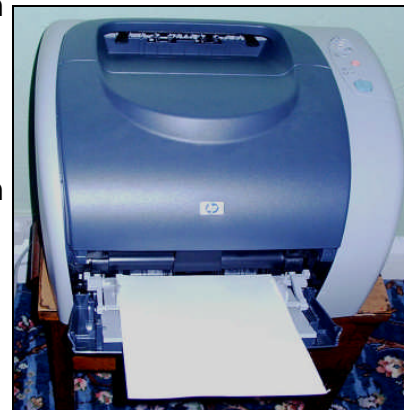


Leger ME:  
Leger ME:

# Pathways

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

Welcome to Pathways number 2. Since publication of our first edition, I can now report that Leger ME has a constitution, and has fully functional bank accounts with the Halifax. I would like to thank everyone for the generous donations we have received. All cheques received have now cleared. This has allowed us to purchase a laser printer for LME which is a Hewlett Packard LaserJet 2550. The level of support we have received is more than sufficient to guarantee the future for Pathways & Leger ME.



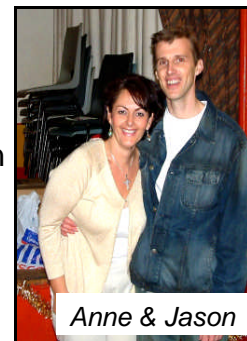
In this edition I have featured two issues, firstly Incontinence and ME and Atherosclerosis, which I don't believe that anyone has featured in an ME newsletter previously. These are health issues which all M.E. patients should be aware of because of implications for state benefits and general health. Like many severely disabled patients, Christopher Reed (Superman) recently died from a heart attack, mainly because of poor health, due to inactivity. Only half of people admitted to DRI survive a heart attack. This sends a message to us all with M.E., a disease where activity is restricted. This certainly prompted me to have my cholesterol checked by my G.P. What about yours ???

With this issue we are enclosing a copy of a BRAME (Blue Ribbon for the Awareness M.E.) information sheet. The next Pathways is due in February. A number of LME meetings and outings are planned. Further details can be obtained from myself on 01032 787353 or at:- [mvys03487@blueyonder.co.uk](mailto:mvys03487@blueyonder.co.uk). 10 Thellusson Avenue, Scawsby, Doncaster, DN5 8QN.

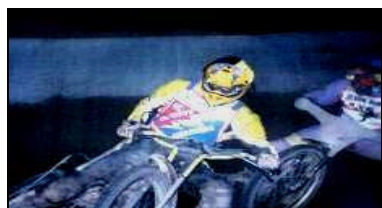


## LEGER ME CHRISTMAS PARTY

We will be holding our Christmas Party on Sunday 12th 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. There will be a Christmas quiz, raffle, tombola, Christmas gifts and cards for sale. Justine (Ann and Jason's daughter) will entertain us with her singing. 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 £2 per person. 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, 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](mailto:ann.bowker@btopenworld.com). Any food contributions towards the buffet would be most welcome.



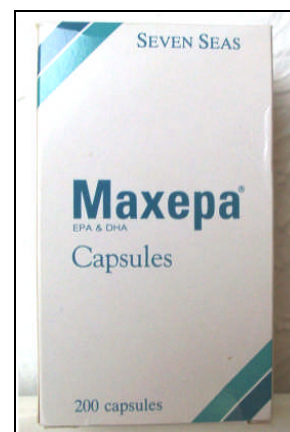
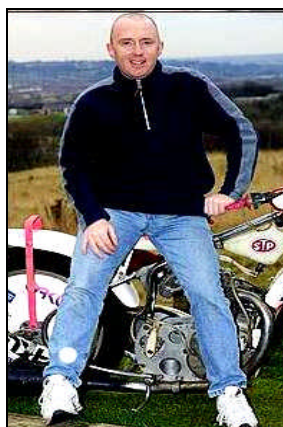
Anne & Jason



Gary in Action Riding for Eastbourne Eagles in pre M.E. days

## Interview with Gary Frankum

(see page 2) Although Gary may look well he is in constant pain, and like many other sufferers, at times even the slightest effort can bring on pronounced fatigue; this in addition to the fact that relapses can occur at any time.



Why this product may have a double benefit for people with ME  
See page 9

***This Morning interview with Gary Frankum (Speedway Rider) 3/11/2004.***

*Before the show went to the news break Lorraine Kelly said" We will be talking to a man who says ME has destroyed his life." In the studio of ITV's "This Morning" was guest Gary Frankum (GF). The interviewers are Phillip Schofield (PS) & Lorraine Kelly (LK). Also in the studio is Dr Chris Steele (CS).*

PS. And he joins us now. (Addressing Gary). Umm, now you say that, you've had a build-up to do this interview. You have had to have an overnight stay in a hotel.

GF. That's right.

PS. And that you are going to be knackered for the next couple of days because you have been here today talking to us.

GF. That's right, umm, because people like going on about ME being just tired but there is a lot more to being tired. Like I am sitting here now in constant pain.

PS. What hurts?

GF. All my body. I have come off my bike many times at high speed. I have had my leg in plaster and my arm in plaster & been bruised all over but nothing like this. It is constant pain.

PS. This is when you were a very well known speedway racer. You have raced at every level. As you say it was part of your job. Unfortunately, you have come off the bike a few times and have broken various bits of your body but this is like nothing you could have ever imagined.

GF. No, because you just take each day as it comes, 24/7. You can take tablets but after you have taken tablets for so long they become immune, you know, to your body, so they don't work and you have got to lay off.

LK. And also because you had got the added, sort of, difficulty of people not understanding what is wrong with you and for a long, long time people weren't sympathetic—including doctors—were not very sympathetic about this condition.

GF. That's correct, yeah. I mean Doctors, um, the government accepted that ME is an illness and rightly so, but when you go to claim benefits there are thousands of people out there with ME trying to claim benefits and it's like a lottery. Because a doctor could come along and he could believe in ME or he doesn't believe in ME and this is wrong because ME is a serious, serious physical illness.

LK. What does this mean for you during the day? How is your day? I mean, what does it stop you from doing? What does... Presumably, you wake up as tired as when you went to bed?

GF. That's right. You can go to sleep for... I've gone to sleep for 18 hours in the day and I've woken up as if I've not been to sleep at all and you can't really plan anything. That's the problem with ME you can't plan your day because you don't know how you are going to feel.

LK. Is it constant or sometimes do you get... relapses or... Do you get any sort of remissions at all?

GF. You can get times when you get better but you are very, very limited. I explain to people that it is like a dodgy car battery. Sometimes your car will start when you turn the key and sometimes it won't. You know... I think that's...

PS. (turns to Dr Chris) the problem with it, Chris, is that this affects every part of his life... his daily function as a human being. Yet, it is hard to find, almost impossible to prove, and that's the problem.

CS. Yeah. Look at Gary; he is a fit young man. You would not realise that he is sitting here in pain especially in the muscle groups etc. And I just want to say about the fatigue, it is not tiredness, it is extreme fatigue.

CS. Some patients are so bad they have a cup of tea and they are exhausted. Gary has told you that he will be exhausted for the next two or three days and this is exhaustion, this is extreme fatigue. The way we diagnose ME is how long has the patient had this extreme fatigue and by definition we say it is over 6 months and this may be ME.

We have got no ME tests so you really need to take a very accurate history from the patient. When did it start? Two thirds of ME cases come on after viral infections.

Before we came on air this morning we had loads of emails about ME. There are a lot of people with strong feelings about it.

PS. Saying what?

CS. Not being diagnosed. Suffering for two or three years. No one has investigated them, tried to make the diagnosis. Frustration. Stressing this is not just tiredness. This is extreme...

PS. (To Gary) This came on after the flu?

GF. Yeah, I had that flu really bad. Like what Dr Chris was saying about people. There are children

who can go to school one day and they are off for three days. Yet, there is this law about children not going to school and parents are being threatened because ME is not greatly recognised.

PS. The problem is....

GF. They are struggling, parents are struggling because...

LK. Kids can get it as well can they, can children get it too?

CS. Children, yeah, adolescents, yeah.

CS. Apart from the tiredness of course, there is the widespread muscle pain and aches. The joints ache as well. But the joints are not swollen or red as they would be, say in arthritis though. Then of course, you get depression. Is the depression part of the disease or is the patient depressed because of the ... you know... umm... severe effect it has on their lifestyle?

PS. But what you end up with is something that is so debilitating, that it is quite possible for you to use this as an excuse to, I don't know, take a few days off work, to get back your life...to back off a bit.

People do, unfortunately for you, do use ME, as a very sort of loosely worded term.

GF. Well, it must be very sad, as I would not wish ME on anyone because ME is awful. It has changed my life and it has changed thousands of people who suffer from ME, their families, their friends, their partners. I mean, living with someone with ME must be horrendous.

LK. Can you do anything about it? You were saying that you take some medication.

GF. What I take is... I take painkillers, very strong painkillers

LK. Is that all you can do?

CS. The patients have to take painkillers but also antidepressants have been used on patients, not necessarily because they are depressed but antidepressants have a painkilling effect. Tricyclic antidepressants have a pain relieving effect. They improve the quality of sleep for the patient as well and of course, they may lift the mood.

Of course, there are two things that patients with ME should look at in terms of therapy and one is called Graded Activity. Now, this is not Graded Exercise but activity, and graded means that you slowly, very gradually increase the activity you are doing. For example, the patient could be confined to bed, and for them the severe activity could be to go to the armchair in the corner of the bedroom. Well, in the next week or so they may have to go a little bit further to the armchair in the other side of the room, so they are gradually increasing their physical activity. Then the other treatment is called Cognitive Behavioural Therapy, where you see a psychologist and they talk to you to change your old behaviour to new behaviour to improve your attitude. Those two treatments, graded activity and the cognitive therapy are the ones that are showing the best response.... Just one other interesting thing, there was some research done a year ago where the scientists found that the brains in patients with ME are actually deficient in essential fatty acids. These are the fish oils, and one in particular, EPA, so maybe patients with ME should look at highly concentrated fish oil capsules with high EPA in them and it is worth a try. (*Maxepa* editor)

PS. And what you need is, you need recognition, you need understanding.

GF. That's right.

PS. From everybody.

GF. That's right. From everybody, especially from the Benefits Agency. Sadly, like I said, the doctors should be educated about ME and people with ME shouldn't be having the problems that they are having. Because there are a lot of people. There are stories about people taking their lives because they have run out of any hope, there are no doctors to help them, they try and claim benefits and the benefit doctor says there is no ME. I have gone through it. I have had a doctor come out to my house and he asked me "What is wrong?" and I said that I've got ME and he said there is no such illness as ME. What hope have people got, when the Government accept it, yet the Benefits Agency are letting doctors, do that to the people. It is ruining their lives.

PS. Thank you.

GF. Thank you very much for having us on air. I really appreciate that.

PS. We wish you well, obviously.

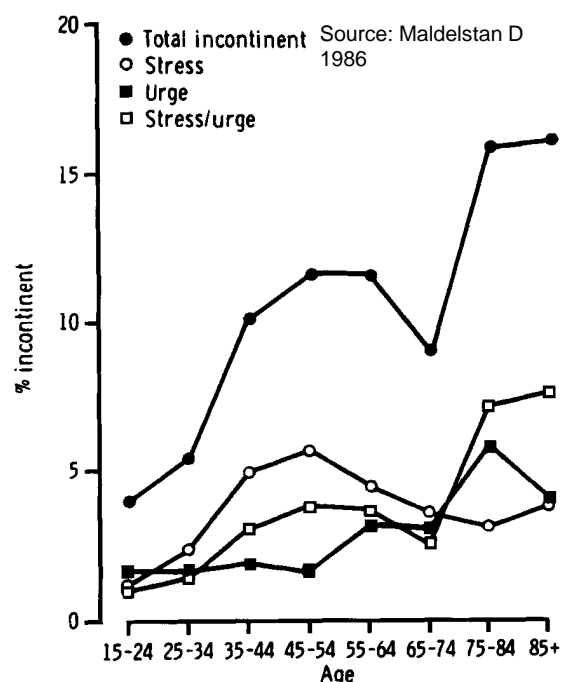
GF. Thank you very much and thank you for your show on ME.

\*\*\*\*\*  
 \* **Simple Treats** \*  
 \* *A pot of tea,* \*  
 \* *A home-made bun,* \*  
 \* *A garden chair,* \*  
 \* *Some dappled sun –* \*  
 \* *Such joys may not,* \*  
 \* *Impress a king,* \*  
 \* *But as for me,* \*  
 \* *They're just the thing.* \*  
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## Urinary Incontinence and M.E.

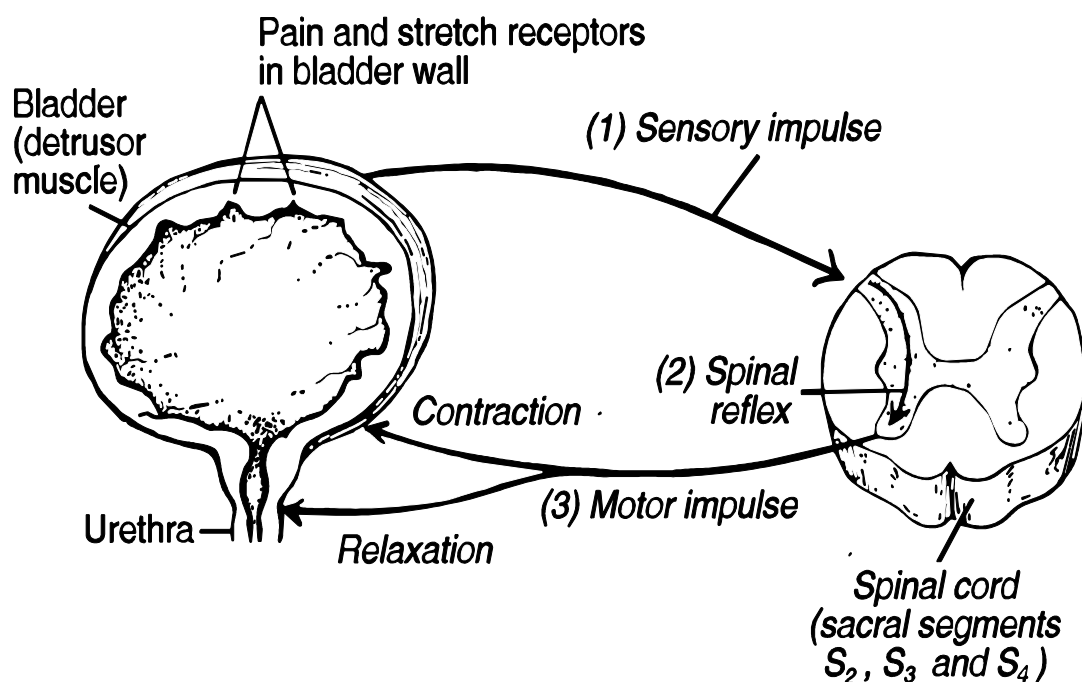
Incontinence is one of those subjects that people don't very often talk about. I see it as a very important issue for LME members for three reasons. Firstly, many people with fatigue syndromes suffer from incontinence directly as a result of the disease. Secondly, a number of people suffer incontinence for other reasons. Thirdly, incontinence is a factor in the DWP IB50 form and the DLA form for the award of state benefits. Usually when someone asks me to help them with an IB50 form, that is when the problem looms. It is important that it is reported in the DWP forms because if a person only loses control once a month it is worth 3 points and no bladder control is worth 15 points. So the 15 points secures the benefit irrespective of any other medical problems.

Urinary incontinence has been described as a 'common problem' in the community but it is difficult to estimate its exact magnitude due its medical definition and because many individuals are reluctant to seek help or even admit that they have a problem. Some patients may devise their own strategy for management so that it is hidden from others. As far as general health goes, it is not important or life-threatening. Urinary incontinence can affect all age groups although the elderly population is predominantly affected. Incontinence should not be seen as a problem with age or disease for which there is no treatment.



Sex	Age	%
Female	15.64	8.5
Female	65+	11.6
Male	15.64	1.6
Male	65+	6.9

## The Control of the Bladder and Micturition.



The bladder receives urine from the kidneys. Its function is to store urine until it is voided. The bladder is under parasympathetic neurological control. In cases of newborn babies where the neurological control is yet to be established or certain spinal injury cases the control of the bladder is what is known as a

Spinal Reflex Arc. When the bladder is full, a stretch receptor in the bladder wall sends a message to the spinal chord. When sufficiently full the reflex to empty the bladder is triggered. The bladder wall contracts and the Sphincter Muscle (a muscle tap that normally is closed ) relaxes to allow the bladder to empty. The brain has to learn to control this reflex, in a similar way to a child learning to walk. It is therefore quite a complex process involving higher brain centers.

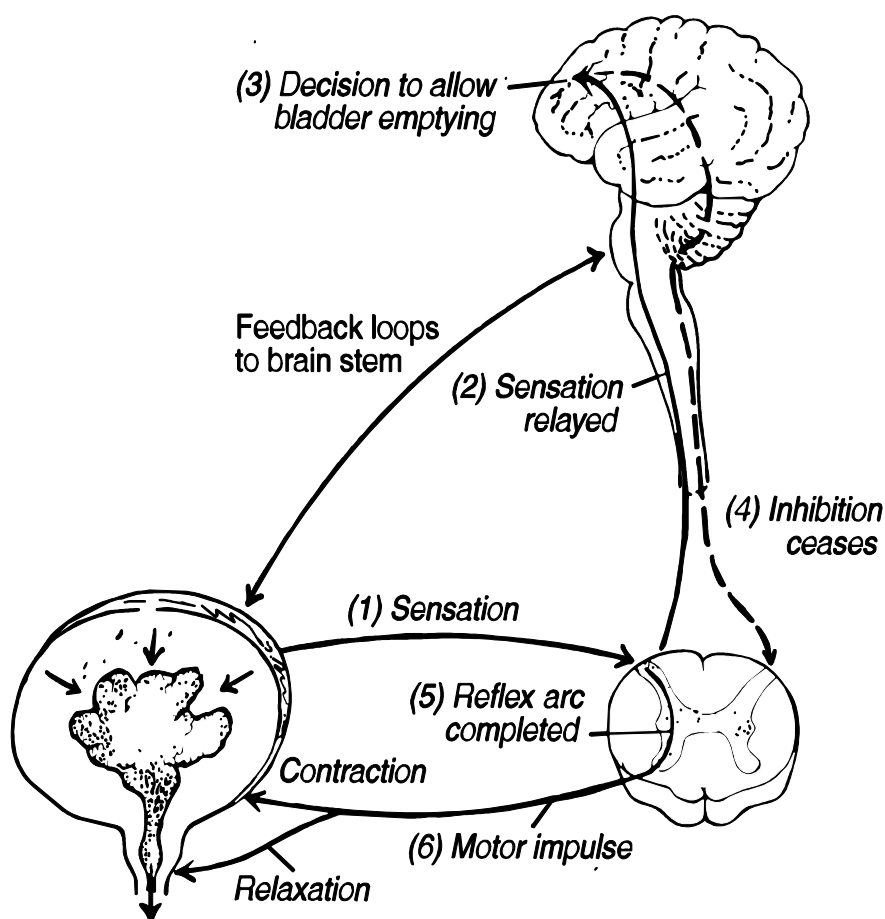
## Causes of incontinence

Physical, mental, social and environmental factors all contribute to the development of incontinence. In fact anything which interferes with the control mechanism e.g. aging, stress, acute illness, diabetes, constipation, medication, alcohol, immobility, psychological factors and severe cerebral disease.

### M.E. Related Issues.

People with M.E. are prone to incontinence because the disease has a neurological component, and so the neurological mechanism for control may be damaged. Some people are not affected, but the majority are to some degree. Usually the magnitude of the problem is related to the severity of the M.E. itself, and it comes & goes as the M.E. does. I've only seen two cases of uncontrollable incontinence in 500 or so cases.

There is a second problem. M.E. sufferers tend to produce more urine because of disturbances in the way body water is controlled by the pituitary gland.



## Management Options

**Absorbent pads.** These are usually used first. There are many available at pharmacies and in the high street shops. There are more substantial versions like nappies available for hospitals and care homes. There is also a vast range of pads and various waterproof garments available.

**Pelvic Floor Exercises** are usually advised by specialist nurses. To produce any benefit, the exercises need to be done regularly and take time to show improvement. They work best for younger people, but are less successful in the elderly age group.

**Bladder Training** is useful for cases of urge incontinence but requires perseverance by the incontinent person to achieve results. The aim of the technique is to encourage the person to extend the time between visits to the toilet.

**Bladder Emptying** is a manipulative technique to empty the bladder more completely. This requires training from a specialist nurse.

**Drug Treatments.** Drugs which inhibit bladder contractility are

Anticholinergic agents, e.g. Propantheline; Musculotropic relaxants, e.g. Flavoxate Hydrochloride this group are direct-acting smooth muscle relaxants which act predominantly on the bladder.

Tricyclic Antidepressants, e.g. Imipramine Hydrochloride. Imipramine has anticholinergic, as well as antihistamine and local anaesthetic properties. It may also cause increased outlet resistance as a result of peripheral blockage of noradrenaline uptake. This group is effective against bed wetting. There may be a side benefit for M.E.'s taking this group of drugs e.g. Amytriptyline.

Calcium channel blockers, e.g. Terodiline Hydrochloride. These drugs limit the availability of calcium ions which are required for the contractile process. These are used to treat urinary frequency by diminishing unstable detrusor muscle contractions.

Adrenergic antagonists, e.g. Indoramin Prazosin, These drugs are to reduce the muscle tone in the bladder neck, prostate and proximal urethra, increasing micturition flow rate.

Adrenergic Agonists are drugs which increase outlet resistance, adrenergic agents, e.g. Ephedrine. The smooth muscle of the bladder neck contains many receptor sites which, if stimulated, increase outlet resistance. These drugs are useful in management of stress incontinence.

Oestrogens. The reduction in the levels of oestrogen following the menopause causes changes in the urethra. Oestrogen therapy is useful in the management of incontinence when due to oestrogen deficiency. Sensory urgency may be caused by atrophic changes and these patients respond well to Oestrogen Replacement Therapy. The oestrogen may be given systemically or applied in the form of skin patches. Oestrogen therapy is not suitable for other forms of incontinence.

**Portable Urinals** These are devices which consist of a funnel or condom-like collecting device usually made of rubber strapped to the waist. The urine is piped via valves to a collecting bag either strapped on the leg or in special clothing with a drainage tap. These are used when other methods of control are inappropriate.

**Catheterisation** is the placing of a tube into the bladder via the urethra to allow drainage into a collection device. There are two techniques. Intermittent catheterisation may enable a patient to drain the bladder with a catheter which they put in and take out themselves. The patient will need training by a nurse, continence advisor or doctor. This technique has improved the lives of many incontinence sufferers. Permanent catheterisation may sometimes be used in patients who have untreatable incontinence and are developing skin problems from contact with wet garments or bedding. This may be necessary in the worst M.E. cases. The catheter is of the Foley type which is held in place by an inflatable balloon of sterile water in the bladder. These have to be inserted by a doctor or trained nurse. Very often the collection bags can be seen at the sides of hospital beds.

**Surgical Intervention** This may be necessary in some cases to alleviate incontinence due to e.g. repair of the Pelvic Floor Muscles in women, or removal of enlarged prostate in men. Sometimes a Colostomy Style Urinary Diversion operation is performed, especially in children with congenital birth defects. Here the ureters (tubes from the kidneys) are brought to the surface of the skin in the lower abdomen bypassing the bladder. A bag or other collection device is needed.

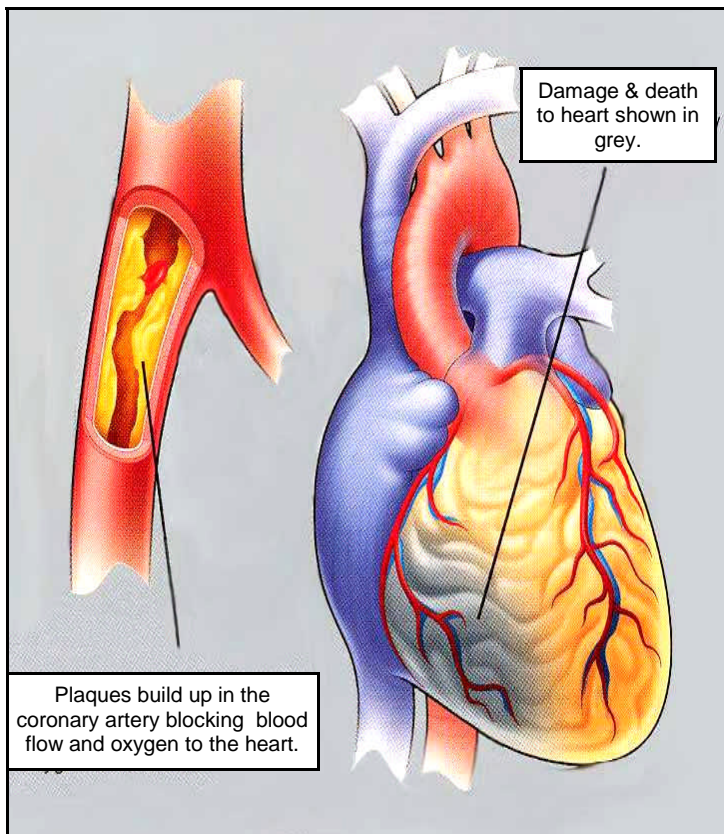
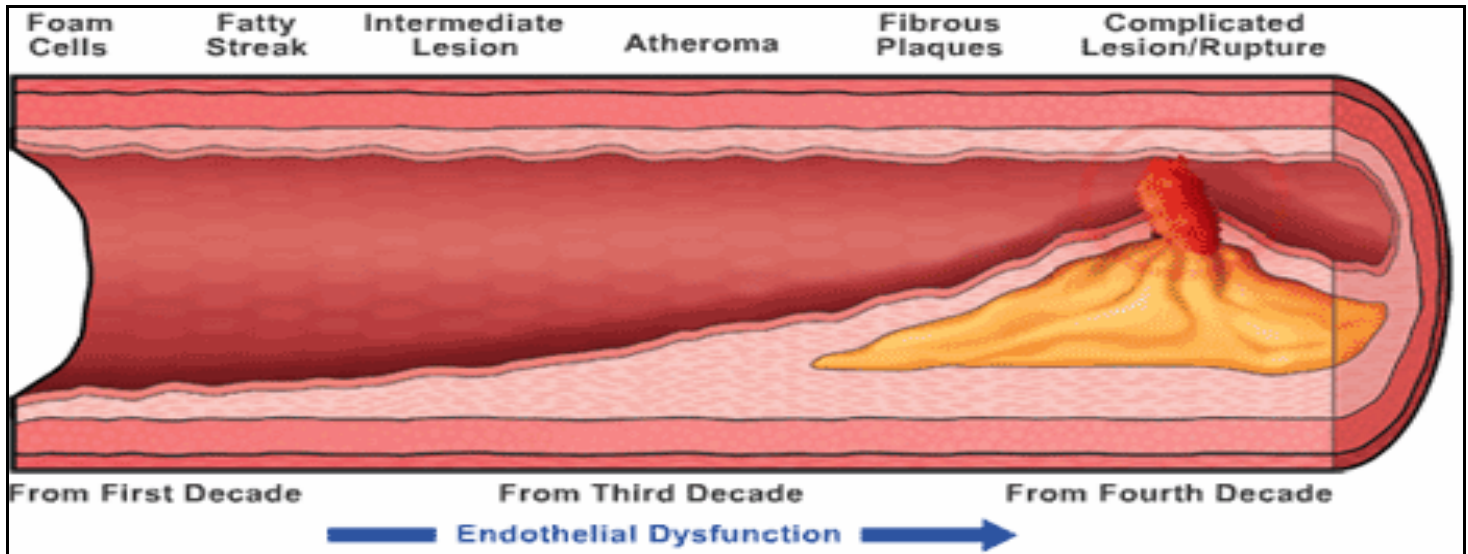
### ***Help and advice.***

If there is a problem the first port of a call should be your doctor's surgery. This is because the cause needs to be investigated and the appropriate treatment prescribed. Not all incontinence problems are primary, but may be secondary to another health problem. If that problem is fixed, the incontinence will disappear, as in for example certain infections. It is quite normal for a doctor to ask for a urine sample to be tested at the surgery. There is a product called 'Multistix' which is a plastic strip with a series of pads on the end to test different things which is usually dipped in the urine sample. The colour changes indicates different problems. e.g. Nitrites an infection, sugar for diabetes. A 'U & E' (Urea & Electrolytes) blood sample will also possibly be taken to confirm the workings of the kidneys. From then on it depends what the doctor finds in his examination.

Usually the patient will be referred to the practice nurse or District Continence Advisor, and an assessment is made. Usually the first strategy is pelvic floor exercises and other physical techniques. Drug treatments are more commonly tried before catheterization and as a last resort surgery. The exact techniques depend on the cause of the problem and individual circumstances. Some hospitals have a 'drop in' advisory service. The exact services depend on local arrangements. In many cases, it may be possible to approach the practice or district nurse first. No one should suffer from incontinence, as all cases can be managed in some way or another. – Mike

## The Atherosclerosis Time bomb.

Over the course of one's early life through to middle age, your arteries become 'furred up' and narrowed with plaque or atheroma (the Greek word for porridge. which is what the 'furring up' looks and feels like). In addition, the walls of the arteries themselves become hardened (or sclerosed, the Greek word for stone). This makes the arteries less flexible and more prone to damage and blockage. Hence the medical term for this condition, atherosclerosis (porridge and stone).



Furred up coronary arteries can suddenly become fully blocked by blood clots, starving the heart of blood flow and leading to a heart attack. Over time, these arteries can become fully blocked, starving the heart of blood flow and leading to heart attacks.



Two sections of arteries taken from two young people after they died. The top section belonged to a 31 year old non-smoker, the one below from a 30 year old smoker. The red stained area on the lower section of artery shows the extent of the fatty streaks and raised lesions on the artery.



A stage of development of atherosclerosis in an artery. People who smoke have an increased level of atherosclerosis in their arteries. This build-up of fatty material, called atheroma, can cause the inside lining of the artery to rupture, leading to a clot.

## ***The Risks Of Coronary Heart Disease***

Coronary Heart Disease is the UK's biggest killer, responsible for around 120,000 deaths each year and approximately one heart attack every two minutes. Death rates from CHD in the UK are amongst the highest in the world ultimately leading to one in four deaths in men and one in six deaths in women. Sufferers of CHD have one main thing in common: the blood supply to their heart is insufficient to keep the heart functioning normally.

We are all at some risk of developing CHD. The level of risk we have is our personal 'score' of all the known contributors to CHD added together. These contributors are known as 'risk factors': things that add to our risk of developing CHD. The biggest single, unavoidable risk is age: generally as you go through your 40's and 50's your chance of having a heart attack increases, often rising to 1 in 10 to 1 in 7 in the next ten years. If you are of South Asian origin or have a family history of early CHD, your risks are increased. If you smoke or are overweight, you are further adding to your risk. CHD is the UK's biggest killer, killing nearly twice as many women each year than breast cancer (see Premature Deaths By Cause, UK). The UK also has one of the highest rates of CHD in Western Europe. UK deaths from CHD are highest in Scotland and the North of England but it is a serious problem across the country. South Asians (from Bangladesh, India, Pakistan and Sri Lanka) living in the UK also have a higher premature death rate from CHD than average. The exact reason for this isn't known. The risk factors for heart

disease (betting odds) that you cannot do anything about are called 'non-modifiable' and those that you can do something about are called 'modifiable'.

### ***What Is Cholesterol?***

Cholesterol is a lipid (fat), which is mainly made in the liver (for the most part overnight) and also absorbed directly from some foods. There are two kinds of cholesterol: 'Good', and 'Bad'. Poor diet, smoking, lack of exercise can all lead to high levels of bad cholesterol.

'Good Cholesterol' HDL (high density lipoprotein) cholesterol (HDL.C) is called 'good' cholesterol. It is called good cholesterol because higher levels of it are protective against Coronary Heart Disease (CHD). HDL.C brings cholesterol back to the liver where it can be eliminated, which allows less cholesterol to build up in arteries.

Bad Cholesterol. LDL (low density lipoprotein) cholesterol (LDL.C) is also known as 'bad' cholesterol. The higher your level of LDL.C, the greater the chance of developing CHD, because this is the cholesterol that builds in the coronary arteries and turns into damaging plaques. Approximately 65% of the cholesterol in your arteries is bad cholesterol. Your doctor can measure the levels by a simple blood test. The recommended levels are:

Total Cholesterol < 4.0mmol/l  
HDL Cholesterol > 1.1mmol/l  
LDL Cholesterol < 2.0mmol/l  
Triglycerides < 2.0mmol/l  
Ideally you should reduce your total and LDL cholesterol as much as possible.

However, in order to achieve the maximum benefit you should adopt sensible lifestyle changes as well,

Things We Can't Do Anything About ( <i>'Non-modifiable'</i> )	Things We Can Do Something About ( <i>'modifiable'</i> )
Age Gender Family history of early CHD South Asian ethnicity	Cholesterol Smoking Being overweight Diet high in saturated fats Physical inactivity Stress High blood pressure Diabetes

### Contributors to Pathways No. 2:

Mike Valentine, Carolyn Byrom, Margaret Lewis,  
Trevor Wainwright, Anne & Jason Bowker,  
Garry Frankum, Gillian Barlow & Elizabeth McDonagh.

such as quitting smoking, improving your diet and taking regular exercise. Your cholesterol naturally increases with age. Therefore, your aim should be to keep it as low as possible. If you don't already know your cholesterol level, especially your bad cholesterol level, it is a good idea to find out. If you are already taking steps to reduce your cholesterol, then it is a good idea to ask your doctor to test your cholesterol periodically to find out how well you are doing.

Many doctors surgeries now have software within their computer systems capable of assessing the risks of CHD based on physical measurements and lifestyle. While it may be possible to modify things like smoking, being overweight, a diet high in saturated fats, physical inactivity, stress, high blood pressure and diabetes, it may not be possible to control the cholesterol levels without medical intervention. There are a number of drugs your doctor can use, and broadly they fall into seven families; Statins, Fibrates, Omega 3 Triglycerides, Cholesterol Adsorption Inhibitors, Bile acid Sequestrants and Nicotinic Acid Derivatives. All have their strengths weaknesses and side effects, and guidelines exist advising doctors what drugs to use depending on the patients circumstances.

Only the people with the highest risk of CHD will receive NHS treatment. People with a lower, but significant risk will not be treated at NHS expense, yet they may feel that they should be treated. The cut off point is determined more by medical/political economics rather than medical need. Over recent years it has been Government policy to transfer certain medicines from Prescription Only Medicine (POM) to Over The Counter (OTC). Simvastatin is a cholesterol lowering drug which has been POM for many years. Recently an OTC version has been licensed. This gives people with a moderate risk, who would not be treated at NHS expense a chance to treat themselves and at their own their expense. The cost is about £13 for a month's treatment. It is twice as effective as plant sterols e.g. Benacol.

However statins have a few side effects. The most common side effects are fatigue, upset stomach, gas, constipation, and abdominal pain or cramps. Liver enzymes may rise to more than three times their normal levels while a person is taking statins, but stopping the drug usually causes the level to fall back to normal. Regular blood tests are recommended to check liver function while taking statins. Muscle pain is a very rare side effect. Statins patients should immediately report any severe muscle pain, weakness, or brown urine to their doctor, who may want to do a blood test. Muscle pain can be a sign of a severe muscle reaction (rhabdomyolysis).

In a recent conversation with Dr. Myhill, I asked her for her view on statins. She doesn't use them because the side effects disturb selenium metabolism and there is a risk of myopathy. She explained that there were no cholesterol issues in her patients. She said that M.E. made people have a healthy lifestyle, especially with the stone age diet and restricted life style.

'Maxepa' is a product sold to lower cholesterol, and may be prescribed on the NHS by your G.P. It is derived from fish oils and contains Eicosapentaenoic acid (EPA). Now isn't 'Hi Q', an EPA product supposed to clear the M.E. brain fog, which was strongly recommended by Dr. Puri is flurry of news features some twelve months ago? Well several of use have tried Maxepa prescribed by our G.P. We have found it works well. I tell my doctor that Maxepa works well for controlling my M.E. problems, and he says it works well for my cholesterol. EPA is also found in Cod Liver Oil. *Mike*

### **RECIPE CORNER** **Carrot and Banana Cake** This makes 8 slices

225gm / 8oz wholemeal self-raising flour  
2 level tsp. baking powder  
100gm / 4oz carrot, finely chopped  
2 bananas, mashed  
2 eggs  
50gm / 2oz walnuts, chopped  
100gm / 4oz brown sugar  
2tsp ground cinnamon  
1 tsp vanilla essence  
150ml / ¼ pint corn oil (sunflower oil)

Mix all the ingredients together in a large bowl until combined. Pour into a greased 500gm / 1lb loaf tin. Bake in the oven at 180°C / 350°F / Gas Mark 4, for 1¼ hours.

## ***Common Issues Concerning Fatigue Syndromes. Patients and the Police***

*Following an encounter with the police by one of our members, I made representations on that person's behalf. The police asked me to supply a single page information sheet that they could issue to their officers. This is what I came up with as guidance that they could issue to officers*

- 1) ME /CFS is used to describe of number of diseases known as fatigue syndromes. Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), & Fibromyalgia Syndrome (FMS).
- 2) Medical research shows reduced blood flow in certain areas of the brain, with hormonal and immune system changes. As a consequence there are mental and physical aspects to the disease. Some patients are very debilitated. There is no cure or specific diagnostic test.
- 3) To the untrained eye patients will ME/CFS will appear to be normal and healthy. The best cases are able to live a near normal life; the worst are in bed 24 hours a day. Most cases are somewhere in between. All ages are affected 5 –85.
- 4) Patients with M.E. describe it as 'suddenly becoming 85' or 'being stuck in 1st gear'. What may be a normal task is like a full days work to a patient.
- 5) Mental health issues include poor short term memory, slurring and Nominal Aphasia. Aphasia is when someone can't find to right word, may stammer or say the wrong word, not realizing they have done so. This is a fatigue effect which can have implications when interviewing patients, especially under pressure. This problem resolves on rest, usually after 24 hours.
- 6) Patients with fatigue syndromes usually have sleep disturbances, and may need to sleep at abnormal times, especially during the day. Most will be on drugs to control symptoms, usually painkillers and antidepressants. Controlled drugs are sometimes prescribed.
- 7) Making a patient stand or walk a short distance may bring on a relapse, which can leave some housebound, or bed bound, from which recovery may take days to weeks. Most patients are aware of their limitations and know what they are. Any pressure on patients to exceed their limitations could be regarded as assault.
- 8) Some M.E. patients can react adversely to smoke and fumes. This includes perfume and toiletries, petrol and household cleaners.
- 9) Some patients have a complication known as gut fermentation (auto brewery syndrome). Ingestion of sugars in food results in alcohol being produced in a patients blood. In a typical case a teaspoonful of sugar will produce a blood level of 5 mg/100ml after one hour. This may be of significance in drink/drive cases where the law assumes blood alcohol is from intoxicating liquor. Patients may not be aware of this issue. The problem can be treated with a special diet, or antibiotics.
- 10) Generally, DVLC allows ME/CFS patients keep their private car licences, but they are excluded from HGV/PSV. Many can only drive 10 – 20 miles with full concentration. Automatic gearboxes or controls adaptations help. Some can safely drive only at certain times of the day.
- 11) The main cause of death with ME/CFS patients is suicide, followed by accidents. About half of CFS/ME patients have other serious medical conditions which can be life threatening if mismanaged. About one third of patients have clinical depression.
- 12) In some cases where children have taken much time off school, Social Services have totally misunderstood M.E., and some doctors have mistaken ME/CFS for 'Muchausen by Proxy'. (ref Beverly Allott Case). This has caused much distress to some families. - Mike

## **North of Doncaster**

*Personal Comment by Trevor Wainwright, news what is happening North of the A638 and elsewhere.*

### **Support, Tea and Sympathy, or Action:-**

Support is vital in any illness, but why is there this reluctance to join a group? Take Action for ME as an example. They have maybe 8,000 members out of a total ME populace of 300,000+. This could also apply to local groups. Is there still the stigma of everyone talking about their illness. Support groups can be useful for information, make the first step, contact them. If you think they can help use them to do so, if not try another. Remember many groups are run by sufferers themselves. See the MERSC Website [www.erythos.com/CAME](http://www.erythos.com/CAME)

### **The 2004 Sheffield Conference.**

I turned up in my now familiar 'prison suit'. Compared with last year there was a somewhat smaller turn out, which surprised me. There were only two stalls, one being from a national pharmacy chain. Gwyneth De Lacey was the first to speak, accredited as a local champion, who admitted that she was a new kid on the block, and as such gave a talk on her role, and an update on the services being provided in South Yorkshire and North Derbyshire. She gave an interesting talk on bids and restrictions, which she said was very virtual, and involved restrictions. Mark Adams spoke next, another 'new kid on the block'. As with Gwyneth, he was new to public speaking yet gave good presentation and outline of what was to be expected. As with Gwyneth he reiterated the financial limits, and yes I felt for them both in their frustration in being given something with which to help others only, to find there are limits.

Dr. Anne Macintyre was the main speaker. Anne spoke about the illness and how she was diagnosed, and was ill before the diagnosis. She talked about the vulnerable, particularly the children, and about enforced exercise. She paid credit to the work of MERGE, and the bravery of Vance Spence who was only able to work for two hours a day, but in those two hours did so much. I had not known this about Vance, and was duly impressed. There are so many brave people with this illness. During the interval there was an opportunity to have a cuppa an' a chat and during which questions were written down to be asked. During this time I took the chance to speak briefly to Anne, it was great that she remembered me from 1997. In the second half Anne mentioned the work of the CFSRF and their very important work along with MERGE, as the only two organisations working for a cure, which was very informative. If you want to know the full story please visit the Sheffield Group website on [www.sheffieldmegroup.co.uk](http://www.sheffieldmegroup.co.uk) where they are producing a report on the talk which will be available for download from their site.

### **Research**

One group, now in its 11th year, was founded in 1993 as the Persistent Virus Disease Research Foundation, and became the Chronic Fatigue Syndrome Research Foundation (CFSRF) in 1999. Its aim to concentrate entirely on research into ME/CFS and informing the medical profession of any new findings. They have made great strides in understanding the illness and its problems. Their first project, carried out by Professor Len Archard and Dr Russell Lane, found evidence of excess lactic acid in people with ME, which contributed to muscle pain. The first breakthrough in understanding the illness and the presence of enteroviruses. Since then the Foundation has funded the following:-

- Dr's Wilhemina Behan and Ian Holt - The role of mitochondria in the illness.
- Dr Mike Carter - A gene expression study.
- Dr Ian James - A study assessing 5HT transmitter function.
- Dr Geoffrey Clements - Multicentre research using samples from one specimen to other laboratories to establish consistency in results.
- Professor J. E. Bantalava & Dr Peter Muir – Long term enterovirus persistence.
- Professor S. Holgate and Drs Wendy Barclay and Robert Powell - Specific gene expression, research which could lead to a diagnostic test.
- Dr Jonathan Kerr has now joined the gene expression team.

ME is a complicated illness, but thanks to such as the CFSRF, the complications are being overcome. They receive no Government funding and entirely depend upon public and corporate donations, and a Medical Trust Fund grant. To learn more about the Foundation their address is 2, The Briars, Sarratt, Rickmansworth, Herts WD3 6AU. Tel: 01923 268641 Fax: 01923 260352 Email: [info@cfsresearchfoundation.org.uk](mailto:info@cfsresearchfoundation.org.uk). Visit their website on [www.cfsresearchfoundation.co.uk](http://www.cfsresearchfoundation.co.uk), and if you have any spare cash, I am sure they will welcome it and put it to good use. I have supported the Foundation since 1997 and will continue to do so through MRERC, which is a duly organised constituted group and independent of other such groups in the area of Castleford. In my next column, I will give details of The Blue Ribbon for the Awareness of M. E. campaign. (BRAME).

## **Gulf War Syndrome (GWS) 'Does Exist'** Adapted from the BBC News 16/10/2004

Scientists in the US say they have demonstrated the existence of the illness known as "Gulf War Syndrome". The findings are in a report by the influential Research Advisory Committee on Gulf war veterans' illness, leaked to the New York Times. Committee chief scientist Professor Beatrice Golombe said that exposure to certain substances in the Gulf may have altered some troops' body chemistry. The veterans' illnesses had until now been unexplained. Acetylcholine (Ach) is a key neurotransmitter which controls many signals in brain, nerves and body, working things like muscles, blood pressure, sweating, and regulation of autonomic nerve signalling system.

In order to protect the soldiers from exposure to nerve gases like Sarin, they were given a substance called Pyridostigmine. The mechanism by which this works is on a key enzyme, cholinesterase. Not every veteran suffers from GWS, but there is enough evidence to show a causal relationship in the U. K. Australia, Canada and U.S.A. Animal studies have shown that exposure below the level likely to cause any symptoms caused a permanent change in Ach regulation. The best evidence is that there is a certain genetic type which is less adept at clearing the agents, because they have slow metabolising enzymes of organo-phosphorous bromides. They think GWS is a mixture of this problem and their genetic make up. The research was on existing papers as the committee was

prevented from doing its own research to evaluate the existing evidence.

*Comment: The MOD argues that there is no single cause of the illnesses reported by veterans from the conflict. I'm not convinced. This is possibly the same well known*

*mechanism by which certain farmers exposed to organo-phosphate sheep-dip chemicals have suffered an M.E. like syndrome. Mike.*

*Cartoon thanks to 'Interaction.'*



## **Linking Up**

Ever thought it would be nice to be in contact with other members of our Support Group by telephone, letter or email? Why not sign up for the new **Linking Up** Contact Service. It is available to everyone, sufferers and carers alike, all ages welcome. It is a great way to contact people, compare experiences and make new friends. It is simple and free to join. Fancy giving it a try? We already have 14 members! Updated lists are sent out within two weeks after each edition of Pathways is circulated, so if you would like your details to be added to the next list then get your form filled in and posted back quickly. For further information you can contact Carolyn on 01204 495727 (after 1pm please) or, by email at the following address:- [carolyn@c-r-b.freemove.co.uk](mailto:carolyn@c-r-b.freemove.co.uk)

## **The Leeds Fatigue Clinic**

In the first edition of Pathways I wrote to you about my experience at the Leeds Chronic Fatigue Clinic at Seacroft hospital. I have now had my first appointment with Dr. Buckley and believe me attending this clinic a "real tonic". The staff treat you with such dignity and you feel not only are they there to help and advise you about your condition you are also made to feel "special". *Margaret*

## **Flu Jabs Reminder**

Now is the time to consider flu vaccination. Carers should certainly have a vaccination. There is a caution with M.E.s in that a flu jab or vaccination may make M.E. worse. One lady with M.E. that I spoke to, who has regular flu jabs told me that during the past ten years she has had a couple of adverse reactions. It is really up to the person and their doctor. I have information about this from the M.E. Association. I can be contacted on the help line 01302 787353. *Mike*

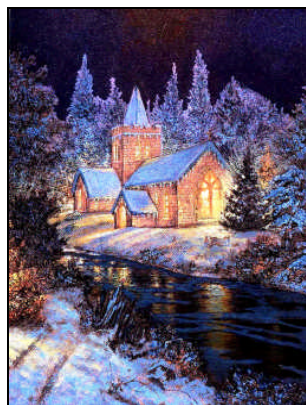
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Pathways



Festive Season

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Please contact Mike on (01302) 787353 for further information

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