

Responses from the DWP about the Department's classification of ME/CFS

Margaret Williams 1st November 2011

On 18th July 2011 Professor Malcolm Hooper wrote to the Secretary of State at The Department for Work and Pensions (DWP) about an apparent discrepancy between two major Departments of State on the same medical issue, namely the different categorisations of ME/CFS, the Department of Health (DoH) classifying it as a neurological disorder and the DWP classifying it as a mental disorder (http://www.meactionuk.org.uk/dwp_doh_classification.htm). The letter was copied to the Secretary of State for Health.

Whilst no acknowledgement was received from the DWP, on 11th August 2011 a reply was sent on behalf of the Secretary of State for Health, signed by Adam Butler of the DoH Customer Service Centre (reference TO00000632586), which said:

"The Department of Health has always relied on the definition set out by the World Health Organization in its International Classification of Diseases (ICD) under ICD Code G93.3, subheading 'other disorders of the brain'....You suggest that guidance used by decision-makers in the Department for Work and Pensions (DWP) is unsatisfactory. The DWP's Health and Benefits Division was responsible for drafting the guidance. I note you have written directly to the DWP and hope you receive a helpful reply....I hope this clarifies the Department's position".

On 28th August 2011 Professor Hooper responded to the letter from the DoH and a copy was sent to the Secretary of State at the DWP (<http://www.meactionuk.org.uk/Butler-letter-reply-28-8-11.htm>) from whom a response had still not been received.

However, it seems that on 27th July 2011 the DWP did send a snailmail letter to Professor Hooper which he did not receive: on 28th September 2011 telephone contact was made directly with the Ministerial Correspondence Manager at the DWP, who kindly emailed a copy of the unsigned letter that was on the DWP's file.

That letter made no attempt to address the substance of Professor Hooper's letter; it was sent by someone in the DoH Correspondence Team (reference TO/11/26695) and it said:

“Thank you for your recent correspondence. Government Ministers receive a large volume of correspondence and they are unable to respond personally on every occasion....The Government is looking at a wide variety of issues relating to benefits and pensions. Ministers believe that reform is necessary in a number of areas, and on 16 February they presented the Welfare Reform Bill to Parliament....Ministers do welcome all views, and I would like to thank you for your comments”.

During the telephone conversation on 28th September 2011 with the Ministerial Correspondence Manager he volunteered that it was not an acceptable response. When asked for the name of the person who had signed it, the Ministerial Correspondence Manager confirmed that there was no signature, nor was there the person’s printed name, nor the name of a team manager on it, even though the new Permanent Secretary has made it a requirement that all correspondence must bear both the printed name of the signatory and the printed name of the relevant team manager.

In a curious twist, a snailmail letter dated 13th September 2011 was subsequently received by Professor Hooper; it bore an illegible signature, no printed names and a completely different reference (TO/11/32085); the Ministerial Correspondence Manager confirmed that, inexplicably, it was not on the DWP’s tracking system and he could not trace it as it had not been saved into the DWP’s electronic database.

It was, however, an important letter, so a scanned image was duly sent to the Ministerial Correspondence Manager, who was unable to identify the signatory.

The letter of 13th September 2001 that was missing from the official DWP file referred incorrectly to “Myalgic Encephalitis” and it failed to address key issues in Professor Hooper’s original letter. It did, however state the following:

“I can confirm that the Department for Work and Pensions does not classify CFS/ME as a mental health disorder”.

That is a useful statement from the DWP and, quoting the reference TO/11/32085, can be cited by those with ME/CFS embroiled in appeals against refusal of their State and/or insurance benefits.

However, the reasoning given for the apparent categorisation of ME/CFS as a mental disorder in the DWP’s Guidance for HMRC appeared to be little more than a face-saving exercise:

“The Incapacity Reference Guide has a flag against both CFS and ME to alert the decision maker to the fact that a proportion of people with CFS/ME have mental health symptoms. The reason why some conditions are flagged as having a mental health component is because people with mental health conditions are recognised as being potentially vulnerable and therefore appropriate safeguards can be put into place during their claim to benefit. These safeguards include not automatically rejecting their claim to benefit should they fail to return the benefit related questionnaire”.

Professor Hooper found this explanation wholly unsatisfactory and a reply dated 28th September 2011 was sent by email:

“It is incontrovertible that the HMRC Incapacity Reference Guide does classify ME/CFS as a mental disorder, so the alleged explanation in the attached letter (the one that is not on your system) is unacceptable, not least because there is no similar asterisk alongside other classified neurological disorders such as multiple sclerosis, sufferers from which might also be ‘vulnerable’ to not returning their benefits-related questionnaire. I look forward to hearing from you, as this matter is in urgent need of clarification”.

No response was received, so on Monday 10th October 2011 email contact was again made with the Ministerial Correspondence Manager at the DWP: *“Professor Hooper was wondering if you had made any progress on this matter?”*, to which a reply was sent that same day (under the reference TO/11/26695, not under TO/11/32085): *“I’m waiting for policy colleagues to provide the substance of a response. They should be getting back to me by close today, so hopefully you/Professor Hooper should have a reply by the end of the week”.*

Once again, nothing was received by Professor Hooper, so on 28th October 2011 a further reminder was sent by email to the Ministerial Correspondence Manager at the DWP, who responded on 31st October 2011 saying that a letter dated 12th October had been sent by snailmail to Professor Hooper (which he once again did not receive). An electronic copy was attached which said:

“I undertook to respond further and apologise for the delay in doing so. I am sorry that we used the wrong name for the condition in the previous letter. With regard to the classification of CFS/ME, we would like to emphasise that the entitlement to benefit does not depend on the condition itself, the underlying cause or how it is classified, but on the disabling effects of the condition(s) present. The Department therefore firmly reject the view that the HMRC reference guide classifies ME/CFS as a mental disorder. The flag/asterisk appears against CFS/ME because there is evidence that the majority of people with CFS/ME have symptoms that affect mental function and is a genuine attempt

to protect the interests of people with CFS/ME....The reason why no flag is set against MS is because, although associated with depression, there is evidence that the incidence of depression is less than that in CFS/ME. As explained previously, this ensures people with CFS/ME currently do not have their benefit disallowed should they fail to return their questionnaire and removal of the flag could be seen as a retrograde step”.

For the avoidance of doubt, the DWP is incorrect in stating that incidence of depression is less in MS than in ME: there is evidence to show that rates of depression are no higher in ME/CFS than in other chronic medical conditions (Shanks MF and Ho-Yen DO, British Journal of Psychiatry 1995:166:798-801); indeed, the rates of overall psychiatric disorders in ME/CFS are no higher than general community estimates (Hickie I et al. British Journal of Psychiatry 1990:156:534-540).

Once again, key issues in Professor Hooper’s letter were simply ignored. There was no acknowledgement of the fact that the WHO classifies ME/CFS as a neurological disorder in ICD-10, nor was there any undertaking that all departments of the DWP (and hence HMRC) would, as Professor Hooper requested, be notified of the requirement to adhere to this mandatory classification.

Asterisks in the HMRC Reference Guide are appended only to disorders that are stated in the Guide to be unequivocal mental disorders including, for instance, alcohol and substance abuse, eating disorders, hysteria, neurasthenia, overdose, paranoia, personality disorder, psychosis and schizophrenia, yet the same list also includes CFS, ME and postviral fatigue syndrome.

Of note is the fact that “memory impairment” and “memory problems” such as may occur after traumatic brain injury or in Alzheimer’s disease are not flagged as mental health disorders yet, following the logic set out in the DWP letters, it is precisely those problems which could cause clients (formerly known as patients) suffering from such memory impairment to fail to return the benefits assessment form within the allotted time-scale, yet the DWP sees no need to safeguard their benefits.

Moreover Atos, the international information technology services company that -- using computerised tick-box score-points -- works for the DWP in assessing entitlement to State benefits is definitely training its staff that ME/CFS is a mental health disorder (<http://www.meactionuk.org.uk/PACE-Pls-and-the-DWP.htm>), another issue that was not addressed by the DWP.

Indeed, the DWP Medical Services Training and Development on Chronic Fatigue Syndrome Guidelines are clear: *“Most cases of chronic fatigue (sic) are attributable to abnormal illness behaviour....In fact, most patients with CFS will also meet the criteria for a current psychiatric disorder”* (<http://www.meactionuk.org.uk/PACE-Pls-and-the-DWP.htm>).

A further point that remains unaddressed by the DWP is that according to Atos’ own guidelines, if there is any neurological problem, such patients must be assessed by a doctor and not by a nurse or a physiotherapist, therefore everyone with a diagnosis of ME/CFS must be assessed by a qualified doctor, otherwise the entitlement assessment could be deemed null and void (<http://margaretmccartney.com/blog/?p=904>).

Perhaps the All Party Parliamentary Group on ME (APPGME), or even the two patients’ charities (the ME Association or Action for ME) could take up these unaddressed issues with the DWP – it is, after all, their job to represent the best interests of those with ME/CFS.

They might also wish to point out to the DWP that the Norwegian Government has apologised to patients with ME/CFS for not having provided the necessary and proper health services for them. The Deputy Director General of the Norwegian Directorate of Health recently made the following statement: *“I think that we have not cared for people with ME to a great enough extent. I think it is correct to say that we have not established proper health care services for these people, and I regret that”* (<http://www.euro-me.org/news-Q42011-003.htm>).

It may also be appropriate to bring to the attention of the DWP the fact that Norwegian oncologists are treating Norwegian ME/CFS patients with a widely-used drug for lymphoma and autoimmune disorders and that one of those oncologists is on record affirming that in many patients, ME/CFS is *“a very serious and debilitating disease”* and that an *“autoimmune component is probable”* (Co-Cure RES:

31 October 2011).

Indeed, it was in 1995 that the devastating effects were accurately described at a US Congressional briefing by Professor Mark Loveless, Head of the AIDS and (ME)CFS clinic at Oregon Health Sciences University, who said that an ME/CFS patient *“feels effectively the same every day as an AIDS patient feels two weeks before death”* – the only difference being that ME/CFS symptoms can go on for decades until ultimately the body gives up the struggle to survive. As another US researcher has demonstrated, people die from ME/CFS and on average they die 20 years earlier (Causes of Death Among Patients with Chronic Fatigue Syndrome. Jason L et al. Healthcare for Women International: 2006:27:615-626).

This should be compared with the assertions of Wessely School psychiatrists who refer to ME/CFS as a “*pseudo-disease*” (Occup Med 1997;47:4:217-227) and whose views about ME/CFS have informed UK Government policy, for example:

“The vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the condition....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 physical illness or all in the mind? Lecture given in October 1999 by Michael Sharpe, hosted by the University of Strathclyde).

When might people with ME/CFS in the UK expect a similar apology from their Government as received by Norwegians with the same disorder?