

## Problems and Solutions ?

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The interview with Professor Colin Blakemore, Chief Executive of the Medical Research Council (MRC) by Simon Mayo on BBC Radio 5 Live broadcast on 22<sup>nd</sup> February 2005 encapsulated the essence of an iatrogenic problem that since 1987 has compounded the suffering of those blighted by a serious neurological disorder. If his pronouncements had been about any other officially classified neurological disorder but the one in question, Blakemore would surely once again have been pilloried by the media and the public (as was the case over his passionate commitment to vivisection, said to be the reason why -- to his keen disappointment openly expressed on national television -- he was not awarded the customary knighthood that goes with his current post).

In the Mayo interview, Blakemore was asked to answer a question that had been sent in by Stephen Ralph, list-owner of MEActionUK: *“ why, after several years of promises, the Medical Research Council has so far failed to fund any biological research into the physiological issues surrounding ME and Chronic Fatigue Syndrome that are recognised by the World Health Organisation as being a disease of neurological origin? Thus far the MRC has been seen to do not a lot more than perpetuate the status quo of funding psychological interventions (that) do not address neurological, cardiological, immunological and other abnormalities highlighted in international research that so far has been ignored in the United Kingdom”*.

Professor Blakemore's response was not only disingenuous but singularly revealing and might even be described as deliberately misleading: *“I know that this is a very current issue of very great concern to ME sufferers. It is by no means ignored by the MRC: we are funding trials on chronic fatigue syndrome and ME – clinical trials of treatments. I think to concentrate on this question of whether ME is thought to be a neurological or a psychological condition actually isn't going to get us far --- I mean, compare the situation with depression: depression is a brain condition but depression can be treated both by psychological approaches and by drugs, so I don't think we should look down our noses at psychological treatments. We accept that this is a real disease (but) we don't understand its basis. We need high quality proposals – I think everyone would agree that they wouldn't want taxpayers' money wasted on bad science however important the cause”*.

Blakemore's response causes immediate concern.

His declaration that there is no need to worry about whether or not the disorder is either psychological or neurological in causation is notable and would seem not to be in accordance with the rigorous approach that is necessary for progress to be made in medical science. Does he really see no need to search vigorously for the cause of ME? If so, why does such an approach relate only to ME and not to all illnesses whose cause is as yet unknown, including cancer, multiple sclerosis and lupus? What is the purpose of the MRC if not to conduct research into illness that will provide understanding of (and result in treatment for) that illness? After all, diabetes and epilepsy used to be designated as psychiatric disorders until medical research proved otherwise and the treatment that became available as the result of

such research has saved the lives of countless sufferers who, in the case of diabetes, would otherwise have died but who today can lead a comparatively normal and fulfilling life.

Equally disturbing is Blakemore's support for the current MRC trials on "CFS/ME" that have been widely shown to be flawed from the outset by virtue of the entry criteria (the Oxford criteria) chosen by the psychiatrists who are running the trials, when by definition those criteria exclude people with ME. Blakemore was therefore wrong to state unequivocally that the current MRC trials include those with ME. There can be no credible doubt that the Oxford case definition excludes those with neurological disorders and this was confirmed in 1991 by psychiatrist Anthony David (colleague and co-author with Simon Wessely) who referred to the Oxford criteria shortly after they were published:

***"British investigators have put forward an alternative, less strict, operational definition which is essentially chronic fatigue in the absence of neurological signs (but) with psychiatric symptoms as common associated features"*** (Postviral syndrome and psychiatry. AS David. British Medical Bulletin 1991;47:4:966-988).

How can it be acceptable for Blakemore to claim that the MRC is funding trials on ME when evidence abounds that this is untrue?

Blakemore rightly stated that the MRC needs "high quality proposals" for research, yet he openly supports the MRC PACE trials even though those trials cannot possibly fulfil such criteria because of the inherent design flaws that (to no avail) have been brought to the attention of the MRC. What is his explanation?

Is he unaware that in the most recent issue of its magazine "ME Essential" (February 2005), the ME Association's Medical Adviser writes:

***"Now some bad news. The MRC made it clear that priority should be given to funding further behavioural interventions. The ME Association believes that the MRC research strategy is seriously flawed and has called for money to be spent on looking at the underlying physical causes of ME/CFS"***.

Clearly, for someone in his position Blakemore either is improperly ignorant of the international research literature on ME/ICD-CFS; is being misinformed by those with a vested interest in maintaining the status quo that since 1987 has been so assiduously nurtured and propagated by certain psychiatrists and their adherents (notoriously known as the "Wessely School" after one of the group's most dominant members, Professor Simon Wessely of Guy's, King's and St Thomas' School of Medicine) to whom Blakemore is on record as having allegiance, or else --- in the face of the existing published medical and scientific knowledge of the disorder and of the known biomarkers of organic pathology --- he is party to a scandal in the UK that finds millions of pounds sterling for inappropriate and flawed psychiatric trials but denies necessary and appropriate biomedical research, correct investigation, appropriate service provision and delivery of care to those severely physically sick and disabled. People with a neurological disorder are entitled to such provision by the NHS yet for many years those with ME have been designated by adherents to the currently prevalent psychiatric paradigm as "the undeserving sick" and as such are deemed not to warrant expenditure of public funding other than ever-more provision of psychiatric services supplied by the very psychiatrists who deny the existence of the disorder they are claiming to "treat".

Such is the influence of these psychiatrists that they have recently secured funding of £11.1 million (including £2.6 million from the MRC) to carry out more “research” in an attempt to legitimise their own beliefs that ME does not exist except as an aberrant belief in the mind of suggestible patients and naïve doctors and to demonstrate that “ME” is in reality “chronic, medically unexplained fatigue” and as such is a mental health problem.

It was in 1987 that the bid for the take-over of the severely incapacitating and discrete neurological disorder ME was effectively launched by certain psychiatrists and others on both sides of the Atlantic who were involved with the medical insurance industry; in this bid, the specific and WHO classified disorder was deliberately subsumed under the heterogeneous label of “CFS”, which in turn was destined to become a catch-all label for the so-called “medically unexplained symptoms” that have been shown to be either virally or chemically induced and which were rapidly escalating out of control and becoming a serious financial threat not only to governments but also to the medical insurance industry.

Since 1987, the leitmotiv of the psychiatric literature on ME/ICD-CFS has been that patients who present with and suffer from a disorder that the psychiatrists and their corporate masters wish to eradicate are an “unjustified” and “undeserving” financial burden and that it is neither cost-effective, necessary nor appropriate to investigate their “non-existent” disorder. Instead, patients’ “dysfunctional thinking” and their “personality problems” must be managed by psychiatrists.

This project has been remarkably rewarding to these psychiatrists and their respective departments, since they have received many millions of pounds sterling, not only from private charities such as the Sainsbury (supermarket) Linbury Trust (who between 1991 and 1998 provided over £4 million) but also from the pharmaceutical industry, the medical insurance industry (with whom they are deeply involved), Government itself and the MRC.

No intelligent person is unaware that the public purse is not bottomless and that in the NHS, clinical judgments have to be made every day in individual cases as to whether or not further treatment is reasonable and justified. However the issue surrounding ME is different: it is a specific nosological disorder that is being dismissed, denied research and investigation, treatment, and humanitarian care of those afflicted. If it were the autoimmune disorder lupus, for example, about which psychiatrists did not understand but were advising that sufferers were “the undeserving sick of our society” and that there must be a policy of only psychiatric management, would there not be an outcry?

Why should these psychiatrists make a unilateral judgment as to which medical disorder is “deserving” of treatment? The intentional “limiting” of investigations and more worryingly, the withholding of “any other medical care” (*see below*) and the promotion only of psychiatric management strategies for “CFS/ME” has become the mantra of the Wessely School and now of Prime Minister Blair’s Labour Government, as well as the MRC.

We submit that this amounts to denial of the human right of fundamental freedoms under the Human Rights Act, since the Act requires that all public authorities must pay proper attention to a person’s rights when they are making decisions that affect a person. Public authorities include Government Ministers, civil servants, local authorities and health authorities. The Act requires that those in authority do not ride roughshod over people’s rights and must be careful to cause the least possible harm to individuals. To deliberately withhold the provision of appropriate medical care to those with one specific neurological disorder does result in

actual harm and we submit that the time is now ripe for the decision that is known to have been taken by those in positions of authority (namely, that people with ME are “the undeserving sick of our society”) to be robustly challenged in the Courts by means of judicial review.

It can no longer be denied that there is an enormous amount of available published evidence that ME/ICD-CFS is not a primary psychiatric disorder but a multi-system physical disorder of extraordinarily incapacitating dimensions that affects virtually every bodily system, most notably the neurological system, the immune system, the endocrine system, the musculo-skeletal system, the cardiovascular system, the respiratory system and the gastrointestinal system. It has distinct cardinal features that are not difficult to differentiate from psychosocial disorders, but Wessely School adherents are renowned for their intransigent dismissal of any evidence that does not accord with their own construct and so they advise that no-one should even look for such evidence, even to the point of advising Government that “*no investigations should be performed to confirm the diagnosis, which is a clinical one*” (Joint Royal Colleges’ Report on CFS. 1996: CR54: Summary for Commissioners, page 45) because they believe that carrying out investigations would reinforce patients’ aberrant belief that they are physically sick.

Despite the dominance of the Wessely School, at international conferences and in laboratories and coffee rooms of hospitals and research institutions, not only clinicians in other medical disciplines but also other psychiatrists discuss amongst themselves how they do not accept the Wessely School model of ME/CFS and how they can see for themselves that it is striking how physically sick some people with ME are, but they are effectively bullied into remaining silent by the domination, remorseless indoctrination and damaging tactics employed by the Wessely School. These psychiatrists have flooded the literature with their own beliefs to the extent that it would require several volumes to document their publications, but a few quotations serve to illustrate their dogma; one such can be found in an Editorial on medically unexplained physical symptoms in the BMJ by Professor Richard Mayou:

***“Physical symptoms that lack an obvious organic basis are common in medical practice. Management should aim at avoiding unproductive investigation followed by abrupt suggestions of a psychological explanation. Unfortunately many psychiatrists have little experience of treating patients who present with somatic symptoms (and) may need educating about the harm caused by their all too common response of writing a letter concluding that ‘no psychiatric disorder is present’. A single doctor should take responsibility for the patient and family, limiting and controlling any other medical care”.*** (Medically unexplained physical symptoms. Do not overinvestigate. Richard Mayou. BMJ:1991:303:534-535).

What gives Professor Mayou (at the time Clinical Reader in Psychiatry at Oxford) the right to dictate that a single doctor should “control” any other “medical care” concerning a patient with symptoms for whom medicine does not yet have the answer? This is a serious matter, but neither of the two major ME charities has seen fit to challenge it, either at the time of publication or since.

The same theme has been adopted by psychiatrist Michael Sharpe (who used to be at Oxford) and whose similar views are now well-known:

*“In clinical practice, no additional tests, including laboratory tests and neuro-imaging studies, can be recommended. Examples of specific tests (which should not be done) include serologic tests for enteroviruses; tests of immunologic function and imaging studies such as SPECT or PET scans of the head”* (The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study.

K Fukuda, M Sharpe et al. Ann Int Med 1994;121:12:953-959).

*“Purchasers and Health Care providers with hard pressed budgets are understandably reluctant to spend money on patients who are not going to die and for whom there is controversy about the ‘reality’ of their condition (and who) are in this sense undeserving of treatment.*

*“Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and our health service”* (ME. What do we know (real illness or all in the mind? Lecture given in October 1999 by Michael Sharpe hosted by the University of Strathclyde).

Such views about ME have been propounded by the Wessely School for the last 17 years and to their probable gratification have finally been crystallised in a [“CFS profile”](#) as formulated by at least two of the Government-funded “CFS/ME” centres in their job descriptions for candidates who are to deal with “the undeserving sick” (Liverpool and Broadgreen University Hospitals NHS Trust and Epsom and St Helier NHS Trust):

CFS patients are said to exhibit “perpetuating illness behaviour”; therapists will be required to modify patients’ “predisposing personality style”; CFS patients have “complex psychological problems” and “experience barriers to understanding”; there can be “significant barriers to accepting the changes needed in behaviour, which have to be overcome in therapy”; therapists can be required to work frequently in an emotive and demanding environment and patients may be “verbally aggressive”; **“medical intervention is no longer appropriate”**; the aim of therapy is to “reduce healthcare usage”; the service is extended to patients who have mental health problems; the post-holder is expected to “implement a range of psychological interventions with individuals, couples and families” and to work with other members of the multi-disciplinary team to “raise awareness of the approach adopted by the new centres to GPs and other local service providers”.

Clearly, the intention is to portray throughout the UK the “CFS profile” and the desired psychiatric management of such patients.

We submit that urgent action now must be taken and that since all efforts to enlist the support of MPs have proved ineffective, the only route left is via the Courts by Judicial Review (JR). The procedure for JR is that firstly, a written application is made to the Administrative Court at the High Court in London; this will be considered by a Judge who will either allow it to proceed or refuse permission for it to proceed. If the Judge refuses permission, there is an automatic right to a Hearing in person before a Judge, who may grant permission for a full Hearing. Should permission still be refused (and the Prime Minister’s apparent influence over appointment of certain members of the judiciary has been raised in the media), there is the option of lodging an appeal to the Court of Appeal. Should this be unsuccessful, a fresh cause of action may be submitted to the European Court of Human Rights in Strasbourg.

Legal Aid may be available to bring Judicial Review proceedings.

Those in the UK wishing to consider bringing an action for Judicial Review in relation to denial of human rights for those suffering from ME (which includes the forcible removal by Court Order initiated by psychiatrists not only of children and young people but also of adults with ME from their home without consent) may wish to contact Jamie Beagent in the Human Rights Department at Messrs Leigh Day & Co on 0207-650-1200 or directly by email at [jbeagent@leighday.co.uk](mailto:jbeagent@leighday.co.uk) or by post at Priory House, 25 St John's Lane, London EC1M 4LB.