

Time for a Reality Check at the UK Department of Health?

Margaret Williams

3rd April 2004

In response to a letter about myalgic encephalomyelitis (ME) sent to the Secretary of State for Health (Dr John Reid), a reply dated 31st March 2004 was sent from the Department of Health on his behalf and was signed by Karen Nicolayson from "Research and Development". On the issue of whether ME/CFS is a physical or psychological disorder, the reply stated: "The Department of Health is neutral on this issue".

A look at information previously provided by the Department of Health is revealing because it shows that the above statement is at variance with what is on the public record.

1. ME was recognised as a physical disorder on 27th November 1987 (see Hansard (House of Commons) for 27th November 1987, column / page 353).
2. In an undated begging letter shortly after this (distributed under the auspices of the UK ME Association) signed by Professor James Mowbray (Professor of Immunopathology at St Mary's Medical School, London), he wrote **"In November 1987 ME was recognised as an organic disorder by the Department of Health.** I know the feelings of frustration and anxiety felt by ME sufferers. If you will help, I know research is the best way to find the answers".
3. In 1988 there was an Early Day Motion (EDM) on ME in the House of Commons; it stated: **"That this House strongly condemns the Yorkshire Television programme 'Where there's life' broadcast by the Independent Broadcast Association on Wednesday 8th June 1988 on the illness myalgic encephalomyelitis: agrees that the programme was based on inadequate and ill-informed research: questions the motive of the programme: concludes that such a programme debases the reputation of Broadcasting and betrayed the thousands of sufferers throughout the country who suffer from the terrible illness, Myalgic Encephalomyelitis"**. One of the signatories to that EDM was Dr John Reid (now Secretary of State for Health).
4. The ME Sufferers' Bill was presented to the House of Commons by Jimmy Hood MP on 23rd February 1988 and passed its first reading unopposed. The second reading was on 15th April 1988. The Bill asked for an annual report to Parliament: **"It shall be the duty of the Secretary of State (for Health) in every year to lay before each House of Parliament a report on the progress that has been made in investigating the causes, effects, incidence and treatment of the illness known as ME"**. Hansard (House of Commons) for 23rd February 1988 at columns 167-168 records **"There is no doubt that ME is an organic disorder. The sufferers are denied proper recognition, misdiagnosed, vilified, ridiculed and driven to great depths of despair"**.

5. In one of her published diatribes on ME sufferers, journalist Caroline Richmond (the founder of HealthWatch), stated: **“Myalgic encephalomyelitis is the first and indeed the only disease legally recognised in Britain, thanks to a private member’s Bill passed in 1988”** (Myalgic Encephalomyelitis, Princess Aurora, and the wandering womb. BMJ 1989;298:1295-1296).
6. On 20th July 1989, Dr Rachel Jenkins, a Principal Medical Officer at the Department of Health (now Professor Jenkins of the Institute of Psychiatry WHO Collaborating Centre) wrote in a letter **“If one reads through the historical literature of this syndrome, it is clear that there is substantial evidence that ME is an infective disorder. That is not to say that there may not be psychological consequences of the viral infection due to the presence of the virus in brain tissue. Furthermore, hysteria should always be diagnosed on positive signs of its presence, not on the absence of positive tests for physical disorders”**.
7. On 5th June 1991 the UK Attendance Allowance Board Secretariat at The Adelphi, 1-11 John Adam Street, London WC2N 6HT (which works in close liaison with the Department of Health) sent a letter signed on behalf of Mrs CV Dowse that confirmed **“Recent research indicates that ME must be a physical reaction to some type of virus infection”**.
8. In a letter dated 13th March 1992 to James Pawsey MP (ref: POH (3) 2484/200), in his capacity as Parliamentary Under Secretary of State for Health, Stephen Dorrell MP set out the official view of the Department of Health on ME: referring to the Disability Handbook produced by the Disability Living Allowance Board, Mr Dorrell stated **“The Handbook recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence, a physical cause for ME is recognised”**.
9. In a letter dated 15th March 1992, this exact view was repeated by the late Nicholas Ridley MP, who wrote to a constituent that **“The Disability Living Allowance Board recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence, a physical cause for ME is recognised”**.
10. On 18th January 1996, the official view of the Department of Health was set out in a letter to Geoffrey Clifton-Brown MP (ref: POH (6) 4139/192) in terms: **“The Government accepts that ME/CFS can follow a post-viral infection”**. This letter was signed by Baroness (Julia) Cumberlege in her capacity as Parliamentary Under Secretary of State for Health.
11. In the British Library Current Awareness Topics Update for March 2000 is listed (on page 6) the following: **Social Security Ruling, SSR 99-2p; titles II and XVI; evaluating cases involving chronic fatigue syndrome (CFS). Fed Regist 1999 Apr 30;64(83);23380-4: “In accordance with 20 CFR 402.35(b)(1), the**

Commissioner of Social Security gives notice of Social Security Ruling SSR 99-2p. This Ruling clarifies disability policy for the evaluation and adjudication of disability claims involving Chronic Fatigue Syndrome (CFS). This Ruling explains that, when it is accompanied by appropriate medical signs or laboratory findings, CFS is a medically determinable impairment that can be the basis for a finding of “disability”. This Ruling ensures that all adjudicators will use the same policies and procedures in evaluating disability claims involving CFS, and provides a consolidated statement of these policies and procedures”.

12. This was reported in the Disability Rights Bulletin, Summer 2000 in the following terms: **“In assessing DLA higher rate mobility component for people with ME, recent guidance advises decision makers to assume in the vast majority of cases that the claimant has a physical disablement. The Commissioner, in CDLA/2822/99, held that an award of the higher rate mobility component can be made on the basis of the physical element of the condition. Guidance (DMG Memo Vol 10-3/00) advises decision makers that, in the vast majority of claims, if a doctor says the claimant has ME or CFS then that can be taken as an opinion that they have a physical disablement”.**
13. A letter dated 30th May 2001 from the Department of Health signed by Linda Percival of the Health Services Directorate (ref: TO 2001 / 15353) states **“To improve services for people with long-term illnesses, the Government recently announced a National Services Framework (NSF). The NSF will have a particular focus on the needs of people with neurological disease. It is very likely that chronic conditions such as ME/CFS will be included”.** (For the record, when he was made aware of this, Chris Clark, CEO of Action for ME and at the time a member of the CMO’s “independent” Working Group on “CFS/ME”, claimed he would be totally amazed if this were true).

From the above, it can be seen that the Department of Health and its associated official bodies are not “neutral” about ME/CFS as claimed on 31st March 2004 on behalf of Secretary of State Dr John Reid. What can be clearly seen is that either the Department of Health does not know what it is doing from one day to the next or, on no good evidence, it has allowed itself to be overly influenced by the psychiatric lobby. In my opinion, this makes their present unquestioning acceptance of the Wessely School’s expediently constructed psychiatric paradigm all the more culpable, because although people are justified in relying implicitly on these documents from official bodies quoted above, they are being badly let down when they attempt to do so.

It is certainly the case that the present Parliamentary Under Secretary of State for Community Care at the Department of Health, Dr Stephen Ladyman MP, has grossly misled both MPs and the public: it was he who by letter dated 7th October 2003 (ref: PO 1036444) stated in support of Professor Wessely’s personal view that **“The WHO ICD-10 classifies CFS in two places; as neurasthenia / Fatigue Syndrome on the mental health chapter (F48.0) and as Postviral Fatigue Syndrome / Benign Myalgic**

Encephalomyelitis in the neurology chapter (G93.3). The WHO has essentially put the same condition in both places". The international ME/CFS community must now be aware that the Health Minister, Lord Warner, had to admit in his letter of 11th February 2004 to the Countess of Mar that this was erroneous: even the letter of 31st March 2004 from Karen Nicolayson concedes this: **"I confirm that the World Health Organisation (WHO), the WHO Collaborating Centre and the Department of Health have now agreed a position on the classification of CFS/ME (and it) has been indexed to the neurology chapter"**.

In view of what the Department of Health has previously stated about ME/CFS, is it not inconsistent for it now to claim in the same letter that it is "neutral" about ME/CFS, yet it accepts ME/CFS as a neurological disorder?

