

A recent article by Natalie Wright in the Independent (Jan 6th, 2018) has made the suggestion that I don't care about people with CFS/ME, based on six words written by a civil servant after a presentation I gave a quarter of a century ago. It's not true of course, I do care, but as people have written to me privately about it in the last couple of years and because this new piece has raised the issue once again here's the background for anyone who wants to know more.

This latest allegation was triggered by a series of documents that surfaced in the National Archives in 2012. These all concerned the then Department of Social Security (DSS) and its review of the Disability Living Allowance (DLA) scheme, including the entry on ME. There were questions being asked about the nature of ME, and whether or not anything could be done to improve outcomes.

One of these documents is clearly a letter written by me. Two ME charities had approached me, unhappy about the new DSS proposals. I shared their concerns, and wrote to the DSS, reinforcing earlier correspondence on the legitimacy of CFS, entitlement to benefits, and the implications of some recent research. Here is the letter

<http://simonwessely.com/Downloads/Other/Awardletter.docx>. . The second must be the minutes as taken by a civil servant of a presentation that I gave to a meeting at the DSS on the same topic a bit later. <https://pbs.twimg.com/media/BsoTImMIEAEaKdP.png:large>. The invite had not gone directly to me, but to Professor PK Thomas, then the senior chair of neurology at the National Hospital for Neurology, and hence one of the leading neurological authorities in the country. He asked me to accompany him, I was relatively junior at the time, and describe our new work.

Context is obviously important. The name ME had been created in 1956, to describe the epidemic that had broken out amongst staff at the Royal Free Hospital in 1955, thought by some, but not all, to be linked to polio. Despite that, I don't think anyone disputes that this had not been a major issue in the UK until the 1980s and a series of high profile media articles, albeit describing something rather different¹, but to which, unfortunately in my opinion, the same diagnostic label had been attached.

That meant that there was renewed interest in a paper that had appeared in 1970 which reanalysed the case histories of the 1955 epidemic and concluded that the epidemic was an example of mass hysteria. And there is no doubt that some continued to view ME as a form of hysteria. It was also viewed as a primary muscle disorder. Newspaper headlines of the period often drew on one or the other.

By the time of the DSS inquiry we had just published a detailed clinical interview study of ME patients at the National Hospital for Neurology, and concluded that hysteria, by then known as conversion disorder, was not an important factor. Hence, I made this clear in the letter and as the minutes confirm, in my presentation. Likewise, we had found that pattern of fatigue was not peripheral, but central, suggesting that this wasn't a primary muscle disorder. A group in Australia led by neurologists had also recently come to both the same conclusions. Both issues were an important part of the previous correspondence and then the direct discussion at the DSS.

The other major issue on the table was management. Put simply there was none available within the NHS, and what was available privately elsewhere was pretty unsatisfactory. However, myself

¹ The 1955 cases were all acute, contagious, paretic, and regarded as benign (hence the original term coined in 1956 had been "benign" myalgic encephalomyelitis. Cases now were usually slower in onset, non contagious, not benign and were about intense fatigue and fatigability.

and colleagues had recently published the first report of using the principles of CBT with ME patients at the National Hospital for Neurology, and the results were encouraging.

One of the things that followed from this was a discussion on the dangers of prematurely assuming that people had permanent or long-term disability. Like all my generation, we had been taught a lot about the “labelling” – namely that the name you give to a condition can contain numerous assumptions about the disorder, which may be erroneous but self-fulfilling. This is still an issue today. One of the core principles of the “Recovery Movement”, currently the dominant paradigm in managing long term conditions and disability, is avoiding this. Back then I was aware of the dangers of the premature (but exceedingly common) assumption that nothing could be done for ME patients, and would undoubtedly have spoken about why we should try and avoid this. Premature labelling of people as being permanently incapacitated was definitely discussed. It is regrettable if this got shortened in the minutes to “benefits can make you worse”, but I doubt that anyone present would have come away with that as a general view – after all, as the earlier letter states, I had by then written at least two letters to the DSS that “CFS is undoubtedly a genuine condition...and sufferers should be entitled to the full range of benefits”. Questions would have been asked if my position had somehow changed in the intervening months. It hadn’t, and they weren’t.

The question as to whether or not state benefits should be linked to co-operation with treatment didn’t come up at that time. It has since, and this was my response.

<https://www.theguardian.com/commentisfree/2015/jul/29/coercing-people-mental-health-problems-work-treatment>