

*On 18<sup>th</sup> 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. Their correspondence follows:*

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Please reply to : Professor Malcolm Hooper 2,Nursery Close Sunderland SR3 1PA  Email: hoopersecundus@talktalk.net
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The Rt Hon Iain Duncan Smith MP  
Secretary of State for Work and Pensions  
The Department for Work and Pensions  
Level 4  
Caxton House  
Pothill Street  
LONDON  
SW1A 9NA

18<sup>th</sup> July 2011

Dear Secretary of State

**re: The major discrepancy between your Department and the Department of Health on the same medical issue**

I write to alert you to a serious error in the Statutory Payments Manual (SPM) which addresses how HM Revenue and Customs administer statutory payments including Statutory Sick Pay (<http://www.hmrc.gov.uk/manuals/spmmanual/SPM50600.htm>). The document (SPM50605 – Medical Referrals - Incapacity Reference Guide) which is currently used by decision makers states that matters concerning policy on these statutory payments are the responsibility of your Department.

The error concerns the description of myalgic encephalomyelitis (ME, synonymously known as ME/CFS or as CFS/ME) as a mental health disorder, despite the fact that the World Health Organisation has formally classified ME as a neurological disorder since 1969.

According to NICE, adherence to the WHO classification is mandatory in the UK (see Communications Progress Report from the Director of Communications, 18<sup>th</sup> September 2002; 2.7.1.5).

ME/CFS is not a mental disorder but a serious multi-system neuroimmune disorder affecting the central, autonomic and peripheral nervous systems as well as the immune, cardiovascular, respiratory, neuroendocrine, gastrointestinal, musculo-skeletal, visual and reproductive systems.

It is a matter of record that there are over 5,000 published papers demonstrating serious organic pathology in ME/CFS; that the Royal Society of Medicine accepted ME as a nosological organic entity in 1978; that the Department of Health accepted ME as an organic disease in 1987; that the Health Minister, the Rt Hon Stephen Dorrell MP, confirmed that “***ME is established as a medical condition***” in 1992; that the Chief Medical Officer, Professor Sir Liam Donaldson, publicly confirmed in 2002 that ME should be recognised alongside disorders such as multiple sclerosis and motor neurone disease; that ME has been classified as a neurological disorder in the UK Read Codes (F286) used by all GPs since 2003; that ME has been included in the UK National Service Framework for long-term neurological conditions since its inception in 2005, and that ME is accepted to be a neurological condition by the UK Government as recorded in Hansard, Lords, 2<sup>nd</sup> June 2008 (the Parliamentary Under Secretary of State for Health, Lord Darzi, was unambiguous: “***My Lords, the Government accept the World Health Organisation’s classification of CFS/ME as a neurological condition....I have acknowledged that CFS/ME is a neurological condition...the Government...have made it clear that... it is a neurological rather than a mental condition***”).

There is thus a major discrepancy between two Departments of State, because your Department rejects the *status quo* and perversely categorises ME/CFS as a mental disorder, along with hysteria, nervous debility, neurasthenia, neurosis and personality disorder.

You may be aware that since 1987, a small but influential group of UK psychiatrists and their supporters known as the Wessely School (Hansard, Lords, 9<sup>th</sup> December 1998:1013) who are closely involved with the medical and permanent health insurance industry have consistently rejected the significant body of biomedical evidence and continue to assert that ME/CFS does not exist except as an aberrant belief held by those who claim to suffer from it and by those clinicians and medical scientists naive enough to believe and support them.

The lead advisor on ME/CFS to your Department, Professor Peter White from St Bartholomew’s Hospital, is a prominent Wessely School psychiatrist, whose vested interest in maintaining ME/CFS as a mental disorder is a serious concern to a number of senior Parliamentarians including the former Chairman of a House of Commons Science and Technology Select Committee and former Dean of Biology; a member of the Home Affairs Select Committee; a Minister of State for the Environment; a former President of the Royal College of Physicians; the Deputy Speaker of the House of Lords, and a former Health Minister and Honorary Fellow of the Royal College of Physicians ([http://erythos.com/gibsonenquiry/Docs/ME\\_Inquiry\\_Report.pdf](http://erythos.com/gibsonenquiry/Docs/ME_Inquiry_Report.pdf)).

An international perspective on the disorder was given in the Press Briefing held on 3<sup>rd</sup> November 2006 by the US Centres for Disease Control to announce its ME/CFS awareness campaign, referring to it as “***this terrible illness***”, Anthony Komaroff, Professor of Medicine, Harvard Medical School, said: “***It’s not an illness that people can simply imagine that they have and it’s not a psychological illness. In my view, that debate, which was waged for 20 years, should now be over. Brain imaging studies...have shown***

***inflammation, reduced blood flow and impaired cellular function in different locations of the brain”.***

However, your Department’s lead advisor on the disorder teaches UK clinicians to ignore the WHO classification of ME/CFS as a neurological disorder (<http://www.meactionuk.org.uk/magical-medicine.htm> pages 53-54) and in 2004 he was awarded an MBE for his work on CFS, the citation being “*For services to medical education*”.

This is disturbing, because since about 1987 the Wessely School have consistently denied and rejected the biomedical evidence on ME: in 1992 they directed that in patients with ME, the first duty of the doctor is to avoid legitimisation of symptoms and reinforcement of disability<sup>1</sup>; in 1994 ME was described by them as merely “*a belief*”<sup>2</sup>; in 1996 they recommended that no investigations should be performed to confirm the diagnosis<sup>3</sup>; in 1997 they referred to ME as a “*pseudo-disease diagnosis*”<sup>4</sup>, and in 1999 they said about ME patients: “*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*”<sup>5</sup>.

I should be grateful if the error in SPM50605 and any associated documents could be corrected immediately and the manuals amended accordingly.

Please also ensure that members of your Department, officials and advisors to the DWP will henceforth act in accordance with the Department of Health and with NICE about the correct categorisation of ME/CFS, the idiosyncratic stance by your Department being an illogical and insupportable position for it to adopt.

Your Department’s error is not a matter of semantics or opinion, since the DWP specifically targets those with a diagnosis of ME/CFS for removal of their Incapacity Benefit/Employment Support Allowance and other sickness/disability benefits, a matter of grave concern to informed clinicians and of immense distress to sick and vulnerable ME/CFS patients of whom, at their worst, 88% are bed/housebound, being unable to shower, bathe or wash themselves, with 15% being unable to eat unaided (<http://www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/get-informed/ME%202008%20%20What%20progress.pdf>).

In the interests of transparency favoured by your Coalition government, this letter will be placed in the public domain.

I look forward to hearing from you.  
Yours sincerely

Malcolm Hooper  
Emeritus Professor of Medicinal Chemistry  
University of Sunderland.

cc. The Rt Hon Andrew Lansley MP

Secretary of State for Health,  
The Department of Health  
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1. Medical Research Council Highlights of the CIBA Foundation Symposium on CFS, 12-14<sup>th</sup> May 1992, reference S 1528/1 (section entitled "The Treatment Process"), now held in the MRC secret files on ME/CFS at the National Archive, Kew, and closed not for the customary 30 years but for the unusually lengthy period of 73 years
2. "Microbes, Mental Illness, The Media and ME – The Construction of Disease". Simon Wessely; 9<sup>th</sup> Eliot Slater Memorial Lecture, Institute of Psychiatry, 12<sup>th</sup> May 1994 (transcript and Wessely's own working notes)
3. Chronic Fatigue Syndrome. Report of a Joint Working Group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners; Royal Society of Medicine (CR54), October 1996
4. "Chronic Fatigue Syndrome and Occupational Health"; A Mountstephen & M Sharpe; Occupational Medicine 1997;47:4:217-227
5. "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 (transcript).

## Prof Hooper's response to the Department of Health regarding the classification of ME

*On the 18th of July, Professor Hooper sent a letter to the Secretary of State for Work and Pensions and to the Secretary of State for Health on the discrepancy between the departments' classifications of ME. This letter is already in the public domain:*

[http://www.meactionuk.org.uk/dwp\\_doh\\_classification.htm](http://www.meactionuk.org.uk/dwp_doh_classification.htm)

*To date he has received no response from the Secretary of State for Work and Pensions but has received a reply from the Department of Health. The following letter is Professor Hooper's response to that reply:*

.....

*From Malcolm Hooper Ph.D., B.Pharm., C.Chem., MRIC  
Emeritus Professor of Medicinal Chemistry  
University of Sunderland, SUNDERLAND SR2 3SD*

*Chief Scientific Adviser to the Gulf Veterans' Association  
President: the National Gulf War Veterans and Families Association, NGVFA, (2002)*

Mr Adam Butler  
Customer Service Centre  
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28<sup>th</sup> August 2011

Your ref: TO00000632586

Dear Mr Butler

re: **The major discrepancy between the Department of Health and the Department for Work and Pensions on the same medical issue**

Thank you for your letter of 11<sup>th</sup> August 2011 sent in response to my letter of 18<sup>th</sup> July 2011 to The Rt Hon Iain Duncan Smith MP, Secretary of State at the Department for Work and Pensions that was copied to The Rt Hon Andrew Lansley MP, Secretary of State for Health, on whose behalf you replied.

I am grateful for the courtesy shown by Mr Lansley, a similar courtesy not having been shown by Mr Duncan Smith from whose Department I have received no acknowledgement, so this letter will be copied to him.

In my letter I drew attention to a serious error in the Statutory Payments Manual (SPM 50605) used by decision-makers, namely the categorisation of ME as a mental health disorder.

In your reply you confirm that this error was the responsibility of the DWP: *“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”*.

It is, of course, the case that Professor Peter White, a psychiatrist who works for the permanent health insurance industry, was and remains lead advisor on “CFS” to the DWP and, despite irrefutable evidence that he is incorrect, he is firmly committed to his belief that ME is a somatoform (mental) disorder and he advises the DWP accordingly.

Herein lies the major discrepancy between two Departments of State: whilst the DWP rejects the WHO ICD-10 classification of ME as a neurological disorder and follows Professor White’s beliefs that it is a mental disorder, the Department of Health nominally accepts the WHO ICD-10 classification of it as a neurological disorder.

There are in fact two related issues, one being the discrepancy between two Departments of State outlined above and the other relating specifically to the DoH, this being the failure of the DoH to comply with the 1995 mandate to observe the WHO-ICD-10 classification system (see below).

### ***The first issue***

To summarise (and reiterate) the position of both Departments of State and their previous public statements about the nature of ME:

1. the Department of Health accepted ME as an organic disease in 1987 (Hansard, HC 27<sup>th</sup> November 1987, column 353)
2. in a letter dated 13<sup>th</sup> 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, the Minister 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”*
3. on 16<sup>th</sup> 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
4. not only the DoH but also the DWP recognises that ME is a physical disorder. 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"*

5. 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"*
6. on 18<sup>th</sup> September 2002, the Director of Communications at NICE issued a Communications Report which stated: *"Following discussions with the Department of Health and other national agencies the Institute has adopted a new classification system that will be applied Institute-wide" (2.7.1.1); "The ICD classification has been used as a basis for the new Institute classification directed at the informed reader" (2.7.1.4); "ICD-10...classification codes are mandatory for use across England" (2.7.1.5)*
7. ME has been included as a neurological disorder in the UK Read Codes (F286) used by all GPs since 2003
8. by letter dated 11<sup>th</sup> February 2004 to the Countess of Mar, the Parliamentary Under Secretary of State at the Department of Health, Lord Warner, confirmed that the DoH accepts the WHO classification of ME as a neurological disorder. That letter was placed by Lord Warner in the House library for access by all MPs.
9. ME has been included in the National Service Framework for long-term neurological condition since its inception in 2005
10. the DoH has confirmed on numerous occasions, many documented in Hansard, that the DoH itself and the UK Government accepts ME to be a neurological disorder, for example on 2<sup>nd</sup> June 2008 the then Parliamentary Under Secretary of State, Lord Darzi, was unequivocal: *"My Lords, the Government accept the World Health Organisation's classification of CFS/ME as a neurological condition....I have acknowledged that CFS/ME is a neurological condition...the Government...have made it clear that... it is a neurological rather than a mental condition"*
11. by letter dated 3<sup>rd</sup> August 2011 (reference TO00000632783), Tim Morgan from the Department of Health Customer Services Centre confirmed the following: *"The ICD-10 is an NHS Information Standard....The NHS has a long history of using the ICD. There is a legal obligation for Department of Health to provide ICD data to the WHO"*

*for international comparison. The NHS was mandated to implement ICD-10 on 1 April 1995, at which time there was a formal consultation* (emphasis added)....*Implementation...applies to NHS organisations and their system suppliers, such as acute and foundation trusts, primary care trusts, and the NHS Information Centre*". (It is, of course, the case that Government officials such as yourself may use bogus names -- known as "office names" -- when writing to members of the public [*"Civil servants use bogus names to sign official letters"*; Roya Nikkhah; Sunday Telegraph; 20<sup>th</sup> June 2004], so the true authorship of both your own letter and that of Tim Morgan remains unconfirmed but must nonetheless be taken as authoritative documents).

You say in your letter: "As you may know, in 2007, NICE published Clinical Guideline 53 (CG53) on the diagnosis and management of CFS/ME in adults and children, to advise the NHS on the treatment of CFS/ME in England and Wales". The documentary evidence outlined above makes it all the more troubling that the NICE Guideline Development Group which produced CG53 expressly rejected the WHO classification of ME as a neurological disorder and voted to remove from its deliberations its initial acceptance of ME as an organic disorder, this being confirmed by patient representative Tanya Harrison in her letter of resignation dated 16<sup>th</sup> July 2007 from the GDG: "*the final straw came when the group voted to remove that ME/CFS is a physical illness*", which reflects the beliefs and advice of Professor Peter White to the DWP.

Mindful of the above evidence, it will not be sufficient for you to reply to this current letter saying that this discrepancy between two Departments of State is a medical matter for the PCTs to address.

It is a policy issue and thus a matter for the two Secretaries of State themselves to address and resolve without further delay.

The WHO has classified ME as a neurological disorder since 1969 and ME cannot be taxonomically considered by the DWP or any other Department to be a somatoform disorder; that the DWP persists in doing so is all the more disturbing when, in another Department of State, the entire NHS is mandated to regard ME as a neurological disorder.

### ***The second issue***

Given that the NHS has been mandated since 1995 to implement the ICD-10 classifications, and given that "mandatory" means "obligatory, compulsory" and that a mandate is "an official or authoritative instruction or command", not only the DWP but also the NHS has patently failed to comply with the 1995 mandate to implement ICD-10 classifications.

Influenced by the Wessely School (who act as advisors to other Government departments and to NICE as well as to the DWP), not only the Wessely School themselves but also many NHS neurologists are in breach of the 1995 mandate that pertains throughout the NHS: 84% of neurologists questioned stated that they do not believe ME exists as a neurological condition (J Psychosom Med 9<sup>th</sup> April 2010), despite the reported evidence of markers of severe ganglionitis having been found in the central nervous system in several *post mortem* samples.

In one particular case, that of 32 year-old Sophia Mirza who died in November 2005 (whose death certificate recorded that she died of [ME]CFS), examination of her spinal cord showed

inflammatory changes affecting the dorsal root ganglia, which are the gateways for all sensations going to the brain through the spinal cord. These inflammatory changes affected 75% of Sophia's spinal cord.

At the inquest held on 13<sup>th</sup> June 2006, one of the pathologists stated: "*ME describes inflammation of the spinal cord and muscles. My work supports the inflammation theory because there was inflammation in the basal root ganglia*".

Dr O'Donovan (the neuropathologist who had examined the spinal cord) stated that ME "*lies more in the realms of neurology than psychiatry, in my opinion*".

Given that NHS staff are mandated to use ICD-10 codes, I should be grateful if you would explain why such a medically unsustainable situation has been allowed by the DoH to remain unchallenged for the last 16 years, since there is a legal obligation for the DoH to provide accurate ICD data to the WHO.

Recently, 26 expert authors (from 13 countries) produced the International Consensus Criteria for ME (Carruthers B et al; J Int Med 20<sup>th</sup> July 2011) and they strongly advocate that ME be removed from the NICE CG53 definition of "CFS/ME".

This should become a priority since, despite the fact that in ICD-10 the WHO currently indexes "CFS" only to ME at G93.3, the Wessely School psychiatrists and their adherents who work for the insurance industry have hijacked the term "CFS" to mean a syndrome of "chronic fatigue" (which is classified in ICD-10 at F48.0 as a mental disorder but which the Wessely School erroneously insist is synonymous with ME).

It is essential that in relation to internationally defined ME, UK Departments of State begin implementing evidence-based policy instead of creating expedient policy-based evidence (which the Wessely School has done successfully for almost 25 years) and separate ME from "CFS/ME". This is now very important, especially as Professor Peter White confirmed in writing to the Editor-in-Chief of The Lancet (a copy of which was sent to me) that: "*The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME*". That statement is mystifying, since the PACE Trial documentation consistently refers to "CFS/ME". Professor White's statement also raises the question as to why he received £5 million from the MRC (co-funded by the DoH, the DWP and the Scottish Chief Scientist's Office) to study chronic tiredness that is prevalent in many primary psychiatric disorders, yet he asserts that the results of his PACE Trial are generalisable to those with a serious neurological disorder that he now claims he was not studying after all.

These issues are of utmost importance not only to 250,000 people in the UK and their despairing families who are struggling to cope with a devastating neurological disorder, but also to the clinicians who see for themselves that people with classic ME are physically, not mentally, ill but who are thwarted in their attempt to investigate and support them by the overarching influence of the Wessely School.

I therefore once again call upon both Secretaries of State to provide informed and firm leadership by re-circulating directions that the 1995 mandate to comply with the ICD-10 classifications must legally be complied with by clinical and clerical staff in both

Departments of State and that any individuals who refuse to comply are held personally and publicly accountable for any failure to observe that mandate.

It is obviously imperative that different Departments of State have a unified position regarding the nature of a serious disease such as ME and it is equally important that the legal requirements of the WHO be observed by the UK, which currently is not the case as far as ME is concerned. I should therefore be grateful if you would clarify what action is being taken by your own Department about these important issues.

Yours sincerely,

Malcolm Hooper

<p><i>Home: 2, Nursery Close SUNDERLAND SR3 1PA Phone 0191-5285536 e-mail: hoopersecundus@talktalk.net</i></p>
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cc. The Rt Hon Iain Duncan Smith MP, Secretary of State, Department for Work and Pensions.

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

Margaret Williams 1<sup>st</sup> November 2011

On 18<sup>th</sup> 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](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 11<sup>th</sup> 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 28<sup>th</sup> 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 27<sup>th</sup> July 2011 the DWP did send a snailmail letter to Professor Hooper which he did not receive: on 28<sup>th</sup> 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 28<sup>th</sup> 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 13<sup>th</sup> 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 13<sup>th</sup> 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 28<sup>th</sup> 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 10<sup>th</sup> 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 28<sup>th</sup> October 2011 a further reminder was sent by email to the Ministerial Correspondence Manager at the DWP, who responded on 31<sup>st</sup> October 2011 saying that a letter dated 12<sup>th</sup> 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-PIs-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-PIs-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?

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## Lord Freud's Response to Countess of Mar

In response to Professor Hooper's correspondence with the Department of Works and Pensions regarding their classification of ME/CFS and their failure to address the issues, the Countess of Mar contacted Lord Freud, Minister for Welfare Reform.

The Countess of Mar has received a reply which can be seen at the link below.

**This significant letter states: "... I can be clear that the DWP does not classify CFS/ME as a mental health disorder". Lord Freud also unreservedly apologised to Professor Hooper: "... let me apologise unreservedly for the handling of Professor Hooper's correspondence".**

Lord Freud's reply to the Countess of Mar: <http://www.meactionuk.org.uk/Freud-reply-to-Mar.pdf>

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