

ME/CFS is an organic disorder

Professor Malcolm Hooper 27th February 2014

Given the decades-long determination of the psychiatric lobby to re-classify and claim ME/CFS as a mental (behavioural) disorder, possibly as a Bodily Distress Disorder, it is encouraging to note that on 12th February 2014 the WHO publicly confirmed that: *“Fibromyalgia, ME/CFS are not included as Mental & Behavioural Disorders in ICD-10, there is no proposal to do so for ICD-11”* and that this has been accepted by the UK Parliamentary Under-Secretary of State for Health (Jane Ellison MP) who, on 25th February 2014 stated on the record: *“The World Health Organisation is currently developing the 11th version of the International Classification of Diseases, which it aims to publish in 2017. No discussions have taken place between the Department and the WHO on the reclassification of ME/CFS, but the WHO has publicly stated that there is no proposal to reclassify ME/CFS in ICD-11”*.

With all the current furore about the US Institute of Medicine’s handing out to mostly non-experts in ME/CFS the task of compiling a brand new case definition and the equal concern about the American Psychiatric Association’s current revision of the DSM (Diagnostic and Statistical Manual of Mental Disorders), it may be helpful to be aware not only of the WHO’s position but also to recall that twenty two years ago the UK High Court of Justice ruled on the status of ME/CFS/PVFS.

There have been many court cases in the UK involving claims for ME/CFS; many claimants have been successful but have been compelled to sign very tight gagging orders, meaning that they must never discuss the legal action or reveal the outcome. To do so would be in contempt of Court, a situation in which no sane person would ever contemplate placing themselves.

Over the years, Dr (now Professor Sir) Simon Wessely has been involved in numerous such cases, sometimes appointed to act for the plaintiff and sometimes acting for the defendant. His view about the nature of ME/CFS is well-known: according to his published work he firmly believes ME does not exist and that CFS is a behavioural disorder.

Not all cases, however, were kept out of the media. In November/December 1992 the case of Ronald Page v Simon Smith was a landmark case and was widely reported in the press. Mr Page had previously suffered from ME and alleged that the road traffic accident in which he was involved (for which he was not liable) had caused a severe and permanent relapse of the condition.

The case was heard before Mr Justice Otton (High Court of Justice; Queen’s Bench Division; No: 92-NJ-135), who remarked that: *“This is one of the most interesting cases I have ever had the privilege of trying”*.

The Approved Judgment (Transcript Writers: Beverly F. Nunnery & Co) was clear: the Judge stated that the condition did not always receive the sympathy and understanding it deserves, this being manifested as scepticism by some doctors due to the reluctance of the medical profession to recognise the disorder and to accept it as a **medical** condition.

The Judge noted the failure of the public in general to appreciate that it is a genuine (physical) illness and he noted the tendency, even the temptation, to associate the symptoms with sloth, indolence, malingering and hysteria. He said: *“Even in this case one doctor saw fit to make a diagnosis of paranoid schizophrenia which I am satisfied was totally erroneous and Mr Page is entitled to my saying so”*.

The Judge posed eight questions, the first being: *“Is there a condition, disease or illness called ME?”*, the second being: *“What are the principal or typical symptoms or characteristics of this condition”* and the third being: *“What causes it?”*. The remaining questions pertained to the individual circumstances of the case, specifically, did the RTA materially contribute to the plaintiff’s post-accident condition?

Appearing for the plaintiff was Dr William Weir, then a consultant physician at The Royal Free Hospital, London, who, it was subsequently noted, was well-regarded by the Courts; his evidence was that there is compelling evidence pointing towards the presence of a virus in ME/CFS/PVFS and that the immune system is found to be in a state of chronic activation, suggesting that some agent is provoking that activity.

Also appearing for the plaintiff was Dr Simon Wessely, then senior lecturer in psychological medicine at King’s College Hospital Medical School and the Institute of Psychiatry and honorary consultant psychiatrist at the King’s College and Maudsley Hospitals; it was recorded in the Judgment that he had not examined the plaintiff (which was in keeping with his non-examination of the patient in other legal cases). The Judge noted in particular Dr Wessely’s assertion that: *“the only facts that can be substantiated (about ME/CFS/PVFS) are, first, that CFS is not due to neuromuscular disease....Second, CFS is associated with a high rate of psychiatric disorder over and above that due to the psychological consequences of physical disability”*. Mr Justice Otton further noted that Dr Wessely *“excludes neurological or virological causes”* and that Dr Wessely stated: *“the discouraging material from the ME Association may have contributed to (the plaintiff’s) relapse”*, also noting that Dr Wessely said in his report that the most difficult part of the plaintiff’s case was in showing that the accident had contributed to his relapse.

The third medical expert appearing for the plaintiff was Dr (later Professor) Leslie Findley, then a consultant neurologist at the Regional Centre for Neurology and Neurosurgery at Oldchurch Hospital Romford; his evidence was that: *“There is no doubt that [CFS]... exists and is a genuine and common condition”*. The Judgment noted Dr Findley’s opinion that: *“Physical, psychological and infective stresses of all types can result in deterioration”* and that *“traumatic stress is now well recognised as a cause of relapse”*.

The experts called on behalf of the defendant included Dr Adrienne Reveley, then consultant psychiatrist at the Maudsley Hospital and whom Dr Wessely confirmed in evidence that he knew quite well, who stated (erroneously) in her evidence that: *“nowhere in any of the descriptions of CFS is trauma referred to as a precipitant”* and that the balance of probability was that trauma has nothing to do with ME and that *“the ME literature was a vehicle for (the plaintiff’s) condition”*.

The next witness for the defendant was Dr David Kendall, honorary consultant neurologist at St George's and St Helier Hospitals. In evidence he said: *"I must say that first of all I am a total disbeliever in this syndrome...there are the devotees of this diagnosis who support it with a fervour which is little short of religious...My view is that this condition does not exist as a clinical entity other than in the minds of the sufferers and it follows from my own argument that if this is correct trauma can neither initiate nor aggravate the condition...My own view about this matter is that there is no clinical, pathological or epidemiological reason to suppose that this is in any way due to viral disease...(and) to me the symptoms so closely resemble those of non-organic illness that my view from the early days of this disorder has been that it is emotionally rather than physically determined"*. In his Judgment, Mr Justice Otton noted that in Dr Kendall's opinion, the plaintiff's condition was *"entirely psychiatric in origin...He did not believe in ME"*.

The third witness for the defendant was Dr McKeran, consultant neurologist at the Maudsley, St George's and St Helier Hospitals. He was asked to comment on Dr Wessely's report and said that the specificity of symptoms and their significance to the aetiology and pathogenesis remain unclear: *"The evidence is not sufficient to draw a firm conclusion of organic origin, but he would not rule out organic factors"*.

In coming to his conclusion as to which parts of the medical evidence he preferred, the Judge noted that he was faced with an impressive body of medical opinion on behalf of the plaintiff and the defendant and that it was *"irreconcilable"*.

In his Judgment, Mr Justice Otton said in answer to his first question (*"Is there a condition, disease or illness called ME?"*): *"I do not share Dr Kendall's scepticism on this disease. He has not persuaded me that the condition does not exist as a clinical entity other than in the minds of sufferers....I accept Dr Findley's opinion as a neurologist: 'There is no doubt that [CFS] (synonymous with Myalgic Encephalomyelitis) exists and is a genuine and common condition' "*.

"Question 2: what are the principal or typical symptoms or characteristics? ...I accept Dr Weir's finding from his work in this field that 'a characteristic feature is an extreme variability of their severity together with a tendency to relapse if the patient over-exerts himself even on days when he feels marginally better' ".

"Question 3: what causes it? On the evidence before me and the present state of medical knowledge as opposed to theory and speculation, I am unable to answer this question with total certainty...I was impressed by Dr Weir's research conclusions...I am prepared to find on the balance of probabilities that the chronic activation of the immune system is due to an agent provoking this activity probably by an as yet unidentified virus. I also accept his conclusion that the condition can be triggered by a viral infection or emotional stress or the trauma of an accident. I accept without reservation that he had had experience of other patients who have been diagnosed as suffering from CFS as a result of the trauma of an accident". In this regard also I accept Dr Findley's evidence which is based on similar clinical experience".

"I accept the majority view of the experts that physical, psychological and infective stresses of all types can result in deterioration in the condition and impair recovery....Once it is established that CFS exists and that

a relapse or recrudescence can be triggered by the trauma of an accident...it becomes a foreseeable consequence”.

The plaintiff duly won his case and was awarded £162,153.00 in compensation.

However, the defendant appealed and the award (some of which had been given to the plaintiff) had to be handed back because the appeal was successful (30th March 1994: Court of Appeal Civil Division before Lord Justice Ralph Gibson, Lord Justice Farquharson and Lord Justice Hoffmann: OBENF 93/0098/C; Transcript Writers: John Larkin Verbatim Reporters; [1994] 4AllER 522 CA).

The issue was not whether or not ME/CFS exists as a medical (ie. physical, not mental) disorder nor about its classic symptomatology: the challenge was that the road traffic accident could not have caused the plaintiff's ME to relapse and therefore the defendant was not liable to pay compensation.

The case then went to the House of Lords, where the Judgment was handed down on 11th May 1995, the case having been heard before Lord Keith of Kinkel (who found against Mr Page); Lord Ackner who found for Mr Page); Lord Jauncy of Tullichettle (who found against Mr Page); Lord Justice Browne-Wilkinson (who found for Mr Page) and Lord Lloyd of Berwick (who found for Mr Page), so it was 3:2 in favour of Mr Page (1995:2AllER 736; reported in Personal & Medical Injuries Law Letter, December 1995:68-70). In that Judgment, there was repeated reference to ME/CFS as a **physical** disorder (although on 12th May 1995 Frances Gibb, The Times' legal correspondent, referred to it as a mental disorder). Their Lordships, however, sent it back to the Court of Appeal on a legal technicality.

Finally on 12th March 1996 came the Judgment of The Master of The Rolls, Sir Thomas (later Lord) Bingham (whose own daughter-in-law was severely affected by ME), together with Lord Justice Morrit and Lord Justice Auld (Court of Appeal Civil Division on Appeal from the High Court of Justice: QBENF 93/0098/C), which upheld the original Judgment of Mr Justice Otton in favour of Mr Page after a nine year legal battle. The case was reported in the All England Law Reports on 10th July 1996: ([1996] 3AllER:272-280; Transcript Writers: John Larkin Verbatim Reporters).

In the Judgment, The Master of The Rolls said about Mr Justice Otton's original findings: *“I discern no error in the judge's approach....I have no doubt but that the judge was fully entitled to reach the conclusions he did on the evidence before him....In my judgment, his findings on this matter were both careful and correct....I am of the opinion that the judge's conclusion on this issue is unassailable. Despite the contrary opinion reached by Ralph Gibson LJ when the issue was last before the Court of Appeal, I have for my part no hesitation in upholding the decision of the judge. I would dismiss the defendant's appeal”.* Lord Justice Morrit and Lord Justice Auld both agreed.

It is thus enshrined in UK law that ME/CFS is a physical, not psychiatric, disorder, although the mechanism by which a relapse may occur following trauma is via “nervous shock”.

Curiously, it proved to be extremely difficult to obtain all the transcripts. It was variously said that they had been inadvertently lost by the Transcript writers; that they had not been approved by the Court; and that they no longer existed, none of which was true.

Now why should that be? Case law is there to be quoted and relied upon.