Evidence that the official UK position is that ME/CFS (or CFS/ME) is a neurological disorder

Margaret Williams 22nd November 2010

Whilst awaiting the results of the MRC PACE Trial on the efficacy or otherwise of directive behavioural modification on ME/CFS, it may be helpful to consider an updated review of the UK Government's official position on the classification and status of the disorder.

It hardly needs to be reiterated that terminology is confusing but vitally important: ME is a classified neurological disorder (WHO ICD-10 G93.3, with CFS being coded only to G93.3, hence ME/CFS) but a group of doctors who work for the insurance industry (known as the Wessely School) have inverted ME/CFS to "CFS/ME" because they do not accept that it is a chronic inflammatory neuroimmune disorder and insist that it is a functional (psychiatric) disorder that is amenable to cognitive restructuring, which they intend to demonstrate in the PACE Trial.

It is a matter of record that these doctors also intend to drop the "ME" component and refer to it as a syndrome of chronic fatigue, which is a classified psychiatric disorder (ICD-10 F48.0). By using their own criteria and thus having widened the case definition to include anyone who is chronically fatigued (which the researchers are inexplicably allowed to refer to as CFS/ME), there is a real danger that, as noted in the Chief Medical Officer's Working Group Report of 2002: "The concern here is that the definition of the illness becomes so broad that CFS/ME will essentially cease to exist as a defined clinical condition".

Given the evidence cited below, there cannot be any debate by anyone about the nature and status of ME/CFS: Hansard is replete with assurances from Ministers of State that both Conservative and Labour Governments accept ME/CFS as a neurological disorder; it is particularly notable that the UK Chief Medical Officer is on record stating that the Department of Health recognises ME/CFS as a genuine and disabling neurological condition and that health professionals (and thus the health professionals who work for the insurance industry) must recognise it as such.

In November 1987 ME was recognised as an organic disease by the Department of Health (Hansard: 27th November 1987:353).

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 and the Bill was ordered to be brought in and to be printed (Bill 99). The Bill required 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". The short title, extent and commencement states: "This Act may be cited as 'The Myalgic Encephalomyelitis Sufferers' Act 1988. This Act extends to Northern Ireland. This Act shall come into force on 1st January 1989".

In one of her many published diatribes on ME sufferers, journalist Caroline Richmond (an ardent Wessely School supporter) 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).

By letter dated 5th June 1991 Mrs CV Dowse for the UK Attendance Allowance Board Secretariat at The Adelphi, 1-11 John Adam Street, London WC2N 6HT (which worked in close liaison with the Department of Health) confirmed "Recent research indicates that ME must be a physical reaction to some type of virus infection".

By 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" (ie. it is not somatisation or a functional disorder).

By 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".

On 16th August 1992, Stephen Dorrell MP, Minister of Health, went on public record confirming that "ME is established as a medical condition" when he addressed a meeting of the Leicestershire ME Group (ie. the Minister confirmed that it is not somatisation or a functional disorder).

An early record of MPs' deep concerns about the malpractice of the insurance industry relating to people with ME/CFS is to be found in the House of Commons debate chaired by Sir Alan Haselhurst on 21st December 1999 (Hansard 147WH – 166WH).

In summer 2000, the Disability Rights Bulletin reported the position about eligibility for Disabled Living Allowance (DLA) for those with ME/CFS: "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".

On 27th November 2001 the Countess of Mar tabled the following question: "To ask Her Majesty's Government whether the psychiatrists on the Chief Medical Officer's Working Group on Chronic Fatigue Syndrome/myalgic encephalomyelitis have withdrawn; if so, for what reason" (HL1659). On 17th December 2001 the Parliamentary Under Secretary of State, Department of Health (Lord Hunt of Kings Heath) replied: "We understand that the psychiatrists on the Group felt unable to support it, as it does not sufficiently meet their concerns". The CMO's Working Group Report did not, despite the Wessely School's best endeavours (of which there is abundant written evidence), state that what it referred to as CFS/ME is a somatisation disorder, so five members of the Wessely School walked out and refused to sign the Report. The point surely was the CMO's Working Group Report was supposed to be about the needs of sick people, not about the concerns of doctors who work for the insurance industry.

On 11th January 2002 the UK Chief Medical Officer (Professor Sir Liam Donaldson) went on record about the nature of CFS/ME; BBC News / Health reported: "He said CFS/ME should be classed as a chronic condition with long term effects on health alongside other illnesses such as multiple sclerosis and motor neurone disease".

On 12th June 2002 (Hansard: Column 973), in welcoming the then new Under Secretary of State for Health (Mr David Lammy MP), John Bercow MP (now The Speaker) pointed out to the Secretary of State: "In the House since 1997, interest in ME or chronic fatigue syndrome has been manifested in no fewer than 116 written and oral parliamentary questions; a number of early day motions…and several Adjournment debates". Mr Bercow continued: "There has been a long-standing argument about the cause of ME or chronic fatigue syndrome, but about its appalling symptoms and consequences there can be no doubt….It is severe and potentially disabling….The House and the wider public must understand that ME sufferers experience sheer exhaustion and excruciating pain. Those are often the daily endurances and harrowing ordeals of sufferers….There is an overriding need…for more research, not least into the physical causes of the affliction….We now have the endorsement of the chief medical officer, Sir Liam Donaldson, for the proposition that this is a recognised disease". Mr Bercow was asked by Mr Russell Brown MP: "Does the Hon Gentleman believe that great problems remain locally because some GPs continue to fail to recognise ME as an illness?", to which Mr Bercow replied: "I do….the Government should not only provide advice and communicate the new culture to GPs but put their foot up the backside of those who have consistently misunderstood and displayed insensitivity towards people suffering badly….The issue is too big for political games". The new Parliamentary Under Secretary of State replied: "I want to make it absolutely clear that the Government endorse the view of the working group that this is a chronic illness. Health and social care professions should recognise it as such….Research has demonstrated immune, musculoskeletal and neurological abnormalities" (ie. the Minister accepted that it cannot be somatisation or a functional disorder).

On 7th January 2004 the Countess of Mar asked the Minister (Baroness Hollis of Heigham): "Is the Minister in a position to give an undertaking that people suffering from myalgic encephalomyelitis – ME will not be forced to undergo cognitive behaviour therapy and graded exercise programmes as a basis for obtaining benefit….Adequate information is available to show that this is an organic and not a psychological illness", to which the Minister replied: "My Lords… I would not wish to challenge her statement on that….My understanding is that someone who has ME – whatever the cause, the symptoms are clinically recognised – would normally be entitled to incapacity benefit".

By letter dated 11th February 2004, the then Health Minister, Lord Warner, clarified the position of the Department of Health: "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". The point about this clearly contrived

clarification -- which was widely interpreted as being designed to absolve the Wessely School's erroneous re-categorisation of ME/CFS as a mental disorder (see below) -- is that, given that the WHO classifies ME/CFS as a neurological disorder, there were no options, so there was nothing to "agree" about.

Hansard for 23rd March 2004 records at column WA96 the following: "In the light of the letter of 11 February 2004 from the Lord Warner to the Countess of Mar in which he stated 'The second edition of the WHO Guide to Mental Health and Neurology in Primary Care (note that this was incorrect: it should have been "The WHO Collaborating Centre Guide to Mental Health") will have only one code for CFS/ME – this is G93.3, why, under the heading 'Terminology and Concepts', CFS/ME is not mentioned under G93.3". The background to this is that in 2000, the UK WHO Collaborating Centre for Mental Health at the Institute of Psychiatry misclassified the disorder as a mental (behavioural) disorder in its "Guide to Mental Health in Primary Care" by using Wessely's own material on CFS/ME. The Guide was funded by the Department of Health. Despite strenuous complaints and despite ICD-10 classifications being mandatory in the UK, sales of the Guide were allowed to continue unabated until almost 30,000 copies had been sold. Eventually, an erratum was issued but this did not prevent the disorder being wrongly classified as a mental disorder in the NHS Mental Health Data Manual, nor did it prevent Ministers of State and Members of Parliament from receiving the impression that it was the WHO itself (not the WHO Collaborating Centre in the UK) that had re-classified the disorder as a mental disorder. In September 2001 the WHO issued a statement repudiating the unofficial re-classification by the UK Collaborating Centre. The matter was raised in Parliament on 22 January 2004, where Earl Howe noted the suggestion that Professor Wessely had "effectively hijacked the WHO logo to give credence to his own view of ME as a mental illness" (Hansard [Lords] 23 January 2004:Vol 656:No 7:1192). The ME Association Newsletter of March 2004 stated: "The issue mattered because the psychiatrists had stifled access to research funds for any UK researchers wanting to study organic causes". In responding to the Countess of Mar, Lord Warner was compelled to concede that the WHO Collaborating Centre at the Institute of Psychiatry had got it wrong: "The Collaborating Centre amended this second edition…This explanatory text does not detract from the fact that there is now only one ICD code for CFS/ME, which is G93.3".

By letter dated 8th November 2007, the Parliamentary Under Secretary of State, Ann Keen MP, confirmed that CFS/ME is indeed included in the National Service Framework for chronic neurological conditions: "We have long recognised the WHO classification of CFS/ME….The National Service Framework (NSF) for Long-term Conditions, published in March 2005, sets out a clear vision of how health and social care organisations can improve the quality, consistency and

responsiveness of their services and help improve the lives of people with long-term conditions, including CFS/ME".

On 2nd June 2008 the Countess of Mar asked Her Majesty's Government: "Whether the current NHS review will include consideration of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) as a long-term neurological condition". The Parliamentary Under Secretary of State, Department of Health (Lord Dazi of Denham) replied: "The review…will increase awareness and ensure better care for people with CFS/ME and will help to support local delivery of the NSF (National Service Framework) for long-term neurological conditions…. The Government accept the World Health Organisation's classification of CFS/ME as a neurological condition of unknown cause….I have acknowledged that CFS/ME is a neurological condition". Baroness Howe of Idlicote then asked the Minister: "Can the Minister explain to the House why the Royal College of General Practitioners continues to insist on categorising CFS as a mental illness?". Lord Dazi replied: "The Government has made it clear that they consider that CFS/ME should be classified as a neurological condition. It is for professional bodies to look at the evidence base and I will encourage the Royal College of General Practitioners to look at the WHO classification which, as I said earlier, is that it is a neurological rather than a mental condition".

By letter dated 19th June 2008, Stephen Atkinson on behalf of the Department of Health confirmed: "I would like to assure you that the Department recognises CFS/ME as a neurological disease".

By letter dated 25th November 2008, the Northern Ireland Minister for Health, Social Services and Public Safety, Michael McGimpsey MLA, confirmed: "I know that in the past there has been some debate about the nature of ME but there have been a number of studies and reports in recent years clarifying that it is a very real and debilitating neurological condition".

On 23rd February 2010, in an Adjournment debate on ME, Gillian Merron, Minister of State (Public Health), Department of Health, stated: "I want first to put on the record that we accept the World Health Organisation's classification of ME as a neurological condition of unknown cause".

By letter dated 28th May 2010, Kay Ellis confirmed on behalf of the UK Chief Medical Officer: "The Department's view is that it is important to recognise that CFS/ME is a genuine and disabling neurological illness and health professionals must recognise it as such".

On 11th October 2010, in a debate on ME in the House of Lords, the Countess of Mar said: “ME has been classified as a neurological condition at least since 1968 (this should have been 1969)…however, for all these years, sufferers from this awful debilitating illness have been ignored, derided and mistreated….Many thousands of peer-reviewed scientific papers from researchers around the world demonstrate that ME is a physical disease which has endocrine, immune and cardiovascular effects, as well as neurological symptoms….It is distinct from chronic fatigue which is a symptom of many diseases….Despite this, there is a school of thought, dominant throughout the last three decades, that this is a psychosocial behavioural problem, easily dealt with by cognitive behavioural therapy and graded exercise….There is a school of psychiatry determined to claim the condition for its own, both in the UK and internationally. After many years of working in this sphere, I have observed the means by which any valid arguments for a biological cause are mocked and eventually overwhelmed….By writing numerous papers which, of necessity because there is no-one else to do it, are peer-reviewed by their colleagues, they appear to have proved that there is no need for further research and that the doctors responsible for diagnosing and treating ME do not need to conduct any more than the basic range of tests on their patients….It seems that, no matter how often Ministers and senior officials confirm their acceptance of the seriousness of this condition, nothing will change until the culture both within and outside the NHS changes….May I ask the noble Earl whether the coalition continues to accept that myalgic encephalomyelitis is a neurological illness as categorised by ICD-10 G93.3?”. The noble Earl, the Parliamentary Under Secretary of State for Health, (Earl Howe) replied concisely: “The noble Countess, Lady Mar, asked whether the coalition accepts that CFS/ME is a neurological condition. The Government accepts that it is a neurological condition”.

Despite this abundance of evidence that CFS/ME (or more correctly, ME/CFS) is a neurological disorder, it seems that those doctors who work for the insurance industry remain ruthless and unremitting in their determination to categorise it as a functional (somatic) disorder (functional disorders being expressly excluded from insurance cover, so people with ME/CFS who have a legitimate claim are likely to find that their insurers refuse to accept their claim on the grounds that they are suffering from an excluded disorder, a situation of which the claimant would be unaware until making a claim, since ME/CFS is not listed as a policy exclusion) and that they continue to dismiss and/or ignore the ever-mounting biomedical evidence that makes their sustained position risible.

What is deplorable is that, despite Ministers’ repeated assurances that they accept ME/CFS as a serious neurological disorder, these doctors are never held to account by Ministers because no-one will accept responsibility for doing so, to the

grave detriment of people trying to cope with what amounts to medical abuse in addition to the ravages of the disease itself.

The adage “Profits before Patients” is sadly still alive and well, whereas patients are not, but who cares?

May be reposted.