

INFORMATION ON COGNITIVE BEHAVIOURAL THERAPY,
PROFESSOR SIMON WESSELY AND PRISMA

April 2001 (amended 17 May 2001)

It seems a forgone conclusion that the forthcoming report of the UK Chief Medical Officer (CMO) on the management and treatment of chronic fatigue syndrome (CFS) / myalgic encephalomyelitis (ME) will advise that the treatment of choice is **cognitive behavioural therapy (CBT) and graded exercise (GE)** and that no distinction will be made between CFS and ME. This would be in stark defiance of all the evidence, both published and anecdotal, that CBT is not helpful in CFS and is positively harmful in ME and that CFS is not synonymous with ME.

The underlying reasons for such an intransigent stance by some of the more influential members of the CMO's Working Group require public examination.

In all medical disciplines, it is now fashionable to place much importance and reliance upon so-called "evidence-based medicine". Without this essential classification, therapeutic interventions are unlikely to be contemplated as a National Health Service (NHS) treatment.

Currently, there are claims by psychiatrists of the "Wessely School" that CBT (including graded exercise) is the "evidence-based" treatment of choice for CFS. Despite ME being formally and separately classified as a neurological disorder in the International Classification of Diseases (ICD 10: G 93.3), these psychiatrists do not recognise the existence of it, asserting that it is nothing more than a dysfunctional belief that one has a condition called ME and that such beliefs, together with many other "medically unexplained" illnesses such as tension headache should form part of a single, unified psychiatric disorder which they have called a "functional somatic syndrome". (1) These psychiatrists strongly promote CBT for all patients whom they deem to be suffering from a "medically unexplained" disorder.

Do the data justify the classification of CBT for ME / CFS as "evidence-based"?

Prins et al recently presented a report in the Lancet (2) which leaves the clear impression that there is now a powerful case for the provision of CBT as a *specific* therapy for CFS patients. No mention is made of its application in cases of ME. Careful examination of the paper and the literature raises many questions about whether this particular intervention fulfils the necessary criteria to validate its being classified as evidence-based medicine even in cases of undifferentiated CFS.

The first review of the relevant literature in 1996 (3) found a group of five methodologically limited studies from which little about efficacy could be concluded. Subsequently, a Cochrane Collaboration review to 1998 (4) could identify only three methodologically acceptable random controlled trials (RCTs): one supported (5) and one did not support (6) the use of CBT, while the third (7) employed a relaxation control.

Thus, with the addition of the report by Prins et al, there is now a grand total of two RCTs which have compared CBT (in a pooled total of 113 patients) with an ‘active’, though not indistinguishable, intervention (in 110 patients).

While both trials show statistically significant benefits on the primary outcome measures, the conclusions that can be drawn about efficacy are limited given the paucity of trials, the small number of patients involved, the problems surrounding the true comparability of CBT with ‘active’ controls such as relaxation or group support and, of course, the potential effect of publication bias.

If “evidence-based” status were to be sought on the basis of such statistics for (for example) homoeopathy, its advocates would be derided, discredited or simply ignored by the medical establishment.

A further important consideration is case selection: overall, current evidence does not support the claimed efficacy of CBT in CFS and its efficacy in ME has never been evaluated. The dramatic improvement reported by some UK trials of CFS patients (almost all carried out by subscribers to the Wessely School) has not been replicated in well-designed US and Australian studies in which patients have been clearly distinguished from psychiatric patients and who more closely resemble those with fatiguing neurological illnesses. (8)

Thus no conclusions can yet be made about the effectiveness of ‘group’ CBT nor about the long term cost-effectiveness of it, and certainly about the applicability of CBT to the various sub groups of patients currently encompassed within the heterogeneous and undifferentiated “CFS” classification, especially those who are most severely and chronically affected (ie. those with ME).

The issue of cost-effectiveness is controversial: whilst its advocates maintain that there is an attractive cost implication, (9) others point out that a course of psychotherapy typically lasts for 12 weeks or longer and note that cost is a major limitation. (10)

Further, if prevalence estimates of CFS are indeed 2.6% (using the 1991 Oxford criteria) as claimed in the Joint Royal Colleges’ Report on CFS, (11) then the logistics of making CBT (administered only by experts in CFS) available to 1.43 million eligible patients become insurmountable.

Given the forceful promotion of CBT by its advocates, the evidence that CBT(GE) might cause actual harm for those with ME / CFS needs fair and balanced appraisal.

Such evidence includes abnormalities of muscle and evidence of enteroviral sequences in the blood and is to be found in the work of many experts on both sides of the Atlantic, for example:

Dr Wilhelmina Behan (UK) has found evidence of mitochondrial abnormalities in ME/CFS/PVFS (12); her slides show clearly visible and very swollen muscle cells, with hypertrophy of the mitochondria, which confirms that the muscle cells are disordered and dysfunctional.

Dr Paul Cheney (USA) is categorical that such patients should not have to do aerobic exercise; he advises that if there is a defect in mitochondrial function and the mitochondria are pushed by exercise, then the DNA is killed (13)

Dr Wilhelmina Behan & Lorna Paul (UK) have produced firm laboratory evidence demonstrating delayed muscle recovery from fatiguing exercise: these findings show convincingly that in ME / CFS there is a *continued* loss of post-exertional muscle power (giving and *additional* loss of power), with delayed recovery for at least 24 hours, whereas sedentary controls recovered full muscle power after 200 minutes (14)

Professor Len Archard (UK) has shown persistence of enterovirus RNA in muscle biopsy samples, suggesting that some cases of ME/CFS result from a previous inflammatory viral myopathy (15)

Daniel Galbraith and Geoffrey Clements (UK) have demonstrated evidence for enteroviral persistence in sera of patients with ME / CFS, detectable in patients for up to 24 months, providing good evidence for viral persistence (16)

Russell Lane and Len Archard (UK) have shown by muscle histometry that patients with ME / CFS do not show the changes expected as a result merely of inactivity (17)

Professor Richard Bruno (USA) has found parallels between the post-polio syndrome and ME / CFS and believes there is a common pathophysiology (18)

Professor Martin Lerner (USA) has documented evidence of cardiac impairment (obtained from biopsy data) in patients with ME / CFS (19)

Professor Kenny de Meirleir et al (Belgium) has demonstrated significantly decreased exercise capacity in CFS when compared with healthy controls; this could affect physical abilities to a severe extent (20)

At the recent American Association of Chronic Fatigue Syndrome (AACFS) Conference held in Seattle in January 2001, evidence was presented by D. Racciatti et al from Italy, which showed that objective examination of skeletal muscle tissue revealed evidence of a degenerative process of muscle tissue in CFS patients, as typically occurs in mitochondrial myopathies; this objective evidence supports an organic basis for the disorder (21)

These few illustrations are merely representative of a considerable literature; they serve to indicate that more attention needs to be given by psychiatrists to the muscle abnormalities which are known to be present in at least some patients with ME/CFS/PVFS.

Very recently, the Medical Adviser to the ME Association (Dr Charles Shepherd) has published the fact that he continues to receive more adverse reports about graded exercise (a component of CBT) than any other form of treatment and that there is clear confirmation that many people with ME / CFS are suffering relapses through such programmes. (22)

Dr Shepherd reminds people that doctors have now been warned by their insurance companies that any form of exercise treatment needs to be prescribed with just as much care as drug treatments, otherwise they could be taken to court. (22)

The very same results have been found by both Action for ME (AfME) in their survey of 2,338 respondents (23) and also by Dr Lesley Cooper (a former member of the CMO's Working Group) in a separate survey jointly sponsored by the ME Association and AfME (24). In both these major surveys, graded exercise was felt to be the treatment that made more people worse than any other

A detailed survey by an independent ME researcher (DM Jones MSc) has recently confirmed the same results. (25)

Additionally, a survey carried out by The 25% ME Group for the Severely Affected found that graded exercise / CBT caused a chronic and severe condition. (26)

In all these surveys, it was found that not only did graded exercise / CBT make most participants worse, but even for those who were not made worse by such programmes, graded exercise was not helpful.

Chris Clark, Chief Executive of AfME (and member of the CMO's Key Group) states in a widely circulated letter dated 13th July 2000 that *"Professor Wessely is personable. Having said that, I am on the record as stating that he is wrong and his views have caused damage"*.

Apart from studies published by members of the Wessely School (including that produced by the Cochrane Database Systematic Review (4) with which Wessely is known to be involved) there is no evidence that CBT is effective. Even its keenest advocates within the Wessely School acknowledge that CBT as a therapeutic measure for CFS / ME is not of longterm benefit (27, 28) and in his presentation at the 1998 Boston Conference on CFS, psychiatrist Michael Sharpe himself conceded that the difference between CBT-treated patients and untreated controls disappeared after time: outcome improvements are known to have declined 17 months after treatment ends, suggesting that these patients are not recovered.

Why, then, is CBT, including graded exercise, now being inflated to "evidence-based medicine" status, and why is it being so strongly advocated (to the exclusion of any other treatment modality such as rest, pacing, dietary modulation and nutritional supplement, all of which have been shown to be of at least some benefit in these surveys) by the most influential members of the CMO's Working Group?

Could the reason be Professor Simon Wessely and his association with PRISMA?

In the UK it is known that Wessely is actively involved with PRISMA and it is widely believed that Professor Leslie Findley is also closely involved with PRISMA.

What is PRISMA?

PRISMA stands for Providing Innovative Service Models and Assessments. It is a research project funded by the European Commission's Information Society Technologies (IST) Programme. The address is www.prismahealth.com

The PRISMA research project claims it aims to provide a systematic analysis and synthesis of the current and future impacts of new information and communication technologies on government services throughout Europe. It claims that its analysis of services involves identifying best practices within the European Union and that it is "developing long-term visions, building scenarios of desirable future-oriented best practice models" and that these models can be applied by PRISMA users (including service providers and decision makers) using the PRISMA toolbox.

Work is being carried out in close consultation with a large number of selected test beds of e-government in practice around Europe, with experts working through service panels.

The work of PRISMA is closely related to the eEurope 2002 Action Plan, especially the government online and health online Action Lines.

Statistics show that long-term disability is hard to treat and that after three years of disability, only a very small percentage of people recover from their illness.

PRISMA is especially concerned with long term disability from the perspective of governments, service providers and insurance companies. It claims to have developed a “unique treatment programme” for such “hopeless” patients (those with CFS are included) and it claims that such patients “avoid physical exercise and social activities, as they fear these may trigger new bouts of complaints”.

The PRISMA programme places heavy emphasis on training these people to regain a “normal life again, with exceptional (*sic*) good results”.

At PRISMA, they believe that the medical system in many countries has difficulty in providing the kind of treatment which they promote: in the PRISMA Round Table, they discuss these issues with “leading experts in medical care, the insurance industry and government officials and provide recommendations to healthcare policy makers”.

Of special concern is that in PRISMA Company Information, Professor Simon Wessely is a Corporate Officer of PRISMA; he is a member of the Supervisory Board of PRISMA (an interest which he seems never to declare). In order of seniority, he is higher than the Board of Management. He is listed as a world expert in the field of medically unexplained illnesses, including Chronic Fatigue Syndrome.

In response to a parliamentary question in the House of Lords by The Countess of Mar, Lord Falconer of Thoroton, Minister of State in the Cabinet Office, confirmed that where relevant to the UK’s e-government initiative, the PRISMA findings will be taken into consideration.

Those with ME will not be surprised to learn that PRISMA promotes CBT for all “medically unexplained” illnesses.

Perhaps this explains the otherwise inexplicable.

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