamines, some better than others. Many of these drugs are marketed on the pharmacy shelves under various brand names and are available without a doctor's prescription. As antihistamines are drugs, there are safety issues like side effects, drug interaction, safety in pregnancy and safety issues concerned with certain diseases. Some are prescription-only medicines because of these issues. For example one manufacturer introduced the non drowsy anti histamine tefenadine (Syndol) but in the early 1990's it was withdrawn because its interactions with other medicines and certain foods caused heart problems.

Other Hay Fever Products

Eye Drops. For many people the main misery is watering eyes. There is a drug called sodium chromoglycate which is a mast cell inhibitor available, in the form of eye drops, from pharmacies, without prescription.

Nasal Sprays. A beclomethasone nasal spray is also available. This is a weak steroid and works by depressing the immune system locally within the nasal passages.

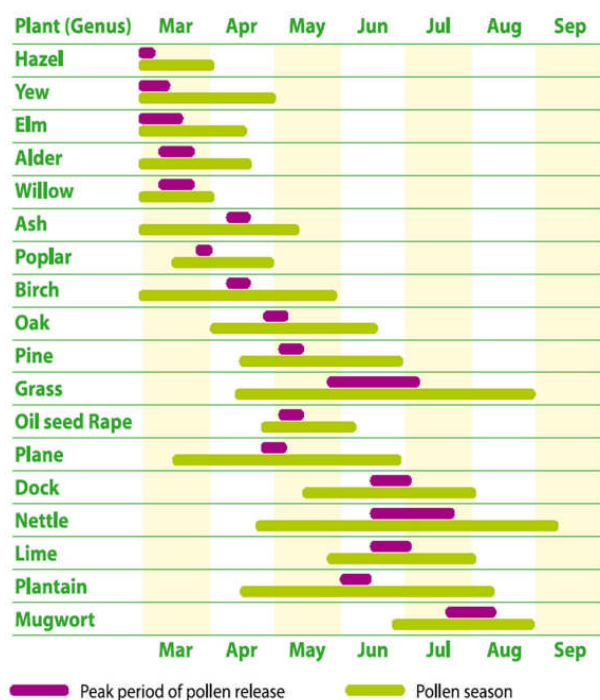
Other treatments. These include things like desensitising vaccines such as EPD (Enzyme Potentiated Desensitisation) available from special clinics.

Other Issues There are other medical conditions e.g. nasal polyps that can cause similar symptoms to Hay Fever. If medicines don't seem to help, or there are persistent or unusual problems, your doctor is the person to see.

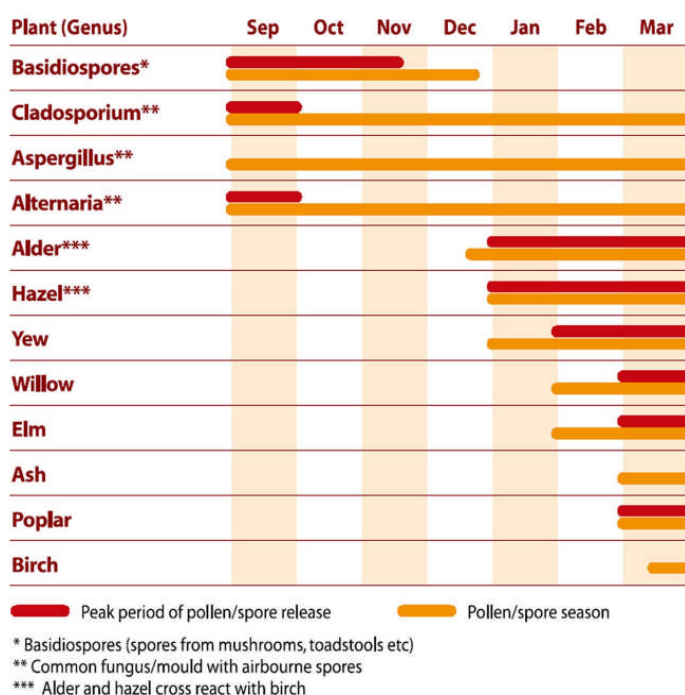
Generalised UK pollen & fungal spores calendar

The calendars below show the general pattern of allergenic pollen and fungal spore release in the UK. The exact timing and severity of pollen and spore seasons will vary from year to year depending on the weather, and also regionally depending on geographical location.

Summer



Winter



Up to date pollen forecasts can be obtained from the website <http://www.zirtek.co.uk/Allergies.aspx>

The Yellow Peril. In recent years, around Doncaster in early May the fields are just a sea of yellow from the flowering oilseed rape crop. It is just twenty years since the cultivation increased dramatically. Oilseed rape is attractive not only for the food and feed industry, but also as a renewable raw material e.g. for bio fuels.

The problem is that in recent years, at the beginning of May, many people have started to suffer with Rhinitis which coincides with the main flowering season. Rapeseed oil tends to find it's way into many bakery products and margarine. The problem is that the sensitivity to oilseed rape pollen is also carried over to food products containing rapeseed oil.



Don't Let The Food Bugs Bite!

As summer is almost upon us, it's time for outdoor meals and the bugs, Which would spoil faster at an outdoor buffet: a well-done beef burger or coleslaw? You may think eating cooked meat sounds safer than the mayonnaise-rich side, but you'd be wrong. Foods made with mayonnaise and vinegar based dressings have preservatives which stop bacteria growing, while those containing protein are especially prone to bacteria, which can double in amount every 15 to 30 minutes in the heat.

<u>Type of food</u>	<u>Temperature Tip</u>	<u>Leave outside</u>	<u>Healthy Hint</u>
Raw meat, poultry & sea food	Keep below 4°C	No longer than one hour	Refrigerate or store meat in a refrigerator before cooking.
Cooked meat,	Always cook thoroughly	No longer than two hours	Never put cooked food on the same platter that held raw food.
Raw veggies	Keep at room temperature	No longer than two hours	Vegetables lose nutrients when they become limp from heat.
Salads	Keep below 4°C	No longer than two hours	Salads with cooked eggs should be taken Inside after an hour.
Condiments	Keep at room temperature or cooler	As long as needed, but not in direct sunlight	They can lose freshness if allowed to stay in the sunlight too long.

Signs that you've caught a food- borne illness include mild to severe nausea, vomiting and diarrhoea.-
Sandy Nye

Summer Recipes**BUTTERFLY TROUT FILLETS**

A great catch for Barbecue or Oven

For a flavoursome dish, you can't beat these delicious butterfly trout fillets – boned, stuffed with zesty lemon-flavoured cream cheese and a sprig of dill.

You can either barbecue them in their foil dish or cook in the oven.

Find in Asda in the fish chiller:-
'Stuffed Rainbow Trout Fillets' £3.98 (360g)

Or get the fishmonger in any supermarket to bone the trout fresh for you and make them up yourself.

THEN, for the Grand finale:-

For a sweet, indulgent finish, tempt your guests with a sticky meringue roll filled with toffee sauce, dairy cream, and topped with chopped pecan nuts:-

'Toffee Pecan Roulade' from the supermarket freezer (most supermarket stock these).

FETA AND MELON SALAD

A colourful salad that's refreshing too.

Serves 4

You will need:-

1 watermelon
1 pomegranate
200g Feta Cheese
1 lime
Olive oil
Ground black pepper
Fresh mint

Cut half a ripe watermelon into cubes, discarding the seeds, and place in a large bowl.

Remove the seeds from a pomegranate and sprinkle over the melon.

Crumble 200g feta cheese over the top.

Mix the grated rind and juice of a lime with 3 tbsp of olive oil and pour over the salad. Season with freshly ground black pepper, and garnish with fresh mint.

DOCTORS' NOTES ON PATIENTS' CHARTS**(ACTUAL NOTES—UNEDITED!)**

Submitted by Maggie Rothwell to the Kirkless ME newsletter.

Patient has chest pain if she lies on her left side for over a year.

On the 2nd day the knee was better and on the 3rd day it disappeared completely.

She has had no rigors or shaking chills, but her husband states she was very hot in bed last night.

The patient has been depressed ever since she began seeing me in 1993.

The patient is tearful and crying constantly. She also appears to be depressed.

Discharge status: Alive but without permission.

Healthy appearing decrepit 69 year-old male, mentally alert but forgetful.

The patient refused an autopsy.

The patient has no past history of suicides.

Patient has left his white blood cells at another hospital.

Patient's past medical history has been remarkably insignificant with only a 40lb weight gain in the past three days.

Patient had waffles for breakfast and anorexia for lunch.

Between you and me, we ought to be able to get this lady pregnant

Since she can't get pregnant with her husband, I thought you might like to work her up.

She is numb from her toes down.

While in the ER, she was examined, X-rated and sent home.

The skin was moist and dry.

Occasional, constant, infrequent headaches.

Patient was alert and unresponsive.

Rectal exam revealed a normal size thyroid.

She stated that she had been constipated for most of her life, until she got a divorce.

I saw your patient today, who is still under our care for physical therapy.

Exam of genitalia reveals that he is circus sized.

The lab test indicated abnormal liver function.

The patient was to have a bowel resection. However, he took a job as a stockbroker instead.

Skin: Somewhat pale but present.

The pelvic examination will be done later on the floor.

Patient was seen by Dr. Blank, who felt we should sit on the abdomen and I agree.

Large brown stool ambulating in the hall.

Patient has two teenage children, but no other abnormalities.

Linking Up The Latest News:-

Our new Yahoo Talk Group has been formed for all those on the internet in order to add to the ways of 'linking up' with others and breaking the isolation this illness brings to so many.



bty71939223 · mike@danum.me.uk | Group Owner - [Edit Membership](#) [Start a Group](#) | [My Groups](#)

leger-me · Leger ME Doncaster

Home

Messages

Pending

Spam? [Empty]

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Management

Info Settings

Group Information

Members: 7

Category: [Chronic Fatigue Syndrome](#)

Founded: Apr 16, 2007

Language: English

Yahoo! Groups Tips

Did you know...

Real people. Real stories. See how Yahoo! Groups impacts members worldwide.

Yahoo! 360°

Share your life through photos, blogs, more.

There's something new for moderators! Learn, share, and take your group to new heights with Moderator Central. [Check it out.](#)

Home


Activity within 7 days: **16 New Messages** - [New Questions](#)

Description [\(Edit\)](#)

A group for members of Leger ME/CFS to keep in touch with each other.

Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers

Information Helpline (01302 787353). Quarterly Newsletter 'Pathways'. Group Meetings, Support and Social Events. Website with Information, Links and Information Downloads. Networked Disability Support, Signpost and Liaison Service. Clouds Counselling Service. Danum ME Case Support and Review Service. Linking Up a telephone, penpal, e-Pal, Befriending Service. Networking to Allied Organisation. Liaison with The Sheffield and other CFS/ME Clinics.



Most Recent Messages [\(View All\)](#) Search: [Search](#) [Advanced](#) [Start Topic](#)

Re: Advice required

Hi Carloyn Paula played her part well today, she is now relaxing. Both Margaret and myself were in at the interview, me with pen poised to take notes. We

Posted - Sun Jun 3, 2007 5:56 pm

Trevor Wainwright
[mersc_wy](#)
Offline
[Send Email](#)
[Invite to Yahoo! 360°](#)

Re: Advice required

Hi Trevor, Another thing and this is very important for Paula to remember:- When the doc. asks her questions tell her to reply "as if it is her Very Worst ME

Posted - Sun Jun 3, 2007 4:33 pm

carolyn
[carolyn2462003](#)
Offline
[Send Email](#)
[Invite to Yahoo! 360°](#)

From John Greensmith

Hi Forwarded by Trev on behalf of John PERMISSION TO FORWARD, REPOST AND USE IN NEWSLETTERS. To: All M.E. online groups, my M.E. chums, volunteers of ME Free

Posted - Sun Jun 3, 2007 12:37 pm

Trev Wainwright
[mersc_wy](#)
Offline
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Trev Wainwright

Join the 'Talk Group' by going to www.leger.me.uk and clicking on the blue button labelled 'Talk Group'. Sign up and you will get a confirmation email from the moderator within 24 hours which then enables you to talk with other members via posting messages which go direct to the email inbox of all the members. It's a great way to communicate and make friends, share your thoughts and opinions, and even to just have a good old rant on a bad day.

The June 'Update of Linking Up' will be sent out a week after you receive your copies of Pathways. I'm pleased to say we have gained two new members, and may I ask everybody to make them feel welcome.

Carolyn
carabee@btinternet.com

Above is the talk group home page which can be accessed by clicking the blue 'talk group' bubble on <http://leger.me.uk/>. In order to use the site you must register a Yahoo user name and then register as a user. Experience from other talk groups suggests this is necessary to avoid being hijacked by hackers.

Right is a reply form which can be used to respond to a 'thread', a particular line of correspondence. An alternative is to set things up to respond via your email browser. Any replies are seen by all members of the talk group, but there is a way to contact people individually.

Home Messages Pending Spam? [Empty] Post Files Photos Pending Polls Members Pending Calendar Invite Management

There's something new for moderators! Learn, share, and take your group to new heights with Moderator Central. [Check it out.](#)

Post Message [Post Message Help](#)

☒ If you reply to the message author or the group owner, your email address will be displayed in the message you send.

New! Compose your message with Rich-Text Editor (Beta).

To: leger-me@yahoogroups.com

From: bty71939223 <mike@danum.me.uk>

Date: Sun Jun 3, 2007 7:49 pm

Subject: Re: Advice required

--- In leger-me@yahoogroups.com, "Trevor Wainwright" <mesc_wy...> wrote:
> Hi Carloyn
> Paula played her part well today, she is now relaxing. Both Margaret and myself were in at the interview, me with pen poised to take notes. We weren't in that long.
> Trev
>
> From: "carolyn" <carabee...>
> Reply-To: leger-me@yahoogroups.com
> To: leger-me@yahoogroups.com
> Subject: (leger-me) Re: Advice required
> Date: Sun, 03 Jun 2007 15:32:23 -0000
>
> Hi Trevor,

What language is this post in? [English]

Yahoo! Groups Tips

Did you know...

The only place for moderators, by moderators. Go to Moderator Central.

Yahoo! 360°

Share your life through photos, blogs, more.

News from the Sheffield NHS CFS/ME Clinic

I have recently attended two meetings at the Sheffield ME/CFS clinic on behalf of Leger ME.

27th April. At this meeting we discussed a formal draft constitution and rules for a Patient/Users/Carers representative group. Myself and Liz have attended these meetings quarterly for three years on a regular basis since the conception of the clinic. The idea is to widen the representation and include representatives from PALS (Patient Advice and Liaison Services) and other groups, and have a clearer, defined, role. There would be travelling expenses available, something of a frustration so far because travelling has been at myself or Liz's expense. Ideally we need someone else other than myself or Liz to attend these meetings. If you are interested in helping the group this way please let me know.

1st April This was a Local Implementation Team meeting. It reviews the service and is really a management meeting. I frequently come away from these meetings feeling frustrated, because really it is difficult to understand the inner workings of NHS management. Of the issues raised were old faithful limited funding of the service, and waiting lists. It usually does include some brainstorming and tries to find more effective ways to deal with patients. Irrespective of whatever the shortcomings of the service are, it must be supported at all costs in the interests of M.E. sufferers. We have to be thankful that there is now a clinic at least that will provide some support, which is a lot more than three years ago when there was nothing.

Annual Stakeholder Meeting

The South Yorkshire and North Derbyshire CFS/ME Service will hold a stakeholder event which will take place on Friday, 6th July, 2007 at St Mary's Conference Centre, Bramall Lane, Sheffield. The focus of the event will be employment and education for adults, young adults and children with CFS/ME. Speakers will include Anne Gregorowski, Nurse Consultant, Adolescent Health, Great Ormond Street For Sick Children NHS Trust, and Darren Bickerstaff, Condition Management Programme Project Manager. Other speakers will be named nearer the time. If anyone is interested in attending this meetings please contact me as I will not be able to attend this meeting and someone should attend on behalf of the group. Mike

The NICE Guidelines

The National Institute for Health and Clinical Excellence (the body responsible for laying down guidelines on NHS treatments) has been working on producing guidelines on ME/CFS. This of course is what people with ME/CFS have been waiting for, especially those who have suffered disbelief and lack of knowledge on the part of their doctors for many years. However, the **draft** guidelines which NICE published last year were widely criticised by patient groups and by the All Party Parliamentary Group on ME. Chair Des Turner MP described it as 'not fit for man nor beast' and Dr Ian Gibson MP of the Inquiry described it as 'useless'. The closing date for submissions to NICE on the draft has now passed, but it can still be found on <http://www.nice.org.uk/page.aspx?0=368933>.

During the consultation period, many excellent submissions on the draft were made to NICE by the main ME/CFS charities, by patient groups and by individuals, protesting loudly about its emphasis on graded exercise and cognitive behavioural therapy, and about its playing down of physical research and symptoms.

The final publication has now been delayed until August. *Ute (Sheffield ME Group).*



Two Diary Days in London Waving the Flag by Trevor Wainwright**May 10th**

To No. 10 Downing Street I nipped onto the forecourt of the DoH, changed into the Convict Suit and assembled my banner. It read "ME, A Life Sentence". The rest of the group were waiting opposite Downing Street, small in number but big on hope. Introductions were made; Neil & Phil were from London, Di, Suzanne (who was also deaf) and Anne who was her carer and interpreter were from Peterborough. Suzanne was given the honour of knocking on the door of Number 10. We had a brief banter with the custodian before he accepted the submissions from The 25% Group, Doris Jones on behalf of Dr Dick van Steenis, Tymes Trust, Mental Health, The Deaf with ME, Lupus and M.E., Lymes & M.E., Brucellosis & M.E., and M.E.Research.U.K.

To Westminster We got the usual strange looks from the people in there, including a high ranking police officer. Consular Evans, from Yvette Cooper's Office joined us and asked what it was we hope to achieve and how they could help. What we needed, I told her, was a specific test for ME to be diagnosed as an illness in its own right, separated totally from CFS. I quoted the media stories where people were said to have recovered from ME but how could it be so when there was no specific test for it, how did people know it was not some fatiguable illness for which the treatment be it CBT, GET, some potion or other worked.

The three main elements as far as we were concerned were specific test using the gene study carried out by the C.F.S.R.F. who had already identified certain chemicals produced by the active genes and had been promised the drugs to treat them if they could raise the money. Treatment itself to suppress the active genes, then cure to prevent the genes becoming active in the first place, again other illnesses were cited to help us state our cause. Matthew Walsh, assistant to David Wilshire, MP for Spelthorne, asked about our cause, so once again we were able to reiterate what we had said to Consular from Yvette's office.

May 12th

To Regents Park; a wheelchair came into view, driven by a woman wearing a fluorescent jacket, it was Di. For a short while it was just the two of us then we were joined by Christine, a sufferer from London who saw the banner "ME A Life Sentence". Tributes were paid in discussion to those who had died and the recent deaths reported in East Anglia (Suffolk?). Di also spoke of BRAME's support for the event and how Tanya and Christine were unable to join us due to the impact on Tanya's health following their ongoing commitments. Hayley and Ross left but not before thanking us for our efforts and wishing us good luck, and a request that we keep in touch for further events particularly similar ones next year. We were then joined by Phil. The final three poems were AIDS poems set to the structure of The Lord's Prayer, called Three Prayers for the Crying. They featured:

Prayer 1 - For the Politicians: It spoke of being legislated against, hypocrisy behind which lay the power and the glory and was never admitted.

Prayer 2 - For the Journalists: Spoke of the kiss and sell story and of those who had written of mental sickness against us.

Prayer 3 - For the Experts: Their funding come, their findings done, asking for deliverance from Departmental Ignorance.

At the end of each poem we all repeated the closing word as written **aME**n.

**ME**

ME is living in me, it's under my skin,
I'm losing weight; I'm going so thin.
Boy can it fight and punch from the right.
By day and by night I get such a fright.
Do I give in? Let it take over my skin.
No! I can fight, isn't that right?
And with all my might yes I will fight

S B 1996

North of Doncaster *Personal*
Comment by Trevor Wainwright

Another Winston?

Yes, AfME have announced that the former Second Sea Lord Peter Spencer takes up his new post as of 30 April 2007, as Chief Executive of Action for M.E. I seem to remember another former Lord of the waves being given charge of an organisation when the people were under threat from a greater menace. Yes, Winston Churchill, former First Lord of the Admiralty, a man of courage, not afraid to speak out, not afraid to challenge. Now we have a former Second Sea Lord in charge of one of the largest ME Organisations, and the people still under threat and in the grip of yet another deadly enemy and its allies. The enemy is called M.E., and its allies are disbelief and ignorance. Those collaborators and exponents of this ignorance are also our enemy's allies.

Well what of Peter Spencer, will he have the same courage as Churchill, (I mean Winston, not the nodding dog, which Chris Clark was said to be like, but the great leader himself). Will he say something along the lines of:

We must not flag nor must we fail. We must go on to the end. We shall learn all we can from those who suffer. With growing confidence and growing knowledge we shall defeat this despicable illness whatever the cost may be. We must take our campaign to the streets, we must raise the funding ourselves, in the streets, in the public houses. We must be prepared for arrogance, we must be prepared for ridicule. We must challenge the medical evidence that shall be against us. We must be prepared to challenge on all fronts, we must be prepared to challenge the politicians, we must be prepared to challenge the media, we must be prepared to challenge the experts. We must not be afraid to voice our concerns and make them known to all in authority. We must persevere, we must remain true to our cause, we must never surrender"

If he has half the guts of Winston Churchill, then I welcome him to the fold. If he's got half Churchill's guts, he should make one heck of a difference. I for one hope he does and that he drags the ME World out of apathy and forward. For so long we have been without a leader; for so long we have looked for a leader worth following, worth believing in. Have we got him in Peter Spencer? Is he prepared to offer Blood, Sweat and Tears? Time will tell.—Trev

We have invited Peter Spencer to come to see us in Doncaster in the Autumn.—Mike.

If it was ME

Sitting here wondering about ME,
 If it wasn't someone else but it happened to me.
 How would I cope and fight to live?
 Would my attitude be positive?
 Looking at my reflection, despair in my eye,
 Would I be brave and live life to the full?
 Or admit defeat, leaving everyone dull?
 God! I can't even imagine that life.
 Now I treasure my life and think,
 How often I've raved and ranted,
 but no more will I go on taking it for granted.

Irene Fleming 1996

Did You Know...

- Bean sprouts and mushrooms - are the whole plant.
- Spinach, lettuce and cabbage - are leaves.
- Celery and fennel - are stems.
- Onions, leeks and globe artichokes - are the leaf and stem together.
- Carrots, turnips and radishes - are all roots.
- Brussels sprouts - are the bud of the plant.
- Cauliflower and broccoli - are flowers.
- Tomatoes, aubergines, marrow and peppers - are all fruits.
- Potatoes and yams - are both tubers.
- Wheat, oats, rye, barley, rice and maize - are all cereals
 (the seeds of plants - usually members of the grass family).