

To Mr J Slater
C/o request-130828-6c0a8eab@whatdotheyknow.com

DWP Business Management Team

Our Ref: VTR 3886-3684
DATE 31 October 2012

Dear Mr J Slater,

Thank you for your Freedom of Information request response that was received by the Department for Work and Pensions (DWP) Freedom of Information (Fol) Requests on 26 September 2012 and immediately forwarded for response by DWP Business Management Team Freedom of Information Officer.

In your email you asked: *DWP Document: Training and Development Continuing Medical Education Programme Fibromyalgia - Guidelines for the Disability Analyst MED/S2/CMEP~0035 Version 5 Final Module: 14*

I took the above Condition Guides at random and I read it to compare it to published research and statements made by the DWP regarding the role of HCP.

- 1. Given that the DWP claim that evidence based medicine is key to WCA why was the last medical update for the "Fibromyalgia - Guidelines for the Disability Analyst (v5)" completed in July 2009, over 3 years ago?*
- 2. When is the next medical update scheduled for this guide?*
- 3. As the last update was completed by Dr Peter Ellis' what is his medical specialism (e.g. rheumatology)? This is not counted as personal data under the DPA as Doctors are required to provide their qualifications and GMC registration details upon request.*

The DWP has stated numerous times that the role of the HCP is not diagnostic in nature and as such along with the help of LiMA) nurses can carry out the role of disability analyst. However, this guideline states:

What is the differential diagnosis in this case? Give the likely diagnosis/diagnoses."

Differential diagnosis in relational to diseases and their treatment falls within the role of a Doctor and the DWP states that diagnosis skills are not required for an HCP which is why Nurses can carry out the role.

- 4. Why are HCP being asked to undertake differential diagnosis in this guide if that is not required for their role?*

The guide includes the following two statements:

"In 1995 the "Copenhagen Declaration" recognised the existence of the syndrome and so ensured that the condition is now established as a distinct clinical entity."

"It is widely felt that this classification, although initially useful, is an over-simplification of a condition which is complex, multifactorial and not in the strict sense a discrete entity." Clearly the two statements are mutually exclusive and suggest that the author is biased against the agreed consensus, which contradicts the stated objective of the guide.

5. *How can a document that has supposedly undergone a QA assessment contain such contradictory statements?*

Text From Guide

"Medically unexplained physical symptoms represent by far the most frequent cause of referral to specialist outpatient clinics, and it is not surprising that each specialty has its own compartment in which such patients can comfortably be accommodated.

Rheumatologists have their fibromyalgia, cardiologists their non-cardiac chest pain and gastroenterologists, irritable bowel syndrome. It is not surprising therefore that FMS shares common features with a number of other conditions.

Chronic fatigue syndrome

The clearest overlap is with chronic fatigue syndrome (CFS). Some of the shared characteristics are illustrated below."

The following characteristics are then listed:

- Pain*
- Fatigue*
- Myalgia*
- Tender points*
- Sleep disorder*
- Infectious links*
- Prevalence*

These characteristics also overlap with the following:

- Influenza (and other serious viral infections)*
- Serious Bacterial Infections*
- HIV*
- Dengue Fever*
- Epstein-Barr Virus Infectious Mononucleosis#*

6. *What clinical evidence does the DWP have that CFS and fibromyalgia are the 'clearest overlap' using the listed characteristics, as this statement clearly implies, as opposed to the others listed above?*
7. *If the DWP has no evidence supporting the statement then why is it included in the guide?*

The following published research suggest a totally different view which is supported by tangible evidence (unlike the guidance document)

August 2012 - Is chronic fatigue syndrome the same illness as fibromyalgia: evaluating the 'single syndrome' hypothesis. Abbi B, Natelson BH. Source From the War Related Illness and Injury Study Center, DVA Medical Center, East Orange, NJ and Pain and Fatigue Study

Center, Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York, USA.

Abstract

Chronic fatigue syndrome (CFS) and fibromyalgia (FM) are medically unexplained syndromes that can and often do co-occur. For this reason, some have posited that the two are part of the same somatic syndrome-examples of symptom amplification. This hypothesis would suggest that few differences exist between the two syndromes. To evaluate this interpretation, we have searched the literature for articles comparing CFS to FM, reviewing only those articles which report differences between the two. This review presents data showing differences across a number of parameters-implicating that the underlying pathophysiology in CFS may differ from that of FM. We hope that our review encourages other groups to look for additional differences between CFS and FM. By continuing to preserve the unique illness definitions of the two syndromes, clinicians will be able to better identify, understand and provide treatment for these individuals. PMID: 22927538 [PubMed - as supplied by publisher]

September 2011 - The Science of Fibromyalgia. CONCISE REVIEW FOR CLINICIANS Daniel J. Clauw, MD; Lesley M. Arnold, MD; and Bill H. McCarberg, MD; for the FibroCollaborative. Mayo Clin Proc. 2011;86(9):907-911.

Abstract

Fibromyalgia (FM) is a common chronic widespread pain disorder. Our understanding of FM has increased substantially in recent years with extensive research suggesting a neurogenic origin for the most prominent symptom of FM, chronic widespread pain.

Neurochemical imbalances in the central nervous system are associated with central amplification of pain perception characterized by allodynia (a heightened sensitivity to stimuli that are not normally painful) and hyperalgesia (an increased response to painful stimuli). Despite this increased awareness and understanding, FM remains undiagnosed in an estimated 75% of people with the disorder. Clinicians could more effectively diagnose and manage FM if they better understood its underlying mechanisms. Fibromyalgia is a disorder of pain processing. Evidence suggests that both the ascending and descending pain pathways operate abnormally, resulting in central amplification of pain signals, analogous to the "volume control setting" being turned up too high. Patients with FM also exhibit changes in the levels of neurotransmitters that cause augmented central nervous system pain processing; levels of several neurotransmitters that facilitate pain transmission are elevated in the cerebrospinal fluid and brain, and levels of several neurotransmitters known to inhibit pain transmission are decreased. Pharmacological agents that act centrally in ascending and/or descending pain processing pathways, such as medications with approved indications for FM, are effective in many patients with FM as well as other conditions involving central pain amplification. Research is ongoing to determine the role of analogous central nervous system factors in the other cardinal symptoms of FM, such as fatigue, nonrestorative sleep, and cognitive dysfunction

Text From Guide

"Some may take the view that by giving the resulting disorder a medically respectable title it will contribute to illness behaviour and learned helplessness. It must be recognised that unless a condition is labelled there will be difficulties for physicians, the legal profession, insurers and benefits decision makers in dealing with these patients.

Few if any insurance or social security systems will permit compensation for general aches, pain and misery. However, when we as a Health Care Professional encounter an individual who is clearly distressed and debilitated most of us will be content to apply a label like fibromyalgia, if the clinical evidence generally supports it, so ensuring that the person can be classified and handled within the system. The term fibromyalgia syndrome is a clinical construct that allows physicians and others to describe and communicate to themselves a definition of one expression of chronic distress."

8. *Given that fibromyalgia is a distinct condition (included in ICD10) why does the above text refer to it as no more than a label? The only possible reason for using this tone is to diminish it in the eyes of the HCP.*

Recent research suggests that fibromyalgia may actually be associated with central nervous system dysfunction and anatomical changes in the brain. It is strange that a so-called evidence based guide contains no mention of probably physical cause/manifestation. The tone of the guide is clearly intended to leave the reader with the impression that fibromyalgia is not a real condition and is 'all in the mind' (a common medical claim throughout the ages when a condition is not yet fully understood and especially when the majority of people who have it are women!). This is supported by the inclusion of section 8.2 which clearly attempts to present fibromyalgia as a major depressive disorder without mentioning other studies that do not support this approach.

9. *Please provide me with the large number of studies that have assessed the possible association between FMS and major depressive as stated in section 8.*

The guide states as one of its objectives: "Describe an approach to the provision of medical advice which is pragmatic, medically logical and in keeping with the current consensus of medical opinion."

The published guide is biased towards presenting fibromyalgia as a psychological illness and attempting to link it with Chronic Fatigue Syndrome (CFS). Given that this is clearly not representative of current medical opinion the document is not meeting a key objective

10. *The guide is obviously biased and does not reflect current medical consensus. If WCA for people diagnosed with Fibromyalgia are assessed using this guide and refused benefits, are the DWP aware that it can be used as evidence at appeal that the assessment was fatally flawed?*

In answer to **Qs 1, 2, 8 & 9** DWP recognises Fibromyalgia as a distinct medical condition. Please find attached to this email the revised guide 'Fibromyalgia – Guidelines for the Disability Analyst which was issued to Healthcare Professionals (HCPs) in August 2012, and the list of the clinical references used in relation to the guidance can be found at page 32. Under section 21 of the Act, we are not required to provide information which is already reasonably accessible to you, either through the internet or the facilities at your local public library.

This document has been produced as part of a programme for HCPs to carry out medical assessments as approved HCPs. All HCPs undertaking these medical assessments must be registered medical or nursing practitioners who in addition, have undergone training in disability assessment medicine and more specific training. The training includes theory training in a classroom setting, supervised practical training, and a demonstration of understanding as

assessed by quality audit. These documents must be read with the understanding that, as experienced medical or nursing practitioners, the HCPs will have detailed knowledge of the principles and practice of diagnostic techniques and therefore such information is not contained in these documents. In addition, these are not stand-alone documents, and form only a part of the training and written documentation that a HCP receives. As disability assessment is a practical occupation, much of the guidance also involves verbal information and coaching. Thus, although the documents may be of interest to non-medical readers, it must be remembered that some of the information may not be readily understood without background medical knowledge and an awareness of the other training and guidance given to HCPs.

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In reply to **Q 3** HCP primary qualifications are held in the public domain and appear on the GMC's website. Please refer to www.gmc-uk.org then click on "check a doctor's registration" and complete the appropriate fields.

We cannot supply any further information relating to professional standing or qualifications of the Doctor named and information relating to post-graduate qualifications of a HCP, as it constitutes that person's personal data. This information cannot be disclosed in accordance with Section 40 of the Freedom of Information Act 2000 as disclosure would breach that person's right to privacy under the Data Protection Act 1998. In applying this exemption the Department has balanced the public interest in withholding the information against the public interest in disclosing the information and consider there is no overarching public interest argument in favour of releasing this information.

In answer to **Q 4** differential diagnosis is provided to enhance the HCPs understanding of the medical condition.

In response to **Qs 5, 6, 7 & 10** the Fol Act is about supplying recorded information held by the Department rather than explaining things or confirming whether your assumptions are correct or not, these questions are not valid Fol requests.

If you have any queries about this letter please contact me quoting the reference number above.

Yours sincerely,

Central FoI Team

e-mail: freedom-of-information-xxxxxxx@xxx.xxx.xxx.xx

Your right to complain under the Freedom of Information Act

If you are not happy with this response you may request an internal review by e-mailing freedom-of-information-request@dwpgsi.gov.uk or by writing to DWP, Central FoI Team, Caxton House, Tothill Street, London SW1H 9NA. Any review request should be submitted within two months of the date of this letter.

If you are not content with the outcome of the internal review you may apply directly to the Information Commissioner's Office for a decision. Generally the Commissioner cannot make a decision unless you have exhausted our own complaints procedure. The Information Commissioner can be contacted at: The Information Commissioner's Office, Wycliff House, Water Lane, Wilmslow Cheshire SK9 5AF www.ico.gov.uk