

Pathways

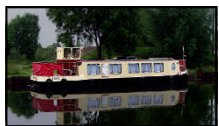
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The newsletter of Leger M.E. Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Are Disbelieving Doctors Extinct ?

With the CMO's report and Sheffield Clinic, we would expect that all the disbelief and bias would disappear. Although we have the Gibson Report, and the NICE guidelines imminent, we would expect this to be the case. However recent events would suggest otherwise. We have two excellent ME doctors being pursued by the General Medical Council. Recently I came across a case of Incapacity Benefit Refusal of a established case, given zero points! In July the DWP steamrollered through the 10th revision of the guidelines for Disability Living Allowance. So what is happening ? Only time will tell.

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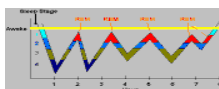
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You Write *A selection of letters and emails from the Leger ME office*

Jenny writes: When I was Chairing the York & District ME Support Group, I became aware of approaches that were tackling ME in a very new way and seemed to be promoting significant and often rapid improvements in some individuals. One of these was the Lightning Process which came to prominence earlier this year following an article in the Daily Mail by Esther Rantzen who described how her daughter Emily recovered from ME using the process. It was also featured on Radio 4 towards the end of July in an audio diary of a 13 year old, "Leo Rusty and ME", with a follow up on BBC's *You and Yours*.

The training process includes elements of Neuro Linguistic Programming (NLP), osteopathy, self hypnosis and life coaching. These include series of body movements, postural changes and advanced language patterns. It is believed this results in the building of new neurological pathways which produce an improved physiological response. These changes impact positively on symptoms of ME including tiredness, muscle fatigability, digestive difficulties and immune dysfunction. The schedule is by appointments on 3 consecutive days. The first and second days are usually around 3 hours long in a small group, and day three is either 1 hour, one to one, or 2 - 4 hours as part of a group. This is usually followed by one or two 20 - 30 minute phone calls to support you in applying the process when you return home. On day one participants learn the process, and start to use it immediately. The other sessions are for fine tuning. Individuals are benefiting from this approach, though it is new and an evaluation, which is underway using scientific protocols, is yet to be completed.

Jenny trained as an occupational therapist, but due to ME/CFS she did not complete the training. Now she is recovering, she has trained as a Lightning therapist. From late September, she is planning to be working to help people with ME/CFS, and is hoping improve their lives. The Lightning Process website www.lightningprocess.com contains further information. One of the issues I raised with her was the cost. She says it will be around £560 for the 3 day training programme, based in York. I have heard mixed reports on the Lightning Process. If you want to meet Jenny or know more about the process yourself, she has agreed to speak at our 23rd November group meeting. - Mike.

Andy Writes The Doncaster Disabled Peoples Alliance has recently set up a social enterprise whereby we will be refurbishing equipment as used by disabled people and then re-selling on to people at a lower cost. The group will be trading under the name of RED (Recycled Equipment for Disabled people). We are interested in items such as wheelchairs, crutches, bathroom aids and any equipment which may be lying about or gathering dust in an attic or a garage. The organisation is hoping to recycle as much as possible, this will avoid items being sent to land fill sites or ending up unwanted and dumped on the streets or country lanes.

The DDPA/RED are working in partnership with Doncaster Re-furnish and all donated equipment will be collected by them and stored at their warehouse at Carcroft where it will be refurbished. We would be grateful if anyone could help with donations of equipment, or knows of organisations that may be able to help us. We are also looking to recruit new volunteers, especially those with an electrical or mechanical background to help refurbish these items. If you would like to become a volunteer for the DDPA you would be most welcome.

Andy has agreed to attend one of our monthly meetings, possibly in September. Does anyone have an unused wheelchair or other disabled equipment? If so the DDPA can be contacted on 01302 349490 or e-mail admin@ddpa.org.uk or write to: DDPA, Andy Hendry, Hay Wake House, 28 Christchurch Road, Doncaster, DN1 2QL.—Mike

Trevor Writes Well I suppose it had to happen, it dropped through the letter box - a request for Paula to go for a PCA (IB50) medical. So first a phone to the organisation behind the event to ask about the doctors, "are they aware of ME?" I asked. "Well they are doctors" was the reply "so what - that means nothing" I countered, adding "a car mechanic may know about Vauxhalls, but that does not make him a Ford expert". With this I closed the conversation, having decided it was going nowhere. So the next plan, get some advice, so via the internet out went my request and the replies came back, all except

from one list who returned my post saying "this is more suited to a discussion list". I replied "I need help, not a debate". It was to no avail, so I unsubbed, which was a change, usually it is me that gets unsubbed by the moderator, cos' I've upset them or one of their pets. The info came in and I ran page after page off, all good quality information, all relevant, the hardest choice being which to use, I did have an idea though. We would take with us: The BRAME Information Sheet, Tymes Trust *Advancing the care of People; with ME*, Tymes Trust *Quick Tour of ME Symptoms and Management*, *The Carers Practice*. Margaret and I wrote plus an overview of the Canadian Definition.

On the morning DWP rang and asked if we would come early due to a cancellation and were rather surprised when we said no, "but we can get home early if you do was their reply". Did they really have a clue we thought, did they think illness symptoms came to order. We arrived, parking as near to the premises as possible. In we went to the reception then into the consulting room, all three of us which was a surprise, I had expected to have been kicking my heels in the waiting room. I had taken with me a notebook and sat there ready with pen in hand to take any notes. So the interview began. To my surprise the doctor was pleasant and treated us with respect, particularly Paula. He allowed us to ask questions as the interview progressed; at all times it seemed that his concern was for Paula as a patient and not just a statistic. During one part, where Paula had to lie down and lift her legs up one at a time, I mentioned that during moderate movement lactic acid was produced by even moderate exercise which led to pain and fatigue. At this, the doctor replied that he had heard of many theories. I mentioned that this had been fact since 1995 when the CFSRF then the PVDRF funded research by Len Archard and Russell Lane which had proved this.

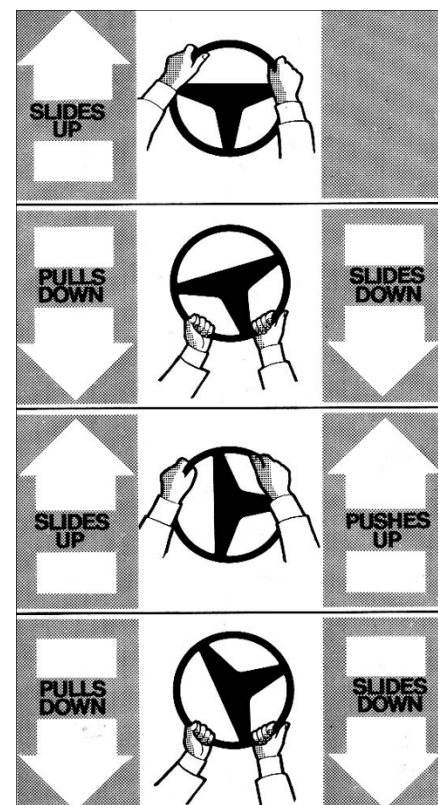
At the end of the interview we were asked if there was anything further we would like to add. At this I asked if he would like to know more about ME. He said yes, he was always willing to learn more. I explained that I was the Patron of a peoples movement and offered him the information I had brought. He willingly took it and we left the premises. Getting into our car we saw him walking to his car carrying with him the information; he looked over nodded and smiled. Just over a week later the Brown Envelope came through the door. Paula's benefit was to continue for the time being.

I have LME group leaflets for the PCA and IB50 forms for INCAP and Income Support available via the office or website. Mike.

Michelle Writes After reading Trevor's letter in You Write, about advanced driving, I took the plunge and contacted my local IAM group, and enrolled for a course. The first thing they did was to give me a refresher lesson on how to hold a steering wheel the quarter to two, or ten to two position, and how to feed the steering wheel through your hands. Apart from the safety aspect of having full control of steering, I found that using their technique is less tiring and seems to take less effort, with a consequent benefit to the ME.

The thing is that you've benefited from the first session already, and further study can make you an even better driver. As you progress, you'll learn the System of Car Control and use gear and brakes less often. This will cause less wear and tear on you and your car. Surprisingly, the police in Sheffield say that using this technique they can get 100,000 miles out of a clutch.

I did the IAM Advanced Driving Test in 1985. That's a two hour test with a police driver. Whether I could do it now, with ME, is anyone's guess. After I passed the test, I did about 25% more to the gallon. I think refreshing driving skills is a good thing to do. I will contact the local Doncaster IAM group and see if they are prepared to give us a talk and demonstration at a group meeting –Mike.



The steering wheel technique as shown in 'Roadcraft', the police drivers instruction manual.

Sam Writes: I have a private ex directory telephone line which I allow to be used for group business. It also is registered with the telephone preference service. One morning I was woken at 5.00 am and 6.00 am by two SMS telephone calls from 08456 021111. This is a commercial number, producing junk SMS messages. I view such calls as intrusive and offensive. I have complained about these particular calls to OFTEL. I have instructed BT to remove the SMS facility from this line, as this has been installed by BT without agreement or permission.

BT are devils. Something similar happened to the help line. I have an answering machine on 01302 787353 for the group helpline. I ended up having calls missed and the helpline went silent. It was not until a urgent message was missed and I pursued the issue that I realised that BT had put the 1571 answer system on without my agreement. I was very angry, and literally blew my top with them. The messages are deleted after a time, and I had no idea about this. You can have 1571 permanently removed free of charge. I have a number logging system on the helpline, so if a call is made, even if a message is not left, I know who has called, providing the number is not withheld. —Mike

John Writes: I suffer from MCS (Multiple Chemical Sensitivity). For the first time in many years is agreed to stay overnight at a expensive central London hotel in Lambeth. I contacted the hotel, with all the details. When I arrived, it was obvious that the information which I supplied had been taken seriously. The staff were very curious and considerate and obviously had been well briefed about my requirements and made good a effort to accommodate. I was invited to approve rooms etc. and everything was fine. Later that evening when I arrived back on the corridor to my room at around midnight, all the fire doors had been closed, and there was a extremely strong odour of what appeared to be a cleaning agent. There was no ventilation in the corridor or room. This started an allergic reaction. Fortunately, I did carry medication and was able to deal with the problem. The following day I was not able to enjoy the day because of fatigue. The day after I awoke with swollen ankles, knee and arms and painful joints, which is the usual rebound problem after such an exposure. I wrote to the hotel asking for the identity of the product used and the manufacturer. However, after paying lip service, the hotel management have gone silent. This information would have been useful to my doctor because it could have been included in my desensitisation treatment. Any ideas ?

This rings true with me, because I was once declined admission to a convalescent home for this reason. What is most likely to have happened is that no one had briefed the maid or cleaner. The trouble is that if the hotel give out the information you require, they are admitting liability and leaving themselves open legally. Apart from wearing a spacesuit, I think that the only option is to avoid environments you can't control.

You don't have to smell or taste the problem substance to be affected, as it only takes a very small amount of antigen to provoke a reaction. Very often the culprit is an after shave or perfume, and that is why smellies are banned in many ME group meetings. One of the well know supermarkets started using fragranced till receipts. They were quickly withdrawn when it was realised they caused allergic reactions. A well known brand of toilet cleaner was withdrawn for the same reason. —Mike.



Review of the Sheffield CFS/ME Clinic

I received the following letter dated 6th July 2007. It was a Local Implementation Team (LIT) members' questionnaire of the CFS/ME Service, South Yorkshire and North Derbyshire (Adults and Children) from Julie Leeson, Director of Therapy Services, Sheffield Care Trust and Jan Appelbee, Cost per Case Manager, Sheffield PCT.

The CFS/ME South Yorkshire and North Derbyshire Service (Adults and Children), is a specialist regional service since February 2005 and currently hosted by Sheffield PCT provider services. Staff delivering the service are employed by Sheffield PCT, Sheffield Children's Hospital NHS Trust and the largest component by Sheffield Care Trust. As the service is now well established and roles and responsibilities are more clearly defined we feel it is timely to review the service to ensure we are making best use of the resources available. The review is currently focusing on the adult service, however all colleagues involved in both the adult and children's service are invited to comment.

The review will be carried out by Jan Appelbee, Cost Per Case Manager, Sheffield PCT on the commissioning arm of Sheffield PCT, and Julie Leeson, Director of Therapy Services, Sheffield Care Trust. The aim of the review will be to examine current and predicted future service requirements and look at the staff resources required to deliver this within the available financial resources.

Whilst we cannot predict the outcome we anticipate that the review will conclude that the service can be delivered equally, or more effectively, with a wider skill and grade mix and this will have impact on current staff employed.

At the point at which formal consultation takes place then SCT and Sheffield PCT and their HR department will need to be clear with staff the arrangements that will be put in place for any redeployment of affected staff. We will also need to be clear with staff about preferencing arrangements, redeployment rights and all related issues.

We attach a brief resumé of the proposal. An informal meeting with staff was held on 20th June to initially introduce the review. At this meeting it was explained that as from 20th June 2007 there will be a 4 week informal review, after which a draft proposal for the service will be sent out, based upon all the feedback received during the four weeks. Following on from this there will be a 90 day formal consultation period before any final changes are agreed. We would welcome your comments and input, and therefore the purpose of this letter is to ask you as a member of the CFS/ME LIT to discuss this service review with your colleagues, and to return the attached questionnaire.

At the group meeting of the 20th July we discussed the Questionnaire with members from the Rotherham group. We came up with the following:

1. Are you a member from ? South Yorkshire

2. The CFS/ME service/ clinical network was established to provide · A. a direct specialist service to those with moderate to severe problems · B. and to increase capacity within primary care to manage those with mild to moderate problems through skills/ knowledge-building, support and advice
In your opinion what proportion of time should be spent on each A = **75** % B = 25 %

3. What interventions do you think the specialist team/s should be able to offer to people with CFS/ME?

a) Diagnosis.

b) Palliative (Appeasement). Treatment to reduce the impact in the individual. This should include practical and emotional support from staff like OT, Counsellors and Physio's. This should be ASAP after diagnosis, and be based on individual needs. Medication for both physical and mental health issues. Lifestyle advice.

- c) Disease-modification treatment. (e.g. B12, Q10, EPD)
- d) Transfer of care to other agencies.
- e) Mediation in education, employment and welfare.
- f) Carer support.

4. What support/development do you think the specialist team/s should be able to offer to staff working in primary care or other relevant services?

- a) Support for GPs in making a diagnosis
- b) Guidelines and Information. Chief Medical Officer's Report aid memoir (Prof Hutchinson). Information from other services ie. Dr Myhill, M.E. Association, Action for M.E. Media like the DVDs from ME Research and Invest in ME initiatives
- c) Training and Courses e.g. local LMC meetings.
- d) Support for expert patients programmes specifically for ME/CFS.
- e) Support for local initiatives and services in satellite areas.

5. In your opinion what works well at present

- a) We get a cast iron diagnosis. We think that the disbelieving doctor is now extinct in Doncaster. This is the major success of the clinic.
- b) When available (subject to resource limitations): Counselling, emotional support, pacing and management (e.g. memory, energy) advice for grade 1 (Mild) Cases who can attend at Fairlawn's.
- c) Groups of 10.
- d) Support for education and return to work.

6. In your opinion what does not work so well at present

We feel the services are fragmented and patients are left in limbo with no local support..

- a) Access to services in the first place - mainly waiting list issues.
- b) All services for Grade 2 (moderate) and Grade 3 (severe) cases. The main issues are access, mainly travelling and ability of patients to travel and keep appointments. Doncaster is 30 miles from Fairlawns,
- b) Palliative Treatments. Medication Policy absent. Dietary advice absent.
- c) Disease modifying treatments absent.
- d) Referral to support groups.
- e) Own testing and diagnostics are absent, at present these are referred back to the GP.
- f) Mediation with DWP in Benefits disputes. There is a situation where the clinic will not give specific information on individual patients in a suitable form to enable the DWP to make an undisputable decision. This is due mainly to unsuitable DWP paperwork.
- g) Patient information and literature.

7. Given that the resources are very small and spread across a wide area how do you think the service could be improved?

- a) Use the support groups and voluntary services.
- b) Take on volunteers as many hospital trusts do.
- c) Make better use of available staff. We are concerned that apart from 'patients seen', there is no measure of outcome or quality and no audit.

8. How would you like to see the service develop in the future?

- a) More services to grade 2 and 3 patients.
- b) Use of lay tutors like are currently used in Expert Patient programmes.
- c) Provision of an ME/CFS Specialist with a profound understanding of the issues involved and having the right clinical knowledge.

9. Please give any further comments or ideas

- a) We would like to see acknowledgement of ME/CFS as a neurological condition as classified by WHO.
- b) We have a consultant at Doncaster Royal Infirmary, Dr. Ode, who has a better working

knowledge of ME/CFS. He uses disease-modifying treatment like Q10, and B group vitamins. We think he is doing a good job for grade 2 and 3 cases in Doncaster. We would suggest you clone him for the clinic.

- c) Development of an Expert Patient service empowering patients to self-manage the condition.
- d) Development of documentation for assessment of condition for welfare rights. Existing DLA/IB50 forms inappropriate.
- e) Annual conference for stakeholders.
- f) Further development of treatment pathways.

The Rotherham, Sheffield and North Derbyshire Groups submitted their own responses along similar lines. I emailed our group members for comments, and two of the responses received follow

Hello Mike, I have read your e-mail with the Sheffield Clinic Questionnaire, I totally agree with the questions answered about ME/CFS and what can be done for the future.

*I was totally gob smacked when I read that Dr Myhill and another doctor had to answer to the GMC about THEIR future, and at what cost in suffering to ME/CFS members would that be if they were made to stop treating people like myself, and probably many more waiting in the wings not knowing what is wrong with them. If there is plenty of true help and knowledge made widely available then those people in the wings can make a small diagnosis of themselves for them to then take the step to go to these doctors that we need and clinics and say "can you help me I am suffering this and this and I think it is what I have read about ME/CFS" Then that person can be looked at with no tuts and sighs like "You're wasting my time", but with compassion and care they may have saved themselves from becoming grade 2 to a grade 3 just because the CARE and the KNOWLEDGE is **THERE**.*

Plus with this help now don't they think that these dedicated people would save the DLA money as early diagnosis to help early recovery if possible means the member does not lose their job that they may enjoy doing and that helps their self esteem as they still feel capable of doing something important. I know myself what it feels like to lose your job through illness and for people to look at you and say "well what do you do then?" and you tell them early retirement through illness and they think WHY you haven't a limb missing you look fine WHY are you not working, then you try to explain but they have this look as if to say "oh yeah" with the sarcasm another one getting money for nothing, and that makes you feel crap and then you feel depressed as you ask yourself then "Is that what people think, that your kidding" then you just want to curl up and shut yourself away and go down with upset that, yes, you have lost your job.

Sorry Mike for going on a bit but as I say when I read about those doctors having to go to GMC it made me feel angry. Thanks for the moan.

Gillian at Wath-on-Dearne.

Dear Mike, Regarding question 9a: "We would like to see acknowledgement of ME/CFS as a neurological condition as classified by WHO." Don't you think CFS is caused by a weakened immune system combined with one or more chronic infections (Mycoplasma/EBV/HHV...)? This is usually the case ?

Free spirit

That comment about chronic infections would be inappropriate and out of context. ME/CFS is immune system mediated neurological and other organ damage very similar mechanism to motor neurone disease and multiple sclerosis. The immune system is dysfunctional rather than weakened, and this causes multiple chemical sensitivity and autoimmune disease, other issues encountered by many patients. Occult infections e.g. mycoplasma, candida are likely to be opportunistic secondary infections that occur in many diseases where immune function is compromised rather than the perpetuation of the condition. *Mike.*

Postscript: At the time of writing, the first draft of the Review has taken on many of suggestions we and the other groups have submitted. Mike

A review of the rationale for using Vitamin B12 injections in ME/CFS

by Dr. S Myhill.

Many people with ME/CFS respond to B12 injections. The rationale behind its use is not freely available from NHS sources, so Pathways asked Dr. Myhill for her personal view. I have included references should anyone wish to research the subject further.

Over the last 26 years of treating over 3,000 patients with chronic fatigue syndrome, I have developed a programme of treatment which I believe all patients must do as the foundation before proceeding to other treatments. Vitamin B12, by injection, I see as an integral part of this programme and it is effective for many, regardless of the cause of their chronic fatigue syndrome.

Those patients who respond to B12 are not obviously deficient in B12, indeed blood tests usually show normal levels. The "normal" levels of B12 have been set at those levels necessary to prevent pernicious anaemia – this may not be the same as those levels for optimal biochemical function. B12 has a great many other functions as well as the prevention of pernicious anaemia. However what is interesting is how B12 is beneficial in so many patients with fatigue, regardless of the cause of their CFS, and it suggests that there is a common mechanism of chronic fatigue which B12 is effective at alleviating.

Professor Martin Pall has looked at the biochemical abnormalities in CFS and shown that sufferers have high levels of nitric oxide and its oxidant product peroxynitrite. These substances may be directly responsible for many of the symptoms of CFS and are released in response to stress, whether that is infectious stress, chemical stress or whatever. B12 is important because it is the most powerful scavenger of nitric oxide and will therefore reduce the symptoms of CFS regardless of the cause (reference 1,2,3,4,5,6). Nitric oxide is known to have a detrimental effect on brain function and pain sensitivity. Levels are greatly increased by exposure to chemicals such as organophosphates and organic solvents (reference 7). When sensitive tests of B12 were applied (serum methylmalonic acid and homocysteine) before and after B12 therapy, the following symptoms were noted to be caused by subclinical B12 deficiency: parasthesia, ataxia, muscle weakness, hallucinations, personality and mood changes, fatigue, sore tongue and diarrhoea (8).

The "foggy brain" with difficulty thinking clearly, poor short term memory and multitasking, are often much improved by B12 (reference 9,10,11). Mood and personality changes, so often a feature of patients with chemical poisoning, can be improved by B12 (reference 12). The physical fatigue and well being are often both improved. In a study, twenty eight subjects suffering from non-specific fatigue were evaluated in a double-blind crossover trial of 5 mg of hydroxocobalamin twice weekly for 2 weeks, followed by a 2-week rest period, and then a similar treatment with a matching placebo. The placebo group in the first 2 weeks had a favourable response to the hydroxocobalamin during the second 2 week period with respect to enhanced general well being. Subjects who received hydroxocobalamin in the first 2-week period showed no difference between responses to the active and placebo treatments, which suggests that the effect of vitamin B12 lasted for over 4 weeks. It is noted there was no direct correlation between serum vitamin B12 concentrations and improvement. Whatever the mechanism, the improvement after hydroxocobalamin may be sustained for 4 weeks after stopping the medication. "A Pilot Study of Vitamin B12 in the Treatment of Tiredness," Ellis, F.R., and Nasser, S., British Journal of Nutrition, 1973;30:277-283.

Vitamin B12 has no known toxicity, and any surplus is simply passed out in the urine. It is theoretically possible to be allergic to B12, but in the thousands of injections that I have sanctioned this has only ever occurred after several injections and causes local itching, redness and swelling (although the commonest cause of redness and swelling is poor injection technique). It does not seem to matter whether hydroxocobalamin or cyanocobalamin is used. I usually start with 1-2 mgs daily by subcutaneous injection, then adjust the frequency according to response – some patients will respond straight away, some need several doses before they see improvement. I would do at least 10 injections before giving up. Many of my patients learn to inject themselves.

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- (8) Neuropsychiatric disorders caused by cobalamin deficiency in the absence of anaemia or macrocytosis J Lindenbaum et al New Engl J Med 1988; 318: 1720-1728.
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Action for ME's New Boss

Sir Peter Spencer was born in Brighton, Sussex in 1947 and was educated at both Cambridge and Southampton Universities. He served in the Royal Navy from 1965 until he retired in the rank of Vice Admiral in January 2003. Sir Peter joined the DPA as Chief Executive and Chief of Defence Procurement on 1 May 2003 having been selected by open competition. He has now retired from that position, and took up the position of Chief Executive of Action for M.E on the 30th April 2007. He is Married and has 4 children. His interests include music, books, theatre and cinema and sport, especially sailing, cricket and rugby. The appointment represents a big change for the former Second Sea Lord. Sir Peter has moved from a public sector environment with an annual budget of £6 billion, to a voluntary sector organisation employing 20 people. Nevertheless, the new challenges he faces are considerable. George Armstrong, Chair of the Trustees, says "Peter will bring an intelligence and a depth and range of experience to this post which will not only build on the successes of recent years, but also lead us towards a greater achievements. This is an exciting time for Action for M.E, and will be of benefit to people with M.E." Peter said: " I am looking forward to joining Action for M.E. I have witnessed first hand the devastating effect M.E. can cause and I am committed to working with the team to meet the challenges the field is currently facing".

ME

ME is living in me, it's under my skin,
I'm losing weight; I'm going so thin.
Boy can it fight and punch from the right.
By day and by night I get such a fright.
Do I give in? Let it take over my skin.
No! I can fight, isn't that right?
And with all my might yes I will fight

S. B.

Family Love

Family gather round I have to tell you I'm sorry.
But I have ME.
They look astounded, do they look down?
No
"Fight" they say, hard to care?
No
They are there, A look of sorrow,
Find it hard to swallow.
Family love they give me a hug,
Stay be me and give me tea.
Go for a walk, hide away some may say.
Come together you'll get better.

S.B.

Both poems from the 1996 AIDS Anthology *HIV is living in ME* Adapted for ME by Trevor Wainwright.

Boat Trip on the Ethel July 2007

This is the 'Ethel', she is a converted wide beam canal barge which is based on canal at Thorne. She was ours for the day –Mike.



It is rumoured that the Ethel Trust has other skippers beside Phil Harrison, but for every boat trip Leger ME have organised he seems to around. Throughout the entire trip he kept up a commentary about the canal and surrounding area which greatly contributed to the enjoyment of the day.



On leaving the mooring we pass the boat yard heading for Stainforth. On the way we saw fishermen, waterside back gardens, and were greeted by a spotty dog.



We passed the Canal Tavern, and saw a 'Tom Pudding', formally used to carry coal on the waterway. The more able helped with the lock gates at Bramwith.



We moored just past Bramwith bridge. Liz had arranged a meal. We turned right up the Dutch river. Phil spun the yarn about the men marooned on top of the cooling towers.



Passing over the aqueduct, we saw the level of the river Don was raised. There was much debris which had been washed down the river during the recent floods. The guillotine gates would have been closed to isolate the canal from the river should it have risen too high. We then turned around and headed for home. As usual, thanks go to the Ethel trust and the boat crew for a great day out



The Clouds ME/CFS Community Counselling Service Project Update.

Following the 'Clouds' Counselling Pilot Project last year and based on the experience gained from that project, a more permanent service has been established.

Mike Apart from providing a members counselling service, what else did you learn ?

Sally I gained valuable experience. What was especially helpful was attending the doctors training lecture on ME/CFS at DRI in March 2006 and the various visits to the Sheffield ME/CFS Clinic User group meetings and Forum sessions run by the clinic. The main things were that apart from problems related to ME/CFS, the spectrum of issues raised were of a general nature, and not specific to ME/CFS.

Mike What has happened since the pilot project finished ?

Sally The *Clouds* Community Counselling Service is now established at the Vermuyden Medical Centre at Thorne and we are a team of five.

Mike What sort of service exactly are you offering ?

Sally We are offering a confidential, one-to-one counselling service offering a listening ear and support for people with problems in the Thorne, Moorends and Hatfield area.

Mike Is the service just for ME/CFS sufferers themselves ?

Sally No. The *Clouds* Community Counselling Service is not restricted to just ME/CFS issues. At the moment I am the only Counsellor that accepts CFS/ME referrals both from Leger ME and doctors' surgeries. The service can help anyone including Carers, friends and family, and the issues don't have to be linked to ME/CFS. The *Clouds* Community Counselling Service is open to anyone.

Mike How can the service help anyone with ME/CFS ?

Sally I have given some thought as to how Counselling can help those who have either been diagnosed or are awaiting diagnosis of this illness both from the client point of view and from my own as having had this illness for probably as long as thirty years to some degree or other. Firstly, I feel it is most important for the client's illness and experience of it to be recognised, acknowledged and as far as possible understood. Recently, so I understand, there has been acknowledgement at the Sheffield Clinic that CFS/ME is a neurological illness. Secondly, there is no known cure at the moment. However it is possible to treat medically many of the varying, different arising symptoms. It has been established that some drugs do help some people. Thirdly, it is also recognised that stress exacerbates CFS/ME. Therefore any other issues in the client's life that are causing difficulties can be explored and resolved. Last but not least it is my personal belief that positivity, creativity and hope are important and support must be given to keep them alive and well. We may have CFS/ME and it is frustrating and debilitating but we live, have lives to lead, and as people still have skills and much to offer.

Mike Is the service just for ME/CFS sufferers themselves ?

Sally No, however at the moment I am the only Counsellor that accepts CFS/ME referrals both from Leger ME and doctors' surgeries. The service can help anyone including Carers, friends and family.

Mike In what manner can counselling help ?

Sally We can help with a wide range of issues which may or may not include Bereavement, Loss, Depression, Anxiety, Stress, Anger, Guilt, Low self esteem, Abuse, Relationship problems, Addiction. No problems are excluded.

Mike What qualifications do you have to enable you to run the service ?

Sally I am a diploma-trained counsellor, assisted by five trained counsellors.

Mike Are there any professional standards that you work to ?

Sally All *Clouds* counsellors are members of BACP. All counsellors in are bound by its Ethical

Framework for Good Practice in Counselling and Psychotherapy, and subject to Professional Conduct Procedure for the time being in force.

Mike When and where does the service operate ?

Sally It currently offers two sessions per week, Mondays 9.30 am to 6.00 pm, and Fridays 9.30 to 5.00 as the Vermuyden Centre, Fieldside, Thorne. Additional sessions are held on Wednesdays 9.30 to 1.00 p.m. at the Bridge Centre, Thorne.

Mike How do potential clients make contact ?

Sally Initial contact is by leaving a message on 07962-907053. Your call will then be returned within 24 hours.

Mike is there a charge for your service ?

Sally No, the service is free.

The House of Commons Health Committee Inquiry into NICE

Adapted from Rotherham groups newsletter (Hope for ME)

1.6.1 Overwhelming evidence has been submitted to NICE that CBT/GET is not only of no lasting benefit, but may result in a permanent worsening of the condition for a substantial number of patients. This is because it has been conclusively demonstrated that exercising muscle in ME/CFS patients is a prime contender for free radical generation. An article called 'A Final Farewell to the Psychiatric Fallacy?' refers to the work of the Vascular Research Unit at Dundee. It points out that in ME/CFS, raised levels of isoprostanes (abnormal prostaglandin metabolites which are highly noxious by-products of abnormal cell membrane metabolism) have been demonstrated and that these raised levels of isoprostanes precisely correlate with patients' symptoms. Such raised levels of isoprostanes have never been documented in any other known disorder. The way the bodies of people with M.E. react to exercise is abnormal in a number of different ways. These abnormalities are so pronounced that exercise tests are one of the series of tests, which can be used to confirm a suspected M.E. diagnosis. The table was originally compiled by Marjorie van de Sande in 2003. Abnormalities found so far include:

<u>Response to Exercise</u>	<u>Healthy People</u>	<u>ME Patients</u>
Sense of Well Being	Invigorating, antidepressant	Pain, Increase in malaise
Resting heart rate	Normal	Elevated
Heart Rate at maximum	Elevated	Reduced heart rate
Maximum oxygen uptake	Elevated	Only ½ that of sedentary controls
Age predicted target heart rate	Can achieve it.	Can NOT achieve it.
Heart Functioning	Increased	Decreased
Cerebral Blood Flow	Increased	Decreased
Cerebral Oxygen	Increased	Decreased
Body temperature	Increased	Decreased
Breathing	Increased	Irregularities ,shortness of breath
Cognitive Processing	Normal, more alert	Impaired
Oxygen delivery to muscles	Increased	Reduced
Gait (Walking) kinetics	Normal	Abnormalities
Recovery period	Short	Days, weeks months or longer or may not occur. The relapse or damage may be permanent and even fatal.

We are all creatures of habit and the first principle is to get the physical essentials in place. A regular pre-bedtime routine: your "alarm" should go off at 9 p.m., at which point you drop all activity and move into your bedtime routine. We have been brainwashed into believing a hard bed is good for you and so many people end up with sleepless nights on an uncomfortable bed. It is the shape of the bed that is important. It should be shaped to fit you approximately and then very soft to distribute your weight evenly and avoid pressure points. If your sleep is disturbed by sweating, then this is likely to be a symptom of low blood sugar. Another common cause of disturbed sleep is hyperventilation, which often causes vivid dreams or nightmares. However, I often use a benzodiazepine such as diazepam at night which reduces the sensitivity of the respiratory centre. If sleep is disturbed by pain, then one must just take whatever pain killers are necessary to control this. Lack of sleep simply worsens pain. If one wakes in the nights with symptoms such as asthma, chest pain, shortness of breath, indigestion etc, then this may point to food allergy being the problem with these withdrawal symptoms occurring

during the small hours. Some people find any food disturbs sleep and they sleep best if they do not eat after 6 p.m. If you do wake in the night do not switch the light on, do not get up and potter round the house or you will have no chance of dropping off to sleep. Getting the physical things in place is the easy bit. The hard bit is getting your brain off to sleep. I learned an astonishing statistic recently which is that throughout life, the brain makes a million new connections every second!! This means it has a fantastic ability to learn new things. This means it is perfectly possible to teach your brain to go off to sleep, it is simply a case of pressing the right buttons.

Applying this to the insomniac, firstly, he has to get into a mind-set which does not involve the immediate past or immediate future. That is to say, if he is thinking about reality then there is no chance of getting off to sleep - more of this in a moment. Then he uses a hypnotic medicine which will get him off to sleep. He applies the two together for a period of "conditioning". This may be a few days or a few weeks. The brain then learns that when it gets into that particular mind-set, it will go off to sleep. Then the drug is irrelevant. However, things can break down during times of stress and a few days of drug may be required to reinforce the conditioned response. But it is vital to use the correct "mind-set" every time the drug is used, or the conditioning will weaken.

I do not pretend this is easy, but to allow one's mind to wander into reality when one is trying to sleep must be considered a complete self-indulgence. It is simply not allowed to free-wheel. Everyone has to work out their best mind-set. It could be a childhood dream, or recalling details of a journey or walk, or whatever. It is actually a sort of self hypnosis. What you are trying to do is to "talk" to your subconscious. This can only be done with the imagination, not with the spoken language. Each time that you work towards acquiring the self-hypnotic state, regardless of the depth that you have achieved and whether or not you have responded to any of the tests, give yourself the following suggestions: "The next time I hypnotise myself, I shall fall into a deeper and sounder state." You should also give yourself whatever suggestions you desire as though you were in a very deep state of hypnosis. You may ask "If I'm not under hypnosis, why give myself the suggestions?" You do this so that you will begin to form the conditioned reflex pattern. Keep at it. One of the times that you work at achieving self-hypnosis the conditioned response will take hold. You will have self hypnosis from that time on. It is like learning to drive a car with a clutch. At first you must consciously go through the process of putting your foot on the clutch and shifting gears. Usually there is a grinding of the gears and you feel quite conspicuous about this, but gradually you learn to do this almost automatically and you gain confidence in your driving ability. The same is true of hypnosis. As you work at your task, you gradually get the feel of it and you achieve proficiency in it. I instinctively do not like prescribing drugs. However, I do use them for sleep, in order to establish the above conditioning and to restore a normal pattern of sleep, after which they can be tailed off or kept for occasional use. Indeed, viruses can cause neurological damage (for example polio) and this could involve damage to the sleep centre. So often CFS patients get into a bad rhythm of poor sleep at night, which means they feel ill for the day, which means they get another bad night. They

Sleep Hygiene

- A regular bed time - 9.30pm
- A busy day with the right balance of mental and physical activity
- Not having a bed fellow who snores
- Small carbohydrate snack just before bedtime (eg nuts, seeds) helps prevent nocturnal hypoglycaemia, which often manifests with vivid dreams or sweating.
- Perhaps restrict fluids in the evening if your night is disturbed by the need to use the toilet.
- No stimulants such as caffeine or adrenaline inducing TV, arguments, phone calls, family matters or whatever before bed time! Caffeine has a long half life, so none after 4 p.m.
- Dark room - the slightest chink of light landing on your skin will disturb your own production of melatonin (the body's natural sleep hormone). Have thick curtains or blackouts to keep the bedroom dark. This is particularly important for children! Do not switch the light on or clock-watch should you wake.
- A source of fresh, preferably cold, air.
- A warm comfortable bed.

are half asleep by night and half awake by day. Furthermore, their natural time for sleep gets later and later. They go to bed late and if they have to get up at the usual time, chronic lack of sleep ensues. Indeed, there is now evidence that the biological clock is dependent on normal adrenal function and we know this is suppressed in CFS.

So often some medication is needed to facilitate sleep. Most CFS patients react badly to drugs in normal doses. Firstly I like to use combinations of low dose herbals, natural remedies. If there is no improvement with a combination of the above, or if there are intolerable side effects, then I would go on to a prescribed drug. Some people may need combinations. Everybody works out their own arrangement which may have to be changed from time to time. I am always asked about addiction to sleep medicines. My experience is that this is rare, especially if drugs are used as above to develop a conditioned reflex. One has to distinguish between addiction and dependence. We are all dependent on food, but that does not mean we are addicted to it. We are all dependent on a good night's sleep for good health and may therefore become dependent on something to achieve that. This does not inevitably lead to addiction. Addiction is a condition of taking a drug excessively and being unable to cease doing so without other adverse effects. Stopping your hypnotic may result in a poor night's sleep but no more than that. This is not addiction but dependence.

If you find your dose of hypnotic is gradually creeping up, then this may be because you have become less disciplined about establishing the conditioned reflex. Go back to the basics as above. When your normal sleep pattern has been restored you can begin to reduce or tail off completely your hypnotic medication but only if good quality sleep can be maintained. If your sleep begins to suffer, you must go back on the medication that worked before because the need to sleep is of paramount importance in CFS patients.

<u>Medicine</u>	<u>Dose</u>	<u>Supply Class</u>	<u>Comments</u>
Valerian root powder .	400 mg, 1-4 capsules at night.	Over the Counter	This is shorter acting and can be taken in the middle of the night
Nytol (diphenhydramine)	50 mg, 1-2 at night.	Over the Counter	This is a sedating antihistamine . This is longer acting - don't take in the middle of the night or you will wake feeling hung over.
Melatonin	3 mgs tablets, 1-3 tablets at night	Prescription Only Medicine	Some people just need 1 mg. Natural anti sleep hormone. It seems logical to me therefore to try this first. Has caused depression in several of my patients, so be aware of this.
Amitriptyline	5 mg initially, then 10-25 mgs at night	Prescription Only Medicine	Most CFS patients are made worse and feel hangover with "normal" doses.
Surmontil	10-30 mgs at night.	Prescription Only Medicine	Most CFS patients are made worse and feel hangover with "normal" doses.
Temazepam	10 mgs. at night	Prescription Only Medicine, Controlled Drug	Short acting. Now a controlled drug doctors reluctant to prescribe due to abuse by drug addicts.. Replaced by 'Z' hypnotics .
Zopiclone (Zimovane g.)	3.75 -7.5 mg	Prescription Only Medicine	Medium Action
Zaleplon (Sonata)	5-10 mg	Prescription Only Medicine	Short acting
Diazepam	2-5 mg	Prescription Only Medicine Controlled Drug	Helpful if sleep is disturbed either because of hyperventilation (it reduces the respiratory drive) or for muscle spasms (it is a good muscle relaxant)

Recipe Corner

SMOOTHIES

Delicious, easy and fast to make, nutritious and easy to swallow, smoothies are the perfect meal in a glass and are suitable for everyone. We even have two dairy free recipes at the bottom.

Fruits of the Forest

Place 6 *frozen* 'fruits of the forest' in a blender with 150 ml of fruit juice, 1 heaped tablespoon of yoghurt and 1 tablespoon of runny honey (or to taste). Whizz and drink.

Strawberry and Mango

Place 1 large ripe Mango and 250g Strawberries in a blender and whiz until smooth. Add 2 tbsp Greek Yoghurt and 25 ml cold milk and whiz again. Serve immediately.

Pear and Raspberry with Maple and Vanilla

Peel a very ripe pear and cut into chunks. Drop into blender with half a punnet of Raspberries, 15g Vanilla Yoghurt and Maple Syrup to taste. Blend. *(You can replace the yoghurt with vanilla ice-cream if you fancy a milkshake).

Coconut Milk, Mango and Lime

Blitz the flesh from one ripe medium sized, non-fibrous Mango with 200 ml coconut milk and the juice of a Lime. * (Thin with a little water if necessary).

Strawberry with Lime and Mint

Put 2-3 cubes of ice in a glass. Blend half a punnet of Strawberries with the juice of 1 Lime, 6 *fresh* mint leaves, 1 tablespoon of Honey and 1 tablespoon of sugar (or to taste). Blend, garnish with a sprig of mint and serve immediately over the ice.

Did You Know...

- *Bean sprouts and mushrooms - are the whole plant.*
- *Spinach, lettuce and cabbage - are leaves.*
- *Celery and fennel - are stems.*
- *Onions, leeks and globe artichokes - are the leaf and stem together.*
- *Carrots, turnips and radishes - are all roots.*
- *Brussels sprouts - are the bud of the plant.*
- *Cauliflower and broccoli - are flowers.*
- *Tomatoes, aubergines, marrow and peppers - are all fruits.*
- *Potatoes and yams - are both tubers.*
- *Wheat, oats, rye, barley, rice and maize - are all cereals*
(cereals are the seeds of plants - usually members of the grass family).

SYCIL INFORMATION & AWARENESS DAY

Often when people have a problem it is made worse by not knowing where or who to go to for help and often by the time help is found the original problem could have got much worse. Advocacy can help to avoid this, by helping people find out about the choices that are available to them, make informed choices about what they want for themselves, speak up for what they want and make sure that their voice is heard. The ENABLE Advocacy Service at South Yorkshire Centre For Inclusive Living (SYCIL), is holding An Information & Awareness Day, on 2nd October 2007 to coincide with National Advocacy Awareness Week. The event will be held at SYCIL's new offices at M & M Business Park, Doncaster Road, Kirk Sandall, from 10 am – 3.30 pm. Eleven different organisations will be attending on the day with information about the services which their organisations can offer, and advocates from ENABLE Advocacy and Doncaster Advocacy will be available to help anyone who needs support to understand the information which is on offer. For further information please contact Helen Butler, ENABLE Advocacy Service Co-ordinator on (01302) 892947.

History of DiAL Doncaster by John Burke, Community Development Officer, DiAL

DiAL was formed in 1976 when Ken Davis, whilst living in an institution, became aware of the additional problems caused by lack of information among his fellow residents and users of the Centre. He realised that, in the community, it was even more elusive among those isolated from contact with the centre or other services. He therefore set about, with others, in establishing a telephone information service specialising in matters related to physical impairment. Over a six month period the idea developed more comprehensively to embrace the notion of a free, impartial and comprehensive service of information, advice, practical help and counselling to anyone, lay or professional, working within the caring service. DiAL Derbyshire was born, the letters standing for Disablement Information and Advice Line. The service caught the imagination of others. It was by no means the first specialist information service for the physically impaired, but it came at a time in the UK of a general growth of interest in the subject. In October 1977 a seminar was held to explore and exploit this interest. The result was the beginning of a national network of DiAL. type services.

By June 1978, a Steering Committee was elected from representatives of local DiAL groups to form a National Association of Disablement Information and Advice Services, now known as DiAL UK. Its aim was to facilitate the spread of a network of local DiAL services. DiAL Doncaster was formed in early 1983 when Mr John Gaskell was seconded from ICI to Doncaster District Association for the Welfare of the Disabled under a Government sponsored scheme. His role was to visit disabled people in Doncaster MBC to ascertain what was needed most within the disabled community. The results of his survey showed an information and advisory organisation could provide a comprehensive service covering all aspects of disability to disabled people, their families, carers and professionals and would be beneficial to the people of Doncaster.

A steering committee was formed. The inaugural meeting was held in Bentley Library in October 1983. It was there that DiAL Doncaster's operation began. From 1986 to 1988, DiAL Doncaster was based at the Concorde Centre, Netherhall Road before moving to West Street in August 1988. In early 1989 DiAL Doncaster was offered accommodation at St Catherine's Hospital in Balby and then became an advice and information support group to complement the new Wheelchair Assessment unit which was to open in April 1990. DiAL Doncaster became affiliated to the National Association and is now one of a chain of over one hundred Information Advice Centers situated throughout the British Isles.

DiAL Doncaster became funded by Joint Finance, (i.e. via the Health Authority, the Local Authority) and has to apply to other funding agencies for monies. The funding enables DiAL to develop its services. In November 2004 we moved to our present accommodation on Shaw Wood Business Park, Shaw Wood Way, Doncaster. DN25TB. DiAL Doncaster now has a team of highly trained of 30 staff which is a combination of Volunteers and paid staff, who are involved in many aspects of the service. It has a Management Committee of fifteen. There is also a Welfare Benefits and a Home Visiting Service, as well as staffing a telephone help line and providing an outreach service for people who live in outlying areas. During the last financial year (2005/2006) DiAL Doncaster has gained over £2,000,000 in benefit claims for the people of Doncaster as well as giving specialist/general advice on many other subjects regarding disability issues. DiAL can provide full and up-to-date information on local and national support groups, learning disabilities, transport and access, caring for someone in the home, housing, eating out, holidays, community alarm systems and many other subjects. **THIS SERVICE IS FREE, IMPARTIAL AND STRICTLY CONFIDENTIAL .** Some of the questions we have been asked

- I think my son might be dyslexic, are there any support groups?
- How can I get a blue badge?
- How do I register as sight impaired or severely sight impaired?
- How do I go about getting a wheelchair?
- I am a deaf person and have been invited to attend a meeting. How do I get an interpreter?
- I'm newly disabled - Am I entitled to any financial help?
- My wife is in a wheelchair - Do you know of any suitable holiday accommodation?

Contact Details: Telephone: 01302 327 800 Web: <http://www.dialdoncaster.co.uk>

North of Doncaster. *Personal comment by Trevor Wainwright***A Worthy Patron ?**

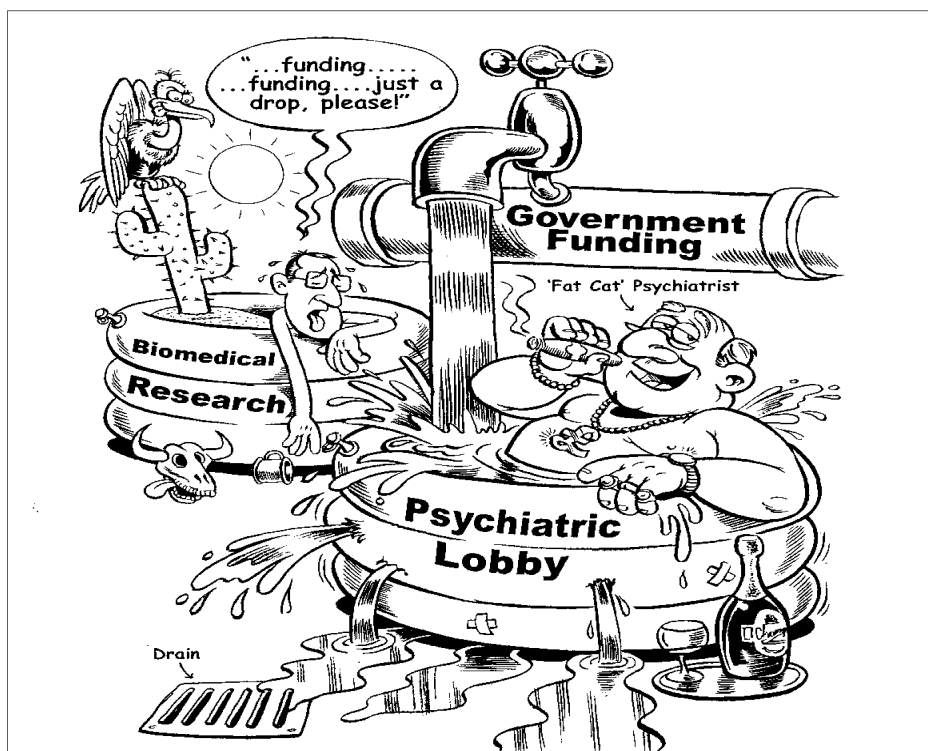
As many may know I am not backward in coming forward when it comes to Patrons, particularly celebrity ones who think all they have to do is be a smiling face on a website and post a few so-called words of encouragement, or appear smiling on the cover of a newsletter and that's the last you see of them. Action for Young ME have as yet never had Patron but they do have a Celeb Founding President or something. This is set to change as AYME have announced their first and to date only Patron. Dr Nigel Speight a Patron of other ME Charities has agreed to take on the role of AYME's Patron in recognition for his outstanding work for AYME as medical advisor and children with ME over the course of AYME's history.

When I asked him why he has taken on this role he said "I have been a Consultant Paediatrician in Durham for 25 years; interested in ME for the last 20 or so. I have helped 20 families whose children were threatened by Care Proceedings because of professional disbelief in ME. My other interests are Childhood Asthma, Child Abuse and Neglect, ADHD and Food Allergy. Recently I have become very interested in the Lyme Disease/Atypical Infection theory as to cause of ME".

I first met Nigel at a talk he gave in Doncaster, was immediately impressed by him, he was one of the few that have managed that with me, he came across as an OK Guy, particularly how he took the time to listen to and talk to parents of children with ME. He became interested in ME. through seeing new cases and being impressed by how genuine they were and how the psychological theory just 'didn't fit'. His personal conviction is that M.E is primarily an organic illness, and the role of psychological factors in the causation is around 0%. With regards to children with ME he says "The most important step in protecting them from this nightmare scenario is that they be officially diagnosed as M.E. The term CFS is mealy-mouthed by comparison and cuts no ice in the playground, when a child returns to school after a gap of 9 months". I recall one occasion when a woman from Australia had heard that Nigel was to visit, asked if I could get in touch with him and arrange contact. Nigel had given me his card, a quick phone call and Nigel said "ok forward my details". Contact was made and the woman met up with Nigel in Australia, describing him as both

charming and compassionate. So yes I will say something positive about one Patron at least. I am pleased that AYME have paid Nigel the tribute of inviting him to be their Patron. It is time people like Nigel were paid such tribute, again proving far worthy of the term Patron than some smiling celeb only in it for the publicity or some Minister making it look like they care. At least Nigel has done something positive. Just one question though, why have AYME taken so long to ask him.

My final words on the subject are to wish him well in both retirement and his new role. In next issue's North of Doncaster a report of what happened 10 years ago, a significant event at the time, with a question to follow.



M.E. Funding Politics. Here is a cartoon from 'The Quarterly', a magazine for the severely affected by the 25% Group. I think it explains the funding into NHS ME/CFS research for the severely affected without further comment.