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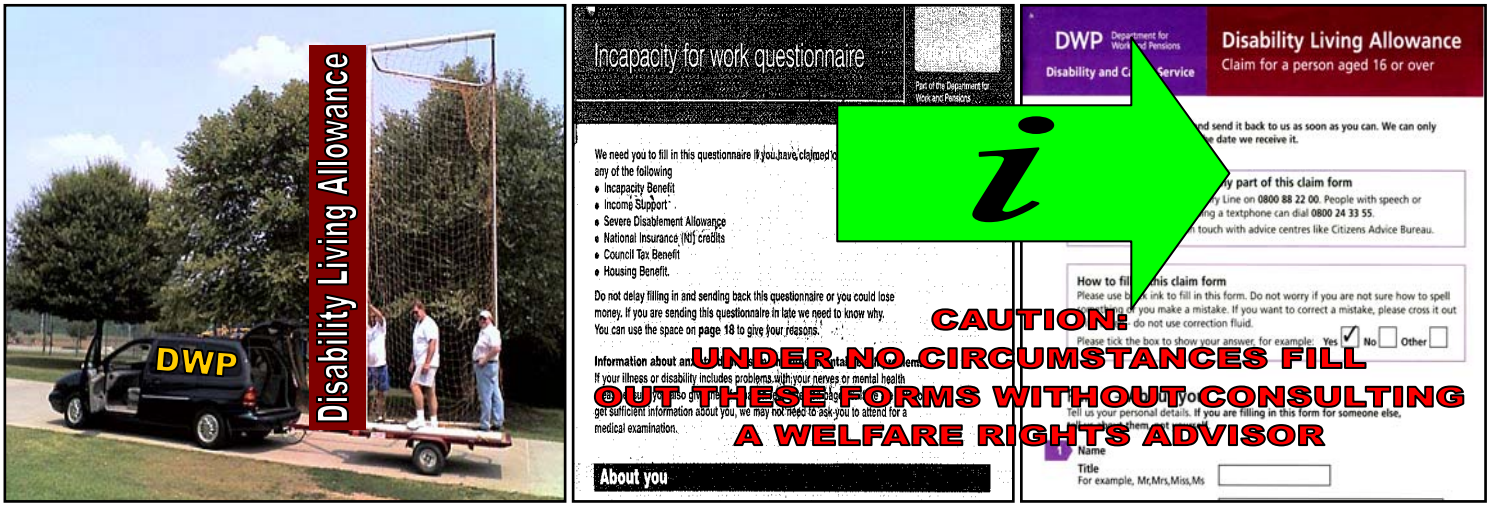
Pathways

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.

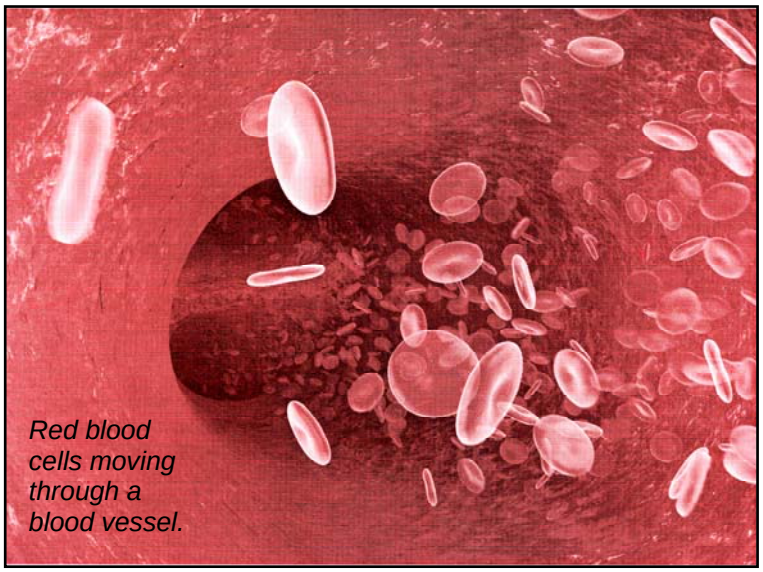


Department of Works and Pensions Link Personal Capability Assessment to Disability Living Allowance Forms.

Did you know the DWP can look up IB50 medical examination results and refuse a DLA application on this basis without consulting a doctor? *See page 11*. DLA is a very contentious state benefit, where ME/CFS is concerned, the eligibility criteria are not directly embedded within the regulations, but rely on the Commissioners (House of Lords) decisions. We have invited Sandra, a member of the DWP staff public relations team to our meeting on 18th April at the Redmond Centre, so you can ask her yourself.

Blood Vessel Stiffness and Inflammation in ME/CFS.

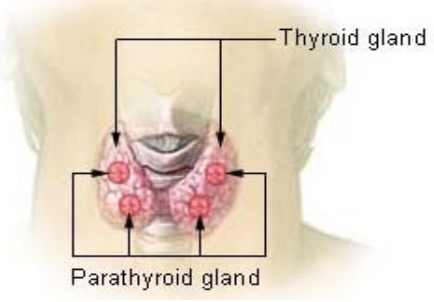
An important characteristic of blood vessels is the flexibility of their walls. This affects how each pulse of blood from the heart is transmitted through the cardiovascular system from the larger to the smaller arteries, and ultimately to the capillaries and back to the heart via the veins. Stiff arteries have been linked to high blood pressure, kidney problems and heart disease, and, surprisingly, may also contribute to the orthostatic hypotension experienced by some ME/CFS patients. *See the page 12.*



Red blood cells moving through a blood vessel.

Thyroid Issues and ME

The blue butterfly is adopted as a logo by many thyroid organisations worldwide. The thyroid is a butterfly shaped organ in the neck. This organ has been implicated with ME/CFS, but the issues are not clear cut. *More on page 6*



You Write

Isobel writes: *Here is a feature from the Sidney Morning Herald, April 12th, 2007 (Australia) which may be of interest to Pathways readers.*

Victims give clues to the answers

The development of an autopsy protocol may help unlock some of the mysteries of chronic fatigue syndrome, writes Julie Robotham. UNDER the microscope, it could not have been clearer. Sophia Mirza's brain and spinal fluid showed indisputable evidence of inflammation and cell death. The discovery, by the neurologist Abhijit Chaudhuri and a neuropathologist colleague, marked the first time a serious abnormality confined to the central nervous system had been identified at the post-mortem examination of a patient whose principal diagnosis was chronic fatigue syndrome.

In turn, that ensured the 32-year-old became the first person in Britain to have the syndrome - also known as myalgic encephalomyelitis, recorded as the cause of her death. In Adelaide last month, Chaudhuri and specialists from all over the world took the first steps towards developing an autopsy protocol that would allow samples to be consistently collected and analysed from the bodies of people who die, like Mirza, after a long battle with the syndrome. These would form the basis of an international tissue bank in an attempt to shed light on what goes wrong in the baffling condition, which often strikes young and previously healthy individuals. It could help "establish the condition as a valid neurological problem", Chaudhuri says, and might lead to treatments.

Chaudhuri, a consultant neurologist from the Essex Centre for Neurological Sciences, says the protocol is intended to allow non-specialist pathologists to collect and preserve samples, which could then be examined by a neuropathologist. The move comes amid concern that brain and spinal cord tissues which might shed light on the disorder are being lost because pathologists do not appreciate their significance. In Mirza's case, and in another autopsy on a young British man, "there was no way [their illness] could be explained by a primary psychiatric condition", Chaudhuri says, referring to a widespread assumption that the condition - which typically begins after a viral illness and is estimated to affect up to 140,000 Australians - is related to mental stress.

Daniel Peterson, an American physician who specialises in chronic fatigue syndrome, says its name has allowed it to be trivialised. "These are very complex patients to understand," he says. "We've been held back by biases." Peterson, who is establishing a research centre at the University of Nevada, says he is most interested in forms of the condition that arise after recognised infections, which seem to trigger immune disturbances. The specialists' meeting in Adelaide was organised by Christine Hunter, via the Alison Hunter Memorial Foundation, which Hunter formed after the death a decade ago of her teenage daughter, who had chronic fatigue syndrome. As the protocol is formalised, the group will seek endorsement from experts around the world, she says, to accelerate its acceptance by the wider medical community

.

Elizabeth Salisbury, a senior staff specialist in tissue pathology at Royal North Shore Hospital, says formal guidelines would encourage those conducting autopsies to retain appropriate tissues for later genetic, antibody or biochemical testing. "One of the difficulties with a disease like CFS is [it] is very much an emerging science," says Salisbury, who is not involved in the protocol's development. "We don't necessarily understand all the pathological changes that account for the signs and symptoms." Salisbury says families of patients who die after having chronic fatigue syndrome or other complex; elusive disorders usually support tissue removal. "They really do want the answers," she says. Colin Neathercoat, a director of the advocacy group ME/CFS Australia, says the cost of supporting patients with long-term disability from the syndrome is enormous, and more funding is needed for research into its origins and possible treatments. "We would desperately like to see government engage in this growing problem and recognise its impact on the Australian economy, let alone its impact on sufferers," he says.

The Sophia Mirza case is widely known in ME/CFS circles. The medical cause of death was recorded as:

1a) Acute aneuric renal failure due to dehydration
b) CFS
2) Previous history of meningitis, dorsal root ganglionitis (*inflammation*) and hepatic steatosis *(fatty liver a normal finding in many other diseases).*

The Inquest took place on 13th June 2006, at Brighton Coroner's Court. They decided that Sophia died as a result of acute renal failure arising as a result of Chronic Fatigue Syndrome.

The aneuric renal failure, (the inability to produce urine) due to dehydration arising as a result of CFS'. It was also stated that some dorsal root ganglions where inflamed. Water in the body is under the control of the pituitary gland which is in turn under neurological control from the hypothalamus. Many of the pressure groups have used this case as fodder to support the **'physical not mental'** or '**real not psychiatric'** argument of ME/CFS. The lesson from this case is that ME/CFS can be fatal in the right circumstances, but I believe that this is a rare case. Over the past 16 years a number of group members have died, the causes being cancer, heart attack, stroke, suicide and accidents, which are the same as in the general population. Otherwise, it looks like Oz has the same sort of problems as us Poms with ME/CFS do. —*Mike*

Jenny writes: *Thank you for putting together a piece for your newsletter, which as always was written with lots of thought - I especially liked your references to placebo and driving tests. I would like to clarify that the Lightning Process views ME as a physical disorder, which happens as an inevitable result of unconscious neurological pathways set up often as a result of a viral infection failing to resolve (see example in the Introduction to the Lightning Process book). The patterns are very typical and consistent in people with ME. They would often not be recognised by individuals in terms of anxiety or stress. They are not recognised/addressed successfully by CBT, which as we know is often very beneficial in managing the condition but does not produce the dramatic shifts over short time scales often witnessed with the Lightning Process. Also I would like to clarify that Lightning Process is not simply a placebo affect - placebos show the phenomenal power that our minds can have over our bodies. This is illustrated by the higher than placebo effect results that are being obtained by practitioners. This is not reflected in the Action for ME article for some reason. There is a pilot study being overseen by Prof Findley that should be out fairly soon that will show a far greater improvement than that implied by AfME, and is more a reflection of what I have witnessed as a student and practitioner of the Lightning Process. The changes I have seen over 24 hours in some people are remarkable. Something I would have never thought possible.*

Ann Writes: *I know an 18-year-old girl whose ME began in her mid-teens, she became very debilitated after a while, and later embarked on the Lightning Process, came on in leaps and bounds (literally) and then faded - just took a nosedive and is now back in bed barely able to sit up! She lives in YWCA accommodation but doesn't have much company although she has carers and, of course, mums and friends visit/help if and when they can. The healthcare professionals dealing with her case are in the main on the ball. I'd be grateful for any views/ suggestions/advice/recommendations re these queries. Many thanks to you in advance.*

These two letters illustrate the two extremes of the Lightening Process outcome which I featured in Pathways 14. Jenny tried the treatment and found it so helpful for herself that she invested her own money and she trained as a LP therapist. Opposingly, Ann's friend appears not to have been helped, and it is possible that the LP may have caused her harm. As a health professional I am all too aware that any intervention (treatment), be it surgery, medicines, psychotherapy, alternative, herbal etc., will have its successes, failures, and adverse outcomes. The job of the health professional is to identify what strategy is most likely to be beneficial, ineffective or adverse, and act accordingly. No strategy is 100% safe. Very often hospital patients are told that there are risks with a general anaesthetic. With the skill of the health professionals, the risks can mostly be minimised to around 1:100,000, about the same level of risk as having an accident when crossing the road. I have recently come across two members who have been attending CBT sessions at the Leeds CFS Clinic. There is no doubt that the therapists have done their job and have helped these people and given them the confidence to deal with their illness, but at the same time have put them into a degree of denial about the real issues around ME/CFS. This can result in an issue was with Anne's friend, declining help they need, or not understanding or reporting their condition accurately or taking inappropriate action. One of the functions of Leger ME is to try and put these issues into context and help members reach a balanced view.—*Mike*.

Ashley Writes: *I have always doubted CBT. I thought this would be of interest which I have*

[Cognitive behaviour therapy for chronic fatigue syndrome from the patient's perspective] [Article in Dutch]- Source: Medisch Contact, Feb 2008 by MP Koolhass ImmuneSupport.com

Background: In recent years, Chronic Fatigue Syndrome, also known as Myalgic Encephalomyelitis (ME/CFS), has been getting a lot of attention in scientific literature. However its etiology remains unclear and it has yet to be clarified why some people are more prone to this condition than others. Furthermore, there is as yet no consensus about the treatment of ME/CFS. The different treatments can be subdivided into two groups, the pharmacological and the psychosocial therapies.

Most of the scientific articles on treatment emphasize the psychosocial approach. The most intensively studied psychological therapeutic intervention for ME/CFS is cognitive behaviour therapy (CBT). In recent years several publications on this subject have been published. These studies report that this intervention can lead to significant improvements in 30% to 70% of patients, though rarely include details of adverse effects.

This pilot study was undertaken to find out whether patients' experiences with this therapy confirm the stated percentages. Furthermore, we examined whether this therapy does influence the employment rates, and could possibly increase the number of patients receiving educational training, engaged in sports, maintaining social contacts and doing household tasks.

Method: By means of a questionnaire posted at various newsgroups on the Internet, the reported subjective experiences of 100 respondents who underwent this therapy were collected. These experiences were subsequently analysed.

Results: Only 2% of respondents reported that they considered themselves to be completely cured upon finishing the therapy. 30% reported 'an improvement' as a result of the therapy and the same percentage [30%] reported no change. 38% said the therapy had affected them adversely, the majority of them even reporting substantial deterioration. Participating in CBT proved to have little impact on the number of hours people were capable of maintaining social contacts or doing household tasks. A striking outcome is that the number of those respondents who were in paid employment or who were studying while taking part in CBT was adversely affected. The negative outcome in paid employment was statistically significant. CBT did, however, lead to an increase in the number of patients taking up sports.

A subgroup analysis showed that: Those patients who were involved in legal proceedings in order to obtain disability benefit while participating in CBT did not score worse than those who were not. Cases where a stated objective of the therapy was a complete cure did not have a better outcome. Moreover, the length of the therapy did not affect the results.

Conclusions: This pilot study, based on subjective experiences of ME/CFS sufferers, does not confirm the high success rates regularly claimed by research into the effectiveness of CBT for ME/CFS. Overall, CBT for ME/CFS does not improve patients' well-being. More patients report deterioration of their condition rather than improvement.
Our conclusion is that the claims in scientific publications about the effectiveness of this therapy, based on trials in strictly controlled settings within universities, has been overstated and are therefore misleading. The findings of a subgroup analysis also contradict reported findings from research in strictly regulated settings.

Source: Medisch Contact, February 2008, ISBN: 978-90-812658-1-2, by Koolhaas MP, de Boorder H, van Hoof E. The Netherlands http://www.immunesupport.com/library/showarticle.cfm?id=8724

I think that this is more reality, and along the lines I would expect to see. What is quite clear is that some degree of preselection is required to target those who could benefit most, before CBT can be offered. – *Mike*

Ross Writes: I have been trying The Master Cleanse Diets or the Lemon Ade Diets as described by Stanley Burroughs in his book. I have based mine on the Maple Syrup option, and cut out my prozac, food supplements and other medicines. I tried this for four weeks. Since then I have felt better, been able to do more and lost weight. Looking on the internet, there are many companies which support the scheme and many advocates. So what's wrong with it?

Send in a yellow card for the prozac. Most ME/CFS patients react adversely to SSRI type drugs, unless they have depression, and many have had a similar experience to you. If you went to a dietician they would say the Master Cleanse Diet is unbalanced and unsuitable in the long term. I have concerns about vitamin and nutrient depletion with such diets as they compound ME/CFS. If your are constipated, overweight, have high cholesterol or are diabetic, there may be some short terms benefit. Only fully balance diets are in the long term sustainable. A balance calorie restricted diet, targeted to give a minute weight loss help many people with ME/CFS –*Mike*.

People With ME: Jane Colby.

I first met Jane when she was working for Action for ME a number of years ago. We have had her on several visits to Doncaster ,and Jane has spoken at DRI. In her pre ME days she was a School Headmistress, and this has now translated into her being involved with the children with ME, and The Young ME Suffers (Tymes) Trust. What follows is a transcription of her letter to the Daily Mail on the 27/12/2007.

Don't just dismiss this link with ME and polio

Jane Colby: She believes that ME is related to polio

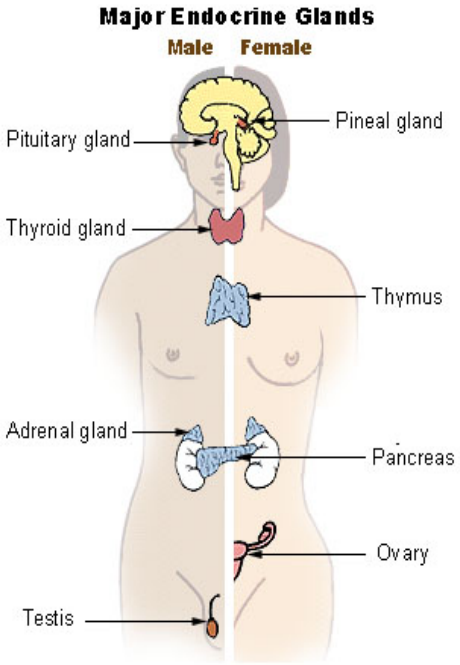
VICTORIA LAMBERT'S appreciation of poliomyelitis and post polio syndrome (Good Health) should have included the fact that ME and polio are almost certainly sister diseases, caused by the same family of viruses. Ten years ago, in my book "ME: The New Plague", I argued that ME was a persistent viral infection related to poliomyelitis. When my study of ME in schools was published in the Journal of Chronic Fatigue Syndrome, it hit the headlines because it revealed that ME was the biggest cause of long-term sickness in children and staff. On his TV show on the subject, Adam Bolton described. ME as "attacking school children now'. Some children are bedridden or in wheelchairs, others can't swallow and have to be fed by tube. Sounds familiar? It should do. Yet the British scientists lab. work that underpinned my work was generally dismissed. This tragically led to misunderstandings and even to the mistreatment of children and young people in the UK which still persists today. We now require proper science about the link between ME and polio, not the psychobabble we've had to put up with for the past ten years. We must stand up for these genuinely sick children. The reason no one believed ME was a persistent viral infection related to poliomyelitis is outlined at:
www.tymestrust.org/tymesmagazine.htm along with news of the latest developments.
JANE COLBY, Young ME Sufferers Trust, Stock, Essex.

The Human Factor: A preview of The Colby Report 2008, by Jane Colby, TYMES Trust.

No one to turn to early in 1996, the phone rang at the home of Mary, one of many local group volunteers throughout the country who have ME themselves and are willing to be a listening ear for others with the condition. When she answered, there was a silence, broken only by the sound of a child crying. This was particularly distressing because, without knowing the problem which triggered off the call for help, Mary was powerless to do anything about it. For some time she kept contact with the caller. At one point the girl tried to speak, but what followed were simply sobs which turned into a paroxysm of tears. Mary reassured her. Don't put the phone down, I will wait until you feel ready to speak. But in the end the receiver was replaced without any words being exchanged. Dialling 1471, Mary discovered that the source of the call was a nearby school. It was a sobering thought to realise that this child, surrounded by friends, teachers, welfare and class assistants, had no one to whom she could turn but a stranger.

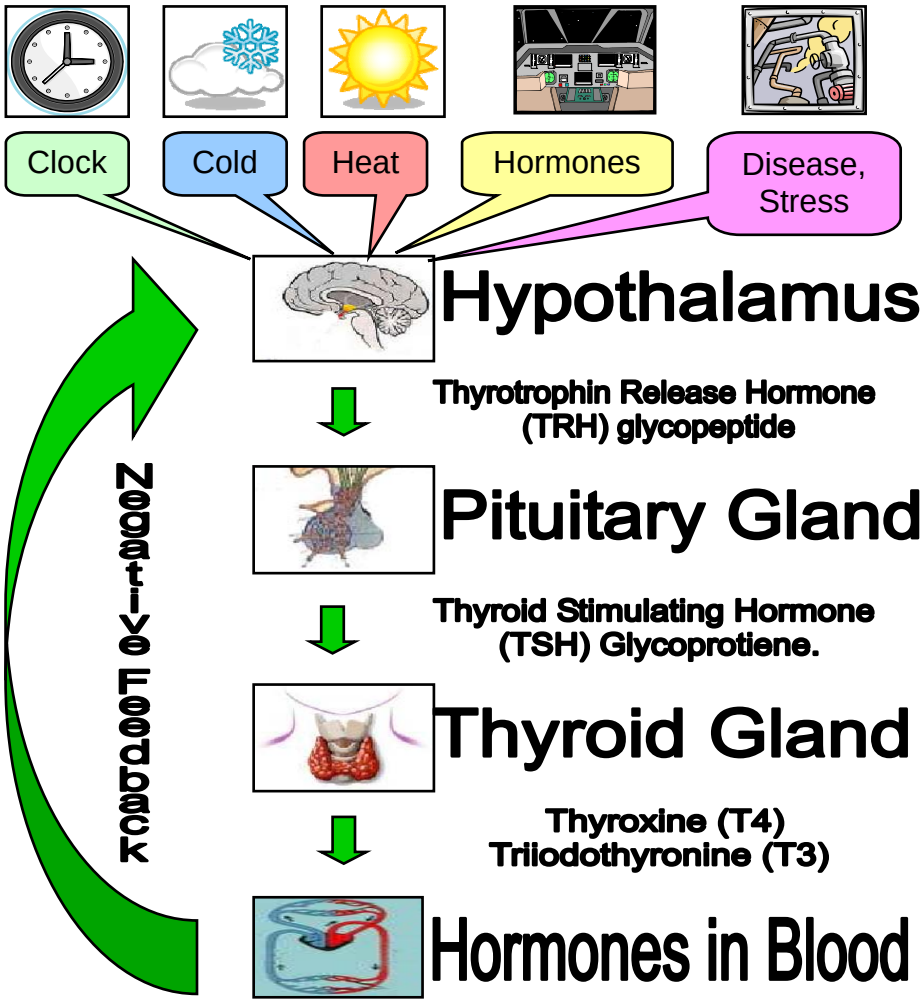
In the process of researching ME in schools, Dr. Elizabeth Dowsett and I observed that many schools where there were known cases (some, indeed, with a number of cases) declined to take part in our study, although it was entirely confidential. It is a sad fact that the disbelief which originally surrounded ME and which still persists in less well informed medical and educational circles has seemed to be particularly common in those who deal with children, where suspicions that it is the parents who are actually causing the illness are all too frequent. Children are not easily able to speak for themselves. When things go wrong with their bodies, their difficulty in getting someone to listen is even more acute than that which adults face. All too often, adults in positions of authority expect children to listen to them, but only make token attempts to reciprocate. In addition, children may not even realise that what they are feeling is abnormal, and then it is truly up to adults to do their realising for them……..*The remainder of the narrative is on www.tymestrust.org –Mike*

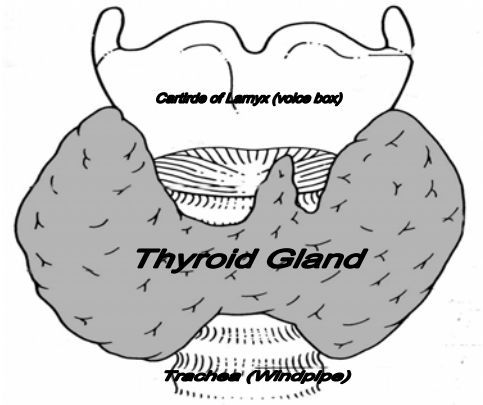
ME/CFS, Thyroid and Body Temperature.



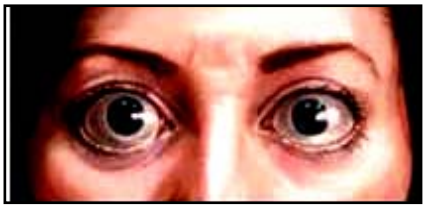
The thyroid gland is a ductless endocrine gland located in the neck which releases hormones into the bloodstream. The ones of interest are thyroxine (T4) 90%, and triiodothyronine (T3) 10%. An additional hormone, Calcitonin contributes to the regulation of blood and bone calcium balance. As well as using energy derived from food for maintenance, function and movement, our bodies use food energy to keep warm. The thyroid gland is the main mechanism for control of body temperature. The basic control, mechanism (thermostat) is in the hypothalamus, in the brain. On top of this, are small daily (circadian) variations in temperature, which are influenced by hormones and other factors.
When thyroid diseases occur, they tend to be of two main types. Hyperthyroidism is when excessive activity leads to an increase in body, temperature and hypothyroidism, where under activity leads to a reduction in body temperature. One novel exception is De Quervain thyroiditis (inflammation) starting as hyperthyroidism, and can end as hypothyroidism.

Control of Thyroid function

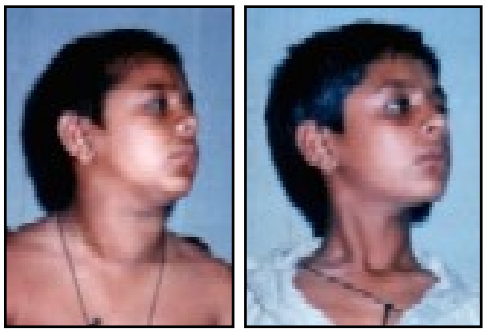




The production of thyroxine and triiodothyronine is regulated by thyroid-stimulating hormone (TSH), released by the anterior pituitary. The thyroid and thyrotropes form a negative feedback loop: TSH production is suppressed when the T4 levels are high, and vice versa. The TSH production itself is modulated by thyrotropin releasing hormone (TRH), which is produced by the hypothalamus and secreted at an increased rate in situations such as cold (in which an accelerated metabolism would generate more heat).



Graves disease is an autoimmune disorder that involves over activity of the thyroid (hyperthyroidism). One of the hallmarks often shown to medical students are bulging eyes



Left is a patient with goitre, usually a sign of an underactive thyroid, but not always. Right is the same patient after treatment.

Is ME/CFS a Hypothyroid Disease?

Personally I think no. Some symptoms are under but some are of over activity. A typical NHS doctor will agree, and a private doctor will disagree. The typical NHS lower limit for 'normal' T4 is 8 pmol/l; however Biolab, a private laboratory used by private doctors set their limit to 12 pmol/l. Many ME's score between 9 and 12 pmol/l, at the lower end of normal, and so are interpreted differently by the two systems. ME/CFS patients show some hypothyroid type symptoms, and may eventually develop hypothyroidism in later life. I think that the thyroid control system can fatigue, just like any other body system in ME/CFS. Any thyroid problems are secondary, as a result of ME/CFS, rather than primary, and a result of the thyroid system malfunction. Thyroid drugs may give symptomatic relief, but are not the answer. They may be justified in the first few years of ME/CFS after onset. *–Mike*

Condition	**Hyper thyroid diseases**	**Hypo thyroid diseases**	**ME/CFS**
T4/T3 in blood	Higher than normal	Lower than normal	Usually low end of normal
Body Temperature	Higher Heat intolerance	Lower Cold intolerance	Usually lower
Fatigue syndrome	Can be present	Present Weakness Drowsiness	Always present OK at first, but weakness follows
Weight	Weight loss Increased appetite	Weight gain (unintentional). appetite decreased	Loss or gain
Neurological	Nervousness Restlessness. Anxiety Increased sweating Hand tremor	Depressive	Can be a mixture of anxiety and depression
Bowel Movement	Frequent or diarrhoea Nausea and vomiting	Constipation	Can be Frequent or Constipation depending on IBS symptomology
Hair, Nails and Skin	Itching - overall Skin blushing or flushing	Thin, dry and brittle hair Paleness Dry flaky skin Thickening of the skin Thin, brittle fingernails	Usually pale, if fatigued.
Sleep	Sleeping difficulty	Normal	Usually sleep phase delay
Cardiovascular	Heartbeat and High blood pressure up. Palpitations, heart arrhythmias	Heartbeat and High blood pressure down	Heartbeat up blood pressure lower.
Other possible symptoms that may occur, but are common to other diseases	Goitre , Weakness Diarrhoea, Breast development in men Protruding eyes (exophthalmos)	Joint or muscle pain Slow speech , Puffy face, hands and feet Decreased taste and smell ,Thinning of eyebrows, Hoarseness Abnormal menstrual periods, Overall swelling, Muscle spasms (cramps) and pain, atrophy. Uncoordinated movement, absent menstruation Joint stiffness Appetite loss Ankle, feet, and leg swelling. Short stature	Joint or muscle pain Slow speech Decreased taste and smell Thinning of eyebrows Hoarseness Overall swelling Muscle spasms (cramps) Muscle pain Muscle atrophy Uncoordinated movement Joint stiffness
Treatments	Anti thyroid Drugs: thiouracil, iodates, beta blockers, surgery.	Pro thyroid drugs:T4, T3, iodine supplements, .	No proven treatment except for pacing.

Controversial Issues with Thyroid Drugs.

Thyroid function tests. These are blood tests routinely carried out by NHS doctors, and should be repeated if any thyroid drugs are given or thyroid issues are suspected. Laboratory tests to determine thyroid function usually include T4, T3, and TSH. However other more advanced tests may be considered. Sometimes, dangerously, these are omitted by private doctors.

Depression. As part of the diagnostic workup, thyroid function tests must be considered. As hypothyroid disease is a problem associated with depression, and may be the root cause and need to be eliminated. In some cases of severe depression thyroxine is used as adjunct treatment to antidepressants, but this practice is confined to hospitals.

Weight Loss When thyroxine (T4) was first synthesised in the early 1950's, it was haled as a wonder weight loss drug, because excess T4 in disease produces weight loss. However, it was soon found that if used above normal body levels (100-150ug daily), hyperthyroid issues loomed. A major cause of death was heart arrhythmias, usually ventricular fibrillation normally associated with heart attacks. It is still sold unscrupulously on the internet for this purpose, but its use is dangerous.

ME/CFS Many ME/CFS problems are associated with brain malfunction. Cells of the brain are a major target for the thyroid hormones. T3 and T4 have separate transport mechanisms, across the blood brain barrier. Up to 80% of the T4 is converted to T3 by peripheral organs such as the liver, kidney and spleen. T3 is about ten times more active than T4. Some doctors believe that the T4 to T3 conversion is compromised in ME/CFS, and so give T3, or a thyroid supplement with excess T3. This practice is deprecated by many NHS doctors, and has resulted in some well known private doctors being summoned to the General Medical Council, and risking being struck off.

Armour thyroid. Armour Thyroid is a type of hormone replacement therapy. It differs from other therapies in two important ways, in that it is a 'natural' preparation, being made from minced up pig thyroid glands, not as synthetic compounds. It provides T4 and T3, in a 4.22:1, more rich in T3 than would be found in humans (usually between 10-14:1). I have heard claims that it also contains other unspecified thyroid hormones, which make the cocktail less vicious than T3 and/or T4 alone, which make it more suitable for ME/CFS. It is about 20 times more expensive than T4, and unlicensed in the UK. This means that any doctor prescribing it in the UK takes full responsibility for any adverse issues, rather than passing on liability to the manufacturer. For this reason alone many doctors will not prescribe it. Because it is based on a natural product, there is inherent variability, and more potential for adverse reactions like allergies. When I qualified as a pharmacist in 1972, there were still many patients being prescribed the NHS equivalent product, and one of my goals was to get them all changed over to the safer and cheaper synthetic versions. *–Mike*

Battle

I battle with the nausea
and also with the pain
I strive to get some order
out of my muddled brain.
The constant chills and all the ills
I struggle with in vain
But the one I fight the hardest
is the battle to stay sane!!

Jane Andrews

Bessie

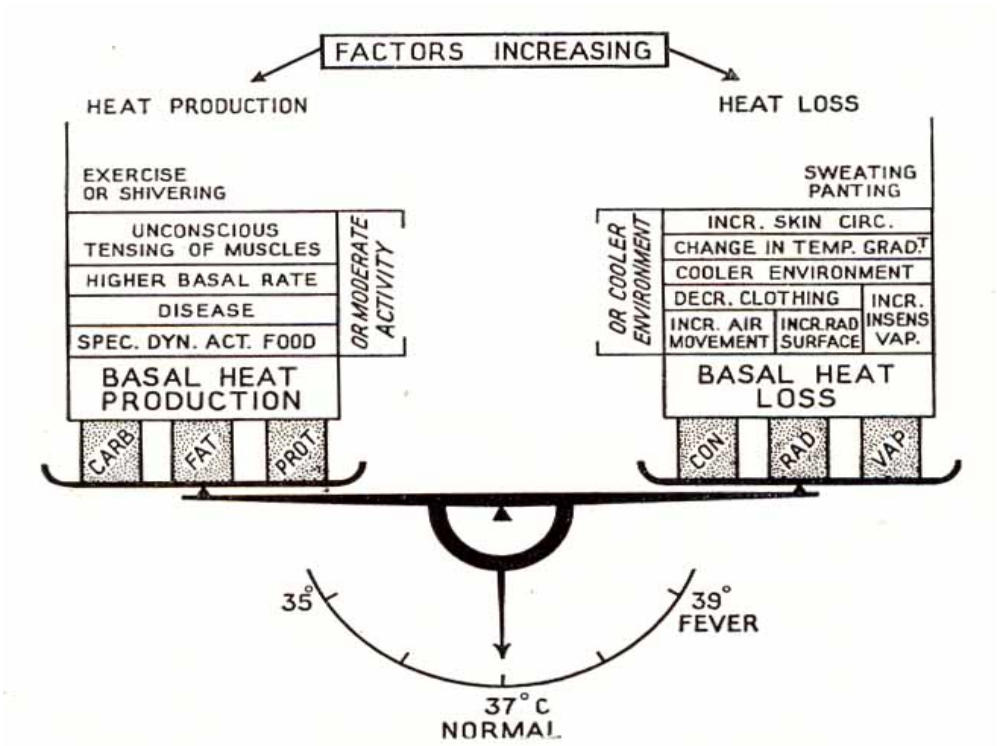
A summers day 'twas really warm
The sun shone in the sky
Deciding where we were to go
We sat there, Sam and I.
I turned the key, the engine purred
But never did we leave,
Poor Bessie never left the yard
'Twas only make believe.

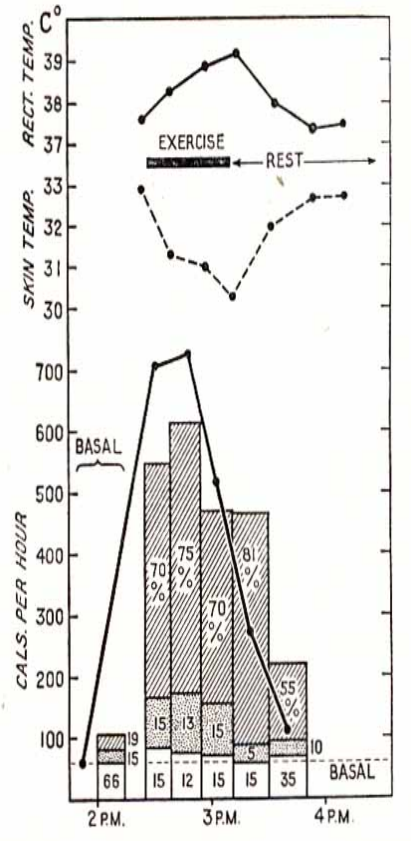
Shirley Clayden

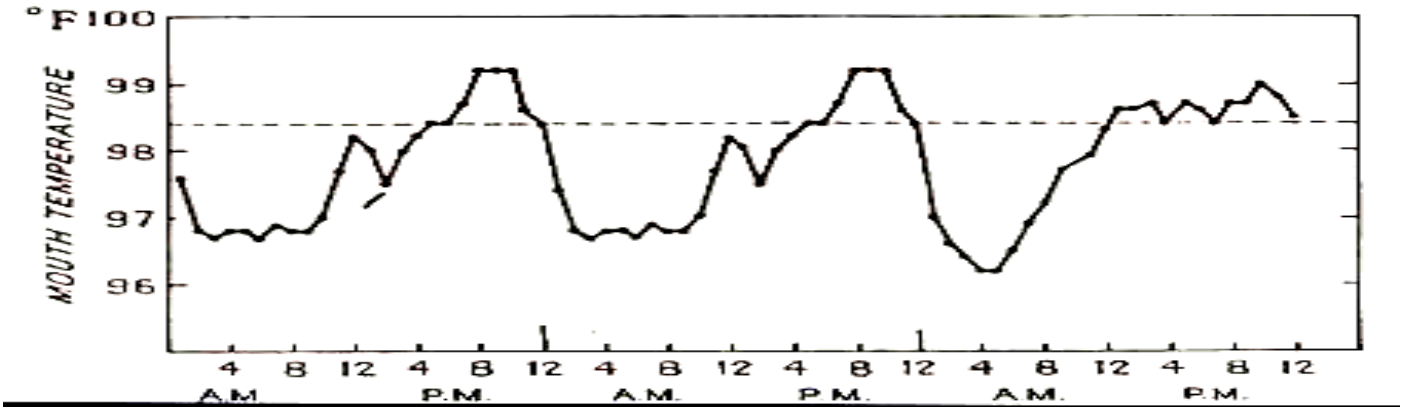
Body temperature

Body temperature is maintained within narrow limits, mainly through the thyroid control system. It is a complex balance of factors. The illustrations are based on research from the 1930's and are taken from a medical text book of the 1950's, but mostly still hold true today.

Balancing the Heat Budget







ME and Daily Variation in Body Temperature.

One of the early things I found with ME/CFS was that my body temperature was below normal (hypothermic). Although I appeared to be feverish, it was well below what it should be, 36.4 °C +. Using a clinical thermometer I now record my body temperature first thing in a morning at the same time, and find that it gives an indication of how bad the ME/CFS is. My normal range is between 35.7 °C on the worst days and 36.3 °C on the best days. It tends to drop cumulatively about 0.1 °C on every stressful day, and rises by 0.1 °C on a good day. In the early days I used a mercury clinical thermometer, which needed very carful handling and was easily smashed. However, I soon found that the electronic type of clinical thermometer was far more reliable and consistent. Anyone with a sharp eye will notice that I am hypothermic. This is a normal finding in ME/CFS. My T4's are high end of normal. I suspect that the actual numbers are different for everyone, and individuals will have to calibrate their own good and bad day numbers.—*Mike*

Recipe Corner

by Carolyn

Here are two recipes. For any of you who are wanting to lose a few pounds here is a tasty slimmers meal, chicken broth. This is a healthy dish packed with grains, protein and veggies, without a trace of added fat in the cooking. If you want the veggies to be less crunchy then just cook them for a little longer – I like mine crunchy.
The second is a simple and quick recipe that you can adjust with another vegetable if you don't like spinach. This costs about 72p per person.

THE TEN COMMANDMENTS FOR REDUCING STRESS

1. Thou shalt not be perfect or try to be.
2. Thou shalt not try to be all things to all people.
3. Thou shalt leave things undone that ought to be done.
4. Thou shalt not spread thyself too thin.
5. Thou shalt learn to say "NO".
6. Thou shalt schedule time for thyself, and for thy supporting network.
7. Thou shalt switch off and do nothing regularly.
8. Thou shalt be boring, untidy, inelegant and unattractive at times.
9. Thou shalt not even feel guilty.
10. Thou shalt not be thine own worst enemy, but thine own best friend.

Sylvia Waites

	Chicken Broth with Pearl Barley	**Spinach, Chickpea and Potato 'veggie'**
Ingredients:	200 g (7oz) pearl barley 1-5 litres (2½ pts) chicken stock 4 skinless chicken breasts – chopped 1 onion, sliced 1 turnip, sliced 1 parsnip, sliced 1 leek, sliced 2 carrots, sliced 2 sticks celery, sliced freshly ground black pepper parsley, chopped (optional)	2 tablespoons sunflower oil 1 large onion, chopped 1 garlic clove, finely chopped 2 tablespoons Medium Curry powder 500g new potatoes, quartered 160g bag of spinach (in most supermarkets) 400g can Chickpeas, drained and rinsed 2 teaspoons of Garam Masala (in most supermarkets) Naan bread or rice, to serve
Method:	Wash and rinse the pearl barley well in cold water. Place in a pan with the chicken stock and bring to the boil, cover with a lid and simmer for one hour. Add the chicken, onion, turnip and parsnip. Mix well and cook for 20 minutes. Add the leek, carrots, celery and seasoning and, simmer for another 10 minutes. Add more stock if needed, then serve topped with chopped parsley.	Heat the oil in a saucepan and cook the onion over a medium heat until soft and golden, stirring occasionally. Add the garlic and curry powder and stir over a low heat for 1-2 minutes until the flavour is released from the curry powder. Stir in 400ml water, add the potatoes and season to taste with salt. Cover and simmer gently for 20 minutes. Add spinach, chickpeas and garam masala and cook until spinach wilts and the chickpeas are hot. Serve with naan bread or rice.
Serves:	4	4
Takes:	1½ hours	40 minutes
Each serving contains:	470 calories, 6g sugar, 6g fat, 2.2g salt	285 calories, 4.4g sugar, 11.1g fat, 0.7 salt

Helpline Bits and Pieces

New Old not New. I get asked all sorts of questions on the helpline. Probably the most recent oddity is a request for an old cassette recorder as a replacement for a member. On saying that brand new ones are available from the local Maplin store, a reply came back,"Can't do that". On further enquiring, it turns out that the person in question suffers from multiple chemical sensitivity (MCS), a complication of ME/CFS, something which I often come across. New electrical goods smells because they emit fumes or volatile organic chemicals (VOC's) into the air as a result of the manufacturing process. Any new electrical goods I get are 'cooked' in a warm room, and then well ventilated. This is a good way to clear VOC's. The VOC's induce fatigue syndrome, and are dangerous, and are a health hazard for some, as for example, they can induce epileptic seizures in the susceptible. There is a none VOC policy at the Redmond Centre where we meet and generally in ME Groups' meetings. Perfumes and other toiletries contain VOC's. You do not have to smell a VOC for it to affect you. A few years ago at a church hall meeting in Intake, a member became paralysed after being exposed to fumes from a polished floor, and had to be wheel chaired out. Some of the other members certainly suffered minor relapses. We did not use that venue again. Eventually, the member got a new old cassette recorder from a car boot sale.

DWP Sharing of Information. I've had a DLA refusal from a member. On delving deeper into the issue, the refusal is based on two things, firstly the DLA for itself and secondly a IB85 medical report which is a form generated by the DWP Lima system during a PCA (IB 50 Medical). I consider this unsatisfactory because, only the output generated by the computer reporting system has been considered. Because the IB85 produced a favourable result, the contents of that report were not challenged. This person told me that many of the statements made by the examining doctor are untrue, and would have been challenged had the content been made known, but because ICB was awarded the results were not challenged. Many of the comments are made by inference from indirect questioning. No account has been taken of the original IB50 form content for DLA purposes. The IB85 reporting system is not common to DLA, and many of the questions asked are not directly related to the DLA form. Numerous times there is a paragraph *'This case was curtailed……not critical to the outcome of this (ICB) claim.'* It is usual practice for the doctor to terminate the examination once the threshold for awarding the benefit has been reached without pursuing the examination any further. This implies that the sort of detailed information required for a DLA claim would not have been investigated. The PCA was about 8 months old, and evidence going back 6 months is only claimed to be considered. This person's condition may have changed significantly in that time. The person who knows most about this person, the G.P. has not even been contacted. For ME/CFS cases, DWP medicals tend to be snapshots, and not a true assessment of the condition. Decision makers tend to ascribe symptoms to mental health issues, as it appears in this case because there were strong mental health issues as well as ME/CFS. So if you have DLA and are filling in an IB50, be careful what you say and always consult a welfare rights advisor. I have since learned that the DWP can consider reports up to two years old.

Health Trends in Members. A number of years ago in his book 'Living with ME', Dr. Charles Shepherd states that people with 'Atopic' diseases are susceptible to ME/CFS. My experience with the group members confirms this. An atopic disease is caused by some sort of autoimmune issue, e.g. the body's immune system turning on itself. Many of the people I have met over the years suffer from or have a family history of asthma, skin problems like psoriasis, and eczema and connective tissue disorders like scleroderma and sarcoidosis. This leaves me certain the root cause of ME/CFS is immune system dysfunction, and does eliminate a mental health cause like depression. The most common additional illness seems to be type 2 diabetes or other glucose intolerance issues with older members. We seem to have three times more diabetics than we would expect to see from general population statistics. Gynaecological issues seem to be more prominent, with early menopause and the need for hormone replacement therapy being about three times what would be expected. There may be some sort of selective filtering because many ME/CFS patients have health checks on diagnosis, (should be) and regularly checked by the G.P. *Mike*.

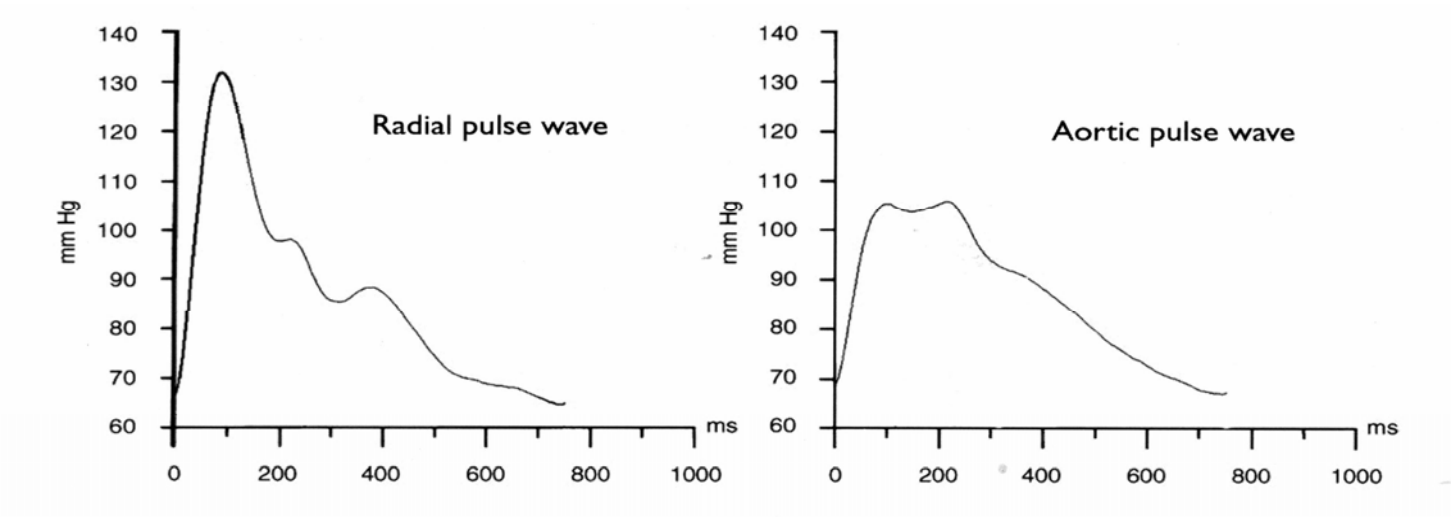
Blood vessel stiffness and Inflammation

From the spring 2008 issue of ME Research UK's Breakthrough magazine.

An essential characteristic of the blood vessels that deliver blood throughout the body is the flexibility of their walls. This affects how each pulse of blood from the heart is transmitted through the cardiovascular system from the larger to the smaller arteries, and ultimately to the capillaries and back to the heart. Normal, healthy arteries have reasonably flexible (elastic) walls which allow the heart to eject blood into the blood vessels easily and smoothly. If the arteries become stiff, the heart has to work harder and, ultimately, blood pressure becomes higher. A certain amount of stiffening occurs normally with age, but diseases such as atherosclerosis can worsen this. Stiff arteries have been linked to kidney problems and heart disease, and may also contribute to the orthostatic hypotension (dizziness on standing) experienced by some ME/CFS patients. Furthermore, increased arterial stiffness has also been reported in children with ME/CFS.

With funding from ME Research UK, researchers at the Vascular and Inflammatory Diseases Research Unit, University of Dundee, have uncovered a range of potentially important cardiovascular findings in ME/CFS patients, including increased oxidative stress (these toxic molecules can, amongst other things, damage blood vessels), abnormal metabolism of acetylcholine (an important neurotransmitter and dilator of blood vessels), and increased early death of white blood cells (which may indicate active inflammation). All this has provided accumulating evidence of a compromised cardiovascular system in patients with ME/CFS, and of the potential importance of inflammation in this disease process.

Increased arterial stiffness has previously been associated with inflammation and the risk of cardiovascular problems in other patient groups, but little is known about these relationships in ME/CFS. Accordingly, Dr Faisel Khan in Dundee decided to investigate the presence of arterial stiffness in adult patients with ME/CFS, as well as its relationship with markers of inflammation. With a grant from ME Research UK, 41 ME/CFS patients attended the blood flow laboratory at the University of Dundee, as well as 30 healthy, age-matched volunteers. Blood samples were obtained from which to measure a number of chemical markers of inflammation and oxidative stress. These included C-reactive protein which increases dramatically in inflammation, as well as isoprostanes and oxidised low-density lipoprotein which are sensitive markers of oxidative stress. Arterial stiffness was measured using a technique called a pulse waveform analysis system, producing a parameter called the augmentation index.



Pulse wave analysis. *When you place your fingers on your wrist just below the thumb, you can feel your pulse; that is, the regular increase in pressure as each pulse of blood travels down the radial artery from the heart into your hand. This pulse can also be detected by a pressure sensor applied to the wrist, and this is the technique used by Dr Khan and his colleagues to determine arterial stiffness. The sensor produces a continuous recording of the fluctuations in pressure caused by each pulse wave, and computer software analyses their shape to determine how flexible the artery is. Stiff arteries cause a certain amount of wave reflection which increases, or augments, the size of the pulse. The augmentation index calculated by the software is therefore related to blood vessel stiffness.*

And the findings ...

Dr Khan found that patients with ME/CFS had significantly stiffer arteries than healthy, age-matched control subjects; their average augmentation index was 22.5%, compared with 13.3% for controls. Patients also had higher levels of C-reactive protein (2.58 versus 1.07 µg/mL) and isoprostanes (470.7 versus 331.1 pg/mL) than controls, indicating significant inflammation and oxidative stress. Furthermore, the extent of arterial stiffness was significantly correlated with C-reactive protein, isoprostanes, oxidised low-density lipoprotein and blood pressure levels, suggesting a relationship between arterial stiffness, inflammation and oxidation.

The cause of increased arterial stiffness in ME/CFS is still unknown. While lifestyle characteristics such as smoking, obesity and physical fitness also play a role in its development, the patients in this study were no different to the control subjects in this regard. In addition, reduced physical conditioning has been associated with increased arterial stiffness, and might be involved to some degree, however, the relationship with inflammatory markers found in the current study suggests that long-term inflammation may be a potential cause of arterial stiffness in ME/CFS, but Dr Khan is careful to emphasise that this is an association ,only and that his current results do not prove cause and effect.

Do these results mean that people with ME/CFS are at an increased risk of developing cardiovascular problems such as heart disease? In his paper recently published in the journal Clinical Science, Dr Khan points out that very few long-term follow-up studies have been carried out in ME/CFS patients, and none on the occurrence of other health conditions such as cardiovascular disease. It is therefore not possible to estimate cardiovascular risk in this patient group at present. However, his work does raise the possibility that suppressing inflammation in carefully selected patients may lead to an improvement in arterial stiffness and a reduction in long-term cardiovascular problems, something already achieved in patients with rheumatoid arthritis. However, further research is needed before this can be answered definitively.

This article is from the spring 2008 issue of ME Research UK's Breakthrough magazine. Copies available free from http://www.meresearch.org.uk and 01738-451234.

'Inflammatory toolbox' Given the increasing evidence (arterial stiffness, isoprostanes, etc.) that inflammation is involved in ME/CFS, it was heartening to read the superb review in Psychoneuroendocrinology on the need for improved recognition and management of inflammation-associated symptoms in medically ill patients. The experts at this multidisciplinary meeting pointed out that medically ill patients present with a high prevalence of non-specific comorbid symptoms, including pain, sleep disorders, fatigue, and cognitive and mood alterations - indeed many of the symptoms experienced by ME/CFS patients! The experts, however, recognised the danger of psychiatrists ascribing these to "somatisation disorder", an action which "is of little operational value if not misleading"; as they say, the enduring fatigue experienced by the vast majority of breast cancer survivors could be easily labelled as a somatisation disorder when in fact it has an organic basis. The meeting recommended that there should be a "toolbox" of standard tools for assessing inflammation-associated symptoms, and a minimum set of inflammatory biomarkers which would . include acute phase proteins (CRP, sialic acid and haptoglobin), IL-6, and inflammatory mediators (prostaglandins E2 and C3A). Including such a toolbox in the assessment of ME/CFS patients - for example, in the regional clinics in England - would be a great advance.

Give us a laugh

by Paul Lack, from Interaction 63.

How many people does it take to change a person with M.E.'s light bulb?
Doctor: "The light bulb is not broken. You just think it is."
Consultant: "The light bulb is broken, but I can't help !"
or "We need to get you to the point where you can change it yourself."
Alternative therapist: "You must learn to love your broken light bulb as it is."
Benefits officer: "Fill in form LBO6 if you think you are entitled to a replacement light bulb, or form LBO8 if your carer is less than 5 feet tall."
Government minister: "Bogus light bulb claimants will be named and shamed."
Spouse/parent/carer: "There you are. That's done now."
Person with M.E.: "Owl! Turn it off! You know I'm sensitive to fight!"

NHS Prescription Charges *by Daniel Richards.*

What are NHS prescription charges?
People visiting NHS medical practitioners e.g. doctors, pharmacists, nurses, and dentists for specific complaints are frequently prescribed pharmaceutical treatments or medical appliances. Some patients are required to pay a charge towards the cost of the drugs to the NHS. The basic NHS prescription charge until 1st April 2008 is £6.85 per item. This doesn't reflect the actual cost to the NHS of the drugs; many of the items prescribed are a lot more expensive.

History of the Prescription Charge.
In 1952 the prescription charge was introduced, three years after the NHS was created. The introduction of the charge was deemed necessary because of the NHS's growing drugs bill. Although, this went against the basic premise behind the NHS, "*a service at the point of use*". In October 1952, the Conservative government set the charge at 1 shilling per prescription form. In 1956, this was raised to 1 shilling per item. In 1965 the prescription charge was abolished, under the Harold Wilson government. However, with the NHS drugs bill rising dramatically, it was re-introduced in 1968, at a rate of 2 shillings and sixpence, with exemptions being introduced for the young and the old, people on benefits, people with chronic diseases such as diabetes. The rate then increased over the following forty years in varying degrees.

Exemptions from Prescription Charges
Not all patients have to pay as there are a wide range of exemptions from prescription charges. However, a patient must demonstrate that he or she falls into an exempt category by means of an entitlement claims procedure. Certain medical conditions also entitle a patient to exemption, but have not been updated since 1968, and there are many chronic illnesses e.g. ME/CFS, Cancer and Multiple Sclerosis, which are not classed as conditions for which medical exemption applies.

Who is entitled to get free prescriptions?
All Under 16's, 17-19 in full-time education and over 60's. If you (or your partner) gets one of the following: Income Support, Income-based Jobseeker's Allowance, Pension Credit Guarantee Credit, NHS tax credit exemption certificate, some war pensioners - if treatment is connected with the pensionable disability, a prescription exemption certificate for low HC2. If you are entitled to free prescriptions, complete the declaration on the back of the prescription and sign it. You may be asked for proof that you are exempt.

Who can get a prescription exemption certificate?
People who have certain medical conditions: A permanent fistula requiring dressing, hypoadrenalism, diabetes insipidus, hypopituitarism, diabetes mellitus except where treatment is by diet alone, hypoparathyroidism, myasthenia gravis, underactive thyroid, epilepsy medication. And unable to leave your home without help. If you are pregnant or have had a child in the past year. Get form FW8 from your doctor, midwife or health visitor to apply for a Maternity Exemption Certificate. The form is sent off to the Prescription Pricing Authority who will issue the certificate.

If you pay, are there any cheaper alternatives?
Discounts are available for patients who need longer courses of medicines, via "Prepayment Certificates". The PPC cost is £26.85 for a 3-month PPC; and £98.70 for a 12-month PPC, and should be seriously considered if you have more than one prescription at month.

Points of view regarding prescription charges.
The introduction of prescription charges was deemed necessary to help contribute towards the funding of the NHS drugs budget, and to help deter unnecessary prescribing and keep costs down. Prescription charges were expected to have raised £446 million for the NHS in 2003-2004. (Department of Health, 2004.) The NHS Drugs Bill, according to the Prescription Pricing Authority, in 2004 came to £6.6 billion per annum. However, there are many social anomalies with the charging system, e.g. The exemption categories takes no account of whether the person can afford

to pay, so there may be wealthy pensioners who get free prescriptions, but many poor families who are not. The inability to afford the prescription charges could have a negative effect on a person's health, where the patient is forced to have to choose which medications they will have. E.g. An asthmatic patient having to choose between having their Ventolin inhaler (A reliever drug for asthma) and their Beclazone inhaler (An inhaler which helps to prevent asthma attacks). A 2001 report by the National Association of Citizens Advice Bureau claimed that as many as 750,000 prescriptions in England and Wales had not been dispensed because of cost that year. Unfortunately, the situation does not look like changing for the better at the moment, so we are stuck with the current charges and another prescription charge rate increase due in April 2009!

The Royal Pharmaceutical Society of Great Britain's Public Relations Unit issued the following on the 28th February:

ENGLISH PHARMACY BOARD REACTS TO CALL FOR FREE PRESCRIPTIONS

Reacting to news yesterday (27th February) that the Citizens Advice Bureau has called for free prescriptions in England to reduce the financial burden on people with low incomes, Paul Bennett, Chairman of the Royal Pharmaceutical Society of Great Britain's English Pharmacy Board, said:
"The current system of prescription charges and exemptions in England is both illogical and unfair. There are clear disadvantages under present arrangements, particularly for non-exempt patients who require long-term medication for multiple chronic conditions."
"There is a case for abolition of prescription charges in England; however the implications of such a move are considerable and should be considered very carefully in light of the likely impact on patients, professionals and the public purse."
"The Society firmly believes in better access for all patients and that there should be no financial barrier to the use of prescribed medicines. However, we must approach these issues with our eyes wide-open; with a clear understanding of the implications of such reforms for pharmacists, GPs, patients, healthcare services and the pharmaceutical industry."

Are you thirsty?

Do you feel tired and thirsty a lot? You could be one of the thousands of people who have diabetes and don't know it. Take our test to find out

1. Are you over 40?
a) Yes
b) No

2. Are you overweight?
a) Yes
b) Slightly
c) No

3. Do you feel thirsty?
a) Yes, all the time
b) Sometimes
c) No

4. Do you have a history of diabetes in your family?
a) Yes
b) A distant relative
c) No

5. Do you feel tired all the time?
a) Yes, I feel exhausted
b) Sometimes
c) No, I have lots of energy

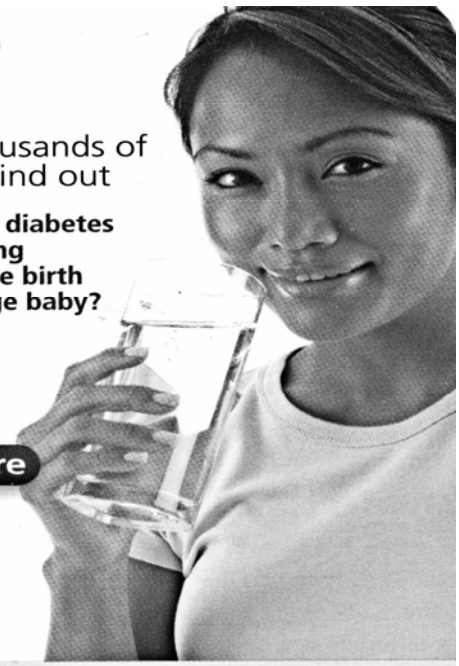
6. Are you south Asian or African-Caribbean?
a) Yes
b) No

7. Do you need to urinate a lot at night?
a) Yes, I need the toilet a few times at night
b) Sometimes
c) No, I don't go at all during the night

8. Do you have blurred vision?
a) Yes
b) Sometimes
c) No, never

9. Have you had genital itching or regular episodes of thrush?
a) Yes, I have recurring thrush
b) I've had thrush a few times
c) No, I never get thrush

10. Did you have diabetes temporarily during pregnancy or give birth recently to a large baby?
a) Yes
b) No



Find out more

For real-life stories about diabetes, visit www.nhs.uk/conditions

If you answered mostly As. Please consult your GP. You may be at risk of type 2 diabetes and are displaying some of the symptoms. **If you answered mostly Bs.** You display some of the symptoms of type 2 diabetes. Consult your GP if your symptoms persist. **If you answered mostly Cs.** You're probably not at risk of developing diabetes now, but stay aware of the symptoms in yourself and others.

Following a number of issues on the helpline, I have included this panel from the Department of Health flyer. Members as part of their annual checkups should have a test which includes diabetes screening. Some Pharmacies offer this service. -Mike

Meeting Report: M.E. and The Ecology on the Digestive System.

Speaker Elizabeth A McDonagh

One the15th February at the Redmond Centre Liz gave a presentation about Food and Nutrition in ME. What follows is her personal handout on her own diet and lifestyle suggestions.

M.E. is an illness of the immune system, often triggered by trauma, infection and/or environmental factors. It is stress-related. This does not mean it is "all in the mind", but rather that stressors of all kinds cause hormone changes which raise the toxic levels of the blood and tissues, reinforcing and perpetuating the immune dysfunction.

The yeast Candida albicans and other yeasts are present in everyone's gut and are normally kept in check by the body's immune system and by the beneficial gut bacteria. Antibiotics kill these bacteria thus leading to yeast overgrowth. Sugar feeds and strengthens the yeasts. Under such circumstances, Candida and its toxins can cause a bewildering range of symptoms including headaches; speech impairment and confusion; sore throats; indigestion, bloating and flatulence; severe constipation; bladder infections; sleep disturbances; arthritic pains; "pins and needles"; paralysis; palpitations; craving for sweet foods and bread; intolerance of alcohol; allergic reactions to foods and chemicals; irritability, anxiety and depression.

Although many sufferers learn to manage their symptoms, ME can be a progressive illness with complete immune breakdown and "Total Allergy Syndrome" at the end of the line. Early reversal of the gut dysbiosis and attention to its underlying causes is essential if health is to be restored. No single diet will effect this reversal. Patients need different protocols according to their symptoms, their lifestyle and their point on the continuum inherent in the progressive nature of the illness. Patients must learn to sense changes in their own bodies and to take responsibility for their own healing. Family understanding and support are fundamental to recovery. Rest is also vital to the restorative process. Many sufferers spoil their progress by doing too much on days when they feel better. Meditation and other stress-reduction techniques can be beneficial.

If you have gut Dysbiosis (e.g. Candida) you can expect to feel worse when you start the diet as the yeasts die off and their toxic products enter the bloodstream. It is vital to rest and to drink plenty of pure water at this time. Other detoxification techniques which may be helpful include dry skin-brushing before showering, deep breathing techniques as practised in Yoga, gentle massage, kinesiological balancing and attention to good bowel action. Herbal formulations may be used to assist the bowel. A warm water enema once or twice a week may be the preferred therapy for some sufferers.

It is very important that you understand and expect the worsening of symptoms which may last up to six weeks. Many people give up the diet at an early stage because they think it is making them worse. If you persevere you can expect to feel substantially better in two months. Progress is usually slow. People experience the occasional better day at first and these become more frequent until, after a time, there are more good days than bad. When you have not eaten sugar and yeast for some time, reintroducing either of them can make you acutely ill and the effect may last for several days. The experience of this is enough to convince many people of the therapeutic value of sticking to the diet. After you begin to stabilise, (i.e. feel better), you may decide to take a supplement with fungistatic properties. Do not take sugar at the same time. You can expect to feel worse again as die -off reactions return. It is wise to introduce any fungistat very cautiously at first so that the "Herxheimer reaction" (as the worsening is called) is kept within tolerable limits.

The ANTI-CANDIDA DIET totally avoids sugars and yeasts, which is necessary if gut dysbiosis is to be corrected. "Hidden sugar" is present in many processed foods, including many savoury items such as tinned and packet soups, baked beans and canned meats. Label-reading is vital. The following terms all indicate the presence of some form of sugar; therefore all are to be avoided. Foods containing sugar should also be avoided. These include:-baked beans (Weightwatcher beans are allowed), biscuits, cakes, candies and candied fruits, chocolate, cookies, desserts, dried fruits,

fruit drinks and fruit juices (unless sugar-free), ice-creams and lollies, icings and toppings, milk and milk drinks (unsweetened soya milk, rice milk, oat milk or nut milks are permitted), pastries, puddings, soft drinks, jam and marmalade, chutneys, sweet pickles, sweets and confectionery, toffee, tinned fruit. (Fruit tinned in its own juice is allowed when symptoms are diminishing). Fresh fruits and fruit juices must be avoided for the first month. Apples, pears and bananas may then be taken in moderation. Avoid very sweet fruits. Foods containing yeasts must be avoided. These include fruits such as grapes and melons, bread, rolls, pitta-bread, pizza, beer, wines and spirits, vinegar (organic cider vinegar is allowed in moderation), pickles, bottled sauces, bought mayonnaise and salad dressings.

Foods prepared with moulds or which encourage moulds are to be avoided. These include peanuts; veined cheeses or those with a mould coating; buttermilk; soured cream; sour milk; cheese snacks; food treated with antibiotics during the production processes (e.g. some eggs, chicken and meat, farmed salmon). Do not eat malted breakfast cereals or take malted drinks. Use the freezer rather than the refrigerator for storing leftovers. Eat food as fresh as possible and discard anything with any trace of mould. It may be necessary to avoid wheat, mushrooms and cottage cheese if these foods provoke symptoms, but some people can tolerate these. Plain live yoghurt (especially goats' milk yoghurt) is excellent if tolerated.

Organically-produced food is best but may be expensive and not always easy to find. If it is not possible to obtain organically-produced food, avoid the skin of fruits and vegetables which have the highest levels of pesticide residues. Avoid the fat of meat and poultry as most of the toxic residues are stored in fat. Avoid tea and fish skin and bone all of which are high in fluoride. Do not eat any food which contains raw egg white. Egg white contains avidin which destroys the important vitamin biotin. Do not use cooking oils which have been extracted with petroleum; choose only cold-pressed oils. Extra-virgin olive oil is recommended. Biotin and olive oil have both been shown to inhibit the growth of the Candida fungus. Corn oil or sunflower oil may be used for cooking.

Do not drink tea, coffee, chocolate or alcohol. Pure water is the best drink (2 litres per day). Bottled water such as Volvic, Evian or Ballygowan water is good but it is more economical to invest in a water filter. Remember to change filter-cartridges regularly or they may return residues to the water. A distillation machine costs more but provides the purest water. Processed foods and processed snacks should not be eaten as they are likely to contain yeast derivatives and sugar. However the diet does not exclude all convenience foods. On some days you may not be well enough to cook so there must be 'easy options'. Some of these are tinned or frozen items.

Frozen vegetables are allowed provided there is no added sugar. Frozen complete meals are not allowed. Frozen meat, fish and chicken is allowed provided there is no added sugar and it is not coated with breadcrumbs. Yorkshire pudding is OK provided you are not allergic to wheat. Stuffings based on breadcrumbs are not allowed. Fish and chips from the chip-shop is OK (occasionally), provided there is no yeast in the batter. Tinned vegetables are allowed if they contain no added sugar and do not induce symptoms. Tomatoes, spinach, sweet corn and Weightwatcher baked beans can be useful. Tinned beans, chick-peas, artichoke hearts etc can save cooking time and can form the basis of delicious pâtés or dips.

An adequate level of blood-sugar, homoeostatically maintained by the action of the hormones insulin and glucagon, is essential for heart and brain function. All carbohydrates are converted to sugars in the digestive system and are absorbed into the blood as simple sugars. When whole foods or complex carbohydrates are eaten this is a gradual process and does not stimulate over-reaction of the insulin-producing cells of the pancreas as does refined sugar. Candida relies on sugars for its food and is not sustained by complex carbohydrates in the digestive system. For these and other reasons, wholegrain and pulses should be eaten in preference to refined foods. Sugar substitutes are best avoided. Snacks are essential to keep up blood-sugar between meals. Raw or lightly cooked vegetables are excellent at providing vitamins and minerals. Drink the cooking water or use it in sauces or soups. Nuts and seeds are the best source of magnesium, a mineral found to be deficient in many Candida sufferers. Shellfish are a valuable source of zinc, a mineral used by many brain enzymes. Original Ryvita, oat-cakes, matzos or rice-cakes may be spread with vegan margarine, olive

pâté (from whole-food shop), tinned fish (e.g. sardines) or home-made pates or dips (e.g. hummus). Marmite and other yeast-derived spreads are not allowed. Plain salted or unsalted crisps are a useful portable snack. Avoid flavoured versions and the ones with added vitamins and minerals (these may not be yeast-free). If you have high blood pressure use the salt-free ones; people with low blood-pressure find a little salt beneficial. Large quantities of salt should never be taken. For added potassium, use Ruthmol or Lo-salt at table instead of ordinary salt. In very hot weather, or at times when perspiration is excessive, ordinary table salt should be used.

After the first month, fruit may be eaten as a snack. Ensure fruit is fresh and avoid melons, grapes and any fruit with traces of mould. Banana is an excellent source of phosphorus, necessary for the cells' energy-releasing mechanisms. Some ME sufferers have been found to be deficient in phosphorus.

Lifestyle suggestions

Avoid cooking in aluminium saucepans, or using foil or plastics in contact with food when cooking. Glass, stainless steel and pottery vessels, unchipped enamelled saucepans and those made of stainless steel or iron are best. As far as possible avoid non-stick pans. Avoid fluoride in water, toothpaste, tablets etc. Even if fluoride has a beneficial effect on the growing teeth of small children, (which is a controversial subject), it is damaging to the skeleton and to the immune system. Toothpastes without fluoride are difficult to find but Euthymol and Sensodyne Original Formula do not contain fluoride. Health-food shops sell toothpastes from homoeopathic suppliers such as Weleda or Nelsons'. These may be gels rather than abrasive pastes and will be free from both fluoride and peppermint so that they are compatible with homoeopathic remedies. It pays to read labels as manufacturers sometimes change their formulations and some manufacturers (e.g. Toms' and Kingfisher) produce two or more toothpastes, only some of which are fluoride-free. Do not use bicarbonate of soda toothpastes. They provide an alkaline environment in which Candida thrives. Toothbrushes may be disinfected with 2% hydrogen peroxide solution.

Rest as much as possible. Do not try to overcome tiredness and continue to work. Use muscles gently when possible to avoid their deconditioning. However do not attempt graded exercise programmes until you are well on the road to recovery. Exercise too soon can exacerbate symptoms and cause permanent damage.

Clear your house of damp and mould. 2% hydrogen peroxide solution can be useful to eliminate moulds from small areas such as the refrigerator door-seal or the washing-machine powder-drawer. (Apply the solution with a cloth and wear rubber gloves). House-plants and their compost can be a source of mould spores. Avoid woodland walks in autumn when there are many fungal spores around. Spores can initiate symptoms.

Avoid, as far as possible, all sources of fumes and toxic chemicals e.g. smoking; smoky atmospheres; drugs; industrial air-pollution; petrol and diesel fumes; chemicals; cleaning agents; dry-cleaning fluids; photocopying and printing fumes; paints and solvents; formaldehyde; fumes from out-gassing of modern furniture and carpets; printed material with unacceptable odour; pesticides and wood-treatment products; synthetic perfumes; perfumed and petroleum-derived cosmetics and scented soaps.

These substances, along with Candida toxins, overload the body's detoxification mechanisms in the liver. Liver enzymes cannot operate without a range of vitamins and minerals as co-factors. Toxic overload depletes vitamin and mineral reserves and if any of the vital micronutrients is unavailable, detoxification will cease until the supply is restored.
Build-up of toxins can then damage liver cells. Fortunately, if they are given a rest from toxins and supplied with the relevant nutrients, liver cells can regenerate.

Remember that all drugs are poisons first and medicines second. There are times when medical intervention is essential to save life. However most drugs have side-effects and thousands of people are hospitalised every year as a result. Antibiotics are widely prescribed, even for viral infections on which they have no effect. Any such prescription destroys bacteria, including the bacteria of the gut micro flora which keep Candida in check.

Thus it has the potential to allow Candida to get out of hand.

Editors Note: Putting issues into context.
Certainly Liz can spend an evening country dancing, so there must be something positive in her advice.

There have always been disputes with a number of doctors about Candida issues and ME/CFS. The most well known Anti Candida advocate is Dr Charles Shepherd, Medical Director of the M.E. Association (MEA), and various NHS ME/CFS clinics. Quoting from Charles' book 'Living with M.E.' "My conclusions are that Candida has no connection with M.E. whatsoever." In the early days of the MEA, the subject was so contentious that it lead to the formation of a breakaway group Action for M.E. under Martin Arber with a more holistic approach. The two M.E. charities are still rivals today.

People who visit private doctors for ME/CFS issues are usually offered 'gut fermentation tests', which are usually carried out by Biolab. After ingestion of a measured quality of glucose, blood samples periodically are taken looking for various abnormal fermentation products like alcohols. The implication is that and overgrowth of yeasts like candida would produce alcohol just like yeasts ferment sugar to produce alcoholic drinks. In practice something like this happens, but the fermentation is not always clean, and by toxic by-products like methanol often appear. This has been given the name 'auto brewery syndrome'. I have seen my own results and those of other group members, and there is no doubt in my mind that Charles is wrong, Martin was right.

Speaking with Dr Myhill, the following are interpreted from gut fermentation tests. Ethyl alcohol (ethanol), if any at all, suggests yeast overgrowth of the gut; other alcohols: methanol, propanol and Butanol, 2,3-butylene glycol -- if raised, suggests bacterial fermentation due to excess fibre reaching the colon. Short chain fatty acids: acetate, if raised, suggests bacterial fermentation due to excess carbohydrate reaching the colon, and propionate , butyrate, succinate, valerate suggests excess carbohydrate or fibre reaching the colon suggests either intestinal hurry or failure to break down carbohydrates due to inadequate enzyme production by the pancreas. Alcohol levels as high as 20 mg/100ml blood have been recorded (80 is the drink drive limit).

Yeasts are part of our natural gut flora, and there is a constant bacteria v. yeasts battle. Normally bacteria win and yeasts are kept in check. In conditions where the immune system is depressed e.g. cancer, after chemotherapy, diabetes or after antibiotics then the balance shifts towards yeasts, and it is not unusual for such patients to suffer from candidal mouth or vaginal infections. In a significant proportion of ME/CFS patients, possibly as high a 50%, a similar favourable yeast balance occurs, which is of course not recognised by many doctors. Although commonly called 'Candida' by patients, a more accurate term would be gut Dysbiosis– because in some cases candida is not implicated, and this cause is other organisms.

Certainly within the first few years of ME/CFS, gut Dysbiosis is a common problem, which in some cases can be more serious that the ME/CFS itself. Antifungal drugs, diets and food supplements certainly make a difference. Veteran ME/CFS patients usually do not have these issues, or if they reoccur, are due to a relapse or other disease and need investigating. Hydrogen peroxide has been sold for many years as a mouthwash or mild antiseptic by Pharmacies, in the appropriate strength, and is not expensive. It is a chlorine free bleach and corrosive. More concentrated it can be used as rocket fuel, in explosives (London tube terrorists bombs) and beaching hair by hairdressers. These higher strengths are dangerous. Mike.

North of Doncaster *Personal Comment of Politics in the ME World, by Trevor Wainwright*

On the verge again! Ten years ago the memories of one event which had it been given the right support could have made a difference to those suffering with ME, the ForT Petition and Lobby at the House of Lords, as featured in the last edition of Pathways. I hope, however, all was not lost as soon after the beginning of 1998 there news came of a potentially Groundbreaking event.

1998 was also the first full year of organised fundraising in Castleford as we went from spasmodic collections to regular monthly collections, a year which would see over £2,900 raised of which over £2,100 went to the then PVDRF and over £720 to BRAME as we took our campaign to the streets, pubs, clubs supermarkets and anywhere else where people were willing to listen to our aims and happily support them, from sales of Blue ME Awareness Ribbons collections. So much for the M.E. Association in 1996 not wanting to help us support them, they lost out on over £4,000, more fool them.

So back to 1998, and the other groundbreaking event, and the BRAME Parliamentary Awareness Meeting in May. Months in the planning and once more AfME and the MEA tried to stop it but once again failed. A follow up to the ForT Lobby and another event that would lead to the CMO's Working Group and the formation of the APPG, with a bit of help from Castleford. More on this in my next column.

Now we stand poised on the brink of another event, an event which challenges once more the all knowing establishment are being challenged, taken to a Judicial Review. The NICE Guidelines are being challenged by the Group, One Click, who have the necessary funding pledged but would no doubt appreciate more and are now taking the big boys on. Oh yeah, some of the main groups have criticised the NICE Guidelines, even written about the dangers but not actually done anything radical. Even though medical research has invalidated the NICE Guidelines, they are still in place and poised to do even more damage to ME* Patients.

As some of you may know I have crossed swords with One Click in the past, in fact I don't think there are many that I haven't crossed swords with. This time I wish One Click every success and say all power to them and hope they win. If they do so, then once again we will be poised on the brink of a momentum to kick start the ME Resistance Movement, as we have been before but failed, such apathy leading to such as the NICE Guidelines. We must continue to challenge and get behind these initiatives more now than ever before or where will we be in another 10 years, will we have moved on or still be in the same place.

Further details about the One Click campaign can be accessed on there website www.theoneclickgroup.co.uk including details of how you too can support the cause.

*(Footnote) I refuse to use the term CFS I find it trivialised the illness, and shall continue to refer to it as Myalgic Encephalomyelitis

Other illness support groups like cancer organisations and the Alzheimer' Society have challenged NICE with very strong evidence and lost.—Mike.