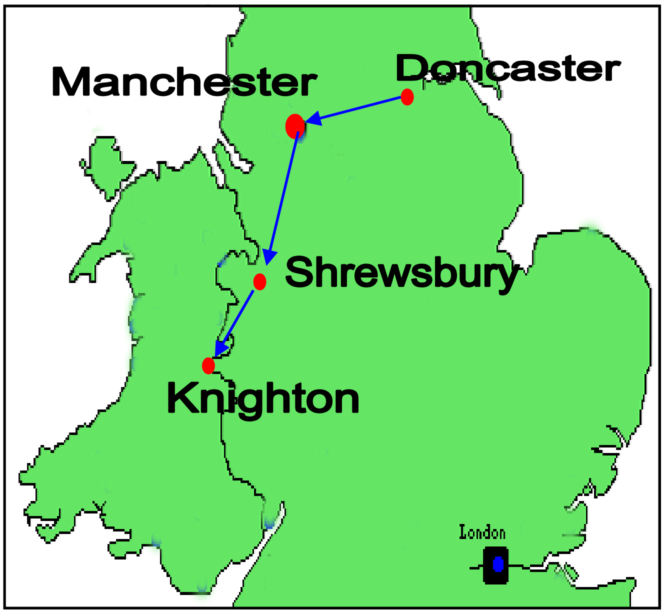
Pathways

Price £ 2.25 (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.



Travel Diary to the Heart of Wales

See page 10

Recipe Corner. Chocolate fridge cake with pecan and meringues and Plum and Almond Tart *see page 7*

I tried to write an article
but couldn't write straight lines
so I wrote a poem
instead with words and rhymes.
It's for a local magazine
that helps folks with M.E.
to offer them some guidance
and ways to feel more free.
I hope my poem helps someone
find hope when they're in doubt,
Cos that's what I am here to do
and what my life's about.

See page 4

Non-invasive structural and functional neuroimaging in ME.

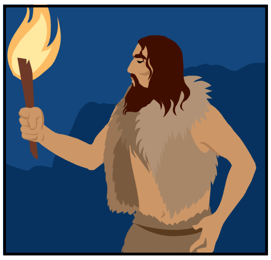
A summary of research in results Neuroimaging and a plan for further Research Studies of ME/CFS by Prof. B.K. Puri *see page 8*

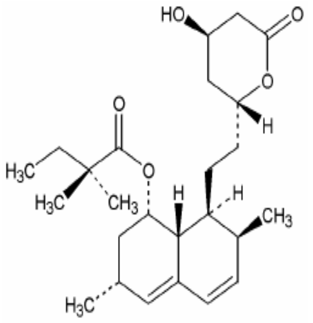
Making a Will, and The Thellusson Will Case

How a badly made Will altered English law and cost the Thellussons of Brodsworth Hall *see page 14*

The Stoneage Diet

Breakfast like an Emperor, lunch like a King, supper like a pauper. Dr Sarah Myhills version of a well known diet strategy. *See page 17*





Simvastatin: 1.5m more to get cholesterol drug—but Is It safe for ME/CFS patients ?

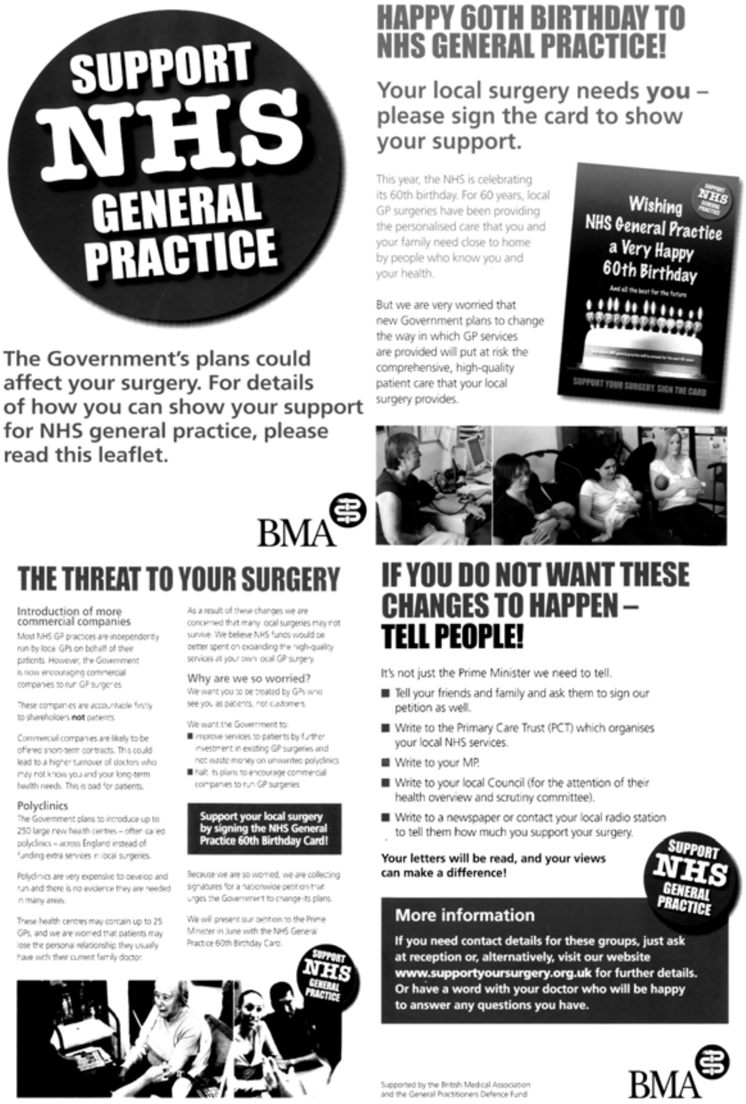
see page 5

You Write

Linda writes *I live in a former mining village with a one doctor practice. I am concerned about the future of my local doctor's surgery, and the possibility of its closing and I would have to go a long way to see the doctor on one of these new 'Polyclinics'. I do not have a car, and where I live there are no buses –and this going to cause me problems. Any ideas ?*

There are a number of small communities around Doncaster like Moorhouse, Melton Brand, Blaxton and Kirk Bramwith which have no public transport. As far as I am aware there are no plans for a Polyclinic in Doncaster. It is government policy that each PCT (Primary Care Trust) has an open access GP doctors surgery 8 a.m.-8 p.m., open 7 days a week, which anybody will be able to attend, even if they are registered with another surgery. This not expected to be a one size fits all, but it will be on the model of other surgeries. Danum Doctors who cover various GP practices around Doncaster (now known as Doncaster Out of Hours) will be moving to DRI, so that people who turn up at casualty will be triaged there and DRI casualty department will be a US style Emergency Room, but that again is different. There is a lot of confusion about polyclinics around in the press. Every PCT has to open an 8-8 surgery- that is Department of Health policy, There will be a number of polyclinics in London, mainly because there are still a lot of old fashioned surgeries (e.g. in the front room of a house) and that is why we are hearing so much about them.

The British Medical Association is aware of this issue, and has produced a leaflet. My local surgery is asking people to sign a petition. - *Mike*



SUPPORT NHS GENERAL PRACTICE

The Government's plans could affect your surgery. For details of how you can show your support for NHS general practice, please read this leaflet.

BMA

HAPPY 60TH BIRTHDAY TO NHS GENERAL PRACTICE!

Your local surgery needs you – please sign the card to show your support.

This year, the NHS is celebrating its 60th birthday. For 60 years, local GP surgeries have been providing the personalised care that you and your family need close to home by people who know you and your health.

But we are very worried that new Government plans to change the way in which GP services are provided will put at risk the comprehensive, high-quality patient care that your local surgery provides.

THE THREAT TO YOUR SURGERY

Introduction of more commercial companies

Most NHS GP practices are independently run by local GPs on behalf of their patients. However, the Government is now encouraging commercial companies to run GP surgeries.

These companies are accountable firstly to shareholders **not** patients.

Commercial companies are likely to be offered short-term contracts. This could lead to a higher turnover of doctors who may not know you and your long-term health needs. This is bad for patients.

Polyclinics

The Government plans to introduce up to 250 large new health centres – often called polyclinics – across England instead of funding extra services in local surgeries.

Polyclinics are very expensive to develop and run and there is no evidence they are needed in many areas.

These health centres may contain up to 25 GPs, and we are worried that patients may lose the personal relationship they usually have with their current family doctor.

As a result of these changes we are concerned that many local surgeries may not survive. We believe NHS funds would be better spent on expanding the high-quality services at your own local GP surgery.

Why are we so worried?

We want you to be treated by GPs who see you as patients, not customers.

We want the Government to:

- improve services to patients by further investment in existing GP surgeries and not waste money on unwanted polyclinics
- halt its plans to encourage commercial companies to run GP surgeries

Support your local surgery by signing the NHS General Practice 60th Birthday Card!

Because we are so worried, we are collecting signatures for a nationwide petition that urges the Government to change its plans.

We will present our petition to the Prime Minister in June with the NHS General Practice 60th Birthday Card.

IF YOU DO NOT WANT THESE CHANGES TO HAPPEN – TELL PEOPLE!

It's not just the Prime Minister we need to tell.

- Tell your friends and family and ask them to sign our petition as well.
- Write to the Primary Care Trust (PCT) which organises your local NHS services.
- Write to your MP.
- Write to your local Council (for the attention of their health overview and scrutiny committee).
- Write to a newspaper or contact your local radio station to tell them how much you support your surgery.

Your letters will be read, and your views can make a difference!

More information

If you need contact details for these groups, just ask at reception or, alternatively, visit our website www.supportyoursurgery.org.uk for further details. Or have a word with your doctor who will be happy to answer any questions you have.

Supported by the British Medical Association and the General Practitioners Defence Fund

BMA

Tracey writes: *After putting claims in for Incapacity Benefit etc I receive nothing (because of my partner working). I get my National Insurance stamp paid because I'm signed off sick by my doctor because of ME/CFS. I would like to work but as my illness is bad then 'good' (I use that term lightly) I can't do regular employment and have thought about agency work as and when I'm able. If I sign up for agency work would I have to come off sick or can you still work so many hours and still be signed off sick? The reason I ask this is because if I come off sick then I don't get my National Insurance stamp paid and the way things are there would be more days that I couldn't work than days that I could work so I don't want to come off sick for say 1 week a month and lose my NI stamp for the other 3 weeks in that month but I would like to do some sort of work. I hope I haven't confused you too much. I think the benefits system stinks....my partners working 6 days a week for us to live and its not like I'm not working because I'm lazy, its because I can't and I/we get nothing to help us.....its disgusting!*

I think that there are several issues here. The sick pay system is not quite as simple as you think. Short term sickness pays statutory sick pay—but this is usually from your employer. Sickness, longer than six months induces Incapacity Benefit and is dependent on National Insurance contributions or specific conditions. If you don’t have enough full time NI credits, you don’t qualify. At that point, Income Support may be possible, but this is means-tested. If your financial circumstances exceed the minimum then you don't qualify, as in the case of a high earning partner. Another income option would be Jobseekers’ Allowance, which you could get for being available for work four hours a week—but there are limits and it is means-tested and depend on National Insurance contributions. Disability Living Allowance is a state benefit for which many group members qualify, but it is difficult to get. It is tax free and in theory you can work with it.

The nature of ME/CFS is such that people appear to be normal, but it is only on stress, (environmental, physical or mental) that ME/CFS problems appear. Very often reasons for relapse cannot be identified, which is similar for other medical conditions like migraine or asthma attacks. The variability may make someone in employment unreliable for attendance and quality of work, thus virtually unemployable. That’s why many with ME/CFS are not working, and if they do it is usually only part time.

Agency work has always been unsatisfactory–mainly because of unreliability of income, security and sick pay issues. Ideal work would be with a small family business which could give you flexibility with the ups and downs of ME/CFS. Several of our members are in this position.
A sympathetic employer may be an option, but this type of job is rare and my experience is that they are not always sustainable. If money is not a big issue and you want something to do then consider working as a volunteer. Dial and SYCIL have taken volunteers into paid employment. On the whole with ME/CFS you have to find your own niche. The whole point of a support group is to share experiences and information to help you cope.

Trevor Writes *It think this newspaper cutting, dated 12/06/2008, may be of interest:*

Supermarket shopper dies after 'Supermarket rage' attack

By Richard Edwards and Caroline Gammell

A shopper attacked inside a supermarket after a row over queue-jumping has died. A shopper attacked at a supermarket checkout was killed in a case of mistaken identity, police believe. Kevin Tripp, 57, who was punched to the ground in front of horrified customers at the Sainsbury's superstore in Merton, South West London, on Tuesday evening, died last night. Witnesses claimed that the assault came after an 18-year-old allegedly offended the suspected assailant's wife moments earlier in the supermarket's car park. The wife then allegedly saw the youth arguing with a member of staff at the customer services counter and alerted her husband. But police suspect the husband mistakenly targeted Mr Tripp, who was standing behind the alleged trouble-maker. Detectives are now treating the investigation as a murder inquiry.

Mr Tripp, a structural engineer, lived in Wimbledon with a long-term partner, Josephine James, 50, and the couple have a five-year-old child called Rianna. He is believed to have suffered from ME, the chronic fatigue syndrome, and ran a website to help sufferers.

Police are studying CCTV footage which reportedly shows a woman making a telephone call and later pointing out the person who had allegedly offended her. Witness Mauricette Kouadio, 40, a customer services staff member, said: "There was a very rude 18 or 19-year-old guy shouting at me at the desk, insulting me and telling me he would 'break my face'. "I would not serve him because he was so insulting," she said. "Earlier he had said something rude to a woman in the car park. "She came upstairs with her husband and said to him 'That's the guy, that's the guy". "Standing behind the youth was an innocent man, waiting to be served. He fell on the floor. "He had a cut to his head, there was blood in his nose, his mouth was full of blood - it was everywhere. He got the wrong guy." She added: "I waited with the man on the floor but he was unconscious. I called the ambulance and the police came." Another witness said: "The victim was simply standing there. He was hit once and then slumped to the floor." A police source said: "It appears that this is a tragic case of a man being mistaken for someone else." A spokeswoman for Scotland Yard said: "We are investigating the circumstances." Mr Tripp was left unconscious. He was rushed to hospital in a critical condition where he was briefly resuscitated but soon slipped into a coma. A 37 years old man from Lewisham has been charged with murder.

Angels

Ten whole painful years, extreme M.E I'd dealt,
Losing everything, alone and lost I felt,

Struggling and crying, pain and fear I knew,
Trying many therapies, chasing every clue,

Wishing, begging, praying, hoping every day,
To free myself from harsh fatigue and to feel ok.

Relapse knocked me down again, from bad to even worse,
"PLEASE God someone help me to escape this evil curse."

Mike was there as usual, to listen to my plea,
Thank Goodness for his kindness, what he gave to me…

Details of Clouds Counselling, to guide me through my strife,
A ray of hope, an Angel, perhaps to save my life.

I telephoned the Counsellor, Sally was her name,
She helped me open-up inside, releasing guilt and shame.

I learned that it's ok for me to grieve and feel in need,
To cry about the active life, I had and used to lead.

I learned about acceptance, who I am is good and fine,
M.E can be a nightmare, but I deserve to shine

I'm still a worthy person; I'm not defect or bad,
It's not my fault I got M.E, I am no longer sad!

Sally helped me massively; she listened and was wise,
She taught me how to think and see the world through brand-new eyes.

Several months have passed now, but I still know she's there,
Should I need a friendly chat or someone just to care.

Now, as I end my poem, I send love from my heart,
To thank both Mike and Sally for helping me re-start,

To have more hope and confidence, more courage, joy, insight,
And an inner knowing that things are now all right.

Hazel Trudeau June 2008

Simvastatin: 1.5m More to Get Cholesterol Drug, but Is It Safe in ME/CFS ?

from the BBC web pages 27 May 2008.

Statins help reduce the risk of heart attack and stroke. The number of adults prescribed cholesterol-busting statin drugs in England and Wales is set to soar under new national guidelines. GPs are being asked to trawl through patient records to pick out "high-risk" patients who would benefit from them. The National Institute for Health and Clinical Excellence (NICE) estimate 1.5m extra adults will get treatment. But the British Heart Foundation warned those most at risk may still miss out on preventative care. It comes just a few months after the government announced vascular screening for all 40 to 74 year olds. It ensures an efficient and equitable method of targeting treatment to those most likely to benefit

Cardiovascular disease accounts for around one in three of all deaths. Under the latest recommendations, GPs would use computer software to pick out those aged 40 to 75 years who are likely to be at high risk of having a heart attack or stroke within the next 10 years. The risk assessment will be based on information such as age, sex, blood pressure and whether a person smokes and not just on whether or not they have high cholesterol. It will also take into account ethnicity and a patients' family history of heart disease. Patients will get invited into the surgery to double-check their risk and to be given lifestyle advice in addition to being offered a prescription for simvastatin, the cheapest of the statins.

NICE said the "systematic identification" of these patients, who may not even realise they are at risk, would prevent 15,000 heart attacks and strokes every year. About 4m people in England and Wales are already taking statins, they estimate. The additional drugs will cost £35m annually with £28m for identifying those at risk in the first year. Dr John Robson, a GP and chair of the guideline group, said it was a "major public health initiative" and would be a welcome addition to the governments' vascular screening programme. "It ensures an efficient and equitable method of targeting treatment to those most likely to benefit" he added. Professor Steve Field, chairman of the RCGP, said NICE were right to move towards preventing illness rather than just patching people up when they are ill. "There is evidence that if we can identify those at risk early enough, we can have a dramatic effect in helping people change their lifestyles and improve their health through specially targeted interventions such as smoking-cessation and earlier access to treatment."

But Professor Peter Weissberg, Medical Director for the British Heart Foundation said relying on patients to attend GP surgeries for assessment will fail to reach many of those from socially deprived and ethnically diverse communities who are most at risk. "This issue will have to be addressed if the government's vascular risk assessment programme is to achieve its aims," he said. He also criticised the decision by NICE to not advocate continued monitoring of cholesterol levels to make sure people at high risk are responding appropriately to statins. "This 'fire and forget' approach is likely to result in many patients being inadequately treated." A Department of Health spokeswoman said they were still working on plans for vascular screening for those aged between 40 and 74 years to minimise their risk of developing disease.

Are Statins Suitable for People with ME ? *The claimed incidence of side effects is supposed to be 1:10000. Over the past twelve months I have reviewed the medication of 40 ME/CFS members. Four members taking simvastatin have suffered side effects which resolved on discontinuation. This was reported to the CSM. The side effects reported to me included myalgia (muscle pain), myositis, and myopathy headache, altered liver-function tests, paraesthesia, and gastro-intestinal effects including abdominal pain, flatulence, constipation, diarrhoea, nausea and vomiting all which cleared on stopping. I do have issues with the doctors who prescribed these because they should have carried out thyroid function and liver function tests prior to prescribing, and these are common abnormalities in ME/CFS patients. There are other drugs that can be used instead of statins, and it is important to keep the cholesterol and lipid levels within the recommended guidelines by using alternatives. I covered this subject in detail in Pathways 2. (www.leger.me.uk)-Mike*

News from Fairlawns *The home of Sheffield NHS ME/CFS Clinic*

The Service Review is now complete, with Anne Nichol effectively being the administrative head of the clinic. Mark Adams has been allocated the job of Physiotherapist for long-term neurological diseases (this includes other conditions as well as ME/CFS). There is a new Champion on behalf of NHS Sheffield, who fund the clinic, and she is Maggie Campbell, who is physiotherapist and has a background in brain injuries. It is reassuring to see that ME/CFS is being treated as a neurological condition. The LPIG (Local Patient Involvement Group), has patient representatives from the clinic as well as representatives from the local ME/CFS groups. I represent the Doncaster group.

The first meeting on the new LPIG took place on 2nd May 2008. Among the issues raised again was the provision of a satellite service in Doncaster. Although initially promised four years ago, this has not materialised because of money limitations. Anne Nichol pointed out that distance was not necessarily a barrier to accessing the clinic, as there are different modes of access. What follows is a template for a letter which is sent to new referral patients.

Dear ______________
You have been referred to the specialist service for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) by Dr. _______. We would like to offer you an assessment appointment where we have the chance to hear about your CFS/ME from your point of view. We would like to offer you a choice about how this appointment can be arranged to best suit you,

If you would like to take up the offer of this initial appointment options available are:

A) Fill in a postal assessment form and return this to us. This would then be followed up by an appointment to enable the therapist to clarify details. This follow-up is likely to last for up to 30 minutes and can be either (1) A clinic appointment at Fairlawns or (2) A telephone call.
OR
B) Do not fill in a postal assessment form but cover the same information by attending a clinic appointment at Fairlawns. This appointment can last for up to an hour.
OR
C) Having a telephone appointment which can be organised at a time to suit you. Again this appointment can last up to an hour

Clinic and telephone appointments can be arranged between 9.00am and 5.00pm, Monday to Friday and can be adapted according to your individual needs.

We have enclosed a brief leaflet describing our service as well as a copy of the postal assessment form to help you to decide whether you would prefer option A(1), A(2), B or C for your initial appointment. Please could you contact us on 0114 2292037 to let us know which of the above options suit you best.

Please feel free to get in touch if you wish to find out more about the service or any of the options. If we do not hear from you by _______ then we will assume that you would prefer not to meet with someone from our service at the current time and we will let Dr _______ know.
We look forward to hearing from you,
Yours sincerely etc …

Although not ideal, it does show that the clinic is prepared to consider other ways of communicating as opposed to the traditional face to face appointment and long waiting list. Email and text communications were also considered, but there were concerns about privacy and security.
The next LPIG meeting will be on the 19th July. Part of my involvement is to represent the 'Doncaster Constituency' for the clinic. So, if you have any issues that you wish to be raised please contact me on 01302 787353.— *Mike*

Recipe Corner

Chocolate fridge cake with pecan and meringues

This chocolate cake is wicked and even better, no baking. Serves 16

Ingredients:-

200g digestive biscuits
110g whole pecans, roughly chopped
110g pistachio nuts, peeled (Chairman's favourite!)
10 glacé cherries
2 ready-made meringue nests, smashed up
150g unsalted butter
1 tablespoon golden syrup
200g dark chocolate

Method:-

Break the biscuits into small pieces directly into a large bowl. Add the pecans, pistachio nuts and cherries and then mix them well together.

Put the rest of the ingredients into a separate, heatproof bowl and put on a low heat over a pan of simmering water until the butter and chocolate have melted.
Combine the biscuit mix with the chocolate mixture.

Line a 30 x 20cm plastic container with cling film, leaving plenty of extra film at the edges to help turn the cake out later. Whack everything into the container, place in the fridge to firm up then turn out and cut into chunky slices.
This cake can be kept in an airtight container for a few days, and it actually improves in flavour!

Plum and Almond Tart

This is a great filling that gives you the delicate taste of almonds and the lovely texture of baked plum. Serves 8

Ingredients:-

500g short crust pastry
350g/12oz blanched whole almonds
300g/10½ oz unsalted butter
300g/10½ castor sugar
3 whole free range or organic eggs
1 handful whole pistachio nuts, shelled
6-7 plums, halved and de-stoned
3 tablespoons vanilla sugar

Method:-

Line a 28cm/11inch loose-bottomed flan tin with the pastry and bake it 'blind'.
In a food processor, blitz the whole almonds to a fine powder and put into a bowl. Then blitz the butter and sugar until light and creamy. Add this to the almonds with the lightly beaten eggs and fold in until completely mixed and nice and smooth. Stir in the pistachio nuts, then place in the fridge to firm up slightly. Once the mixture has chilled, pour it into your tart case about three-quarters full. You don't want to overfill it otherwise it will spill over the edge when you add the plums.
Toss the plums in the vanilla sugar, let them sit for 10 minutes, then push them into the tart mixture. Bake the tart on a tray at 180˚C/350˚F/gas4/ for about 1 hour, or until the almond mix has become firm and golden on the outside but is still soft in the middle. Allow to cool for about ½ an hour and serve with ice cream or crème fraiche.

Thanks to the Mirror on Sunday

Non-invasive structural and functional neuroimaging in ME/CFS

with thanks to M.E. Research UK

Investigator: Prof. BK Puri
Institution: MRC Clinical Sciences Centre, Imperial College, London, UK
Funding: MRC Clinical Sciences Centre, ME Solutions and ME Research UK

Background, aims and methods In historical publications on ‘epidemics’ of ME, symptoms consistent with central nervous system pathology were reported with regularity, and were as characteristic as the post-exercise malaise, myalgia and the range of other symptoms that patients experienced. Professor Donald Acheson, in his famous review, discussed such symptoms, pointing out that they were more consistent with cerebral damage than with other, psychoneurosis-based explanations prevalent at the time. Almost 50 years later, ‘neurological/cognitive manifestations’ form a key element of the Canadian Consensus definition of ME/CFS (2003) which insists that patients must have at least two of a list of six cognitive symptoms, including impairment of concentration and short-term memory, difficulty with information processing, and disorientation or confusion. Such symptoms can impact greatly on quality of life and employment; a high proportion of people with ME/CFS are unemployed, costing approx £3.4 billion annually in the UK in treatments, lost taxes and benefit payments.

It has not yet been established for certain what causes the prominent cognitive dysfunctions in the illness, but factors which might contribute include vascular insufficiency, metabolic dysregulation, or an ongoing infectious process. To date, a variety of structural and functional studies have been undertaken to try to identify physiological changes, but, as the table overleaf shows, the number of discrete studies is small, and the results have been mixed although nevertheless tantalising. As regards brain blood-flow, SPECT imaging seemed a promising technique initially, and areas of low blood flow in multiple brain areas in CFS patients were observed—the work of Ichise et al, Schwartz et al and Costa et al was seminal in this regard. However, other studies have had different results, and the value of SPECT imaging technologies for the diagnosis of ME/CFS (or any subgroups within that rubric) remains unproven scientifically. In separate but possibly related work, there are reports of subcortical “white matter hyperintensities”—areas of bright intensity—on MRI scans in CFS patients (e.g., Natelson et al and Lange et al , but such phenomena are not necessarily specific for this illness, are age-related, and can be found in at least some clinically healthy middle-aged adults.

Considering brain biochemistry, three recent research studies employing magnetic resonance spectroscopy have shown changes in the chemistry of the brain in patients with CFS, especially in relation to raised free choline levels; however, numbers of patients studied have been relatively small. Voxel-based morphometry allows for objective, automated analysis of high-resolution images of the brain, and this technique has recently been used on CFS patients revealing grey matter volume reduction (Okada et al and Lange et al). Significant reductions (11.8% and 8% in each study, respectively) have been reported in the brains of CFS patients compared with healthy controls, reductions apparently unrelated to age or duration of illness. The jury is still out, however, on whether grey matter reduction is a primary feature of the ME/CFS spectrum and on whether it is related to the underlying pathophysiology, or is a finding secondary to other processes. As well as the investigations above, a range of studies have reported cognitive deficits in CFS patients; these include impairments in attention, verbal and visual memory, concentration, acquiring new information, and psychomotor function, further suggesting deficits in basic motor or cognitive functioning.

Of course, as with all research on the full spectrum of ME/CFS patients, specific methodological factors complicate the interpretation of individual research results. The primary problem concerns differences in ME/CFS criteria used in various studies, and the fact that most definitions are so wide that they contain a variety of patient groups—from plain chronic fatigue to frank post-infectious myalgic encephalomyelitis. Sample size is yet another confounding problem (most of these studies have relatively few subjects) and the nature of the control groups can also be problematic. In addition, other factors specific to neurocognitive research might exist (a complication well-discussed in the review by Lange; for example, the various studies have used different neuropsychological tests, different technologies (for instance, SPECT cameras can range from single to triple-head, and MRI scanners have a range of field strengths) and various but distinct data processing methodologies.

Year	Author	Technology	Main finding compared with controls (quote)
2006	Yoshiuchi K	Xenon-CT	Reduced absolute cortical blood flow in rather broad areas
2005	de Lange FP	MRI	Significant reductions in global grey matter volume in both cohorts of CFS patients
2004	Okada T	MRI	Reduced grey matter volume in the bilateral prefrontal cortex
2003	Schmaling KB	SPECT	Pattern of diffuse regional cerebral blood flow in comparison with the more focal pattern of regional cerebral blood flow seen among healthy subjects
2001	Cooke DB	MRI	Presence of brain abnormalities in CFS are significantly related to subjective reports of physical function
2001	Lange G	MRI	Ventricular volumes in the CFS group were larger than in control groups, a difference that approached statistical significance
2001	Lewis DH	SPECT	Results did not provide evidence of a distinctive pattern of resting rCBF abnormalities
2000	Tomada	SPECT	The various clinical symptoms in CFS patients may be closely related to an abnormal brain function
1999	Lange G	MRI	Brain MRI abnormalities exist in a subset of patients with chronic fatigue syndrome
1998	Abu-Judeh HH	SPECT	Thirteen patients had abnormal SPET brain perfusion scans and five had normal scans
1996	Fischler B	SPECT	A pathophysiological role of frontal blood flow in the cognitive impairment and physical activity limitations in CFS is hypothesized
1995	Costa DC	SPECT	Brainstem perfusion is impaired in chronic fatigue syndrome
1994	Peterson PK	SPECT	Findings were not significantly different from those in the control group
1994	Schwartz RB	SPECT and MRI	SPECT abnormalities occur more frequently and in greater numbers than MRI abnormalities do in patients with CFS
1992	Ichise M	SPECT	SPECT provided objective evidence for functional impairment of the brain in the majority of the CFS subjects

Clearly, the body of evidence pointing to brain abnormalities in ME/CFS is tentative, and we cannot yet make definitive statements about the meaning of the body of literature quoted above. As can be seen from the list of studies in the table, however, it is entirely possible that well-conducted, objective structural and functional studies in clearly defined or subgrouped ME/CFS patients might yet be able to provide diagnostic information in place of the present deduction or guesswork about what might be going on in the brain. It is with this background, then, that the revised study at the MRC Clinical Sciences Centre at Imperial College London, jointly funded by the MRC Clinical Sciences Centre itself, and the charities ME Solutions and ME Research UK, will take place.

The lead researcher and grant-holder, Professor Basant Puri of the MRI Unit, Hammersmith Hospital London, intends to examine twenty-six patients (fulfilling the CDC 1994 Criteria and the Canadian Consensus Criteria for ME/CFS) and 26 age and sex-matched healthy controls over the course of 18 months. Each person will undergo a full medical history, a full physical examination, and MRI scanning. Generalised linear modelling will be used to analyse the statistical relationship between clinical symptomatology and parameters derived from MRI images.

The main objectives of the investigation are to assess the nature of any cerebral structural, biochemical and cognitive neuropsychological changes in people with the illness, and the relationship of these to clinical symptoms. The combination of brain chemistry measures, MRI assessments of the structure of the brain and white matter pathways, and global functional MRI may reveal underlying anomalies. The outcome of this research will determine whether or not a much larger study is justified.

A Travel Diary to Heart of Wales

Having been one of Dr. Sarah's private patients for about 16 years, I was naturally disappointed when she stopped the sessions in Mansfield after her riding accident. Arrangements for existing Doncaster patients to access her expertise in conjunction with their own G.P. via telephone post and email have been on the whole successful. My main reason for seeing Sarah was for EPD. a doctor in Sheffield now holds a monthly clinic for EPD, but she is an allergist, and not an ME/CFS expert. My management strategy is to remain one of Sarahs distance patients, and receive EPD in Sheffield. I knew that a at some point in the future, I would need to see Sarah face to face at her home surgery in mid Wales. Other group members have made the journey in the past, and although a long tedious journey for someone with ME, they have found it worthwhile and beneficial.

In mid May, health and family circumstances dictated that I needed an EPD, and an appointment with Sarah was the only available option. So how do I get there ? When a dose of EPD is involved, there are number of strict requirements regarding stress, diet and environment for it to be successful. Driving the 320 mile eight hour trip was out of the question, and being driven by a friend for eight hours would prove equally as stressing. There are plenty of hotels and guest houses in the area, but then there are issues of diet, environment and food. A holiday cottage would be ideal giving me control. In discussing my visit with Hanna, Sarah's secretary, it became clear that I was following in the paths of many others. They came up with a list of B&Bs. and I checked various internet sites.

Having found train journeys relaxing, and not ME-stressing, I considered that this was a good option. The various internet information systems came up with only two realistic four hour journeys with rail departure times 11 a.m. and 3 p.m. from Doncaster, involving changes at Sheffield, Stockport and Craven Arms involving a long walk over footbridges at all 3 stations, some with passenger lifts not being available. Joining trains mid-journey is always a lottery for seating, with opportunities for delays. There are only four trains a day through Knighton in each direction. Shrewsbury is a Doncaster sized station, with all the disabled facilities, and receives frequent trains hourly from Manchester. Manchester Piccadilly Station has moving airport style walkways and escalators, and is more disability-friendly. Trading off I decided to drive to north Manchester, stay overnight and in the morning catch a local train to Manchester Piccadilly, change at Shrewsbury, and stay overnight in the Knighton area. Homecoming would be the reverse.

Moving walkways at Manchester Piccadilly Station

Eventually I booked in at Gumma Farm, several miles away from Knighton. This was a working farm with a B&B sideline. Anne Owens, the farmer's wife was very accommodating with reference to my dietary and environment requirements, although understandably a little puzzled. She offered to arrange a taxi from Knighton station, to Sarah's, and back to Knighton. The only catch being that I would have a several hour wait at Knighton as my appointment with Sarah was at 12.00 and train back departed at 16.15 p.m. After a dose of EPD I am supposed to relax and be stress-free for the remainder of the day, so that seemed to work in fine.

Wednesday: Having arrived in North Manchester the previous day, I purchased the rail tickets. I was supplied with a journey plan; the outward journey changed at Shrewsbury, but the return Journey changed at Craven Arms, and involved a fairly long wait for a connection train. That evening Manchester was hosting the UFA cup final with Glasgow Rangers playing a Russian side. Being prudent, I decided to catch an earlier train than planned. Boarding the local train for Manchester Piccadilly (MP) turned out to be a ordeal. The train has come from Glasgow and was packed with rowdy blue clad Rangers supporters. Beer and wine bottles were making their way around the train. Police were all around, even on the train. However, the journey to MP was short, I left the train on platform 14. This a platform on a viaduct, some distance away from the main platforms, of which I needed platform 8. However the lifts, escalators and moving walkways were a saving grace. The station foyer was a sea of blue, with waves of rowdy Rangers supports arriving canned up. The bustle noise of the station was drowned by bagpipes playing ‘Scotland the Brave’. I sat on platform 8 waiting for my train, and had my packed lunch. After a while I realised that trains were not arriving or departing from the other platforms. Then came an announcement, my train was diverted to platform 13, up in the sticks, so off I went. My ticket was checked many times ,and I received conflicting information from station staff, and the departure screen. Only the echoey PA system seemed to know what was going on. Eventually, the train turned up about 20 minutes late, the updated platform information only reached the staff about two minutes beforehand.

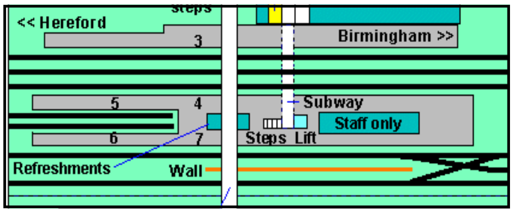
After boarding the train (Arriva Trains Wales to Cardiff), I tried settle to enjoy the journey, but there was a nagging concern. One thing the ME does is affect one ability to deal even the mildest anxiety. If the train were any later, I would miss the Knighton connection in Shrewsbury, and have a four hour wait for the next one. And what of the transfer between platforms? Checking my ticket the guard assured me that once out of the Manchester area, they can generally make up time. Needless to say that I was checking all the times against the timetable at the various intermediate stops. I was first off the train, and was directed to adjacent platform 5 on the same level, sandwiched between the two main lines to wait for the Knighton train with a few minutes to spare.

Not having been to Shrewsbury station before, my childhood curiosity was aroused. The signalling was a mechanical lower quadrant semaphore system. The main feature is that the red and white signal arm of the posts falls to clear the way. Around Doncaster, this technology was replaced in the mid 1940’s by upper quadrant signals, and on main routes coloured lights. I had believed the only place the earlier technology continued to exist was on preserved railways and in museums. Half expecting to see a steam engine, I was brought back to the present by the arrival of my train, or more accurately single decker bus on train wheels which was to take me the 34 miles to Knighton. On departure the train progressed, and then suddenly stopped. The driver scurried up the steps of a signal box , grabbed something, returned and then proceeded. Before Craven Arms station, prior to stopping, at the station we moved to the wrong side of the track. and stopped at the right hand platform on the wrong side. As on roads, trains usually keep to the left hand track. After departing, the train veered sharply right, leaving the main track behind. The was a big white trackside notice. “Your are now entering the ‘Knighton Token Controlled Section”, something normally only used on preserved railways.

We were now on the ‘Heart of Wales Line’. This a single track line, serving rural communities which surprisingly has survived the 1950’s ‘Beeching Axe’. Many of the stations on the line are just platforms, and are request stops. You have to signal the driver or tell the conductor to stop the train. The train was going 120 miles to Swansea, the whole journey taking 4 hours. The land adjacent is agricultural, with swathes of bluebells on either side of the track. The driver had collected a ‘Token’, or key giving him the right to enter the line. Apart from being a safety device to ensure there is only one train on the line at a time, this device locks or unlocks, signals, level crossing gates and enables access to railway drivers’ necessities like toilets, signalling reporting points and telephones. Without that token, signal and points are mechanically locked out, and even the signalman cannot override this. The conductor carried a ticket machine like a bus conductor years ago, and was very chatty. One thing he warned me about was that platform 2 was out of use in Knighton. Several stops were made for stations and level crossings before finally arriving at Knighton. My taxi was waiting. Knighton taxi drivers are as talkative as Doncaster drivers. I learned that, in these parts, Sarah was respected for her alternative views and well known in the area. Also, I heard all about organo phosphorous sleep dipping for warble flies, and how many farmers had been affected with fatigue states, and the practice had stopped. A parallel legacy with the chest problems suffered by miners from our area I thought.

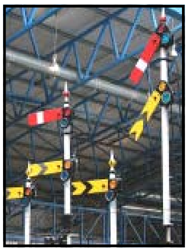
The stages of the journey, first by car, then from Manchester by rail.

A Sprinter Class 150 DMU (Diesel Multiple Unit) used on the Heart of Wales line, in Shrewsbury Station. They were originally manufactured by bus - maker British Leyland, and are capable of being coupled to together to form bigger trains



Shrewsbury Station. Trains from Manchester arrive at platform7 and depart from platform 4. The Swansea (Knighton) service departs from platform 5. There is level access with no steps. Disabled toilets are on the platform.

Lower quadrant signal s of the type used on the line.



A selection on display at York railway museum.

Going south from Shrewsbury. The train passes the biggest working mechanical signal box in the U.K.

The train turns right onto the 'Heart of Wales ' line after Craven Arms

Knighton Station. The station buildings are now a vet's surgery. The shelter blocks what would have been the exit. The white fence is now the exit and adjacent is ia screen showing train arrival and departure information. Platform 2 (foreground) is not in use, although surprisingly was recently ungraded.

A Bed and Breakfast and working farm. Gumma Farm, Discoed, Presteigne, Powys, LD8 2NP,Telephone:- 01547 560243

Upper Weston, accessed from the B4356 is via a steep farm track across the river Lugg valley.

Gumma Farm is a Wales Tourist Board 3-star Farm, a working farm, with all the associated sights, sounds, smells and atmosphere, mainly with sheep and beef cattle. The house itself dates from 1845 and has, like many in the area, taken on B&B to offset the reduced income from farming. I was greeted by Anne, and shown to my room. Looking through the front window was a well-manicured lawn, and the working farmyard could be seen from the back bathroom window. I saw the sheepdogs herding the sheep. Because it was early in the season, and I was the only guest, I watched TV during the evening, and listened to the bedside radio. There was no internet or phone so I had a peaceful night.

Thursday: After breakfast, I was collected by the taxi. The roads around that area are almost all single track, Upper Weston is halfway up the other side of the valley over the hill. It is only accessible from the road by a half mile steep limestone-chip farm track which drops steeply about 100 ft, crossing over the river Lugg and rises again about 120 feet to Upper Weston. It is a working farm, and the only acknowledgement that a doctors surgery exists is a discreet notice at the side of the back door saying ‘surgery’. When my turn came, I was surprised to see a normal healthy Sarah. Following her riding accident I wasn’t sure what to expect. She told me that she only had four days off work after the accident, and from then on it was business as usual. From her office window I could see the entire valley for a few miles in either direction. It must be one of the best views in the country from a doctors surgery.

I was taxied to Knighton Station. During the journey, I notice that the driver was driving very slowly—so I asked him why. Apparently he had to drive down so many farm tracks that the uses ‘snow tyres’ rather than normal tyres, and snow tyres don’t last very long if you drive fast. I arrived at Knighton station about 2.30 p.m. My train was due at 4.15 p.m. It started to rain so I waited in the shelter and read the latest handouts from Sarah. After a while I was joined by an elderly lady who had been shopping in Knighton. Apparently the bus service is not better that the train. She was complaining bitterly about having to pay to travel. There were regional issues because the line crosses the English/Welsh border several times. Apparently The Welsh Assembly had suspended free pensioner travel on the Heart of Wales Line, and was to resume it in October. We were joined by others who had been walking the Offa’s Dyke Path, a local ancient Dark Ages relic.

After boarding the train, I queried with the conductor why I was timetabled to change for a Manchester train at Craven Arms rather than Shrewsbury. Surprisingly his ticket machine had all the national timetables installed, and he was able to tell me that if I stayed on to Shrewsbury, I would catch the same train, but more importantly, there was a tea-room there, Craven Arms is just a platform. However when we arrived in Shrewsbury, a Manchester bound train was half an hour late—due on the adjacent platform in 4 minutes ...so no time for tea. On boarding the train it was announced that it was only going as far a Crewe, then wasn’t, then was wasn’t ditto. Eventually in stark contrast to the Knighton line conductor, this conductor came onto the PA system and in a metallic voice said ”If I get off at Crewe, follow me, otherwise say on the train”! After arriving in Manchester Piccadilly I quickly made my way via the moving walkways to the Glasgow train. And yes, the carriages were a sea of blue with disappointed rowdy Glasgow Rangers supporters returning home . Fortunately I was only on that train for 15 minutes and the taxi was waiting to take me to the North Manchester Hotel. After a dose EPD, I always have a ‘flu-like rebound for several days. It was Sunday before I was able to drive back to Doncaster.

Was it worth it? Yes. The Manchester-Shrewsbury-Knighton route involved very little walking (about 30yards) through railway stations. The overnight accommodation and taxis kept walking and stress to a minimum. Did the EPD work? Yes. Would I do it again ? Maybe, if necessary. If anyone were visiting Dr. Sarah, it would be better to drive, and stay in the area for a day or two as the Knighton area has a number of tourist attractions. As an alternative to staying overnight, you could get a very early train from Manchester to get the 9 05 am train from Shrewsbury to arrive at Knighton for 10 am. You could then return on the 12.20 or 16.20 train. Change at Shrewsbury, not Craven Arms, and remember that platform 2 is not in use at Knighton—*Mike.*

Writing a Will.

Adapted from information provided by HSBC Bank's Janice Warman.

Given that 100% of Britons are unfortunately going to die it seems extraordinary that more than half of us don't actually think ahead and make a Will. Yet for all but the most complicated estates, making a Will is easy, providing you take professional advice. You can buy Will-writing packs from high street stationers, and services abound on the Internet. However, these can create more problems, so the best way to write a Will is by going to a professional. It's not expensive - at least in comparison with the chaos that will be caused by the absence of a Will or one that isn't properly drawn up. Most solicitors, and banks offer Will-writing services and many charities offer advice on their websites.

We in the UK benefit from having the right to decide to whom we leave our money and possessions. Making a Will allows you to choose exactly how your assets are distributed, giving you the reassurance of knowing that you have provided for those closest to you. You decide who benefits from your estate. It prevents the law from superseding your wishes. (In the worst cases, if no Will is left, all assets go to the state) It can help to minimise any Inheritance Tax liability on your estate and allows you to choose your executor and specify your funeral arrangements as well as ensuring that you minimise the amount of Inheritance Tax (IHT) your heirs will pay.

Rules surrounding IHT change constantly. Chancellor Alistair Darling doubled the value of assets married couples and civil partners can leave without incurring the tax to £624,000. This will rise to £700,000 by 2010 . This means most couples won't incur the tax, as 97% of UK homes are worth less than the new threshold. However, the move has not helped those who live together but are unmarried and are not civil partners. Many have married before and are reluctant to do so again. And Inheritance Tax isn't the only thing to worry about. Many families these days are fragmented by divorce and remarriage. If you have estranged children, it's wise to put a note with the will to explain why provision hasn't been made for them, or even to leave a small .amount to show that you haven't forgotten them and are writing the Will with your mental faculties in place. This means they are less likely to contest the Will. Spouses and civil partners can also insure against the tax liability due when their survivor dies. They can take out a whole-of-life policy, which is written in trust for the beneficiaries to avoid it being part of the estate and subject to IHT. Will-writing services really can help and HSBC can advise on making gifts to reduce your estate for tax purposes. Gifts into trust can help ensure beneficiaries won't receive money until they are at least 18. If a beneficiary divorces, the capital in a trust will not be taken into account for the divorce settlement.

You can leave legacies in a Will, or make a gift in your lifetime, to charities or charitable causes. Mike Coulshed, Head of Technical Consultancy at HSBC, says: "We get one or two wealthy clients who want to set up a charity of their own in their lifetime. If they have particular interests, they might fund a scholarship or a particular cause rather than their money being absorbed into the coffers of a large charity." One such charity was created for the poor pensioners of a certain area. "It was a big trust, so there are far fewer poor pensioners there now," says Mike. Another benefits animal charities and has built a new hide for the Royal Society for the Protection of Birds, while a further trust has been used to buy a scanner for a local hospital. "But below certain level it's not really worth creating your own charitable trust," adds Mike. So you may not be able to afford to leave £59 million to charity, like Christina Foyle, owner of the famed bookshop, but you could give enough to make a difference, and, at the same time, cut down on the amount of Inheritance Tax your heirs will have to pay. Well, they say charity begins at home. "Inheritance Tax isn't the only thing to worry about. Many families these days are fragmented"

If you have pets, clarifying arrangements for them will set your mind at rest. You can also set out what happens to your personal belongings as well as your larger assets - all of which may change over time, particularly if you decide to give away jewellery or other possessions earlier. You can also gift money to animal charities or related causes. "You can give money outright or into trust," says Mike. We in the UK benefit from having the right to decide to whom we can leave our money and possessions. By contrast, in Europe - notably. in both France and Spain - there are strict succession laws, the implications or which are that citizens and even owners of holiday homes may not be at liberty to choose who their heirs are going to be. If you have a home abroad, it's vital that you take advice from a local solicitor and ensure that your Will is correctly worded.

TOP TIPS

- Make a list of all your assets.
- Engage a professional, do not use a DIY kit.
- State that this Will revokes all others.
- Have it witnessed by two people who are not beneficiaries.
- Appoint an executor or executors to administer the estate.
- Review your Will if you marry or remarry, or your financial or relationship situation changes.
- Keep your Will at home, with a solicitor or in the bank.

The Costs. As an example, HSBC state that their fees start from as little as £75 (including VAT) for a single Will and from £2,000 (not including VAT) for executorship services. If you need specialised technical advice, there may be a further charge for that advice. They will give you an estimate of the cost when we understand your circumstances and before we involve the specialists. They offer a Will-writing Service for customers wanting to appoint HSBC as executor - with advice to help you make the right decisions about your estate. Access is available to a highly skilled technical team who will advise on particularly complex circumstances. Professional and impartial executorship services are also provided–relieving family members of the burden of being executors. Most of the bigger banks offer similar services.

* * *

My own experience is in using a local family solicitor. They offer the same sort of service that Banks do, but may be more appropriate for people with lower incomes. The Law Society provides standard guidance for solicitors, so that the right sort of questions are asked. Typically after deciding to make a Will, you need to do a financial and asset stock take, and deciding what you would like to happen, then choose a solicitor or other professional. At your first appointment, a standard series of questions will be asked, you assets will be assessed and your wishes recorded. A solicitor will then look at the legal aspects, and further ask for appointments or information which may be needed. Finally you receive a draft Will which you check out. When everything is satisfactory, you make an appointment to sign the Will. Once signed, that becomes legal. Signing has to witnessed by two people. The witnesses are not allowed to see the contents of the Will, only the signature. The cost is typically £75 + vat, unless you are very rich.

Not making a Will can cause complications. Both my grandfathers were coal miners. After the demise of British Coal, the NUM negotiated a compensation scheme for former miners whose health had been damaged e.g. through dust inhalation, pneumoconiosis. One grandfather died in 1973, and the other in1987. I started a claim on behalf of the family in 1994. For the scheme, all legal fees would be paid by the Government. No proper Wills were normally made by miners in those days, but grandfather left a DIY Will. The first hurdle in the claim was to establish who the descendents were. It was then necessary to obtain Court Probate orders for the spouses or surviving children, In one case the compensation inheritance would pass through three estates—the other two. Had Wills been made things would have been simpler. A local Doncaster landowner not making a proper Will resulted in loss to the estate and a legal precedent being set.
-Mike

The Thellusson Will Case *(Wikipedia)*

Brodsworth Hall

The Thellusson Will Case was a law-suit resulting from the will of Peter Thellusson, an English merchant (1737-1797) owner of Brodsworth Hall. He directed the income of his property, consisting of real estate of the annual value of about £5000 and personal estate amounting to over £600,000, to be accumulated during the lives of his children, grandchildren and great-grandchildren, living at the time of his death, and their survivors. The property so accumulated, which, it is estimated, would have amounted to over £14,000,000, was to be divided among such descendants as might be alive on the death of the survivor of those lives during which the accumulation was to continue.

The bequest was held valid (Thellusson v. Woodford, 1798, 4 Vesey, 237). In 1856, there was a protracted lawsuit as to who were the actual heirs. It was decided by the House of Lords (June 9, 1859) in favour of Lord Rendlesham and Charles Sabine Augustus Thellusson. Owing, however, to the heavy expenses, the amount inherited was not much larger than that originally bequeathed.

To prevent such a disposition of property in the future, the Accumulations Act 1800 (known also as the "Thellusson Act") was passed, by which it was enacted that no property should be accumulated for any longer term than either

the life of the grantor; or
the term of twenty-one years from his death; or
during the minority of any person living or ‘*en ventre sa mere’* at the time of the death of the grantor; or
during the minority of any person who, if of full age, would be entitled to the income directed to be accumulated.

The Act, however, did not extend to any provision for payment of the debts of the grantor or of any other person, nor to any provision for raising portions for the children of the settler, or any person interested under the settlement, nor to any direction touching the produce of timber or wood upon any lands or tenements. The Act was extended to heritable property in Scotland by the Entail Amendment Act 1848, but does not apply to property in Ireland. The Act was further amended by the Accumulations Act 1892, which forbids accumulations for the purpose of the purchase of land for any longer period than during the minority of any person or persons who, if of full age, would be entitled to receive the income. It is believed that the Thellusson Will case provided the basis for the fictional Jarndyce and Jarndyce.

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

The Stone-age Diet *by Dr Sarah Myhill.*

(Upper Weston, Llangunllo, Knighton, Powys, Wales, UK LD71SL, 01547 550331)

There are five aspects of diet and gut function which commonly cause symptoms from irritable bowel syndrome to fatigue. These are:

- High carbohydrate intake - this is probably the largest single cause of modern diseases such as hypertension, obesity, syndrome X, heart disease and cancer.
- Food allergy
- Toxins IN the diet. (lectins naturally present in foods; artificial additives, colourings, flavourings; artificial sweeteners; pesticide residues, plasticizer residues, etc) social chemicals (alcohol, caffeine, tobacco etc).
- Gut dysbiosis (wrong bugs in the gut)
- Poor digestion of food due to low stomach acid (hypochlorohydria) and poor pancreatic enzyme production.

This diet tries to address the top three problems at the same time, since they often co-exist in the same patient. This is the diet I like all my patients (including me) to eat long term. This is because it is the evolutionary correct diet and by eating this we can avoid long term health problems and postpone degenerative conditions. I would settle for getting my Parkinson's disease when I am 120! As a general principle it is important to remember that carbohydrates tend to cause fatigue, even in "normal" people. We should be eating protein and fat in the day and saving carbohydrate (CHO) until the evening, when it helps sleep. At present Western diets are completely upside down because we eat cereals and toast at breakfast, sandwiches at lunch and meat in the evening - it makes you feel tired in the day and wakes you up at night! Food allergy is a common cause of many symptoms such as irritable bowel, asthma, mood swings, headache, arthritis, allergic muscles and of course, fatigue. The commonest offenders are grains, dairy, yeast and toxins in the diet. Chemicals in the diet inhibit enzyme systems and slow up metabolism - this applies to drugs as well as food additives and pesticide residues. Avoid additives; colourings, flavourings etc, avoid plastic wrappings (especially if heated!) on food and try to switch to organic foods wherever possible. Gut dysbiosis and poor digestion of foods, whereby foods are fermented instead of being digested, can also cause these symptoms.

This diet, therefore, has foods of low glycaemic index (GI) in the day and moderate GI index in the evening, it avoids the common allergens, avoids mouldy foods and foods of high fermentable substrate and is as free from chemicals as possible. Actually, in the long term I see this as a diet for life. My view is that we should be mimicking stone-age principles - the following is the evolutionary correct diet. Once the diet is established, one does not have to follow it slavishly - but it should make up our staple diet and ultimately the forbidden foods should become treat foods and not staple foods.

Foods allowed in the day

Any meats - choose from chicken, beef, lamb, pork, turkey, duck, 'game' meats such as venison pheasant, goose etc. Bacon and ham. Salami. Liver, kidney and offal is fine too.
Eggs an excellent source of lecithin (eat soft yolks), which reduces blood cholesterol levels.
Any fish - salmon, mackerel, cod, haddock (care with smoked fish, which often contains dyes).
Tinned fish in brine or olive oil is fine. Tinned shrimps, prawns, mussels, cockles etc.
Any green vegetables. Cabbage, Brussels sprouts, broccoli All salads -lettuce, tomato, cucumber; celery, peppers, onion, cress, bamboo shoots etc. French dressing - make your own from olive oil, lemon juice, garlic, mustard.

Any low CHO fruit - apple, pear, orange, grapefruit (no sugar!). Berries are excellent. Seeds - sunflower, poppy, sesame. Nuts - peanut, brazil,. hazel, cashew, pistachio, walnut etc nut butter spreads, tahini (sesame seed spread).
Use cold pressed nut and seed oils liberally such as sunflower, olive, sesame, grape seeds, hemp. linseed, rapeseed and so on.
Soya products
Spices: chilli, cumin, ginger, coriander, pepper, cloves etc
Herbs, salt (ideally Solo - a sodium reduced sea salt), olives, pork scratchings

Drinks allowed in the day

Bottled or filtered water Herbal tea - e.g. redbush ("rooibosch, 11 O'clock tea), rosehip tea.

In the evening

You can eat all of the above, modest amounts of higher GI foods
Rice and potato e.g. rice cakes or puffed rice from health food shops.
Root vegetables - carrots, parsnip, turnip, celeriac
Buckwheat, sago, quinoa.
Banana, avocado, grapes, melon (ie high CHO fruits)
Dried fruit - sultana, apricot, prune, raisin, fig date etc
Pulses - lentil, butter beans, chick peas, flageolets etc
Grape juice, pineapple juice, apple juice, tomato juice - best drunk diluted.
Mixture of nuts, seeds, dried fruit, Arrowroot flour - for thickening gravies
Most foods from packets and tins will have hidden additives, so avoid these. ALL OTHER FOODS ARE FORBIDDEN - this means no tap water, tea, coffee, chocolate, alcohol, wheat (bread, biscuit, cake, pasta, pastry), rye (Ryvita), oats, com, dairy products (milk, butter, cheese, yoghurt, dried milk), vinegar and sugar. Be careful with sausage which contains rusk. Try to avoid drugs and medicines, many of which contain fillers of com, lactose, colourings etc.

Getting Worse on the Diet

This is almost to be expected. The reasons for worsening are as follows:

- Hypoglycaemia - this is the commonest reason for worsening and may take weeks to settle. There are some nutritional interventions which help greatly (see my feature hypoglycaemia - not just about diet)
- Caffeine-withdrawal is again common. It usually resullts in headache which clears in four days.
- Food allergy withdrawal may cause many different symptoms.

Some people report feeling 'flu like. Typically this last four days, but with symptoms like eczema arthritis, allergic muscles and fatigue it can take weeks to clear. One patient with prostatism took 4 months to clear! If the withdrawal symptoms are too bad, then relax the diet a little, wait a few days, then tighten things up again

Meal Suggestions

Breakfast:
Bacon, eggs, fried tomato, mushroom, onion, Smoked fish (kippers, mackeral with lemon juice). Nuts and seeds with soya yoghurt (see probiotics and kefir)
Lunch:
Cold meat, fish (tinned fish in olive oil is fine), prawns, salami, smoked fish, rusk-free sausage (i.e. 100% meat) Salad (lettuce, cucumber, tomato, celery, peppers etc), French dressing. Green vegetables with olive oil, nut and seed oils Home-made soup (made from meat stock only with allowed vegetables). Nuts and seeds with soya yoghurt.
Supper: Meat, fish or eggs, potato or rice, any vegetable, salad. Fruit, soya yoghurt. Muesli

made from rice flakes, millet flakes, nuts, seeds, dried fruit, fresh fruit etc (some health food shops do "gluten free" muesli with the above ingredients). Use soya milk or fruit juice to wet the dry cereal. Puffed rice or rice cakes with soya margarine, nut butter. Buckwheat flakes.
Breakfast like an Emperor, lunch like a King, supper like a pauper

What to do if YOU are no better on the diet

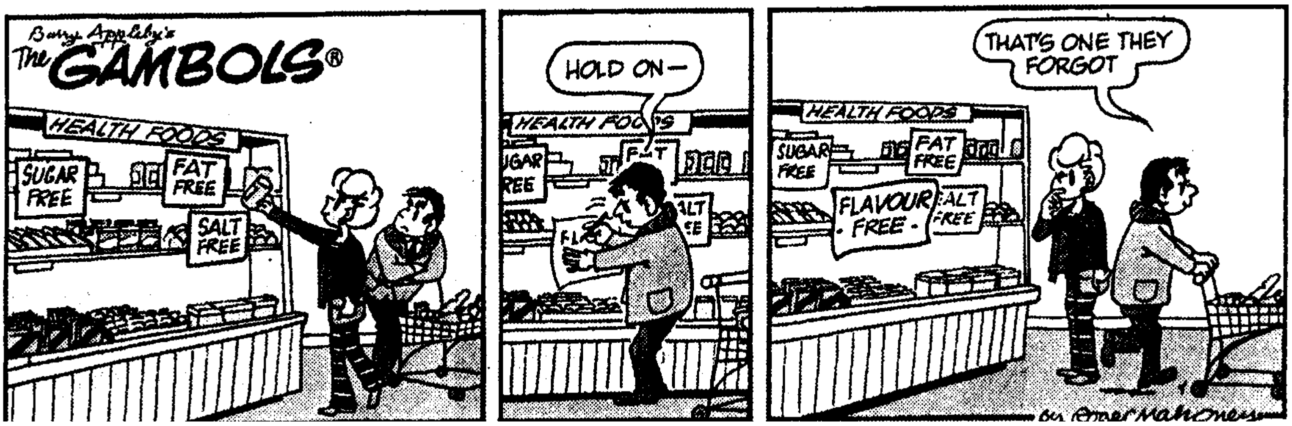
Stick with it! This is the evolutionary correct diet and greatly reduces your risk of heart disease, cancer and degenerative conditions! The two common reasons for not improving are:

1. Because of multiple allergies to foods (so that there is something in the diet that you continue to react to). In this case consider a rotation diet, or starting on desensitisation (see EPD).
2. Because of a gut dysbiosis - i.e. the wrong bugs in the gut. Consider a gut fermentation test or Comprehensive Digestive Stool analysis to look for parasites, bacterial overgrowth or yeast overgrowth.
3. Poor digestion of foods - see hypochlorhydria

If you wish also to lose weight

As a general principle I don't like my CFS patients dieting because cutting calories makes you tired, cold and depressed and you can do without those things! However, if you are extremely strict with CHO, the body switches into a state of ketosis. To break down fats in the body is a two stage process - the first stage is conversion of fats to ketones, the next is ketones to carbon dioxide and water. Both stages release energy for the body to use. However, the second stage requires some CHO - if there is none then ketones are excreted in the breath and in the urine - one literally pees out calories. This is very good for morale when every time you pee you lose calories and weight! To do this diet properly you really need to get the book *Dr Atkin's Diet Revolution* which goes into detail of exactly which foods you need. Also I can supply ketostix which measure ketones in the urine and tell you if you are doing the diet correctly. Atkins permits dairy products but I recommend avoiding these. He also permits various artificial sweeteners which should be avoided.

Recommended reading:
"The Complete Guide to Food Allergy and Intolerance". Brostoff and Gamlin, £9.99.
"Not All In The Mind" - Richard Mackarness
"The Food Intolerance Diet Book" Workman, Hunter and Alun Jones.
“Dr Atkins Diet Revolution”- Dr Robert C Atkins.
“The Detox Diet” Dr Paula Baillie-Hamilton 0-718-14545-3 from www.penguin.com .



Thanks to the Daily Mirror

North of Doncaster *Personal Comment by Trevor Wainwright*

Once again back to 1998 another year for firsts in the ME world, one of which was the BRAME (Blue Ribbon for the Awareness of ME) campaign. Parliamentary Awareness Meeting, following on from the Fighting for the Truth lobby of 1997.

But before that was the first ever Hospital Radio ME Awareness Show. Having done a similar show for AIDS Awareness in 1996, and seeing how others involved enjoyed taking part, I got permission from the station management and away we went. As a run up to the BRAME Event, telephone interviews were done with the participants, local suffers, carers, and a home tutor who openly criticised the education system. Even the technician for the day, Mike, a fellow presenter, knew someone with ME and he gave a wonderful interview on how he became aware, through a “drinking buddy” of whom they wondered at first what was wrong Then as they found out more they were more concerned for him. So on to London once again, another early start and the long journey down, this time with my nephew Colin; we’d worked together for Bosnia and now were working together for ME. Arriving at Westminster there were some familiar faces, once again I met Tony Wright, this time to hand him a petition from Castleford calling for greater awareness of ME in Parliament. Introductions were made, interviews were given; there was a wonderful air of optimism.

Then it was into Parliament and so to the Grand Committee Room. Aafter a series of problems the meeting started with Tony Wright MP introducing the event, then Tanya Harrison who during her opening talk paid tribute to the bravery of Australian ME sufferer Alison Hunter who had recently died as a result of ME,. She had to pause briefly at this, but the audience waited patiently for her to carry on. Tanya also said that the term ME would be used as opposed to CFS. Betty Dowsett began in her usual style almost thumping the lectern as she began with “Why am I here, because my patients need me”, having a go at the government for not doing enough. Simon Lawrence spoke next about the severely affected. It was then that I noticed a young sufferer had left her wheelchair and was laid on a bolster for greater comfort, it wasn’t rocket science to notice that she was having problems, if only those who said it was all in the mind were here now I thought. Dr. John Richardson was next, one of the founders of the Newcastle Research Group. He would eventually be the first recipient of the Mothers against ME Heart Award and well deserved too. During John’s talk I took the opportunity to go outside for a break, shortly afterwards the young sufferer who had been laid on the bolster was brought out in her wheelchair, totally upset at having to go home, “at least you’ve got here” I said to her, “more than some have done”. Going back into the room I noticed Simon had got off his chair and was now sitting on the floor leaning on it for greater comfort; once again I thought of those who said it was all in the mind, mentally thinking why aren’t they here. Steve Jarvis spoke of a benefits survey his group had carried out. Some of the surveys had come from Castleford and Wakefield, and yes we’d contributed to that as well. Finally it was the turn of Megan Shannon who spoke of ME in the USA.

Right Men, NO state benefits unless you can work

After the meeting it was time for me to ring the radio station with a report on the day; it was Mike doing his programme. At the end of my report on yet another event certain groups had failed to stop, I was asked if there were any big name supporters there. My reply was “There were no Esther Rantzens, Princess Michaels or Clare Francis’s’ there, but what we have to ask is after today do we really need them, no we don’t”.

Travelling home that night I thought of what Tanya said in closing her statement: "It is said that every journey begins with a small step, but I hope today is a giant leap towards the acknowledgement and recognition which is deserving of such a chronic and debilitating illness, which is a life-changing experience for all those living with M.E. Please remember that today is not just an event, it is the beginning of a new way forward." The question for today, as we edit Pathways Number 16 is, “Just exactly what has been achieved since.” Some think “Nothing”.