

## NICE TACTICS

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The UK House of Commons Health Select Committee is currently looking at the working of the National Institute for Health and Clinical Excellence (NICE). It is to be hoped that the Committee will apply sustained pressure upon NICE to explain its modus operandi in relation to its draft Guideline on "CFS/ME", given the fact that (i) the Guideline will have far-reaching effects as it will become the template for management of the disorder throughout the NHS and (ii) this modus operandi has been shown not to have followed the principles to which NICE itself is party and to which it is obliged to conform.

Those principles are laid down in the AGREE Instrument (The Appraisal of Guidelines for Research and Evaluation). The AGREE Collaboration started in 1998 and originates from an international collaboration designed to enhance effective healthcare policy throughout Europe by the dissemination of high quality clinical guidelines.

There are currently 23 criteria in the AGREE Instrument. As is clear from its draft Guideline published in September 2006, in the case of "CFS/ME" NICE has failed almost all the pertinent criteria. Evidence of this has been submitted to the Health Select Committee and has been acknowledged.

One of the criteria is the requirement to describe specifically the patients to whom the Guideline is meant apply. NICE has signally failed on this count, since "CFS/ME" is a heterogeneous group of people suffering from unexplained "chronic fatigue" lasting from one month to those with severe ME (also known as "ME/CFS" to distinguish it from the non-classified label "CFS/ME") lasting for over forty years.

When producing a Guideline, NICE is obliged to give equal weight to three main sources of data: "evidence-based medicine" (usually deemed to be random controlled trials), the opinion and experience of physicians with expertise in the area, and the opinion and experience of the patient group for whom the Guideline is intended.

Within the UK ME community there is unanimous condemnation of the draft Guideline as being unfit for purpose. The key issue causing such dismay in this case is NICE's undue reliance upon the

seriously flawed Systematic Review of the so-called “evidence” that supports the use of cognitive behavioural therapy and graded exercise therapy (CBT/GET) provided for NICE by the Centre for Reviews and Dissemination at York. This Review afforded unwarranted support for CBT/GET whilst ignoring not only the biomedical evidence demonstrating the multi-system organic pathology of the disorder but also the experience of thousands of patients, supported by medical science, that CBT/GET simply does not work and can indeed be harmful for those with ME/CFS.

It seems beyond doubt that the “consultation process” now being exploited by NICE is – according to Christopher Booker on 20<sup>th</sup> June 2004 in the Sunday Telegraph – merely an empty exercise. As Booker makes plain, one feature of modern government showing that its condescension towards the electorate has reached the point of parody is the charade known as “consultation”. The Government and its bodies pretend to “consult” those affected by their actions, then carry on doing exactly what they intended in the first place. In other words, entirely predictably, the “consultation” process is a farce, as the Government is not remotely interested in looking at the evidence.

The US CDC has confirmed, and gene research has already shown, that some cases of ME/CFS may be linked to an environmental cause such as organophosphates. Booker sums things up clearly: “These products have been licensed by the Government as safe to use. Any admission that the system is faulty might expose it to huge compensation claims” – hence the policy decision to ignore the submitted evidence.

The Select Committee must take this on board and must insist that NICE explain itself, because the proof that NICE has got it wrong is compelling and undeniable.

The evidence that NICE’s favoured management regime (CBT) does not work is legion, and has been publicised by no less an icon than psychiatrist Dr Raj Persaud. NICE could hardly be unaware of Dr Raj Persaud, notorious for his multi-media broadcasts and for his weekly columns in the press, as well as his many magazine articles and the books he has authored. Not only was he a Consultant Psychiatrist working alongside Professor Simon Wessely within the same hospital Trust, he had a high profile in his post as Director of the Centre for Public Engagement in Mental Health Sciences at the Institute of Psychiatry. In 2002, Persaud was voted one of the top ten UK psychiatrists by his peers at the IoP and the Royal College of Psychiatrists.

When on 26<sup>th</sup> January 2006, Wessely gave his now-infamous Gresham College lecture denying the existence of Gulf War Syndrome, he was introduced by his colleague Persaud, who was fulsome in his praise of Wessely. Persaud was one of the eight Professors who run Gresham College; he has nine degrees and diplomas, including an MPhil, a Masters degree in statistics and a degree in psychology as well as medicine.

Clearly Persaud was a man of stature who knew his chosen field well, at least he was considered to be so until 2005 when he faced multiple and serious charges of plagiarism, both in the UK and from the USA.

However, an internal investigation in April 2006 by Kings College, London, decided that no further action was necessary. Retractions of Persaud's articles were published by the journal *Progress in Neurology and Psychiatry*, as well as by other periodicals including the *BMJ*. Persaud denied the allegations, saying they were "wholly unfounded". He apologised for what he termed an "error" which he maintained occurred when he cut and pasted original copy but omitted to include the references. The matter was therefore closed by Kings College without the need to initiate a formal inquiry.

Thus Persaud's previous iconic status was restored apparently untarnished.

This being so, upon what reason does NICE rely for ignoring Persaud's expert exposition of the ineffectiveness of CBT?

It was on 12<sup>th</sup> March 2003 in the Science section of the *Daily Telegraph* that Persaud efficiently destroyed the aura around CBT in his article "Looking for a counsellor? You need your head examined. Despite the huge growth in the number of psychotherapists, you'd be better off talking to an intelligent friend". The article came from Persaud's book "From the Edge of the Couch" (Bantam Press, £11.99).

The following extracts are taken from Persaud's article in the *Daily Telegraph*.

"Fifty years ago, psychotherapy was dealt a major blow with the first scientific paper to question seriously whether it worked, and whether therapy might sometimes do more harm than good. The study triggered a debate that has raged for half a century. It started when a young German psychologist, Hans Eysenck, analysed the first proper clinical trials of therapy at the Maudsley Hospital, London. (He) compared the improvement rate in thousands of people undergoing psychotherapy with a control group (and found that) 72% of the control group made a similar recovery with no psychotherapeutic assistance".

“When Allen Bergin, a psychologist at Brigham Young University, looked closely at this research, he uncovered a result that has dogged the field since. Therapy could not only do good, but also harm”.

“Therapy has splintered into so many differing schools that it resembles the plethora of small political groupings more often united by a hatred for each other than the natural enemy which, in the case of therapy, is science”.

“The British Association of Counselling had just a few hundred members by the mid-Seventies but has now grown to 16,000 members”.

“This dramatic growth has occurred despite the fact that scientific research continues to question the assumptions on which much therapy is based”.

“A key scientific blow to the therapy empire came in 1975 when Lester Luborsky, professor of psychology at the University of Pennsylvania, published a landmark paper with the title ‘Everyone has won and all must have prizes’. He found that it didn’t seem to matter what particular therapy you had -- it appears to be irrelevant whether you have full blown psychoanalysis or just a few sessions of behavioural therapy”.

“In 15 separate major scientific attempts to pool all the research done into the effects of therapist experience and training on patient outcome, only one ever found a significant positive association between years of therapist experience and patient benefit”.

“Yet another scientific nail in the therapy coffin was the extensive study conducted by Dr William Piper of the University of Alberta in 1991. He analysed 22,500 therapist interventions from audio tapes of sessions, and found the more interpretations the therapist made, the worse the patient got”.

“All this welter of scientific evidence points to the fact that much of the benefit you can get from therapy is practically indistinguishable from what you might obtain from confiding in a reliable, understanding and intelligent friend”.

“(The) defence of therapy (by the American Handbook of Psychiatry) suggests that the rise in counselling is telling us something more worrying – the continued retreat of scientific and rational thinking in the modern age”.

This, it must be remembered, is the view of an expert who was voted one of the top ten psychiatrists in the UK by his peers.

Another criterion that NICE is obliged to observe in the production of its Guidelines is the one concerning the potential cost implications of applying the recommendations; assessment of cost-effectiveness is, or ought to be, carried out for the purpose of maximising health gain. If resources are employed in interventions that are not cost effective, then less health gain is achievable.

In the case of ME/CFS, this is another criterion that NICE has entirely failed to observe.

Whilst neither the Prime Minister's Policy Unit nor the Department of Health (to whom NICE is accountable) seems at all concerned at the monumental waste of public funds from an already financially terminal NHS that will be involved in implementing NICE's flawed and damaging Guideline, members of the Health Select Committee might be expected to mind very much indeed.