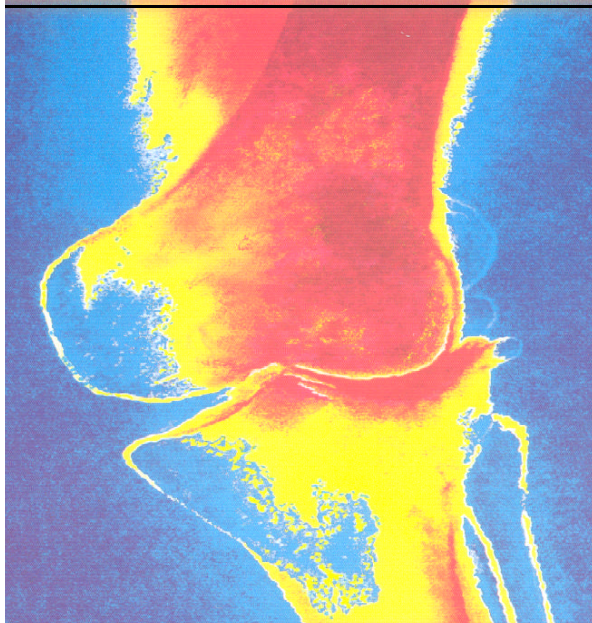




Pathways

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.



THE PANDEMIC FLU THREAT

The Official Government Line as of November 2005. See page 7.

Comment November 2005. See page 9.

ME/CFS, Joints and Arthritis.

Similarities there are between the two conditions. See page 4.



Warm Front Grants.

Reduce energy bills & How to upgrade our thermal efficiency free. See Page 15.



THE PANDEMIC FLU THREAT

The race to find a flu defence strategy. Page 8.

LEGER-ME CHRISTMAS PARTY

We will be holding our Christmas Party on Sunday 11th December at the Church Hall, Church Road, Kirk Sandall from 1.30am to 4.00pm. It will be a family affair and is suitable for all ages. The party is being organised by Ann and Jason. We also need to know how many children will be coming, as we need to make sure that they will each receive a present from Santa. Ann and Jason can be contacted on (01302 882271) or e-mail ann.bowker@btopenworld.com. See page 16.

Issues Arising From the AGM

Counselling Project

During its first year of operation the Leger ME contact line had 274 enquiries. Many of the issues raised can be serviced by supplying information or referring to other organisations e.g. welfare rights. Usually most clients can be serviced in 1-2 hours phone time over several calls. However there is a significant number of clients who have complex long term problems, not easily serviced, who need time and one to one guidance to deal with their illness or that of a relative or partner. While there is counselling available in e.g. G.P. surgeries and with other organisations, the counsellors do not have a profound working knowledge of ME/CFS. It was proposed at the AGM by a member with counselling qualifications that LME organises a specific counselling service specialising in CFS/ME-related issues. This would free up the helpline as well as providing a valuable service to members. We have drafted out a counselling project specification, and we are seeking funds around £3000 to further this project.

Subscriptions

Margaret proposed that subscriptions should run concurrently with our financial year which ends April 5th, rather than the end of September. It was agreed that they will be apportioned accordingly for the interim period. Members will receive a letter explaining the issue in February. This does not represent an increase in the annual subscription.

Canal Boat Trip

It was proposed that we run a boat trip through Doncaster to Mexborough rather than through Stainforth, Barnby Dun and around Thorne. We have made enquiries with the Ethel Trust who operate the boat and in principle there is no problem; the route is suitable and scenic. However there are practical problems. The Ethel will have to make a trip from Thorne where she is moored and back again. The time taken with locks and bridges means that and this will take two days to make the journey and return. The hire cost will be about £260. However there is an opportunity to split the trip up into sections and maybe share it with another organisation. The committee will look into this.

MINISTRONE SOUP

Olive Oil, Garlic – crushed
Carrot, Onion, Stick celery, and Potato, all chopped,
4oz cooked Cannelloni beans
1 tablespoon tomato puree.
Bay leaf, Pasta, Can tomatoes
½ teaspoon Italian herbs
1¼ pints vegetable stock
Parmesan cheese

Fry the onion, garlic and carrot gently in olive oil for two minutes. Stir in the potato and celery and cook for a further minute. Add beans, tomatoes, tomato puree, bay leaf, herbs and stock. Bring to the boil, cover and simmer for 1¼ hours. Add pasta and cook for 10-15 minutes. Season and serve with Parmesan cheese.

FARMHOUSE CHICKEN CASSEROLE

1 lb skinless chicken breasts
(cut into bite size chunks)
1 onion chopped
12 oz potatoes peeled and sliced
1 tablespoon whole grain mustard
1oz pearl barley
150 ml medium dry cider
2 sprigs fresh thyme or 1 teaspoon dried thyme, salt and pepper
8 oz carrots sliced
4 sticks celery sliced
8 oz cooked apple peeled cored and sliced,
low fat cooking spray
300 ml chicken stock

Heat a large flameproof casserole dish and spray with the low fat cooking spray, add the chicken and stir fry for 2-3 minutes, until the chicken is sealed. Add the onions, carrots, potatoes and celery to the dish/pan and cook for 2 minutes. Stir in the mustard, cooking apple, pearl barley, cider and stock. Season to taste, add the thyme, and bring to the boil. Reduce heat and cover. Simmer for one hour stirring occasionally, until the pearl barley is tender and the apple has cooked to a pulp, thickening the sauce.

The Mitochondrial Model of M.E.

Following the features I wrote in previous editions of Pathways, I decided to have the tests. My SODase and CPK came back normal, but the NAD can back very low. Supplementing with Niacinamide (vitamin B3), 100mg daily, brought the levels back to normal. However my NHS G.P. decided to monitor my blood chemistry for adverse effects before and when taking B3. There were definite changes in my blood chemistry due to the B3, but as they were within normal limits treatment has continued. One possible side effect of high dosage B3 is gout, due to altered uric acid metabolism. Another listed problem is raised liver enzymes. So I would advise anyone considering high dosages of B3 to have their blood chemistry checked by their G.P.

I lashed out £200 for the mitochondrial functions tests as featured in the last 'Pathways'. What came back was that my ADP reuptake by the mitochondria for recycling is blocked. So my ATP is rapidly depleted, and converted to AMP, which cannot be recycled. New ATP has to be made, which takes several days before energy levels return to normal. This nicely explains my fatigue in biochemical terms. However, there is a theoretical possibility that ribose, a pentose sugar, may boost the production of ATP, and a theoretical possibility that it could help reduce fatigue. Ribose is used by weight-lifters and body-builders to get extra energy. This suggests, in the short term at least, ribose is safe to take but I have no information about long term safety. As ribose is a sugar and I am diabetic, I am going to discuss the issue with my diabetic consultant.

Wiltshire Farm Foods.

Over the past few years, we used WFF to supply my late father's main meals. All these were included in his care plan from Bamsley Social Services. The cost started around £2.50 for a main meal and just less than £1.00 for a dessert. The arrangement was that the meals would be delivered once a fortnight, frozen. They were kept in a freezer until required and microwaved. WFF have available their own table top freezer and steamer if required.

The meal containers have colour codes on for normal, diabetic, lower fat, reducing, moderate salt, gluten free and vegetarian diets. If you have problems with food allergies or require further information, you can get on the website and find all the information about the products that you require. What does concern me, however, is the heavy use of food additives e.g. sugar like are used many by down market food producers. I challenged the managing director about this, and got a load of rhetoric back. I did consider WFF myself, but on balance preferred to sort out my own meals.

In my early days of M.E. such a facility would have simplified my life. Meals on wheels did not cater for special diets, and most of the DLA allowance was spent on this, paying carers to cook and shop. I have sampled many of the meals first hand. As far as the quality of the meals goes, it is good considering the way they are prepared. If someone with ME/CFS is really disabled. WFF meals it is one option to consider



Wiltshire Farm Foods
The Home of Great Sauciness

Your choice of over
150 delicious meals
and desserts delivered
direct to your door

For a free colour brochure ring 0800 773 773

Delivery throughout South Yorkshire,
North & West Derbyshire, North Nottinghamshire

A regular and reliable service is guaranteed

Contact Information
Wiltshire Farm Foods
Tel 01246 252345 Fax 01246 252346
Email chesterfield@wiltshirefarmfoods.com
Website www.wiltshirefarmfoods.com

Unit 27 Coney Green Business Centre, Wingfield View, Clay Cross, Chesterfield S45 9JW

Order Information

- Delivery FREE
- Minimum order £15
- Payment by cash
- We are happy to accept cheques on orders above £20
- We would like your order to be placed as early as possible prior to the delivery day
- Late orders can be accepted - we will do our best, but cannot guarantee delivery
- Delivery and payment must be made by your delivery driver
- Orders can also be placed by post, telephone or fax
- Our hours are Monday-Friday 9am-5pm Outside these hours, our direct messages can be left on our 24 hour answering machine

ME/CFS, Joints and Arthritis.

When I was working as a community Pharmacist, one of the biggest patient groups I dispensed medicines for was for arthritis. The disease is not linked to M.E., but surprisingly there are many similarities. Sometimes the distinction between rheumatoid arthritis and ME/CFS is not clear cut in the early stages, and it is one of many conditions that needs to be excluded before a diagnosis on ME/CFS can be given.

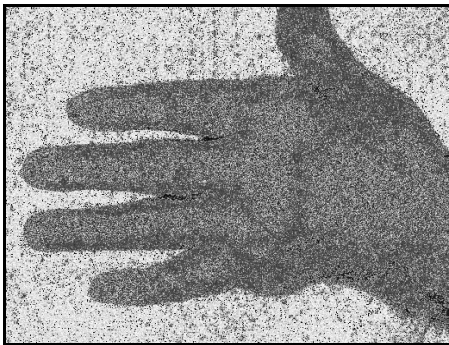
Over the twelve years or so that I've been dealing with M.E. related issues, arthritis is one health problem to which ME's seem to be prone. This feature is for information. As always, any issues arising from this feature should be discussed with your doctor.



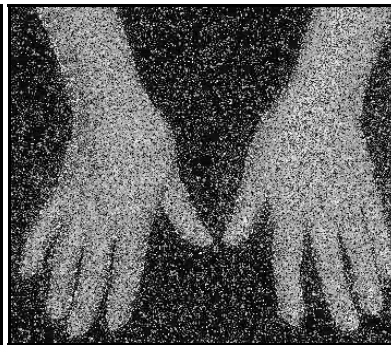
HANDS

by Joanna Dixon Scott
from 'Arthritis News' Spring 1995

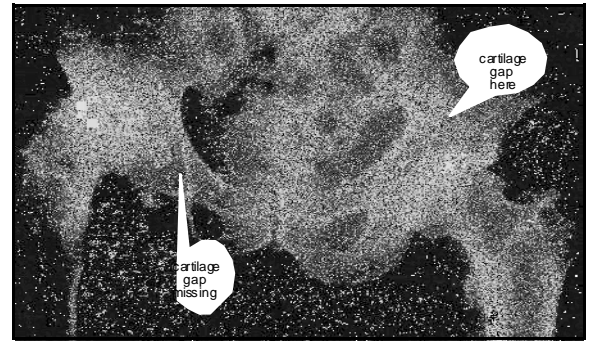
*Chubby and pink, Clutching a toy,
Grasping a pen, Clapping for joy.
Throwing a ball, Catching one back,
Applauding the winner, Patting the back.
Wearing a ring, Holding him near,
Bathing a child, Wiping a tear.
Scrubbing a floor, Baking a pie,
Blowing a kiss, Waving good-bye.
All this and more,
These hands have performed So,
whose hands are these so
stiff and deformed?
They say 'It's RA' and 'No there's no cure,
Keep taking the tablets' I will, that's for
sure!*



Rheumatoid Arthritis



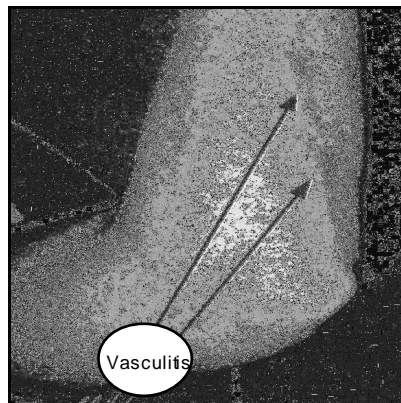
Osteoarthritis



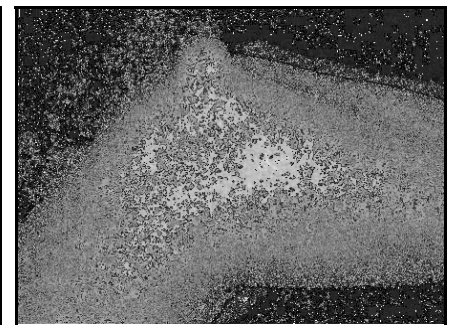
Osteoarthritis, new bone growth (dense white) ends of bone with loss of cartilage gap.



Rheumatoid Arthritis, deformity of fingers



Vasculitis in the arm of a patient with RA giving



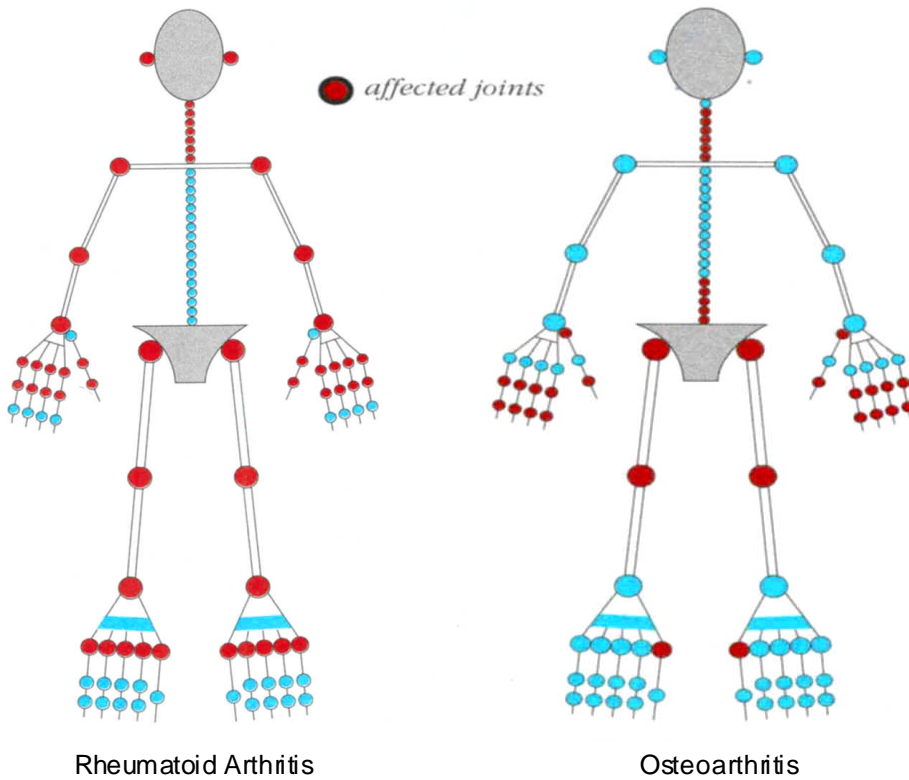
Rheumatoid Arthritis: An arthritic skin nodule.

Alternative Treatments for Arthritis



Did you know that osteoarthritis has been found in the bones of Egyptian mummies and even dinosaurs!

Arthritis like ME/CFS is a chronic condition with no cure. Although there are more medical treatment options, like ME/CFS, arthritis attracts its fair share of alternative treatments. Glucosamine has been used for years as a nutritional treatment. Only recently in Doncaster the NHS has allowed its use as a safer alternative to conventional medicines. Most people who use it say it works well, and continue to buy it privately. Chondrin is a substance similar to cartilage sourced from certain shellfish. It is expensive, and is reputed to help reform and repair damaged cartilage. I have a professional colleague who suffered osteoarthritis as a result of an accident. He took chondrin over a period of six months. He tells me that X-rays over a period of time showed the joint gap widening and healing, which he attributes to chondrin. Not surprisingly he does a roaring trade in this food supplement. MSM (methyl sulphonyl methyl) is another substance reputed to help arthritis, but I have heard of one therapist who swears by it. *Mike*



Rheumatoid Arthritis

Osteoarthritis

Arthritis is recorded diagrammatically by hospital clinics using a skeleton diagram similar to the illustration on the left. Here they are showing how the two main types of arthritis have different patterns of affecting joints.

Using these diagrams, doctors can watch the 'progress' of the disease. Using the word 'progress' may confuse some people unfamiliar with medical jargon. Doctors are usually referring to the disease, rather than the patient!

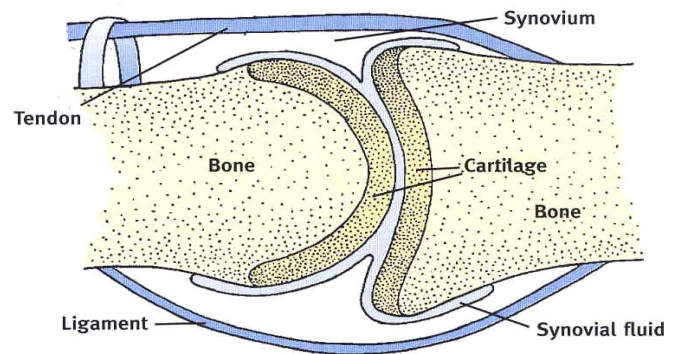
What has gone wrong ?

In a normal moveable joint, the bones are lined with cartilage. This is smooth, and analogous to the white metal bearings used in engineering. The joint is enclosed within a capsule called the synovium, which encloses the synovial fluid. Think of this as being like oil on the bearing. The composition of synovial fluid is completely different from blood plasma. There are two basic types of arthritis, Osteoarthritis (OA), and Rheumatoid (RA) which affect the joints in different ways.

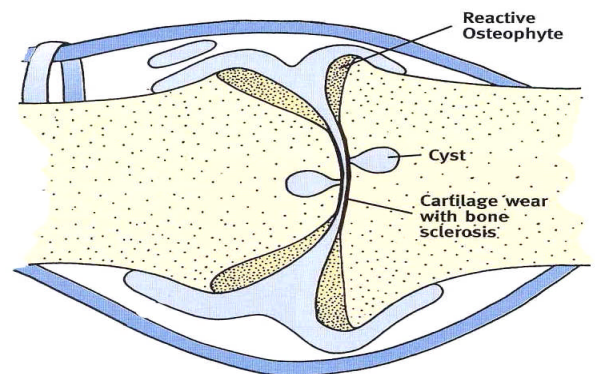
In OA, the joint cartilage is lost, not necessarily by wear, but by a disease process. This leads to bone sclerosis, stress cysts and abnormal bone growth called a reactive osteophytes on the margins of the joints. The cartilage surface may become rough and break up. The joint may creak and crack. This chiefly affects the neck, knees, hips and spine. Like M.E. three women are affected for every man.

In RA, the synovium (joint capsule) thickens, is swollen, hot and inflamed. In the later stages, Pannus, blood vessels may grow into the normally blood vessel-devoid cartilage, and cellular effusion will spread into the synovial fluid. The bone is also eroded, but at the side of the joint.

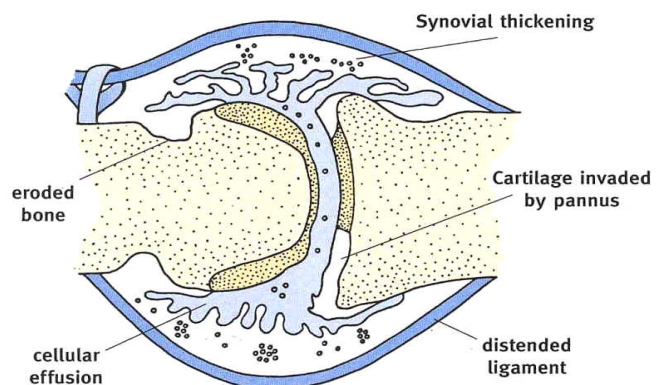
Apart from these two basic types there are versions which are a mixture of the two. Also for RA the presence or absence of 'rheumatoid factor' in the blood is also used to classify subtypes. There are other diseases classed along with OA & RA e.g. Juvenile Arthritis, Ankylosing Spondylitis, Gout, Polymyalgia Rheumatica, and Systemic Lupus Erythematosus.



A Normal Joint



A Osteoarthritis (OA) Affected Joint



A Rheumatoid Arthritis (RA) Affected Joint

Comparison of Rheumatoid Arthritis, Osteoarthritis and M.E./C.F.S.

Characteristic	Rheumatoid Arthritis	Osteoarthritis	M.E./C.F.S.
Prevalence	3%	80% over 55's Most common form.	0.15–0.2%
Age at onset	Any, mainly 30-50.	Any age, mainly 40–60.	Any, mainly 30-50
M:F Ratio	1 : 3	1 : 3	1 : 3
Disease Process	Joints become inflamed swollen and hot.	Cartilage becomes pitted, rough & brittle and may fragment. Joint space narrows.	Not known.
Changes to Joint	Pannus invades cartilage & cellular effusions occur.	Underlying bone thickens and broadens out. Bony outgrowths form at the outer edges of the joint, making it look knobby.	No permanent joint damage. X-rays show up normal.
Origin	Auto-immune	Immune. After an injury or other disease, sometimes many years later.	Auto-immune.
Inflammation	Synovial membrane,	Sometimes inflammation, Thickening of synovial membrane	Absent
Joint Stiffness	Present	May be present after inactivity	Sometimes.
Joint Pain	Present	More painful on movement	Present, moves about.
Joint swelling	Present	Occasionally	Sometimes.
Soft Tissue	Changes in the tendon sheaths and the bursae	Reactive weakening through light use.	Sore weak muscles.
Morning Stiffness	Present	Absent	Often present.
Disease progression (worsening)	For 20% the disease can be relatively inactive, and there is little or no noticeable damage to the joints. 5% will have very active arthritis for many years, and a series of bad flare-ups.	Part of the cartilage may break away from the bone. The bone ends may then rub against each other and the ligaments become strained and weakened, causing a lot of pain and changing the shape of the joint. When the overall disease process finishes, the joints look rather knobby but are usually far less painful.	Changes are immune & neurological, with variable involvement of other organs.
Variability	Most people have some problems with their joints and flare-ups from time to time, going through active and inactive phases.	For some, changes are insidious. Others have a number of years when pain and stiffness gradually worsen, then the condition seems to settle down and becomes easier to manage.	50-60% of ME cases show variability.
Fatigue/Malaise	May be present	Not usually present	Always on exertion
TCAD's help pain	Yes	No	Yes
Exercise Rebound	Movements help up to a point.	Present, sometimes delayed.	Always present. Sometimes delayed.
Which Joints	At first, wrists, hands or feet, later other joints and other parts of body.	Usually hands, knees, hips, feet and spine.	Mainly shoulders, arms and thighs.
Impact on life	20% Mild, 5% Severe	Tends to be related to aging.	25% Mild 25% Severe
Other organs affected & Complications	Intensity-related depression. Amyloid tissue in kidneys, skin, heart, osteoporosis, infection, skin nodules and vasculitis.	Not systemic, restricted only to joints.	Intensity-related depression. Endocrine system, soft tissues.
Treatments	Nutritional, Analgesics, NSAIDs, Disease Modifying Anti-Rheumatic Drugs (DMARD), Cytotoxic agents, Corticosteroids, Joint replacement.	Nutritional, Analgesics NSAIDs, Surgery Joint replacement.	Nutritional, Analgesics, NSAIDs, Pacing.

THE PANDEMIC FLU THREAT (The Official Government Line as of November 2005).

Pandemic flu is a type of influenza that occurs every few decades and which spreads rapidly to affect most countries and regions around the world. The symptoms of pandemic flu are similar to those of ordinary flu, but are usually more severe. Flu viruses are constantly changing, producing new strains. Pandemics occur when a virus develops that is so different from previously circulating strains that few, if any, people have any immunity to it. This allows it to spread widely and rapidly, affecting many hundreds of thousands of people. A new pandemic virus may emerge through the mixing of a human flu virus with an animal flu virus (usually a bird (avian) flu virus). Three pandemics occurred in the last century.

Scientists predict that another pandemic will happen, possibly soon, although they cannot say when that will be. The World Health Organization is on constant lookout for the first signs of a pandemic emerging so steps can be taken to slow its spread or contain it. If a pandemic flu strain emerges overseas, it will almost certainly reach the UK. Once it arrives, it is likely to spread throughout the country in a matter of weeks.

<u>Outbreak</u>	<u>Dates</u>	<u>Estimated Deaths World</u>	<u>Estimated Deaths UK</u>	<u>Age Group Affected</u>
Spanish Flu	1918-1919	20-40 million	250,000	Healthy young adults 20-50 years
Asian Flu	1957-1958	1 million	33,000	Very young and very old
Hong Kong Flu	1968-1969	1-4 million	30,000	Very old and those with underlying medical conditions

It is difficult to say just how serious a pandemic will be. It depends on how easily the particular virus spreads, which age groups are affected most, the severity of the symptoms it produces, and how many deaths it causes. A flu pandemic may occur in two waves several months apart, with each wave lasting about two to three months. It is likely that pandemic flu will affect far more people than ordinary flu. Around a quarter of the population may be affected by the end of the pandemic. The vaccine against ordinary flu will not protect against pandemic flu. But ordinary flu can be serious so it is very important that everyone who is due an ordinary flu jab has one. Once in the UK, a flu pandemic will spread across the country in a matter of weeks and may cause high levels of influenza, intense pressure on health services, disruption to many aspects of daily life and many deaths. The UK government has drawn up an Influenza Pandemic Contingency Plan (see www.dh.gov.uk/pandemicflu). This recognises the exceptional demands that are likely to be placed on the National Health Service.

Anyone is more likely to catch it than ordinary flu because it will spread rapidly and very few people will have any immunity to it. Everyone will be at risk. Some groups of people may be more at risk than others, but every pandemic is different. Until the virus starts spreading it is very difficult to predict who these groups might be. With ordinary flu those groups of people more likely to become seriously ill include the very young, people aged 65 and over, people with existing medical conditions such as lung diseases, diabetes, cancer, kidney or heart problems, people who are immunosuppressed because of certain treatments, or illnesses such as HIV/AIDS. These may be different in a pandemic.

Vaccines have to be made specifically for the particular flu virus causing an epidemic or pandemic. The vaccines take several months to produce. Steps will be taken to produce a vaccine to protect against a new pandemic strain of flu as quickly as possible, but a vaccine is unlikely to be available for the first wave of illness. Depending on the timing of the second wave of a flu pandemic, scientists may be able to develop a vaccine so that people can get protected. Preparation and research are already under way which should help towards making a vaccine available as quickly as possible.

There are antiviral drugs that may be effective in treating pandemic flu. Stockpiles of these are being built up. They will be used in the most effective way to treat those at risk of serious illness. It is difficult to identify in advance those groups of people who will develop more serious illness and who need them most. It is not possible to know the effectiveness of these drugs until the virus is circulating. It is possible that the pandemic flu virus may develop resistance to the antiviral drugs over time. The UK is already building a stockpile of antiviral drugs. How many people we can treat will depend on when a flu pandemic occurs and how far the stockpile has been built up. Antiviral drugs can be used to treat pandemic flu but their use has several limitations. To be effective, they have to be given within 48 hours of the symptoms starting.

<u>Flu Type</u>	<u>Ordinary flu</u>	<u>Pandemic Flu</u>
Occurrence	Every year during the winter	Sporadically at any time of the year
Population Affected	Affects up to about 10%	May affect around 25%
Severity	An unpleasant, but not life-threatening infection.	Could be a more serious infection for everyone
Who is affected	The very young, the very old and people with certain chronic illnesses are most at risk of serious illness.	People of every age may be at risk of serious illness
Vaccinations	Annual vaccination is available for those at risk of serious illness.	A vaccine won't be available to start with when it does become available the aim will be to immunise the whole population as rapidly as vaccine supplies come through
Anti Viral Drugs	Antiviral drugs are available to treat those at special risk	Antiviral drugs are being stockpiled and will be used in the most effective way, according to how the disease develops

Treatment with antivirals should help reduce the symptoms of flu and the length of illness, but will not stop a person passing the infection on to others.

The virus is spread through the air when people cough or sneeze. There are some basic measures that you can take to reduce the risk of infection. Face masks will have little place in preventing the spread of the virus but you can:

- cover your mouth and nose when coughing or sneezing, using a tissue whenever possible.
- dispose of dirty tissues promptly and carefully—bag and bin them.
- avoid non-essential travel and large crowds of people whenever possible.
- maintain good hygiene—washing hands frequently in soap and water protects against picking the virus up from surfaces and passing it on.
- clean hard surfaces (e.g. kitchen worktops, door handles) frequently, using a normal cleaning product.
- make sure your children follow this advice.

Pandemic flu spreads very rapidly because people will have no immunity. Pandemic flu is likely to be more severe than ordinary flu. Groups at particular risk won't be known until the disease starts to circulate – they may be different from those in ordinary flu years

The World Health Organization has an international system in place to watch out for pandemic flu. If it looks as if a pandemic is going to reach the UK, the government will issue warnings and advise on the best course of action that people can take.

Antivirals are being stockpiled but they have limitations. Their effectiveness won't be known until the pandemic flu arrives. If you would like more information:-

Visit www.dh.gov.uk/pandemicflu and www.nhsdirect.nhs.uk call NHS Direct on 0845 4647

THE PANDEMIC FLU TREAT (Comment November 2005)



don't think anyone cannot be aware of the pandemic threat. So really what is the core? What is certain is that the H₅N₁ virus can kill birds and spread throughout the world. The humans who have so far become infected are in close contact with food birds. They have been from the far east where there is very close contact, in fact any people out there live with their birds, almost as we do with pets in the west.

What has not yet been confirmed is human to human transmission. However there is the case of 23 tigers dying in a Far Eastern zoo from the H₅N₁ virus. Anyone who is familiar with cats will understand that their habit of grooming, sometimes each other may well provide an explanation, but the fact it jumped the species gap is of concern. The virus at present seems to be spread only by contact, and not as other flu viruses by air droplets. The main concern is that the virus may mutate or mix with a normal flu virus to produce a hybrid as contagious as normal flu, and as dangerous as bird flu.

The virus itself is a RNA virus, which easily mutates, and changes its composition in a random way. The Far East is a breeding ground for flu viruses. Every year the manufacturers of flu vaccines start looking in the Far East to find which strains are likely to emerge for the next seasons flu jabs. The flu vaccine is prepared by growing the virus in hens' eggs. The virus is harvested, killed and the 'skin' or surface antigen is used to make the flu vaccine. The bits of virus educate the immune system, so can provide a strong defence should the virus present itself. The H₅N₁ virus kills chick embryos in the egg, so the vaccine cannot be made by the usual method. However one strategy is to produce a H₅N₁ virus which is 'attenuated', genetically engineered (modified) so that it does not produce serious disease, but a mild version that is none fatal. In the early days of medicine a doctor called Jenner vaccinated people with cowpox, a related mild strain to the lethal smallpox. There are encouraging results from early tests. However no one has a contingency should the virus mutate and become something other than H₅N₁. Whatever turns up, a vaccine will be made eventually, but the process may take months.

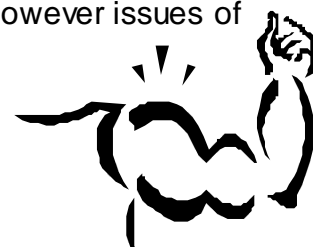
Viruses are homeless RNA genes wrapped in an envelope. The envelope has the ability to bore a hole in its host cell. Once it gets into the cell, the viral RNA hijacks the nucleus, and makes the cell into a virus factory. Once the virus is made, it breaks through the cell wall and goes to infect other cells. The second form of defence is the antiviral drug Tamiflu. This is an antiviral drug which blocks the release of virus from a host cell. However, like many other antivirals it has to be taken early on if it is to be effective, certainly within the first two days. There will no doubt be some arrangements for immediate access to the secret stocks of Tamiflu should a pandemic occur. It is of no use as a preventative or later stage treatment. Also antivirals are not without serious side effects. Some doctors' practices are creating priority lists for antivirals for people with chest and other health problems should a pandemic occur.

Most mortem examinations of H₅N₁ victims shows that the virus is recognised by the immune system. Death is caused by inflammation mediated by neutrophils, a type of white blood cell which over reacts, and damages the lungs. It may be possible that some conventional drugs, e.g. steroids or anti-inflammatory drugs like as used in arthritis may help stop the fatal reaction. Other dangerous immune system over-reactions like anaphylactic shock or angio-oedema can be controlled by conventional drugs.



Flu Jabs & ME/CFS With the threat of pandemic flu, it may be possible that any mutant or hybrid may have a cross sensitivity to conventional flu, so taking the long odds, this year I decided to have a flu jab. Most people with ME have uprated immune systems, and one quirk of the disease process is that we have increased immunity to colds and flu. In fact, when some people with M.E. get a cold or flu, it is a sign they are getting better.

This has been the basis of myself declining a flu jab over the past ten years. I was prepared for some reaction or other after I had the flu jab, but nothing happened. However issues of vaccination were brought home later that week. I trod on a rusty nail. As my tetanus jabs were out of date, I ended up going to the local hospital. I had no choice. They gave me a combined tetanus and diphtheria jab in my arm. The following day, my left arm felt like lead. On the second day, the M.E. flared up which lasted a week or so. I mentioned this to the local G.P.'s practice nurse, the reply I got was "Yes. we know the tetanus jabs hit you like a ton of bricks. All the



The Personal Capability Assessment and IB50 Form.

The Personal Capability Assessment (PCA) originally referred to as the 'All Work Test' is a hurdle which members frequently encounter. It is the gateway for Incapacity Benefit, and other sickness-related welfare benefits. The IB50 form is a questionnaire on which the assessment is based. It is divided into Physical and Mental sections of which members should complete both. The questions are not ME/CFS friendly, and for some a wide degree of interpretation is needed. In many cases members are called for examination by a DWP doctor who is often asked to verify or refute your answers. The information in the leaflet is to assist you to answer the questions as truthfully and accurately as possible within this context. Before you fill in the questionnaire we suggest that you photocopy the form, and use this to draft and record your answers. Contact our helpline or your welfare rights advisor to discuss your responses before filling out the form. Include any non ME/CFS problems e.g. depression or IBS in your answers.

Physical Disabilities Questions Here there are twenty questions. You are asked to tick a box, and then give a short written explanation for your answer. The answer you give must refer to your worst day. Some members have previously given their best day answers and been refused benefit. All answers must also be considered from the work related health and safety and safety context. Any activity which causes pain, a rebound or other adverse effect should be regarded as 'not able to'. For example many ME/CFS patients can walk half an mile, but will suffer pain, and rebound as a result. Don't forget to mention 'rebound', worsening of symptoms due to completing the activity. In this case you cannot complete the activity. Most people with ME/CFS select the 50 or 200 metre option. Beware of selecting the option 'No problem with this activity'

Activity	Qualifier	Common ME Answers	Possible Reasons	Points
1) Walking on level ground.	Cannot walk more than ??	c) 50 metres d) 200 metres	Pain, tremor, drowsiness. rebound.	15 7
2) Walking up and down stairs.	Cannot walk up and down a flight of 12 stairs without ??	c) holding on and taking a rest. d) holding on.	Pain, dizziness, rebound.	7 3
3) Sitting in an upright chair with a back	Cannot sit comfortably for more than ?? without moving	b) 10 minutes c) 30 minutes	Pain, stiffness, discomfort.	15 15
4) Standing without the support ...	Cannot stand for more than ?? before needing to sit	c) 10 minutes d) 30 minutes	Pain, stiffness discomfort. Need to lean on arm or table.	15 7
5) Rising from an upright armless chair	unaided ?? from sitting to standing	b) Cannot rise c) Sometimes cannot rise	Dizziness, muscular weakness, pain.	.7 3
6) Bending and kneeling.	as if to pick up a piece of paper from the floor and straighten up again without help.	(b) Cannot either, bend or kneel, or bend and kneel. c) Sometimes cannot either, bend or kneel,	Causes pain, stiffness, discomfort., need to hold or lean onto something.	15 3
7) Manual dexterity	Cannot ?? in laces or string.	e) tie a bow	manual dexterity problems	10
8) Lifting and carrying by the use of upper body and arms	Cannot pick up ?? capacity with either hand.	c) and pour from a full saucepan or kettle of 1.7 litre d) and carry a 2.5 kg bag of potatoes	Most ME's are clumsy and have problems with manual dexterity Muscular weakness, tremor, Involuntary muscle movements.	15 8
9) Reaching	Cannot raise	b) either arm to his head to put on a hat d) either arm above head ...	Pain, muscle weakness, weak shoulders, stiffness and sometimes limited movement.	15 15
10) Speech	Strangers have ??..difficulty understanding speech.	d) great e) some	pausing mid sentence, forgetting or can't find right word. Talking out of context.	.8 10
11) Hearing	Cannot hear well enough to understand someone talking	(c) on a busy street in a normal voice	Hyperacusis, concentration-problem competing noise.	8
12) Vision in normal daylight or bright electric light	Cannot see well enough to read with glasses	c) 16 point print at a distance greater than 20 centimetres.	eyes fatigue quickly, and can't focus. Glasses don't help, photophobia.	15
13) Continence; other than enuresis	Loses control of bladder during day at least	f) once a month	Some ME's leak and need to wear a pad / change clothes	3
14) Remaining conscious during day	Involuntary episodes of lost or altered consciousness at least	a) once a day. b) least once a week.	drowsy in a morning, or need to sleep during day.	15 15

The Mental Health Questions This is a blank box. You need to write a dialogue mentioning the points that apply to you. Those marked 'all' applied to all in our sample survey..

<u>Section</u>	<u>Problem</u>	<u>applies to</u>	<u>Score</u>
15.	a) Cannot answer the telephone and reliably take a message.	Rare	2
(Completion	b) Often sits for hours doing nothing.	Some	2
of	c) Cannot concentrate to read a magazine article or follow a radio or television programme.	Most	1
tasks.)	d) Cannot use a telephone book or other directory to find a number	Some	1
	e) Mental condition prevents him from undertaking leisure activities previously enjoyed	All	1
	f) Overlooks or forgets the risk posed by hazards due to poor concentration.	All	1
	g) Agitation, confusion or forgetfulness has resulted in potential danger	Some	1
16.	a) Needs encouragement to get up and dress	Some	2
(Daily	b) Needs alcohol before midday	None	2
Living)	c) Is frequently distressed at some time of the day, due to fluctuation of mood	Some	1
	d) Does not care about his appearance and living conditions	Some	1
	e) Sleep problems interfere with his daytime activities	All	1
17.	a) Mental stress was a factor in making him stop work	All	2
(Coping	b) Frequently feels scared or panicky for no obvious reason	Some	2
with	c) Avoids carrying out routine activities because he is convinced they will prove too tiring or stressful	Most	1
Pressure)	d) Is unable to cope with changes in daily routine	All	1
	e) Frequently finds there are so many things to do that he gives up because of fatigue, apathy or disinterest	Most	1
	f) Is scared or anxious that work would bring back or worsen his illness	All	1
18.	a) Cannot look after himself without help from others	Some	2
(Interaction	b) Gets upset by ordinary events and it results in disruptive behavioural problems	Rare	2
With	c) Mental problems impair ability to communicate with other people	Some	2
other	d) Gets irritated by things that would not have bothered him before he became ill.	All	1
People)	e) Prefers to be left alone for 6 hours or more each day	Some	1
	f) Is too frightened to go out alone	Some	1

The Blank Page You need to say something to the effect that activity brings on fatigue. There is no cure etc. If you have previously filled out an IB50 form you may want to say something about what has happened since your last Personal Capability Assessment (PCA).

What next ?

The Physical Score is the greater score of Questions 1 or 2 plus the sum of the scores of Questions 3 to 14. The Mental Score is the sum of points scored in statement (15 to 18) 'Mental Health Disabilities'. For a Successful Claim: Physical Score is 15 or more or Mental Score is 10 or more or if both Mental & Physical Scores are 6 or more.

After you have completed and checked the form, get it photocopied and posted. It may be several months before you hear from the Department of Work and Pensions. There are two main outcomes:-

- You will receive a letter confirming your award. Usually is for a set period of time, after which you may be asked to fill out another IB50 form.
- You are requested to attend a medical examination, which is the most common outcome for our members. Please contact the helpline or your welfare rights advisor for further guidance.

If your benefit is refused, as rarely happens, you must appeal. Please contact the helpline or your welfare rights advisor for further guidance. Do not try and action the appeal yourself. You may need to claim Income Support

Microwave Christmas Pudding

by Allison Morgan from 'Evergreen'

Brandy Butter

75g (3oz) butter,
50g (2oz) soft brown sugar,
2 tablespoons brandy, or to taste

Christmas Puddings

50g (2oz) butter, softened
50g (2oz) soft brown sugar
50g (2oz) self-raising flour
half teaspoon mixed spice
1 medium-sized egg
200g (7oz) ready-made mincemeat
half tablespoon milk, if required

Make up the brandy butter by beating together the butter and sugar until pale. Gradually add the brandy, beating well after each addition until smooth and creamy. Cover and refrigerate until required. To make the puddings, beat together the butter, sugar, flour, mixed spice and egg until the mixture is smooth. Stir in the mincemeat and, if required, the milk to make a soft, but not runny consistency. Spoon into four small, well greased, microwaveable bowls or teacups. Cover with cling film and cook each pudding, one at a time, on full power in a 650-watt microwave for one minute 10 seconds to one minute 20 seconds. Allow to stand for one minute before turning out and serving with the brandy butter or white sauce, cream or vanilla ice cream.

Please note this is a much lighter version of a traditional Christmas pudding. It can be made the day before, refrigerated and then reheated in a 650-watt microwave for 30-35 sec. Allow to stand for one minute before serving. Alternatively, freeze for up to one month and then re-heat from frozen for 40-45 seconds. Allow to stand for two minutes before serving. Serves 4

Per Serving:

Calories 575 Fat 29g Salt 0.8g

So what is the Linking Up Contact Group?

Linking Up is a very user-friendly contact service which has been running for over a year:-

Ever thought it would be nice to be in contact with other sufferers by telephone, letter or email?

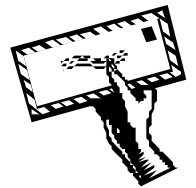


Well now you can by becoming a member of the Linking Up Contact Group. It is available free to all members of Leger M.

E., sufferers and carers alike, all ages welcome. It is a great way to contact people, compare experiences, and make new friends. Linking Up Contact Group updates are sent out at regular intervals under separate cover from your Pathways newsletters.



If you would like any further information or an application form to enable you to join Linking Up, just telephone either Mike your Chairman, on 01302-787353 or Carolyn your Linking Up Co-ordinator, on 01204 -495727.



Wishing you all A Very Happy Christmas and Good Health and Happiness in the New Year. *Carolyn*

Members' Announcements

- 1) The Christmas Party will take place on Sunday 11th December. Arrangements are similar to last year. Anyone who can help with baking or food etc. or on the day, please contact Ann on (01302) 882271.
- 2) We have arranged a open meeting on 17th March with Mark Adams & staff from the Sheffield ME/CFS Clinic in Doncaster Royal Infirmary postgraduate centre. Members will be able to speak directly with Mark and his colleagues. The final details have to be confirmed, but we expect to start at about 2.00 p.m. Watch Pathways or www.leger.me.uk for further details.
- 3) The helpline and support services will be extended from January. We will be having regular drop in sessions at the Redmond Centre, Carcroft. Please contact 787353 for further details.
- 4) We are revamping and increasing our range of information leaflets. So far we have *Basic Information on ME*, *New to ME*, *A Carer's Guide* and *When the DWP doctor visits*. We plan leaflets on the IB50 form, Applying for DLA/AA and Attending a Tribunal.

BOOK REVIEW: "CHRONIC FATIGUE SYNDROME, A NATURAL WAY TO TREAT M.E." by PROFESSOR BASANT PURI

adapted from Sandra's feature in the York Group's Newsletter.

Professor Puri recounts in this book his research and treatment of ME patients with the fatty acid supplement Veg EPA®. Previous studies have found fatty acid supplements to be helpful to people with ME. However, Professor Puri has had the advantage of the use of MRI scanning, which was not available to previous researchers. This enabled him to show that there was abnormality of lipid (fat) metabolism in the brain and also structural abnormalities both of which resolved with Veg EPA®. Professor Puri views ME as a persistent viral infection and one role of EPA is to kill viruses. However, viruses can also inhibit EPA by blocking an enzyme essential to its production.

Environmental pressures via the food industry manipulating our diet can also result in lowered amounts of EPA. These include trans fatty acids, found in any product containing hydrogenated vegetable oils, and excessive Omega 6 oils, e.g. Sunflower Oil. Veg EPA® claims to overcome this problem. Professor Puri found marked improvements in 80% of his ME patients within three months of treatment, no matter how long they had been ill. The dose used was four capsules night and morning. Improvements were noted in fatigue, brain fog, mood, concentration, sleep, muscle and joint pains. Once improvement occurs the dose can be lowered to find a maintenance dose.

The manufacturers say that Veg EPA® contains cold pressed virgin evening primrose oil (EPO) and highly purified EPA (eicosapentanoic acid) from fish oil, which allows higher doses of EPA to be taken. This may explain the dramatic improvements obtained in a relatively short time in people who had been ill for many years. The difference in content can be seen by comparing the content of Veg EPA® with Efamol Marine. The usual dose taken is eight capsules per day.

Users' Report

"I have had ME for 11 long years and for me, Professor Puri's book is the most significant thing I have read on the subject. I have now been taking Veg EPA for about eight months, and I have had a marked improvement. It is the only treatment for ME I have found that makes any real difference. I still get unreasonably exhausted on occasions but I believe I can now see light at the end of the tunnel. There is no guarantee that this will work for everyone with ME, but I do think everyone should consider it" *Brian (York ME Groups)*.

<u>Product</u>	<u>Evening Primrose Oil</u> (Per capsule)	<u>E.P.A.</u> (Per capsule)
Veg EPA®	100 mg	280 mg
Efamol Marine	100 mg	136 mg
Mexepa®		170 mg

"My G.P. has been trialling many of his ME/CFS patients with his patients with EPA in the form of Mexepa capsules on the National Health Service. It definitely works." *Carolyn (Bolton)*.

Comments

I don't think that there is any doubt that EPA helps people with ME/CFS. What concerns me is that these products should be available on the NHS. The situation with a G.P. prescribing them is that there is no product license to treat ME/CFS with Mexepa. On this basis some doctors will prescribe it and some won't. It is worth asking your doctor because the charge for a NHS prescription is £6.40 which is cheaper than buying supplements. Some people are exempt from prescription charges and some have bought prepayment certificates (season tickets).

One way you could get Mexepa on the NHS is to have your cholesterol levels checked by your G.P. Many people with ME/CFS have abnormally high cholesterol levels, and because of the exercise and other limitations imposed by ME/CFS are at a high risk of a heart attack or stroke. Normally a doctor will prescribe a drug like Simvastatin or the statin type drugs. These work well to reduce body cholesterol levels, but make ME/CFS worse because they block coenzyme Q10 and other body enzyme systems related to the production of energy. There are eight families of drugs that treat cholesterol. One of interest is EPA which is in the form of Mexepa, and is licensed to treat high cholesterol levels. When treating ME/CFS the dose of Mexepa is around 2-4 capsules daily, while the other supplements are eight daily. What you also have to consider is that EPA in all forms may inhibit blood clotting and make susceptible people prone to bruising, which is of concern if you are taking anticoagulant drugs.

Meeting with Mark Adams (22/11/05)

Following several meetings which Liz Mc Donagh and I had attended in Sheffield with the Clinical Champion for CFS/ME, lead Commissioner for CFS/ME and The Clinical Network Lead for CFS/ME for South Yorkshire and North Derbyshire, we invited Mark Adams to Doncaster to give committee members a chance to air their views. We have liaised with the Sheffield & Rotherham Groups on this meeting. There were three areas of discussion:-

a) Issues of access and arrangements being made for ME/CFS sufferers in Doncaster.

Mark explained the NHS organisational issues and competing services for limited funds. Patients have previously been referred by their G.P. for assessment, screening and confirmation of diagnosis, to the infectious diseases consultant at Sheffield Hallamshire Hospital. Following the initial assessment, patients would be referred to different specialities within the clinic. Depending on the case, this could take from four weeks to several months. The new specialist CFS/ME clinic is advertising for a Doctor who will be accessible by direct referral from a G.P. This should speed up the process sometime in the new year. Mark is compiling a list of all health professionals in Doncaster with an interest in ME/CFS. The clinic aims to form an association and network with these people. If, for example, a suitably skilled clinician is available locally then the specialist service could support this clinician in delivering care, so that a patient could be treated in Doncaster rather than travelling the 30 or so miles to Sheffield.

b) Issues surrounding welfare benefits and employment, which have not so far been addressed by the CFS/ME service for South Yorkshire and North Derbyshire.

I told Mark of a case history where Incapacity Benefit had been refused, due to misinterpretation by the patient of the IB50 form and the Personal Capability Assessment all work test. Sally gave an example of issues regarding refusal of Disability Living Allowance and the benefit trap preventing anyone from working a small number of hours e.g. for therapeutic work. While these issues are dealt with by us for Leger ME members, non-members are out in the cold. We suggested some sort of information leaflet or service should be based at the clinic. Similar issues are experienced by the Sheffield and Rotherham groups. We agreed that a conference should be held in Spring 2006 inviting Health Professionals as well as Welfare Rights workers etc. to debate this issue.

c) Issues concerning Nutritional and Life style aspects of ME/CFS which have not so far been addressed by the CFS/ME service for South Yorkshire and North Derbyshire.

Elizabeth told Mark about how dietary measures, vitamins and nutritional interventions had helped many members. I explained the issues regarding Candida & Gut Fermentation and various nutritional tests available in the private sector. Our experience is shared by the Sheffield and Rotherham groups. Again, we agreed that a meeting should be held in Spring 2006 inviting interested parties to discuss nutritional and lifestyle issues.

In the meantime, I will liaise with Mark and the groups, and we will meet again on 20th January at 1.00 p.m. at the Redmond Centre, Carcroft as (for want of a better title) the 'Benefits Agency Strategy and Nutritional & Lifestyle working party!! We also agreed that Mark should look into the possibility that someone outside the groups should act as a facilitator, someone to chair the meetings, taking into account everyone's views and acting as referee. Mark will also investigate venues, possibly in Sheffield. If anyone wishes to contribute to or attend these meetings, please contact Mike Valentine on 01302 787353.

If you are seeking Medical treatment for ME/CFS...

We keep up to date on the status of the various clinics and other medical facilities. Some of the various tests can be ordered by your own G.P. privately ..Please call the helpline on (01302) 787353

Warm Front Grants

The Warm Front Team is a Government funded initiative which will help improve the warmth and comfort of your home. If you own your home or rent from a private landlord, and receive an income or disability related benefit, you could have a range of insulation and essential heating measures installed in your home for free. This could be up to the value of £1,500 under Warm Front, or £2,500 under Warm Front Plus. The Team is made up of a group of experts experienced in all aspects of home heating, insulation and energy efficiency, Managed by Powergen Warm Front Limited and funded by the Department for Environment, Food and Rural Affairs (DEFRA) you can be sure that you'll receive excellent advice and service every step of the way. To qualify for a grant you must own your home or rent from a private landlord and receive one or more of the following:



Warm Front

If you have a child under 16 or are at least 26 weeks pregnant, have a maternity certificate MAT B1 and also receive one or more of the following you could get a Warm Front grant:- Income Support, Housing Benefit, Council Tax Benefit or Income-based Jobseeker's Allowance or if you receive one or more of the following: - Working Tax Credit (with a disability element and household income less than £14,200), Child Tax Credit (with a household income less than £14,200), Attendance Allowance, Disability Living Allowance, Income Support (which must include a disability element), Housing Benefit (which must include a disability element), Council Tax Benefit (which must include a disability element) . War Disablement Pension (which must include the mobility supplement), or Industrial Injuries Disablement Benefit (which must include constant attendance allowance).

Warm Front Plus

If you're 60 or over and receive one or more of the following you can qualify for a Warm Front Plus grant:- Council Tax Benefit, Income-based Jobseeker's Allowance, Housing Benefit and Pension Credit

What improvements are available?

If you're eligible for a Warm Front grant, you could have a package of insulation and essential heating measures, from the list below, installed-up to the value of £1,500.

Insulation: Loft insulation. draught-proofing ,cavity wall insulation and hot water tank jacket

Heating system: Gas room heaters with thermostat controls, electric storage heaters, conversion to a solid fuel fire cassette, timer controls for electric water heaters.

Additional improvements . Energy efficiency advice & two free low-energy light bulbs.

If you're 60 or over you could be eligible for a Warm Front Plus grant. You could have a new gas or electric central heating system installed in addition to the package of insulation and essential heating measures listed for the Warm Front grant, up to the value of £2,500.

Act now !

To apply, simply call the Warm Front Team FREE on the number below or, alternatively, you can visit our website at: www.powergen-warmfront.co.uk Once we receive your application our Home Energy Advisor will contact you to arrange a time to visit your home to check your eligibility and recommend a range of insulation and essential heating measures tailored to your needs. With effective home heating and insulation, you'll notice a real difference. Your home will feel warmer and more comfortable and could help you to save money on your energy bills, Simply call the Warm Front Team FREE on:- **0800 952 1555** (Open 8am - 6pm Monday to Friday).

Please quote reference:-CMR.

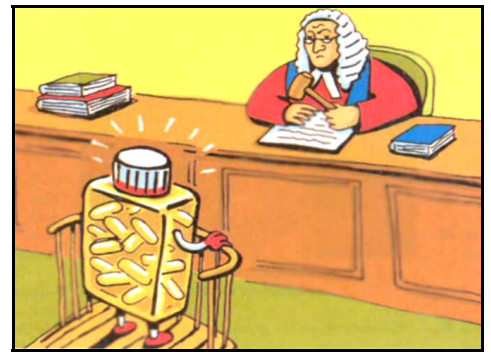


A number of our members have already benefited from Warm Front Grants. They are seriously worth considering, as they could save several hundred pounds a year in heating bills. Mike.

European Court Tighten Rules On The Sale of Vitamins and Minerals.

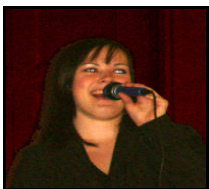
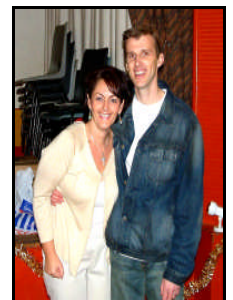
Sense prevails ! The European Court of Justice upheld the Food Supplement Directive. However, this was done with some modifications, which means that most supplements will not be banned. The main points are:

- a) The directive no longer covers vitamins and minerals naturally occurring in the diet.
- b) Admission to the list of allowed ingredients has been simplified.
- c) The burden of proof for showing an ingredient to be unsafe now lies with the regulator and not the manufacturer.



THE LEGER ME CHRISTMAS PARTY

We will be holding our Christmas Party on Sunday 11th December at the Church Hall, Church Road, Kirk Sandall from 1.30am to 4.00pm. It will be a family affair and is suitable for all ages. The party is being organised by Ann and Jason Bowker as last year. There will be a Christmas quiz, raffle, tombola, Christmas gifts and cards for sale.



Ann and Jason's daughter, keen thespian Justine will organise the entertainment as she did last year. Jason will be organising a quiz. There will be party games for the children, along with a visit from Santa himself! There will be a lovely buffet and unlimited cups of tea and coffee!

We aim to make this a very enjoyable event and tickets are available from Ann and Jason at a cost of £3 per person or £2 if you bring food on the day. You will also be able to pay on the door, but it would be appreciated if you could contact Ann or Jason prior to the party so that they have an idea of how many people to cater for. We also need to know how many children will be coming. We have to charge £1 per child extra if they wish to see Santa. Santa tells us that the price of his reindeer food in Lapland has gone up since last year, in addition to this we need to make sure that they will each receive a present from Santa.

Ann and Jason can be contacted on (01302 882271) or e-mail ann.bowker@btopenworld.com

Any food contributions towards the buffet would be most welcome.

Unbelievable from an idea by Gavin (from York group New sletter)

