The Medical Research Council's secret files on ME/CFS

Margaret Williams 10th December 2009

It is an established fact that the MRC has a secret file on ME that contains records and correspondence since at least 1988, which, co-incidentally, is about the time that Simon Wessely began to deny the existence of ME. The file is held in the UK Government National Archives at Kew (formerly known as the Public Record Office) and was understood to be closed until 2023, but this closed period has been extended until 2071, at the end of which most people currently suffering from ME will be conveniently dead. http://www.nationalarchives.gov.uk/catalogue/displaycataloguedetails.asp?CATID=-5475665&CATLN=7&Highlight=&FullDetails=True&j=1

As one puzzled ME sufferer recently noted: "*why on earth have a 73 year embargo on these documents on an illness where a load of neurotic people, mostly women, wrongly think they are physically ill?*" (http://health.groups.yahoo.com/group/MEActionUK/ 14th October 2009).

The MRC's secret files on ME/CFS are closed (ie. unavailable to the public) for an unusually lengthy period of 83 years. The standard closure period is 30 years but, as in the case of these files on ME/CFS, the standard closure period may be extended.

The 30-year rule usually applies to documents that are exempt from release under a Freedom of Information Act (FOIA) request and include, for example, documents concerning the formulation of government policy, documents related to defence, to national security, to the economy, and documents that are considered very confidential.

It may be recalled that during the life of the Chief Medical Officer's Working Group on ME/CFS (1998-2002), lay members were ordered not to discuss the deliberations and were even threatened with the Official Secrets Act, for which no explanation was proffered. A letter dated 16th June 2000 from Mrs Helen Wiggins at the Department of Health NHS Executive Headquarters in Leeds was sent to lay members of the Working Group; this letter stressed that it had become increasingly important that any documents or information, in whole or in part, that might contribute to the report must be kept confidential and to this end, members of the Working Group might be compelled to sign the Official Secrets Act. This was followed up by a letter dated 23rd October 2000 from Lord Hunt of Kings Heath, then Parliamentary Under Secretary of State at the Department of Health (ref: POH (6) 5380/83), confirming that the information held by the Working Group might in certain circumstances indeed be covered by the Official Secrets Act.

If the psychiatric lobby which dominated that Working Group was so confident that it was correct about ME/CFS, why the need to force the suppression of opposing views by resorting to threats of prosecution under the Official Secrets Act in a Working Group that had nothing to do with State security but was supposed to be acting simply in the best interests of sick people? This was in marked contrast to the "Key working principles" set out in the first Briefing Note of March 1999, which stated: "*The Group must have maximum 'transparency' ie. as much information about its activities to be distributed as possible to all potential interested parties*".

One can but wonder how the consideration of ME/CFS could rank as a state secret and of what, precisely, was the Department of Health so afraid that it even <u>considered</u> the use of such draconian powers? For the record, Mrs Wiggins was replaced by Robert Harkins and it was he who sent the letter dated 25th May 2004 (ref: TO1056746) in which he stated that the then new centres for CFS *"will be headed up exclusively by psychiatrists*", which was deemed to be more evidence of Government policy on "CFS/ME".

People wishing to access documents archived at Kew are able to make an application to access documents that are not redacted or closed, but the procedure is lengthy. Prior notification and advance booking are required; people must remove their coats / jackets and leave them, together with personal possessions including handbags, in a locker with a see-through door for which a numbered key is provided; proof of identity is mandatory and every person is newly photographed on arrival.

Legitimate access has been obtained to some of these archived documents about ME/CFS and they make interesting reading, for example:

On 1st June 1988, Dr Katherine Levy of the MRC sent an internal memo: "*I have got caught up in an enquiry from HORIZON on MRC support for myalgic encephalomyelitis. Mrs Currie* (Edwina Currie MP) *is on record…as saying the MRC is supporting nothing…I had a preliminary word with the producer…she evidently wants to quote us and…I do not want us quoted as saying we think we have nothing….**They would make a meal of it!***". Handwritten comments state: "*Is this not the Royal Free Hospital Syndrome and perhaps of controversial status as a disease entity?*". The handwritten comments continue: "*I have also spoken to Dr Swash* (believed to be a member of the MRC Neurosciences and Mental Health Board)*, who is among the agnostics along with… Peter Thomas* (believed to be Wessely's co-author the late Dr PK Thomas, a neurologist who is on record as describing ME patients' muscle weakness as *'simulated'* in Recent Advances in Clinical Neurology, 1990: pp 85-131) *and others: his view is that no research of any significance is being undertaken on this topic in the UK…*". On 6th June 1988, a post-scriptum was added: "***PS I got away with no mention of Radda, the Unit, or Oxford***" (in 1984, Professor Sir George Radda, as he later became when appointed Chief Executive of the MRC in 1996, had published research using nuclear magnetic imaging that confirmed a unique biochemical defect in the way energy was being produced in an ME patient – Lancet 23rd June 1984: 1367-1369).

Another document that has been obtained through legal means is a summary of the CIBA Foundation Symposium on CFS that was held on 12-14th May 1992 (reference S 1528/1). The letter "S" indicates that the document is categorised as "Scientific" and the following quotations come from the section entitled "HIGHLIGHTS":

"*Ned Shorter* (ie. Edward Shorter, the Hannah Professor in the History of Medicine at the Universtiy of Toronto, a well-known disbeliever in ME/CFS) *fascinated the audience with his historical perspective on how symptoms of disease without apparent organic illness vary over time…Why is chronic fatigue* (sic) *so appealing to patients and their doctors? One factor must be that fatigue is difficult to disprove.* ***There is a desire among patients and doctors to upgrade their symptoms in order to stay abreast of science. Virology and immunology are dynamic, progressive branches of science, and patients are irresistibly*** **(sic)** ***drawn to them in order to explain the mysterious origin of their symptoms. This is evidence of a somatization disorder, in which patients believe their symptoms, which are psychogenic in origin, are evidence of organic disease…".***

The section on Epidemiology states: "***CFS…is a collection of symptoms, not a disease***".

The section on "Muscle fatigue" records: "*Edwards* (ie. Professor Richard Edwards from Liverpool, on record as stating: *"Many of the biochemical changes during exercise and many of the symptoms of these patients could be a consequence of their reduced habitual activities"* -- Ergonomics 1988:31:11:1519-1527) *concluded that on physiological and pathological grounds, CFS is not a myopathy;* ***a primary role for psychological / psychiatric factors was deduced from a formal comparison between CFS and myopathy patients***".

The section on Virology states: "*The meeting concluded that exhaustive analysis had failed to prove that CFS is caused by a virus or viruses (and)* ***members were increasingly drawn to the idea that the search for a single identifiable cause of CFS is meaningless…"***

The section on Psychiatry states: "*Studies have shown that the relative risk of psychiatric disorder is increased 2-6 fold in CFS cases compared to controls with physical diseases. Various themes emerged. One is of a subcortical dysfunction analogous to the cognitive problems seen in illnesses such as Parkinson's disease. The most impressive evidence of CNS disturbance was quoted by Wessely (Institute of Psychiatry) as coming from neuroendocrinological* *studies, suggesting a role for hypothalamic disorder as a final common pathway for CFS"* (yet Wessely still maintains that "CFS/ME" is a somatisation disorder).

The Psychiatry section continues: "*Sharpe (Oxford)* (ie. Michael Sharpe, one of the three PACE Trial Principal Investigators) *described a trial of cognitive and behavioural therapy which he is just starting at the Warneford Hospital. The aim is to help patients re-evaluate and, if appropriate, change, unhelpful feelings about their performance and symptoms, and thus break the vicious circle.* ***He admitted that the trial was a purely pragmatic approach without theoretical foundation"*** (it is interesting to see confirmation in an MRC document – and from Sharpe himself -- that this study [BMJ 1996:312:22-26], one of the most-relied upon in the "evidence-base" for CBT in the 2007 NICE Clinical Guideline, was merely pragmatic and without theoretical foundation).

The section titled "The Treatment Process" is particularly notable: "***<u>The first duty of the doctor is to</u> support as much useful function as possible and <u>avoid the legitimisation of symptoms and reinforcement of disability</u>".***

The Section "General discussion" records: "***Shorter felt that from a historical perspective, CFS was an example of a disordered mind/body relationship that would not survive****…It was important to step back and look at the whole phenomenon of somatization".*

"Summarising, ***the Chairman (Kleinman) predicted that in 10 years time…the central issues in the CFS field would be social rather than medical or scientific, partly driven by the economics and funding of the disability systems in various countries****".*

Here, again, is evidence that the problem of ME/ CFS is seen in terms of economic costs to the nation and not in terms of alleviating suffering.

Numerous sections of this document are redacted and censored under FOI exemption 40 (2) and are marked "CLOSED UNTIL 2071".

Section 40 (2) of the Freedom of Information Act usually relates to the protection of personal information; this being so, a perfectly straightforward telephone inquiry was recently made to the National Archives at Kew with a view to establishing why so many sections of a report of a scientific conference should be deemed to be "personal information" and thus closed to the public. Having been advised by staff at Kew to speak to their own FOI department with this query, the questioner duly requested to be transferred to that department, but when the subject of the query was known, there was a long delay before the questioner was put through, not to the FOI department as advised and requested, but to a female member of staff who seemed very agitated and who said that <u>she</u> dealt with these particular enquiries. The questioner was barely permitted to get a word in and was constantly interrupted by this member of staff, who seemed to be reading at great speed from a prepared text. When the questioner was finally able to ask why a report of a scientific meeting should be deemed to contain personal information, the result was a further lecture about how important it is to protect personal information. No explanation was provided in answer to the question posed, even when it was pointed out that personal information in the form of names of presenters at the symposium had not been redacted.

Given the unconvincing sermon on the need to protect "personal information", it is notable that other documents in the MRC file held at the National Archives make no attempt to do so, for example, on 14th February 1997, Karen Finney of the MRC sent a memo to Dr Bryant and Dr Coriat at the MRC, in which she wrote: "*Chronic fatigue syndrome (CFS) and Mr Paul Hulme* (sic). *On 15th January 1997 a query concerning MRC support for ME was referred to me…I agreed to speak to the member of the public, Mr Paul Hulme (*giving his address and ex-directory telephone number -- personal information which was not redacted)*…Mr Hulme wished to know if MRC was funding any specific work on ME/CFS…In reply, I said I thought the MRC did not receive many proposals on ME/CFS…However, Mr Hulme was aware of a study supported by MRC and carried out at the Institute of Psychiatry. He was not happy with the fact that MRC had supported this work because ME* ***'was a***

real illness and not all in our mind'*….Following my telephone conversation, I asked Mr Goldstein (CAG) to run a search for applications on CFS/ME that we had received over the last year, funded or declined….Mr Goldstein's search took a little while due to other pressing matters…Between 15/1 and 7/2 Mr Hulme rang on average twice a week to ask about progress. When Mr Hulme rang on 7/2 I let him know, in general terms…that during 1996 we had received four applications which had been declined on scientific grounds…Mr Hulme requested that I put the result of the search in writing…****I am aware that the follow-up letter requires careful drafting****…Mr Hulme telephoned again on 13/2 to say that he needed my letter urgently (as) he intended to fax a letter to Ken Calman* (Sir Kenneth Calman, UK Chief Medical Officer) *concerning the Council's lack of support for the area, and also other issues surrounding the RCP review* (the 1996 Joint Royal College's Report CR54). ***Dr Davies and the Press Office have been kept informed of developments****. ****I think that a carefully worded letter of reply from someone higher up in the Office might put this matter to rest****".*

It is hardly surprising that the ME/CFS community believes that there is no intention to address the psychosocial bias of the Wessely School and the damage that such bias causes to those who are physically sick, especially given that the MRC Portfolio in Mental Health Research stated "*Mental health in this instance covers…CFS/ME"* (Neurosciences Mental Health Board Strategy and Portfolio Overview Group Scoping Study, January 2005). When challenged, the MRC subsequently stated CFS/ME was classified as a mental health problem for a "*pragmatic"* reason that was claimed to be *"related to the grants classification associated with the activities of one section of the office"* (letter dated 6th December 2005 from Dr Robert Buckle at the MRC -- a member of the PACE Trial Steering Committee -- whose letter continued: "*The Mental Health Scoping Study included the PACE and FINE trials on the basis of the type of intervention being assessed, namely psychological interventions…"*.

Members of MRC Boards are appointed to act *"as a core body of scientific advisors, assessing applications to the MRC"*. The MRC's refusal to accept the international biomedical evidence about ME/CFS may be related to the fact that in 2002 / 2003 the following Wessely School members were appointed to MRC Boards: Professor Trudie Chalder; Professor Anthony Cleare; Professor Anthony David; Professor Anne Farmer, Professor Michael Sharpe, Professor Peter White; Professor Richard Bentall; Professor Philip Cowen; Professor Til Wykes and Dr SM Laurie, with Professors Simon Wessely and Francis Creed having been recent members (http://webarchive.org/web/*/http://www.mrc.ac.uk). Wessely was a member of no less than three MRC Boards: the Health Services and Public Health Research Board; the Neurosciences and Mental Health Group and the Monitoring and Evaluating Group (MESG).

As Dr Jonathan Kerr, Sir Joseph Hotung Senior Lecturer in Inflammation, Department of Cellular and Molecular Medicine, Hon. Consultant in Microbiology, St George's University of London, stated at the Invest in ME Conference held in London in 2006:

"It is rather sad that the MRC does not fund any biological studies such as we are doing, and I think the current…consideration of grant applications to the MRC on CFS is currently with the Neurosciences and Mental Health Board…and I think that (this) immediately biases the decision-making process because that panel is made up predominantly I believe of psychiatrists. It would be desirable if this could be reclassified (by the MRC) *such that there would be money available…for biological approaches…It is a fact that currently the MRC does not fund any biological approaches".*

At the 2007 Invest in ME Conference, Dr Kerr repeated his message:

"We have applied several times to the MRC and on each occasion we were invited to submit those applications and on each occasion we got scores typically of 9, 8 and 3 – the 3 score was obviously from a psychiatrist who was complaining about our way of enrolling the patients, the criteria we had etc…David Tyrell told me the MRC will never fund biomedical research in CFS because they are in the thrall of the psychiatrists – so far, he has been right".

DVDs of both these Conferences are available from www.investinme.org

The late Dr David Tyrell, CBE, FRS, DSc, FRCP, FRCPath was Chairman of the UK National Task Force on CFS/PVFS/ME whose 1994 Westcare/DoH Report was rejected by the Wessely School and gave rise to their own 1996 Joint Royal College's Report (CR54) that denied the existence of ME. In his Foreword to the 1994 Task Force Report, Tyrell wrote: *"We have no doubt that such conditions exist and cause suffering and disability. We discuss the issue of nomenclature at some length for it is not just a semantic problem. It encompasses serious disagreements, which have sadly led to ill will and abusive remarks on such questions as whether the syndrome exists, whether it is 'real' or 'organic' or 'merely' psychological…it is important that…administrators, clinicians, scientists, funding agencies and patients identify the topics in their field on which action is needed…(and) the research community should be developed and strengthened. But we should be prepared for the long haul".*

It has certainly been *"a long haul"* because 15 years later, despite approximately 5,000 published mainstream papers that prove them wrong about the nature of ME/CFS, the Wessely School remains obdurate that "CFS/ME" is a somatisation disorder.

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