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.

Dr Sarah Myhill: Success and Setback.

Photograph: Dr Sarah Myhill riding Maggie.

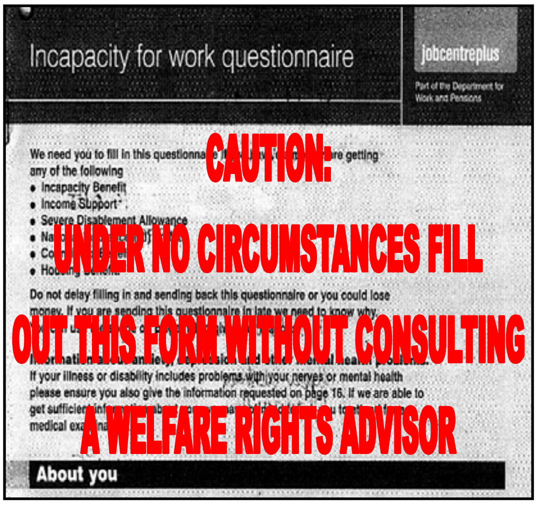
Most members will be relieved to hear that the General Medical Council have backed down on the Fitness to Practise hearing, but Dr. Sarah suffered a serious riding accident on the 21st October. Read her letters on pages 3 & 4.

Christmas Recipes

See page 12.

Disbelieving doctors are not Extinct, after all.

A batch of Incapacity Benefit refusals was reported on the helpline, More information on page16



Incapacity for work questionnaire

jobcentreplus

Part of the Department for Work and Pensions

We need you to fill in this questionna... ...re getting any of the following

- Incapacity Benefit
- Income Support
- Severe Disablement Allowance
- Na...
- Co...
- Ho...

Do not delay filling in and sending back this questionnaire or you could lose money. If you are sending this questionnaire in late we need to know why.

If your illness or disability includes problems with your nerves or mental health please ensure you also give the information requested on page 16. If we are able to get sufficient inf... medical exa...

About you

CAUTION:

UNDER NO CIRCUMSTANCES FILL OUT THIS FORM WITHOUT CONSULTING A WELFARE RIGHTS ADVISOR

You write

Sandy Writes: *Could I ask for your opinion on something? This event has happened several times over the past year, and I put it down to perhaps being food poisoning; but now I'm not so sure. It happened most recently about a week ago, and what made me start to think something else is going on was that I did not vomit or have diarrhoea, only violently shaking chills and widespread and relentless aching over what felt like was every inch of my body. I had to curl up in a foetal position and wrap my entire body in layers of blankets, took some Oxycondin and prayed to be able to go off to sleep. The next morning, these symptoms were gone, but the site of my pacemaker incision was actually sore from the violent shaking. I have looked on WebMD, and they list a number of other conditions that could cause this. I have an appointment with a hyperhidrosis (excessive sweating) specialist in mid-December. I know that hyperhidrosis often has "underlying" conditions. I wonder if I should tell him about these infrequent "spells."*

You did the right thing by going to bed, and it worked. When you get chills it's your body telling you enough is enough and you have to back off. Your problem could be a straight-forward feature of ME/CFS, autonomic nervous system dysfunction. Sweating is controlled by your autonomic nervous system. If it goes erratic as in the case of ME, that's what happens. **Hyperhidrosis can be treated with anticholinergic drugs and prescription versions of roll on deodorant based on aluminium chloride.** ***I do however think it is always a good idea to check out recurring symptoms with your doctor, and always tell your doctor everything. Sometimes the odd things you think are irrelevant can be pivotal in forming a diagnosis. Mike.***

Mike writes: *Hello, I hope you do not mind me writing to you, but I wondered if you would be able to help me. I am doing a PhD which is related to how belief systems may affect the management of ME/CFS for some people. As well as being a Senior Lecturer at the University of Derby I am a CBT therapist and, for a short while, worked at a hospital unit for ME/CFS. As with other chronic medical disorders, CBT has helped people to manage their illness. From my research so far, there appears to be a small percentage of people whose belief systems may interfere with their coping with ME/CFS and hence may need more support than is offer at the moment - which is very limited. My research is concerned with helping people with this medical disorder to improve their quality of life. In order to do that, I need the help of people with ME/CFS and wondered if anyone from your support group may be interested in taking part in my study. Participation involves completing a questionnaire; it does not involve any lengthy writing. Additionally, the second part of the study involves an interview, but, only a few participants are needed for this. All information will be completely confidential, respecting anonymity.*

I'm afraid that the Doncaster lot are very sceptical about CBT, mainly because many have found it doesn't work. However, Uta, the chairperson of the Sheffield group tells me that there is keen interest. If anyone is interested in taking part, and completing the questionnaire, Mike can be contacted at d.stalmeisters@derby.ac.uk -*Mike*.

Edward Writes: *The ME Letter Project aims to write a letter which will highlight the need for research into the physical causes of ME. This letter will then be sent to the Government and the media. As one letter alone would not be very effective we plan to ask as many people who suffer from ME to send a copy. Multiple copies of the same letter arriving around the same time should highlight how many people suffer from ME. As ME also effects the carers and family members of those with ME they will be invited to send a copy of the letter. This will show that ME does not just affect the sufferers and that it is not just the sufferers who want more research. The main goal of the letter is to highlight the need for more research into the physical causes we also hope that the letter will help to raise awareness of ME in general and help to remove the stigma that ME is not a serious condition. We have decided to create a letter which can be downloaded so that even the severely effected sufferers of ME can send a copy. If they are physically unable to send the letter someone else can do it on their behalf.*

Letters were decided on, rather than E-mails, as we believe a pile of letters will have a greater impact than a list of E-mails on a computer screen. Once the letter is complete everyone will be asked to send their copy on the same date so they all arrive around the same time. We are aiming to have the letter completed by the end of February 2008 to give us plenty of time to tell everyone it is ready so we can send it during next years ME Awareness Week. I have written this article to inform as many people in the ME community as possible, as the success of this project will depend on as many people as possible knowing about it. If you would like more information about the project please visit our website which can be found at: http://www.meletterproject.com. If you have any comments or suggestions about the project, or what should be in the letter then you can contact us via our website which has a Contact Us page or send an E-mail to: info@meletterproject.com.

Anne Writes: *Further to my previous comments about Ribose, I really think it is helping a lot.*

I am very pleased to hear that, Anne. *Mike.*

Dr. Sarah Writes: *I have just heard from the General Medical Council (GMC) hat they are dropping all the allegations against me. As some of you may know, I was lined up for a thirteen day hearing in February 2008 and this has now been cancelled. I have to say this is a huge relief. Whilst I knew I had done no wrong, it is not easy living with the threat! The exact reasons why the allegations have been dropped have yet to be given to me. The, GMC are legally obliged to give me these reasons and I shall press them until they do. At this stage they have simply said they are dropping the allegations.*

However, there is no doubt that a large part of that reason is because of the many wonderful letters that patients have written to the GMC on my behalf. The GMC have sent me copies of all those letters and there are many hundreds of them. They are the most extraordinary letters - intelligent, incisive, authoritative and down to earth. They really were the sort of letters that the GMC could not possibly ignore. I have no doubt in my mind that this put great pressure on the GMC to look at the allegations against me in a new light. Having done so, they dropped them all. So I have so many thank you to give to so many people, forgive me if I can't thank you all in person!

There are many other issues that have arisen out of this GMC issue, not least of all is how badly many of my patients have been dealt with by the GMC. For example, with some of my patients their confidential medical GP records have been obtained without their knowledge; in all cases confidential medical GP records have been obtained without patients being informed of their legal right to appeal, and in some cases confidential medical GP records have been obtained without being anonymised. There are many other indiscretions that the GMC have been guilty of and I shall continue to pursue these on behalf of all of us. I also have to thank all those lovely people who have signed the patient support petition; which now has over 900 signatures. I also have to thank the many doctors and health professionals who have also written glowing testimonials on my behalf. Again I know this has put me in a very good light.

I am concerned that the two cancelled hearings I have now faced have a larger political agenda which I shall also be tackling. I shall be keeping all the support letters written by patients together with all the doctors' testimonials and the petition in order that I can use them in the event of any further problems with the GMC. So I thank you all from the bottom of my heart. Sarah Myhill

I wonder if the GMC has a hidden agenda against ME/CFS doctors who question medical dogma. While dealing with doctors through work, I quickly learned how they think and act and it become very obvious who are the ones who are confident. When I first went to the Leeds Fatigue Clinic with M.E. they quickly picked up that I didn't trust doctors, and it subsequently appeared on my medical record. Julie Cameron tells me that Dr Skinner, another doctor who was taken to Fitness to Practice Hearing by the GMC is still practising and can continue to treat for hypothyroidism. Our member, Liz, has attended some of the hearings which were held in London and Manchester, and I have received frequent reports of the proceedings. *Mike*

How nearly I (nearly) broke my neck in a riding accident Oct 21st 2007

By Sarah Myhill

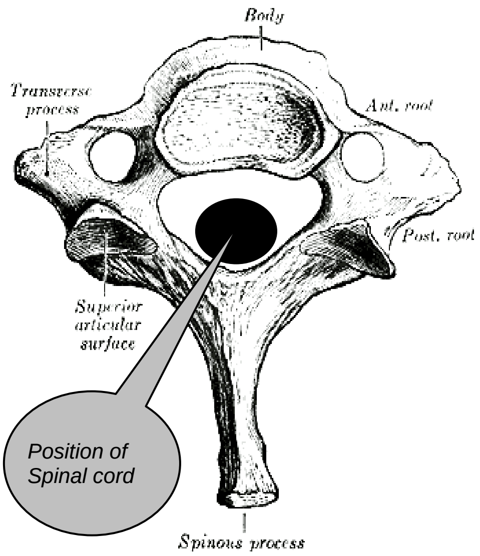
My hobby is team chasing. This is a sport in which a team of four have to go as fast as they can across country over large natural fences. It is half-way between eventing and point-to-pointing. So horses need intelligence, control, balance and jumping ability. The horse ideally needs the talents of an eventer combined with the stamina and speed of a point-to-pointer. It is necessarily a dangerous sport. I lead ride on my 17.0 hands high Belgium warmblood mare that is a Rolls Royce of a ride and has never put a foot wrong in the five years that I have chased her. I also have a great team behind me and as a result of which we were at the top of the National League.

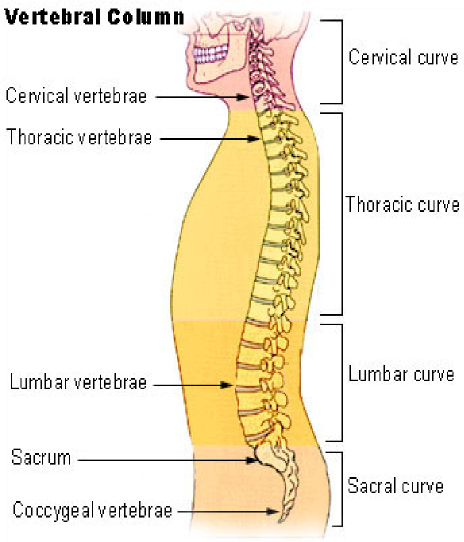
At the Grafton Open Team Chase, we were one of the last teams to go and four fences from home we could hear from the commentary that we were well up on the clock. As I was coming up to a large hedge, in a moment of madness the second horse and rider came past me on the inside. This broke one of the unwritten laws of chasing. I like to angle all my fences– so does Maggie – because this allows the correct striding. This gives us the option of opening or closing the angle which allows one to meet each fence on a perfect stride. Having a horse come inside closed down this option and this upset Maggie. As it happened we needed this option on this particular occasion because we were wrongly strided. I knew she was upset instantly because her ears flicked back and her head came up. Her concentration moved from the fence to the other horse as if to say “What the hell are you doing?” As the second horse took off Maggie took off as well. She was a full stride away from the fence and ended up coming down on top of the fence and somersaulting over.

I was fired out of the front door like a human cannonball and landed square on my head. Maggie landed on top of me and as she rolled her body over me she caused a forced flexion injury of my neck. I felt all the bones in the back of my neck break like a line of dominoes and this was accompanied by intense pins and needles and tingling all down my shoulders and arms. It is interesting the feelings that accompanied this. There was certainly no panic distress or self-pity! My first thought was “what a silly way to die”, closely followed by “the girls are going to be so cross with me”! I also thought of my dear friend Dr Keith Eaton whose dying words were “This is going to be a very interesting experience for a scientist!” I knew my neck was broken and just assumed that death or paralysis would follow shortly. However I remained conscious.

A Close Shave?

Normally horse riding injuries are serious because they involve damage to the vertebra (bones of the spinal cord). The neck bones are slightly different from the rest of the spine because they have a bit called the spinous process which sticks out from the back. In lizards and dinosaurs this forms a crest. In humans it is used to attach tendons which connect the muscle to bone.





What appears to have happened with Sarah is that the main body of the vertebra are intact, and the spinous process is damaged, along with other bones and bruising. The vertebra also has a hole just off centre which forms an armoured chain to protect the spinal cord. In some cases were a piece of bone to compress or damage the spinal cord, the consequences could be serious. The motor nerves run on the outside of the spinal cord, and this would cause paralysis from the neck down it the patient survived. Being a doctor, Sarah was all too aware of this possibility.

Although I couldn't see anything because my face was smashed into the ground, I could hear all that was going on and what I couldn't understand was why Maggie couldn't get up. Then the thought occurred to me that she too had broken her neck i.e. a double disaster. This really was the low point of the day! Unbeknown to me somebody was sitting on Maggie's head to try to stop her thrashing around on top of me and when he jumped off Maggie too got up. Clever old mare managed to do this without kicking me and she trotted off happily to her stable mate Red. Maggie was completely fine! Within a minute or two of Maggie getting up the pins and needles in my shoulders and neck miraculously disappeared as fast as they had come and I suddenly realised that I had feeling and movement in my hands and feet.

I should be able to say that this was accompanied by a wave of relief, but this would not be true. Since I hadn't been in panic mode in the first place I seemed to take a rather disinterested view which amounted to "Jolly good, perhaps I'm not paralysed after all!" From being a complete rag doll on the ground unable to move I was able to grab my head and roll over to communicate to the paramedics that the neck was broken so that appropriate action could be taken.

A C.T. scan done at Banbury Hospital showed multiple fractures of all vertebrae between C2 and T1 inclusive together with fractured ribs and scapula, and associated soft tissue damage. Essentially the forced flexion injury pulled out and/or broke off the cervical spinous processes just like tent pegs. An old spinal fracture was also found – but I have no idea when I broke my back last time! The other really interesting injury which I didn't notice until I tried to read a book was holes in my visual field. When Maggie landed on top of me this created a pressure wave which shot up the arteries and they ruptured at the back of both eyes. So I have flame haemorrhages in both retinae (back of the eyeball) which are causing holes in my visual field. With time and arnica these should settle. I also had the most magnificent black eye and even now, a week later, my left eye is completely purple! So for the first time in my life I have missed a week of work because of ill health. Normal service resumes on Monday.

No pity please – an entirely self inflicted injury!

November 7th 2007 Update

It's been like Christmas here with all the lovely cards received! I now feel so much better I feel a complete fraud. Back on the pointer and went for a lovely bomb today. Hunting on Saturday. Work as normal.

As a result of the injury Sarah has closed her Mansfield clinic early. Patients can visit Sarah in Knighton, and still order tests and medicines via the internet or phone.

PATHWAYS'
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The Pathways praise be a saviour of ME,
Long are the insomniac evenings,
Much worse the pain ridden days,
Lonely isolated, with morose days.

Thankful for the newsletter Pathways,
I ask over and over again cursing the pain,
Where did CFS come from and, why?
Like a fast moving train.

But unlike the train it came first very slow
And when it reached its destination, it refused to go.
Gone is the time when I worked nights and hard days,
But now my energy is gone, there is Pathways.

Doncaster to me is like going to the world's end,
I live in Inkersall, but I've found a good friend.
I have met him only once and we've spoken on the 'phone,
He's given me ease when I'm down and alone.

His help with real issues, the real role he plays,
So I give praise to the marvellous Pathways.
I'm old and of course, seen better days,
ME is for real and not just a phase,

Indiscriminate of class or age, and not just a craze,

By Pearl Hammond.
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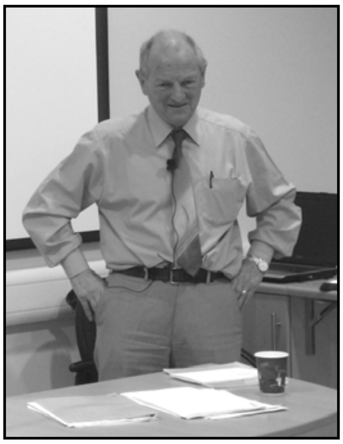
Sheffield ME Group Conference 20/10/2007 (abstract)



Sheffield ME group have a conference every year, and this year the main address was given by Professor Malcolm Hooper Ph.D., B. Pharm., A.R.I.C., C.Chem., the Emeritus Professor of Medicinal Chemistry, University of Sunderland. We were interested to learn from Professor Hooper that he is a Yorkshireman, born and bred in Thurnscoe (a good place to be born) and Goldthorpe, and that he attended Wath Grammar School. He explained that his main discipline is Medicinal Chemistry, which concerns the design and development of novel drugs for the treatment of disease. Chemistry, biochemistry, pharmacology, vaccines, microbiology and some aspects of medicine are involved. The title of the conference was *‘Myalgic Encephalomyelitis: Politics, Medicine and Science.’* The interesting issues raised are:

Oxidative Stress Work has shown that levels of measurable oxidative stress are raised in people with M.E. and are highest in those people with M.E. which collated with severity of symptoms. Isoprostanes (compounds generated by the oxidation of unsaturated fatty acids), HDL (high density lipids), GSH (glutathione) and oxLDL (oxidised low density lipoprotein) within the blood vessels of muscle tissueare involved. High levels of these substances indicate massively raised oxidative stress in people with M.E and related syndromes. Most free radicals are present after the rest period explaining why Graded Exercise (GET) is harmful.

Immunology The first significant research showed abnormalities of the 2-5A RNA Synthetase Pathways in M.E. patients which underlie the inflammatory response. Dr Jonathan Kerr has identified 16 genes which were differently expressed in M.E. patients, associated with Immunology, nerve function, mitochondrial function and gene expression. Abnormalities were found in 83 gene transcription factors involved with CFS patients.

Apoptosis. This is programmed cell death, a process to clean up damaged cells which happens all the time. The levels are raised in ME/CFS patients.

Subtypes Sorting into sub-groups are essential for accurate research Jonathan Kerr’ describes 7 sub-types which he has identified from his genetic studies. These are:

Kerr Type	Gender distribution	Characteristics	Distribution
I	Mixed	Most severe worst cognition and mental health score & poor sleep and least pain	
II	Mainly Male	Marked post-exertional malaise, muscle & joint pain, poor mental health	
III	All female		
IV		Moderate neurocognitive function & cognitive defects with moderate levels of bodily pain & sleep,	Dorset London/ NY 4,
V	All female	Best mental health but poor neurocognitive function, gastrointestinal complaints, most marked muscle weakness & post-exertional malaise	Bristol 5
VI	Mixed	Most severe	Dorset
VII	All female	Most severe, most pain, swollen glands, sore throats, headaches	

The final remarks were *“….there are now over 4,000 published studies that show underlying biomedical abnormalities in patients with ME-CFS. It is not an illness that people can simply imagine that they have and it’s not a psychological illness. In my view, that debate, which has waged for 20 years, should now be over.”*

There is a full report in the Sheffield ME group website:
http://sheffieldmegroup.co.uk/Conference%20Report%202007.pdf

Pain Management in ME/CFS

I recently attended a lecture by Andrew Staples of the Leeds Hospitals' Pain Management Service. Although much of what was discussed was shop talk, Pathways readers might be interested in current thinking on pain control which may help with understanding the problem.

The 'M' in 'ME' stands for myalgia, which means muscle pain, which is present in around 80% of cases. Less common is arthralgia or joint pain which around 28% sufferers report. Pain is the prevalent symptom of FMS sufferers, characteristically focused on hot spots or sore points. It is not unusual for some patients to require strong opiate analgesics like morphine to get relief

What is pain?

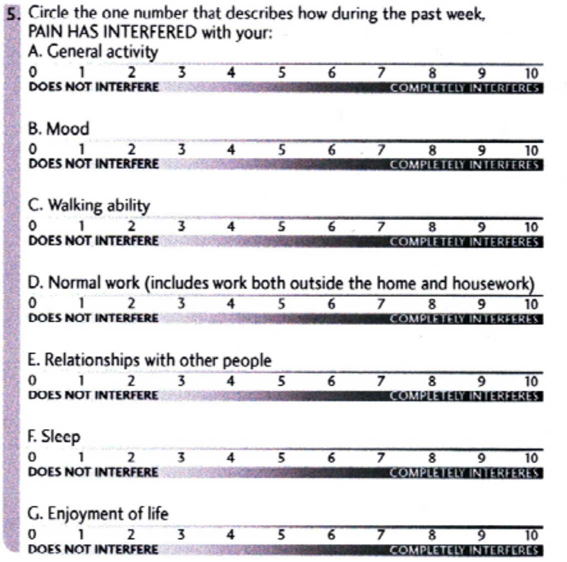
Pain is an unpleasant sensory or emotional experience associated with acute or potential tissue damage. Pain is whatever the patient says it is and exists whenever the experiencing person says it does. Chronic Pain is pain that persists a month beyond the usual course of an acute disease or a reasonable time for an injury to heal or that is associated with a chronic pathologic process that causes continuous pain or the pain recurs at intervals of months or years.

T*he Pain Experience*.

- **Physical pain**. This may be due the illness itself, the effects of the illness, the treatment of the illness, and another co-existing disease.
- **Psychological pain**. The following affect the perception and intensity of pain: Feelings of helplessness, hopelessness, an inability to cope, anxiety, depression, unhelpful beliefs, lack of knowledge and understanding, loss of control, emotional associations and memories of pain.
- **Social pain.** This is the suffering associated with anticipated or actual separation, loss or isolation. It can be made worse by personal or financial problems.
- **Spiritual pain.** This is felt when what is happening does not fit with the person's understanding of the meaning of life. This may (but does not necessarily) include / religious struggle.

Acute pain is caused by something which happens and can usually be pinpointed to a cause. Chronic pain is due to an ongoing condition, like with ME/CFS.

Characteristics	Acute Pain	Chronic Pain
Appearance	Obvious pain	Possibly depressed
Complaint	Loud	'Discomfort'
Understanding	Pain understood	Pain not understood
People affected	Mainly incident	Mostly chronic
Ease of treatment	Simple	May be complex
Adverse effects	Acceptable	Not acceptable
Acceptability of sedation	Sedation desirable,	Sedation usually undesirable
Drugs dose.	Standard, as required doses	Individually adjusted and regular
Speed of onset	Immediate	Eventually
Treatment aims	Relief	Prevention



5. Circle the one number that describes how during the past week, PAIN HAS INTERFERED with your:

A. General activity
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

B. Mood
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

C. Walking ability
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

D. Normal work (includes work both outside the home and housework)
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

E. Relationships with other people
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

F. Sleep
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

G. Enjoyment of life
0 1 2 3 4 5 6 7 8 9 10
DOES NOT INTERFERE COMPLETELY INTERFERES

How is pain measured?

The are no high-tech methods, it's just how the patient feels. Patients are asked to fill in 'Visual Analogue Scores' of which there are many variations. These can then be used check how well any treatment goes.

Pain Control Issues in ME/CFS

Don’t underestimate ME/CFS pain. The worst cases I am aware of in Doncaster are being treated with Fentanyl patches and diamorphine (heroin). These narcotic analgesics are more commonly reserved for advanced cancer cases, and must be supervised by specialist nurses.

ME/CFS is a neurological condition, and the most common type of pain is neuropathic. This means that it is caused by damaged or dysfunctional nerves through the disease process. Neuropathic pain is often described as shooting, stabbing, burning, stinging, or searing, and is usually worse at night. There is usually a deep ache, often described like toothache. Sometimes pain will follow a certain pattern or physical path, for example as in FMS. Sometimes it is associated with numbness or abnormal sensation. It can be triggered by minor irritation, such as rubbing against the sheets at night. The pain can usually be identified to a single or group of anatomically related nerve(s). For example different sides of the big toe are served by different branches of the same nerve. This type of pain is related to the intensity of the disease. Generally antidepressants (tricylcic) or narcoleptic (e.g. gabapentin) drugs control the pain, but the best option is avoidance through pacing and avoidance of stressors (e.g. activity like walking). Alternative treatments that are effective include TENS machines and acupuncture.

The second pain issue is related to acute pain. Sometimes joints, tendons or specific muscles become painful. This is arthralgia. There may be abnormal muscle movements. The pain can appear and disappear in a matter of hours, or persist for weeks and become chronic. The area affected can be usually identified to a specific cause or area, but sometimes not. Generally this results from poor pacing or unaccustomed activity. Very often, this sort of pain will respond to normal analgesic (painkiller) drugs or avoidance. Sometimes this sort of pain can be similar to a heart attack, and result in emergency admission to hospital for a suspected (false) heart attack. (All unexplained chest pain should be treated as a clinical emergency via a 999 call).

A third type of pain in ME/CFS is related to visceral organs of the gut, bladder and uterus. This most often occurs when ME/CFS is associated with irritable bowel type symptomology. This sort of pain can be nauseating, severe, colicky, diffuse (none specific) and may be felt in an area unrelated to the organ concerned (referred). For example stomach pain is felt in the centre of the tummy, whereas the stomach is on the left hand side. This sort of pain will very often respond to anticholinergic drugs like mebervarine or tricyclics, and not the usual pain killer analgesic drugs.

A fourth problem I come across that causes muscle pain in ME/CFS patients is due to drug adverse effects. Most ME/CFS patients are in mid life, and with sedentary lifestyle due to the nature of the illness. As a result, blood lipids and cholesterol go sky high. Doctors are brainwashed into prescribing statin class drugs. The problem I’ve come across most commonly is simvastatin causing rhabdomyolysis (muscle damage) which has occurred in all ME/CFS cases I’ve seen. The problem is documented are being rare (approx. 1: 100,000), but my belief is that statin type drugs should not be given to ME/CFS patients. This is because of hypothyroid, B3 metabolism, and abnormal liver function issues associated with ME/CFS. Stopping the statin usually stops the pain. The cholesterol must be treated with alternative drugs to reduce the risk of a heart attack.

When I do a Case Review for a new member, because of a benefit dispute or for some other reason, I ask about pain control issues. Irrespective of the disease, almost all pain is controllable, and no one should be suffering. If you are suffering form any pain, unless it is an emergency you should be consulting your doctor. Please do not be put off by thinking you are unnecessarily bothering your doctor, or by him saying there is nothing he can do. Many of our members are attending specific pain control clinics like the one held at Mexborough Hospital. Apart from the drugs, alternative therapies like acupuncture are available though the NHS, but can only be accessed via your doctor. If you are applying for state benefits like Disability Living Allowance (DLA) and incapacity-related benefits (e.g. IB50) the fact that you are attending a pain clinic carries weight and vastly strengthens the claim. *–Mike*

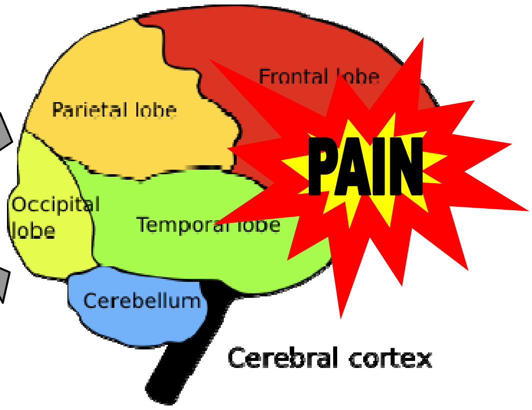
The Mapping the Mechanism of Pain Control

Context Pain Perception Modifiers

Culture, Misconception, Age, Knowledge
Gender, Personality,

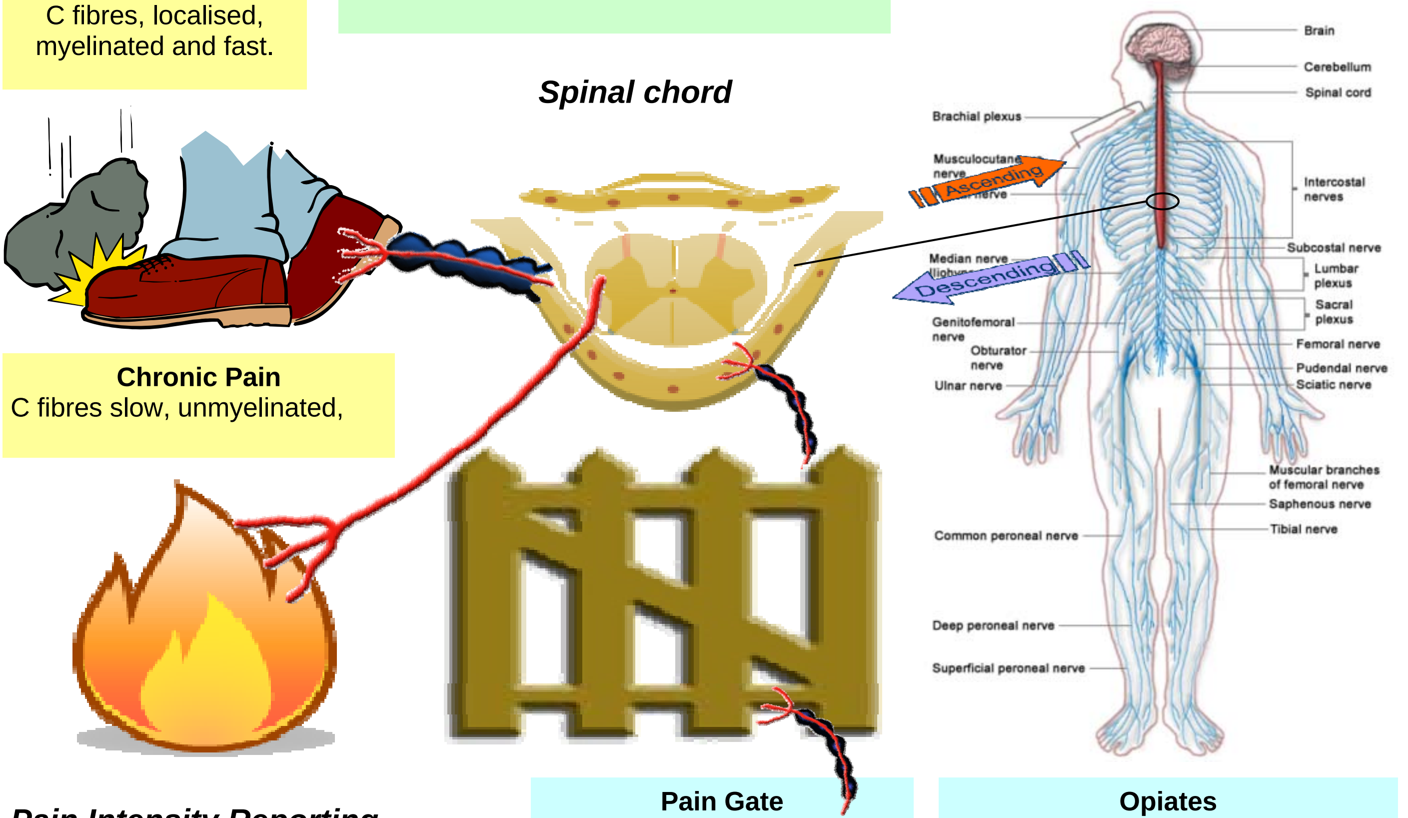
Decreased paint threshold
Insomnia, fatigue, discomfort,, pain present. fear of pain, anxiety, sadness, fear, anger social and mental isolation, boredom, depression.

Increased pain threshold
Sleep, rest, symptom relief, anxiolytics, antidepressants, companionship, divisional activity, occupational therapy, relaxation, information, environmental, music.



Acute Pain
C fibres, localised, myelinated and fast.

Spinal chord



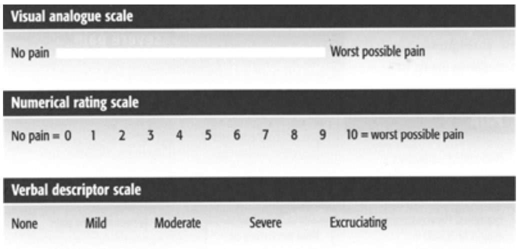
Chronic Pain
C fibres slow, unmyelinated,

Pain Gate
Beta class fibres, myelinated and fast. Simulation of these nerve fibres blocks the pain sensation transmission to the brain. Touch, and heat do this. TENS and acupuncture machines work the same way

Opiates
(e.g. Morphine,Fentanyl, diamorphine, codeine) work on receptors of nerve cells within the brain.

NSAID's
(e.g. aspirin, paracetamol, ibuprofen)

Pain Intensity Reporting



Visual analogue scale

No pain — Worst possible pain

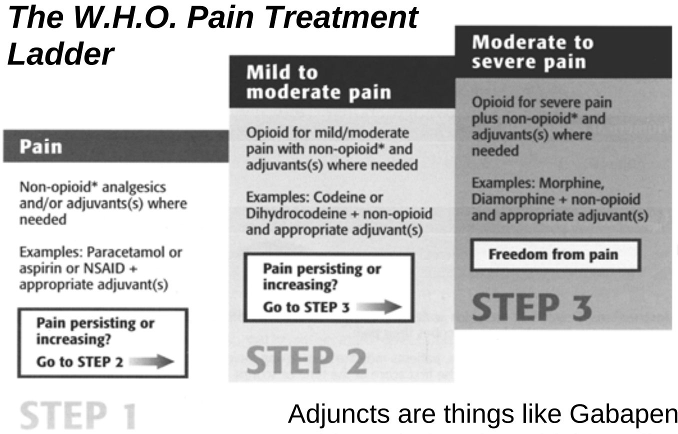
Numerical rating scale

No pain = 0 1 2 3 4 5 6 7 8 9 10 = worst possible pain

Verbal descriptor scale

None Mild Moderate Severe Excruciating

The W.H.O. Pain Treatment Ladder



Pain

Non-opioid* analgesics and/or adjuvants(s) where needed

Examples: Paracetamol or aspirin or NSAID + appropriate adjuvant(s)

Pain persisting or increasing?
Go to STEP 2 →

STEP 1

Mild to moderate pain

Opioid for mild/moderate pain with non-opioid* and adjuvants(s) where needed

Examples: Codeine or Dihydrocodeine + non-opioid and appropriate adjuvant(s)

Pain persisting or increasing?
Go to STEP 3 →

STEP 2

Moderate to severe pain

Opioid for severe pain plus non-opioid* and adjuvants(s) where needed

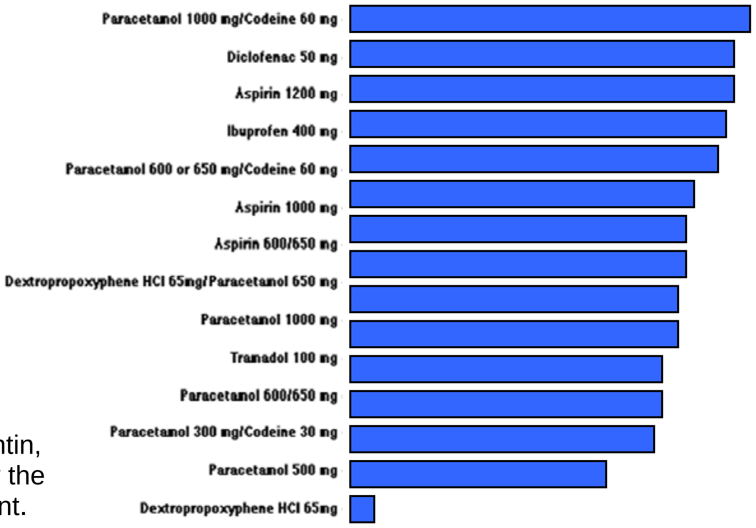
Examples: Morphine, Diamorphine + non-opioid and appropriate adjuvant(s)

Freedom from pain

STEP 3

Adjuncts are things like Gabapentin, steroids and tricyclics which modify the pain response mechanism and are disease dependent.

Potency of Common Analgesic Oral Medication



Group Meeting 23/11/2007: Visit by Jenny Gilmore

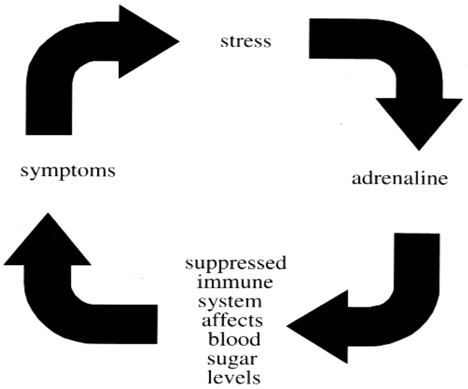
I have known Jenny over the 'phone and internet for quite a number of years as a fellow ME sufferer. I met her for the first time when I went to speak to the York ME group earlier this year. I thought that it would be a good idea to let her speak to the group, and share her ideas.
She is a graduate of the University of London, holds additional qualifications in anatomy and physiology, and studied Occupational Therapy for 3 years in York. At around the time of graduating she got ME which frustrated professional accreditation of her training to be an occupational therapist.

However, this did not stop her from helping people with disability despite spending more than 14 years living with the severe disabling fatigue and incapacity caused by ME. She chaired the York and District ME Support Group for 3 years, and set up a newsletter and friendship network which now links people with ME & Chronic Fatigue Syndrome across North Yorkshire. She was also a Director and volunteer at the Disability Information and Advice Centre in York (DIAC) and is a member of York Chamber of Commerce. She is also a qualified Practitioner of Reflexology based in York. She is a member of the British Institute of Hypnotherapists and a telephone coach for students studying at the European College of Holistic Medicine. Jenny has developed an interest in how her skills can help people with ME/CFS, and has been interested in combinations of the concepts from Neuro Linguistic Programming, Hypnotherapy, Life Coaching and Osteopathy, and attributes her own return to better health to these techniques.

Jenny told us about the placebo effect. This is the effect where a dummy treatment or drug is given to a patient without their knowledge. In many cases, a positive clinical response follows. Why it happens may be the patients own positive thoughts, experience, belief and the ability of the body to heal itself. It is a powerful technique. In one fertility clinic, it resulted in 25% couples referred becoming pregnant. A double blind placebo-controlled trial of a knee operation indicated that the treatment was no better than a placebo, and the technique was abandoned. All new drugs are given placebo-controlled double blind trials. I used to give people a small blue antihistamine the night before a driving test, and a large smarty like red aspirin to be taken one hour before the test, but with no guarantees. The antihistamine may have given good nights sleep due to its sedative effect, but the dose of aspirin was not enough to do anything. However most people believed it and it became popular.

There is a biological mechanism known as the stress response, mediated through the HPA axis, which readies the body's escape from an enemy, the 'fight or flight response'. Blood is diverted from internal organs to the muscles, and adrenalin is pumped into the blood to raise blood sugar ready for action it also causes immune system suppression. In ME/CFS, this response is blunted, the body ramps up the alert level because of the disease process and very often the leads to a vicious cycle of continued unnecessary stress and consequent anxiety.

When treating stress and anxiety, doctors tend to favour drugs, or CBT. However, it is possible for a person to be trained to overcome anxiety and fear, and move forward. I required a training instructor to help me to find new thought pathways. Removing the stress will allow the body's own recovery mechanism to work. Jenny told us that the technique she uses produces a short term favourable result in 90% if cases, and abut 75% in the long term. Typically she charges about £46 per hour for 12 hours training about the same as most local therapists.
For further information Contact: Jenny Gilmore on 01904 655911, or visit: generatingchange.org—*Mike*



Cycle of illness and stress

Product Data Sheet:

Name of Product: The Lightning Process.
Product type: Proprietary combination of face to face with therapist training program that combines concepts from Neuro Linguistic Programming, Hypnotherapy, Life Coaching and Osteopathy.
Indications: Low self esteem, self-doubt and even self-hatred, fear of failure, guilt anxiety & panic attacks, stress & struggle, depression, overwhelmedness, M.E. (Myalgic Encephalitis)/ Chronic Fatigue Syndrome, Obsessive Compulsive Disorder, IBS, addiction, smoking procrastination, insomnia, stage fright
Method of administration: A 3-day training program individually or in groups.
Day one: Exploration of objectives. Knowing your problem. Introduction to techniques.
Day two: Training and practice in techniques.
Day three: Putting things into practice.
1 week: Follow up, by phone or face to face with additional sessions as needed.
Contraindications: If the candidates are doubtful, cynical or just curious.
Special warnings and precautions: To be accepted for training, candidates must agree to commit themselves, understand the programme, accept full responsibility for the effects of applying or not applying this training, recognise that the mind and body can powerfully influence each other, be prepared to look at and challenge their beliefs about the my condition/illness, health, and themselves and be totally prepared to do the sometimes-challenging work of starting to think very differently that's required to get themselves back on track.
Quality control: Therapists must be licensed to practise, subject to training, the register's code of conduct and continual professional development by Phil Parker, The Lightning Process trademark holder. No information is available about Interactions, undesirable effects or clinical trials.

The Lightning Process. The light at the end of the tunnel, or just another flash in the pan?

Extracts from Action for ME's Feature 32 in InterAction (IA) 59 of March 2007.

The feature starts with the caption: *The Lightning Process (LP) attracted national press coverage but alongside the hype and talk of miraculous recovery, InterAction received reports of relapse and failure and decided to find out more.* In their usual style, IA went and asked the people. I myself was contacted by researchers from IA, but having no experience of the LP I could not help. In the feature they quote about one and a half dozen cases, anonymised, of which two were men. There are only four favourable outcomes reported, the rest being unfavourable. If this level is projected, it would suggest a success rate of just fewer than 30%.

The latter part of the feature carries a heading *What do medics think?* They quote Dr Neil Abbot, ME Research UK, that of three studies which have measured adrenalin levels directly, one found levels significantly increased, while the other two found no difference, which is unfavourable to the adrenalin stress model. Dr Hazel O Dowd, Consultant Clinical Psychologist and Clinical Champion for CFS/ME is quoted as being concerned that they do not select on the basis of how problematic adrenalin-driven symptomotology is (i.e. how much of a problem anxiety and its correlates are) but on how committed and motivated people are, which she thought was insulting. Professor L J Findley, Essex Neurosciences Unit, is undertaking a clinical study into the process. He says: '*The theory of the Lightning Process would, at first sight, seem reasonable, but as yet we do not know. Until there is more knowledge and proper guidelines can be developed, individuals practising in this form of training/therapy should keep carefully logged follow-ups of all patients treated. I also think it would be wise if all patients were referred through a medical specialist in M.E./CFS.* Personally I endorse this view. The feature concludes *'Whilst there are some individuals who seem to make remarkable improvements, sadly we have always found that such cases are few in number'.* You can see the feature for yourself on: http://www.afme.org.uk/res/img/resources/IA 59 lightning process.pdf—*Mike*

Recipe Corner: *Two recipes or Christmas from Carolyn.*

Christmas Apple and Cranberry Muffins

Ingredients:

2 cups all-purpose flour
½ cup sugar
1 teaspoon baking soda
1 teaspoon ground cinnamon
½ teaspoon salt
1 egg (lightly beaten)
1/3 cup vegetable oil
1 cup unsweetened applesauce
1 cup fresh or frozen cranberries, chopped into smaller pieces
½ cup pecans chopped

Directions:

Preheat oven to 250F (180C, Gas Mark 4) and lightly grease the muffin tin.

In a large bowl mix together the flour, sugar, baking soda, salt and cinnamon.

In a separate bowl mix the eggs, applesauce and oil.

Add the applesauce mixture to the dry ingredients and mix together gently (do not over mix).

Gently fold in the cranberries and scoop the mixture into the muffin cups until 2/3 full.

Bake for approximately 30 minutes.

Cool for 5 minutes before removing from the muffin tin.

"Mulled Wine"

Firstly a tip about Mulled Wine because the great thing about this drink is that you can keep adding to it. If unexpected guests arrive and you've very little wine left, simply add some more water and fruit. Use the recipe below as a basic guideline, adjusting the quantities of wine if you want it stronger, and adding more sugar or honey if you like it sweeter.

Ingredients
(Serves 12)
2 x 75cl bottles medium to full-bodied red wine (Bulgarian Cabernet Sauvignon is ideal)
1 orange stuck with cloves
2 oranges, sliced
2 lemons, sliced
6 level tablespoons granulated sugar or honey
2 inch (5cm) piece cinnamon stick
2 level teaspoons finely grated fresh root ginger or ground ginger
2 tablespoons fruit liqueur such as Cointreau, Grand Marnier or Cherry Brandy (optional)

Method:
Put all the ingredients in a saucepan with 2 ½ pints (1.5litres) water, then heat to simmering point, stirring until all the sugar has dissolved. Keep it barely at simmering point for at least 20 minutes – but do not boil or all the alcohol will evaporate. **You can make it in advance, then re-heat just before the party. Serve it in warm half-pint mugs (in which case there will be 12 servings) or else in 24 sturdy wine glasses

Friends *by Beth Llewellyn*

Friends, they often tend to come and go
But the true ones you tend to know.
They grow up with you and stay close by,
They're there to see the low times and the high.

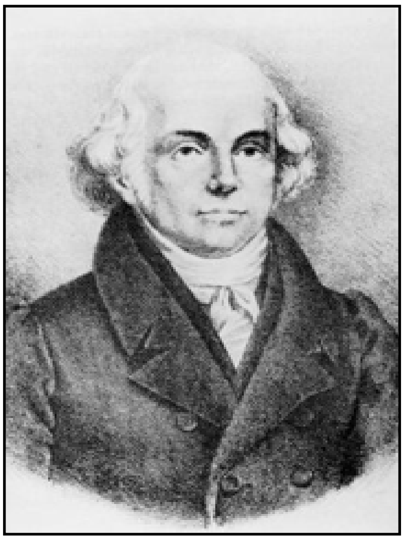
They'll hold your hand through break-ups,
Hug you, eyes not looking up.
Smile in the good times,
And cry when they read between the lines.

They phone you up with the gossip,
Bring the wine and the chocolate.
Tell you their problems and woes.
While you return the favour.
And stop them feeling low.

You've known them years or maybe months,
But at the club you grind and bump.
Eye the boys, share the clothes.
Best friend's secrets nobody knows!!

Further poems from Beth can be accessed on www.somepoetry.me.uk

ME & Homeopathy or 'Summat 'bout Next t' Nowt ?'



Samuel Hahnemann, considered to be the father of homeopathy

Samuel Hahnemann conceived of homeopathy while translating a medical text into German. He was sceptical of the explanation of cinchona bark's mechanism of action in treating malaria, so he decided to test its effects by taking it himself. Upon ingesting the bark, he experienced fever, shivering and joint pain, and symptoms similar to those of malaria, which the bark was ordinarily used to treat. From this, Hahnemann came to believe that all effective drugs produce symptoms in healthy individuals similar to those of the diseases that they are intended to treat. This later became known as the "law of similars", the most important concept of homeopathy. The term "homeopathy" was coined by Hahnemann and first appeared in print in 1807, although he began outlining his theories of "medical similars" in a series of articles and monographs in 1796.

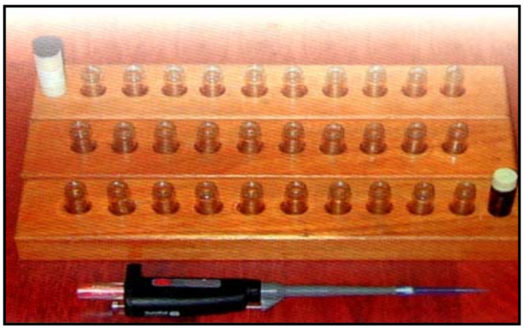
Today, Homeopathy is a safe and effective form of medicine which treats the individual rather than just the disease. It recognises that physical, mental and emotional symptoms of disease are the body's way of expressing internal disharmony. Homeopathy seeks to assist the body's own healing process to cure the cause of the disease rather than suppressing or palliating the symptoms. Homeopathy is a therapeutic system using very low dose preparations selected according to the principle that like should be cured with like. In other words, substances used to treat the condition produce in a healthy person the same symptoms and clinical signs experienced by the ill person. For example, the homeopathic remedy Allium cepa is derived from the common onion. Onions typically cause lacrimation (tears), clear nasal discharge and irritation of the eyes and nose and Allium cepa may be prescribed to patients with hay fever, particularly if both the nose and eyes are affected. A further assumption in homeopathy is that homeopathic remedies become therapeutically stronger rather than weaker when submitted to potentisation; a process that involves stepwise dilution combined with succession (vigorous shaking of the mixture). The remedies are believed to be clinically effective even if they are so dilute that they are unlikely to contain a single molecule of the substance. In summary it is based on the two principles. Firstly the 'Law of Similars' (like cures like) and secondly, the 'Law of cure or direction of cure' (Hering's Law). Symptoms will go in the reverse order of their appearance, from more to less important organs, from within outwards and from above downwards.

Homeopathic remedies are made from plants, metals, chemicals, zoological material, etc and are available in different potencies (dilutions). The remedies are made by taking the original substance then diluting and succussing it a certain number of times. When you see the potency 6c (or sometimes just '6') it means that the substance was diluted 1:100, for 6 times; 6x (or D6) means it was diluted 1:10, for 6 times.

Homeopathy is used to treat a wide range of acute and chronic physical and emotional illness. Homeopaths do not usually use conventional disease categories and often treat people with benign, chronic conditions. Where a condition is beyond the scope of the body's normal self-repair mechanism, treatment is less likely to be curative, but may be palliative. There is some evidence for the overall effectiveness of homeopathy. Specific conditions where there is moderate evidence for effectiveness are those with an allergic component (e.g. asthma, hay fever, and rhinitis) and also influenza. There may be an initial exacerbation of symptoms for a short period of time (which gives the homeopath a positive sign that they have given the correct remedy). A homeopathic remedy should be stopped once the original symptoms are gone or if they change to such a degree that the remedy no longer covers them. If a remedy is continued when it is no longer indicated for the particular symptoms then new symptoms will be produced (homeopaths call this a 'proving') until the remedy is stopped, at which point the new symptoms will disappear causing no long-term effects. (This information is particularly relevant if remedies are sold ‘Over The Counter’ without the patient seeing a practitioner, as the patient will not necessarily know when to stop taking the remedy. Homeopathic remedies can be used in life-threatening conditions, but ideally as a complementary therapy following communication between the GP and the homeopath. It is generally recommended that remedies should not be exposed to bright light or other radiation, although there is no firm evidence for this. There are no drugs interactions with conventional drugs, so homeopathic treatment can safely be used alongside conventional treatment. A reduction in the need for conventional drugs is sometimes seen when homeopathy is used as a complementary therapy, resulting in a quicker period of recovery. Some homeopaths think that homeopathic remedies do not usually work as effectively when used alongside steroids. Strong essential oils (aromatherapy) can act as an antidote to homeopathic remedies and it is believed by many homeopaths that strong flavours, such as coffee and peppermint, can also antagonise their treatment.

Did you know that

- *HM The Queen swears by homeopathy, and even uses it for her sick horses.*
- *Homeopathy is one of the biggest growth industries in the world, worth more than £1billion a year in Britain alone.*



Equipment use to prepare a series of homeopathic dilutions

A few years ago I tried a package of over the counter homeopathic remedies in my Pharmacy. Generally my scepticisms were proven until my customers started coming back asking for a hay fever remedy based on potassium carbonate. As my experience of homeopathy is limited, I grabbed the opportunity when Dr. Elaine Weatherley-Jones, (PhD C.Psychol RSHom Honorary Senior Research Fellow in Complementary and Alternative Medicine University of Sheffield UK) offered to visit the Redmond Centre. She featured on the Radio 4 *You and Yours* series on M.E. on the 7th November - Alternative treatments for M.E. On the of 14th November we had a very deep and meaningful meeting. As some of the issues discussed are at a personal level, I can’t really print them here. However she has forwarded the following information for Pathways about some clinical trials in which she has been involved:

There is no management regime for Chronic Fatigue Syndrome (CFS/ME) that has been found to be universally beneficial and no treatment can be considered a "cure". Patients with CFS/ME may use complementary and alternative medicine (CAM). Our aim was to evaluate homeopathic treatment in reducing symptoms of CFS/ME. Using a gold standard design (patient and homeopath blind to group assignment and data analyst blind to group until after initial analyses to reduce the possibility of bias due to data analyst), we randomly assigned patients to homeopathic medicine or identical placebo.

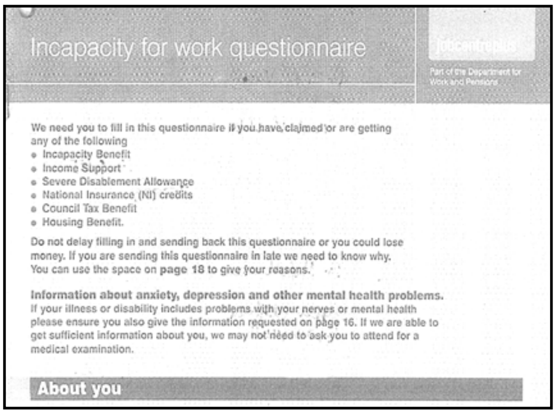
One hundred and three patients with CFS/ME were recruited from two specialist hospital out patient departments (Sheffield s Royal Hallamshire Hospital and the Seacroft Hospital, Leeds). Patients had monthly consultations with a professional homeopath for 6 months. Ninety-two patients completed treatment in the trial (47 homeopathic treatment, 45 placebo). Eighty-six patients returned fully or partially completed post-treatment outcome measures (41 homeopathic treatment group who completed treatment, 2 homeopathic treatment group who did not complete treatment, 38 placebo group who completed treatment, and 5 placebo group who did not complete treatment).

Patients in the homeopathic medicine group showed significantly more improvement on a measure of general fatigue and a measure of physical limitations scale. More people who had the genuine homeopathic medicine showed clinically significant improvement. This study has shown that there is some evidence that the effects of homeopathic medicine are not just due to placebo. Results also suggest that there may be benefits from the homeopathic consultation. Further studies are needed to confirm these results.

Avoiding the Pitfalls and Traps in IB50 Form

CAUTION:

UNDER NO CIRCUMSTANCES FILL OUT THIS FORM WITHOUT CONSULTING A WELFARE RIGHTS ADVISOR



Incapacity for work questionnaire

Part of the Department for Work and Pensions

We need you to fill in this questionnaire if you have claimed or are getting any of the following

- Incapacity Benefit
- Income Support
- Severe Disablement Allowance
- National Insurance (NI) credits
- Council Tax Benefit
- Housing Benefit.

Do not delay filling in and sending back this questionnaire or you could lose money. If you are sending this questionnaire in late we need to know why. You can use the space on **page 18** to give your reasons.

Information about anxiety, depression and other mental health problems.
If your illness or disability includes problems with your nerves or mental health please ensure you also give the information requested on page 16. If we are able to get sufficient information about you, we may not need to ask you to attend for a medical examination.

About you

After being unfit for work for 28 weeks, or before, most people will be sent a form IB50 to assess their capacity for work. This is part of the Personal Capability Assessment (PCA), used to assess the extent to which your condition affects your ability to perform a range of activities. The DWP is quite draconian, and says that the form must be completed within one month, and threatens that Incapacity Benefit will then stop and/or your Income Support may be reduced.

The form is mainly intended to ask about the effects of any physical disabilities or health problems you may have, and also asks about mental health problems. The questionnaire asks you to fill the boxes that most closely match how difficult you find it to perform certain activities. Under each of these activities is a list of related tasks of varying degrees of difficulty. These tasks are called descriptors. A points system is used by the DWP to determine whether you pass the test. Each descriptor is allowed a fixed number of points, ranging from 0 to 15, (the number of points allocated are not shown on the form). To pass the test you need to score 10 or 15 points depending on whether you are suffering from a physical or mental disability.
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.

Several years ago I produced a leaflet which was intended to help fill out the forms. This can be accessed from the group helpline (01302 787353) or website www.leger.me.uk . Before you fill in the questionnaire we suggested photocopying the form, and using this to draft and record to your answers. There are fourteen questions you are asked to tick a box, and then give a short written explanation for your answer. Because some members have previously given their best day answers and been refused benefit, we advise to answer according to your worst day. All answers must also be considered from the work related health and safety context. Any activity which causes pain, a rebound or other adverse affect should be regarded as 'not able to'. For the Mental Health Questions, we supply a list of things to consider when writing a dialogue mentioning the point that apply. There is also a blank page for other information which we suggest you use to say something to the effect that activity brings on fatigue. There is no cure, you are frustrated, can't do what you used to do etc. If you have previously filled out an IB50 form you may want to say something about what has happened since your last PCA.

After you have completed and had it checked by an advisor, get the form photocopied and posted. It may be several months before you hear from the DWP. There are two main outcomes, either a letter confirming the award or you are requested to attend a medical examination, which is the most common outcome for our members. If you have scored less than 15 points, the purpose of the medical is to ensure you are fit for work before being refused benefit. If you score more, it is to check that you are telling the truth and adjust the score. The assessment is typed into a computer terminal by the doctor directly, and from then on everything is automatic. If the award is granted, that is fine, but, if not, benefits stop at the day of examination, and very often you don't know about it until several days later. Also the letter sent out does not give a clear result. The actual result is usually halfway down the 2nd page. The two main reasons for refusal are the DWP doctor didn't believe you, or, more often a complete misinterpretation of the form, which is usually made by intelligent honest people not aware of the pitfalls of the system.

Jobcentre Plus Advice

We strongly recommend that you do not totally rely on Jobcentre advice.

Jobcentre Plus Advice	**Problem with ME**	**Fix**
Be honest about the extent of your disability/ill health. You should not exaggerate, but neither should you underestimate your problems.	Claimants are not medical experts, and reality is that many overestimate their abilities, and don’t report incidental problems like IBS, continence Issues and mental health issues.	Report everything, even if it is not causing trouble. A confident welfare rights advisor will be able to assist in indentifying the issues. See an independent advisor.
The test takes into account your abilities when using any aid or appliance you would normally use, e.g. glasses, walking stick.	Bear in mind that glasses, hearing aids and stick are used for a reason. Very often the fact you use some aid or other one implies a problem.	If you use a trolley, wheelchair or even an automatic car say so. Eyesight and hearing problems get you points. If in doubt, put it down.
Answer questions in terms of your ability to do them in the course of a normal day. For example, if you can only bend down once and not repeatedly this does not mean you can do the activity.	With ME/CFS, you can very often do things e.g. walking. It’s what happens after that is the problems. like rebound, or relapse.	If you suffer a rebound after doing anything, it means you can’t do it safely, and would no be expect to do this in a work environment.
If an activity is of risk to your health, enough to put a reasonable person off doing it, it may be as if you cannot perform that activity.	Anything that causes a relapse/rebound or a danger should be reported. e.g. walking beyond the limit.	Make it clear about the dangers of doing such things and risks related to rebound or relapse.
If a doctor has told you to avoid certain activities including work, make this clear.	Doctors do not generally understand ME/CFS and are very surprised at what some patients say who they have known for years.	Make it clear what you avoid and why. Typical examples are busy street, driving or places with fumes.
If a particular task gives you pain or discomfort, all information needs to be given about this.	If pain and discomfort usually come later, maybe several days after the event.	Make is clear about rebound (relapse) and the consequences.
Complete the form as if it is a bad day, but state that your condition is sometimes not as bad as this. Estimate how often you could perform an activity and how often you could not. Give any extra relevant information in the additional space	If you fill in the form for a range of days, they will take you best day as standard and ignore the rest of bad days.	Always fill in the form as if it was your worst day or worst time of day. It is up to the DWP to prove otherwise.
Give details about mental health problems in the space for additional information and describe how it affects your daily life.	The section on the form is blank square, and no guidance is given. Many ME are in denial about mental health issues, and are not sure what then should say.	Most of the effects of fatigue are in the mental health section. You need to know what to say. Your welfare rights advisor will give you the necessary guidance.

Examples of Pitfalls, Interpretation and Fixes.

Walking on level ground. The options to choose are:

	Descriptors	***Points***
A)	*Cannot walk at all*	*15*
B)	*Cannot walk for more than a few steps without stopping or severe discomfort*	*15*
C)	*Cannot walk more than 50 metres without stopping or severe discomfort*	*15*
D)	*Cannot walk for more than 200 metres without stopping or severe discomfort*	*7*
E)	*Cannot walk more than 400 metres without stopping or severe discomfort*	*3*
F)	*Cannot walk more than 800 metres without stopping or severe discomfort*	*0*
G)	*No walking problem*	*0*

Someone naive about ME/CFS will select option (G) because walking is usually not an issue, but this would result in this section and the text being ignored. Most of the people we surveyed would select 50 metres or 200 metres. The is because walking would could cause pain, tremor, drowsiness or a rebound which would be explained in the corresponding text area.

Vision in normal daylight or bright electric light: The options to choose are:

	Descriptors	***Points***
A)	*Cannot tell light from dark 15*	*15*
B)	*Cannot see the shape of furniture in the room 15*	*15*
C)	*Cannot see well enough to read 16 point print at a distance greater that 20cm*	*15*
D)	*Cannot see well enough to recognise a friend across the room*	*12*
E)	*Cannot see well enough to recognise a friend across the road*	*8*
F)	*No problem with vision*	*0*

The immediate temptation that with ME/CFS will select option (F), because vision is usually not an issue on first consideration, but this would again result in this section and the text being ignored. The considered option would be *Cannot see well enough to read 16 point print at a distance greater that 20cm.* The relaxed eye is set to focus at distance. In order to see close up, the cillary muscles in the lens at work in the eye squash the lens from a rugby ball section to a round football section to focus. These muscles can fatigue, losing the ability to focus after a time. This applies to most people with ME/CFS, particularly in dull light. Glasses don't help to stop the blurring. Photophobia (dislike of bright light and headache or migraine (flashing, streamers etc) are the other issues. This would be explained in the corresponding test area. The only requirement for a normal driving licence is distance vision, not close up vision. The DLVC do not list ME/CFS as a notifiable condition to stop people driving.

Mental Health. The mental health descriptors are not listed on the form, but in a separate leaflet which is not sent with the form. One is **'***Is scared or anxious that work would bring back or worsen illness''.* So just by including something like.. *"I am concerned that a return to work would make my illness worse or permanent."* you will get around his problem, and the point.

The IB50 is based on what you can't do, and has been criticised by many people and mal administration has resulted in many unnecessary tribunals. In the pipeline is a replacement form of 25 questions based on what you can do. I have seen a consultation paper, with 25 questions with 4 answer options. Many need wide interpretation to apply to ME/CFS. It is expected that the new form will apply from late 2008. Meanwhile many welfare rights organisations have expressed their concern. The only advice I can give for the new form is:
CAUTION: UNDER NO CIRCUMSTANCES FILL OUT THIS FORM WITHOUT CONSULTING A WELFARE RIGTHS ADVISOR.—*Mike.*

North of Doncaster *Personal comment about the ME political scene by Trevor Wainwright*

Fighting for the Truth. My column this issue is dedicated to the events of 10 years ago when a small group of people decided they had had enough of psychiatric bias and disbelief. Paul Humm and Paddy More got together to form ForT (Fighting for the Truth) to challenging psychiatric bias and prejudice where the diagnosis, treatment and research of ME is concerned; and campaign to get proper research into ME: epidemiology; aetiology and pathogenesis. In June they circulated a Petition with the following wording: *“We, the undersigned, ask that that Royal Colleges' Report on CFS (CR 54), 1996, be rejected and withdrawn from circulation forthwith.”* Lancet had described the Report as ‘haphazardly set up, biased, and inconclusive, and of little help to patients or their physicians’. Or as the Department of Health weakly put it: “The report will provide a further contribution to the ongoing debate”. Meanwhile, patients suffer, benefits are withdrawn, and at least one person with ME takes his or her life each month. ME persons need help now.

The Petition signed by 12,502 people was presented outside the House of Lords on 26 November 1997, to Lady Mar one of the chief supporters and herself a sufferer of OP Poisoning. Lady Mar in turn presented it to Lady Jay in The House of Lords Chamber that afternoon. So, one would have thought that such an event would have galvanised the main groups into action; far from it. The MEA condemned the Petition in September 1997 and threatened ForT with legal action. The Medical Advisor to AfME wrote to ForT in August saying he considered the petition to be counter-productive, an attitude that would last into the 21st century. After the event The MEA recognised the event (Perspectives 66) and wanted to work with us. AfME thanked ForT for its efforts with a double page spread in InterAction 25 complete with picture with yours truly on it with his banner. So, AfME then was thanking ME patients for challenging the work of Simon Wessely and Michael Sharpe - CR 54 contains 27 references to Wessely, 14 to Sharpe, many of them about GE/CBT and 'Functional Somatic Syndrome'. Now AfME is working directly with Wessely and Sharp, promoting GE/CBT.

Of the prominent doctors with ME, Anne McIntyre was in favour of the Petition, reiterating what I said about it at a talk in Huddersfield in October 1997. Later she went on to endorse it as the staring point which led to the formation of both the CMO’s Working Group and the All Party Parliamentary Group on ME, and said so in the MEA’s *Perspectives* too. Unlike Clare Francis (AfME) who, in a somewhat whiney begging letter, tried to claim the credit for the two groups set up for AfME. So what was my role in it all, having heard about it during a search for a research project to rise funding for? Simply that of a foot soldier collecting signatures in my home town of Castleford and at Huddersfield where I gave a brief impromptu talk about it; Anne’s train was late. I was there to see it presented and be part of the lobby at the House of Lords. How many signatures were from Castleford is not known but we were lumped in with Leeds as the second-placed area for signatures. Scotland won that time. Later though, Castleford would stand on its own at both organising petitions and supporting them, particularly the RiME (formerly ForT) Petition of 2002. Castleford would be the top area, and again in 2004, when working with the newly revamped MEA, and it’s new leadership. When compared to what it took AfME to do in 12 Months for their 1% Petition we did in 6 weeks with more signatures - in short we whupped ‘em good. But despite the events of 10 years ago, the ME Community must ask itself what progress has been made since. What has it done to build on the event of 1997, and those that followed? And answer honestly. For further reading on the ForT Petition log onto http://erythos.com/RiME/Index scroll down and click on the ForT page.

The OneClickGroup. A legal battle is being launched to force the Government's health watchdog to stop defining so-called ME/CFS as a mental illness. Campaigners claim official treatment advice on ME, which affects about a quarter of a million people in Britain, implies the condition is "all in the mind", despite numerous studies which say otherwise. The National Institute for Health and Clinical Excellence (NICE) told doctors in August that they should prescribe psychological therapy and "graded exercise" for sufferers of ME, also known as Chronic Fatigue Syndrome. In what is believed to be the first legal action against NICE over health guidance, the One Click Group, a pressure group with 8,000 members, is taking the watchdog to the High Court in a bid to make it rewrite its policy. However, a similar legal action by another pressure group representing less controversial conditions viz. Alzheimer’s has been unsuccessful.