

## Deliberate Dichotomy?

Eileen Marshall and Margaret Williams

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At the AACFS International Research and Clinical Conference held in Madison, Wisconsin in October 2004, two important points have been astutely brought to prominence by Elsie Owings from Michigan and both have been picked up in the UK.

One was a comment by Professor of Medicine Nancy Klimas from Miami, who said that the conference had been an overall success and had included research presentations from 16 different countries, then, looking both dismayed and puzzled, she said

“But none from England this year and I don’t know why”.

In a personal communication for the present author, Elsie Owings writes: “Perhaps one of your advocates (in the UK) could mention to your governmental representatives that your country’s lack of research on this disease has become noticeable at international conferences”.

The second point is relevant to the MRC PACE trials as well as to the psychiatric regimes to be employed at the 12 Government-funded centres throughout the UK (the setting up of which is being overseen by Professor Tony Pinching who was Deputy Chair of the Chief Medical Officer’s Working Group on “CFS/ME” and is now Associate Dean for Cornwall at The Peninsula Medical School and Medical Adviser to the charity Action for ME): this point was the emphasis that was placed on *never* crossing the anaerobic exercise threshold, as this is known to cause relapses in ME/CFS.

In his Summary of the Conference (see [Co-cure 2<sup>nd</sup> November 2004](#)), Professor Charles Lapp states that the anaerobic threshold, or AT, “is that time during exertion that the heart and lungs can no longer provide adequate oxygen to muscles, and muscle metabolism changes from aerobic to anaerobic. It is well known that the AT occurs unusually early in persons with CFS/ME/FM”.

In his same Summary, Lapp states “CBT was initially brought to attention by British psychologists who subscribe to the idea that somatic symptoms (in ME/CFS/FM) are perpetuated by errant illness beliefs and maladaptive coping. (These psychologists believe that) persons with CFS/ME/FM have certain abnormal cognitions and behaviours that perpetuate their symptoms and impairment. For example, attributing CFS to a physical cause is maladaptive. In this school the cognitive therapists believe that abnormal emotions and physiology are perpetuated by ‘catastrophic interpretations’ that lead to excessive emotion”.

To quote Elsie Owing again: “Of course CBT and exercise were discussed (at the conference), but not as research, and not as treatments either. They were only discussed as coping strategies. These were not the same types of CBT and exercise therapies that Wessely and Sharpe recommend. The CBT recommended by Klimas simply helps patients adjust to the limitations of the disease. It does not attempt to convince them that there is nothing physically wrong with them. And the exercise programme presented at the conference stressed heavily that patients must not cross their anaerobic threshold. There was no

suggestion that patients could build themselves back to healthy standards with such mild exercise.

“As for varying positions on CBT, the Canadian Consensus Criteria draws a pretty good line on that issue, which is one reason why we should all push for the adoption of the essential elements of that document. (It is important) to try to standardise programmes and goals, and, of course, the standardisation needs to be done by the US or Canadian doctors, not UK doctors, since Wessely and Sharpe would jump at the chance. If the standardisation programme clarifies that this is a serious physical illness and that coping and conservation of energy are the expected results, rather than significant physical improvement, then we have some ammunition against the current use of this technique as a brainwashing process for patients who are assumed to be nothing more than hypochondriacs”.

On the issue of CBT and graded exercise for those with ME/CFS, it is already on record that in the UK, the charity Action for ME is supporting both the MRC PACE trials and the CBT and exercise regimes that are to be used at the new centres, but what could be the reason that, under the medical directorship of Dr Charles Shepherd, the ME Association might not support such a policy as was proposed at the AACFS conference?

In its current newsletter (me essential, issue 92, October 2004) the ME Association states: “We have put forward our reasons for opposing the (MRC) trials at meetings (and) the MEA remains unconvinced that the PACE and FINE trials will provide any new and significant information about the benefits and risks of cognitive behaviour therapy, graded exercise and pacing”.

That seems clear enough, but can this be a case of the ME Association running with the hare and hunting with the hounds, because curiously, in the same newsletter the MEA affords four pages of opportunity for those who are to head the newly-funded centres (that are to be based on exactly the same CBT and exercise regimes as the MRC PACE trials) to set out their aims for those centres, and it is noticeable how often “chronic fatigue” is mentioned, not chronic fatigue syndrome or ME.

Some illustrations include the following:

**Professor Christopher Ward, Consultant in Rehabilitation Medicine and Neurology, Derby City General Hospital**, states: “I am designated as the ‘lead clinician’ for this service. Our philosophy is centred on rehabilitation. I am now Professor of Rehabilitation at the University of Nottingham. Many patients with fatigue can benefit from non-specialised services which already exist. This relates to the educational and training role. We will be involved in patient education. I work closely with a specialist rehabilitation nurse, and this has proved to be an especially useful model for our Fatigue Clinic”.

[ **The Penguin English Dictionary** defines “rehabilitation” as the “restoration of former capacities” and **Webster’s English Dictionary** defines “to rehabilitate” as meaning “to help to adjust to normal conditions after illness” ].

**Dr Peter White and Dr Maurice Murphy, St Bartholomew’s Hospital, London** state: “The two Chronic Fatigue Services at St Bartholomew’s Hospital will merge to form the St Bartholomew’s Hospital Chronic Fatigue Service from January 2005. This will uniquely bring together the knowledge and experience of the long-established chronic fatigue clinics.

Specific treatments will include education, graded exercise therapy and cognitive behavioural therapy, along with more conventional psychotherapy. We will continue to train, teach and research the causes of better management of CFS/ME”.

**Dr Hugh Rickards, Consultant Neuropsychiatrist, Queen Elizabeth Psychiatric Hospital, Birmingham** states: “We hope (to) be able to provide specialist advice and help for people with CFS/ME, including advice about the most effective treatments. We are also interested in supporting any local multidisciplinary teams that are to be set up in the West Midlands area”.

**Dr Terry Mitchaell, Consultant Haematologist, Norfolk and Suffolk Chronic Fatigue Service, James Paget Hospital, Great Yarmouth** states: “I became interested in chronic fatigue in 1985. I ran a weekly clinic starting at 7am before my haematology clinic opened at 9am. In 1996 I managed to capture the interest of the director for public health for Norfolk and acquired funding for an occupational therapist to help with activity management. Our approach attempts to stabilise activity followed by graduated increases in normal day-to-day activity. We are alert to secondary anxiety and depression. Currently our success rate in improving patients’ performance status is 60%. We have several service agreements with all the Primary Care Trusts in Norfolk. I will start the new centres and eventually hope to recruit someone to take my place. We try to discuss approaches to management and also some of the up-to-date ideas as to how this illness evolves”.

**Ms Hazel O’Dowd, Clinical Psychologist, Frenchay Hospital, Bristol (covering Gloucester)** states: “I was previously in adult mental health. CBT is a tool to help change and deal more effectively with problems their particular diagnosis gives them. CBT works best for people who can identify aspects of themselves or their coping style which they want to change. Changing the way you think and feel about yourself and your illness can bring about massive improvement in mood, sleep, levels of fatigue, and work. We plan to offer this type of approach in the home for the more severely disabled. However, if people don’t like the approach, they won’t do the therapy. Under those circumstances, CBT cannot be expected to produce results. Graded activity is part of the rehabilitation package we offer, combined with CBT. We do this because the research consensus is that this is the most powerful intervention currently available”.

In the UK, despite the concession on 11<sup>th</sup> February 2004 by the Health Minister Lord Warner that the Department of Health accepts that the WHO classifies ME / CFS as a neurological disorder, in practice the only diagnostic category permitted for “CFS/ME” and the only research to be funded by Government and the only interventions available on the NHS are based upon the strongly-held beliefs of a group of psychiatrists that the disorder is not an organic disorder either in aetiology or perpetuation. By supporting the 12 newly-funded centres, it seems that the ME Association in reality concurs with that view. If it does not concur, then why has it afforded such uncritical prominence to publishing the aims of some of those who will head the new centres, especially when those whose views it is promoting do not seem to know the difference between chronic fatigue (as classified at ICD-10 F48.0) and ME/CFS (as classified at ICD-10 G93.3)?

By contrast, in his Research Overview of the Wisconsin conference, Professor Anthony Komaroff stated that the illness follows a relapsing and remitting course and research has shown abnormalities in many systems in patients with ME/CFS.

Comparison of the views of those who are to head the new centres in the UK with the research evidence presented in Wisconsin (notably immunological; metabolic; including disturbances seen in urinary metabolites; neuro-endocrine; central nervous system, autonomic nervous system, including abnormalities of blood flow; gene expression; ergometric; microbiological and cellular anti-viral system dysregulation) highlights the extent of the problem faced by patients with ME/CFS in the UK, which continues to reject, dismiss and ignore this worldwide evidence.

In view of the ever-increasing evidence from other countries of an organic pathology for ME/CFS, for how much longer can the UK continue to subscribe to the hypothesis of a primary psychiatric cause for this dreadful disorder?