

Some observations on the Executive Summary of the Report from  
The Health Council of The Netherlands

Margaret Williams

13<sup>th</sup> April 2005

**Even though it refers throughout to “CFS”, this Report is not about ME/ICD-CFS (“CFS” being a term used synonymously with ME in the ICD). Instead, the Report seems to be considering chronic “fatigue” but inappropriately uses the terminology as interchangeable, when to do so is scientifically unjustified. If the Report is discussing those with medically unexplained chronic fatigue (as classified in the ICD at section F48.0 as a behavioural disorder), then the authors of the Report should have been specific in the terminology used, otherwise their Report is open to misinterpretation.**

1. The Report states: “CFS patients feel perpetually tired, or even exhausted, every now and again”, but patients with ME/ICD-CFS specifically do NOT feel “perpetually tired” --- they are wholly incapacitated with post-exertional exhaustion and malaise, which is the cardinal feature of ME/ICD-CFS (but NOT of other non-specific states of medically unexplained chronic “fatigue”). Such incapacity is not synonymous with feeling “perpetually tired every now and again”.
2. The Report states that “ME” is “a term that the Committee does not use since it erroneously implies the presence of an inflammation of the brain and spinal cord”. The authors appear to be unaware that there *is* published evidence of CNS inflammation in ME/ICD-CFS (but NOT in other non-specific states of chronic fatigue).
3. Whilst it is true to say that “CFS is a genuine, severely incapacitating disorder”, it is necessary to differentiate ME/ICD-CFS from psychiatric states of chronic fatigue and to point out that whilst psychiatric disorders are indeed “genuine” and “severely incapacitating”, they do not have the neurological features (nor other symptomatology) that is specific to ME/ICD-CFS.
4. Whilst it is true to say that the 1994 CDC criteria are “internationally recognised as the standard”, it needs to be specified as to *what disorder* is defined by the criteria that are “recognised as the standard”, because it is essential to point out that the CDC criteria specifically state: “**We dropped all physical signs from our inclusion criteria**” (ref: The Chronic Fatigue Syndrome: A Comprehensive Approach to Its definition and Study: Keiji Fukuda et al: Annals of Internal Medicine 1994:121:12: page 957). Given that

in ME/ICD-CFS there are always physical signs, to what disorder do the 1994 CDC criteria refer, especially given that the authors themselves state very clearly that: **“Whether to retain any symptom criteria other than chronic fatigue generated the most disagreement among the authors”**. There has long been recognition in the medical literature that the 1994 CDC criteria have significant shortcomings and that they do not relate to ME as described by Ramsay --- hence the calls for their improvement, for example:

(i) in 1996 by Hilgers and Frank called for the inclusion of 17 additional significant symptoms (respiratory; palpitations; dizziness; dyspepsia; dryness of mouth/eyes; allergies; nausea; parasthesia; loss of hair; skin alterations; incoordination; chest pain; personality changes; eczema; general infections; twitches and urinary problems – see “Chronic Fatigue Syndrome: Evaluation of a 30-Criteria-Score and Correlation with Immune Activation”: Arnold Hilgers and Johannes Frank: JCFS 1996:2(4): 35-47)

(ii) in 2003 by Carruthers et al (see “Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols”: Bruce M Carruthers et al: JCFS 2003:11(1):7-115).

It is noted that the Health Council of The Netherlands acknowledges that the limitations of the CDC definition include the fact that “the symptom criteria have not been validated and that the definition was primarily formulated for scientific research purposes” (and not therefore for *clinical* use). How then can such unquestioning reliance be placed by the authors of this Report upon a case definition whose symptomatology has not been defined? What disorder is being discussed? It is not ME/ICD-CFS, because by definition, (ie. the dropping of ALL physical signs), ME/ICD-CFS is excluded from that definition.

5. In the section entitled “The doctor-patient relationship influences the course of fatigue complaints”, ME/ICD-CFS cannot be the disorder under review. The Report states “The outcome of such complaints as chronic fatigue is determined not only by doctors’ instrumental actions, but also by their affective actions”. Even to *mention* “chronic fatigue” in a report that purports to discuss the chronic fatigue syndrome reveals gross ignorance. Are the authors not aware of the fact that as long ago as 1990, the American Medical Association published confirmation that “chronic fatigue” is not the same as the “chronic fatigue syndrome”: following an erroneous News Release about this point, the American Medical Association was forced to issue a correction which said “A news release in the July 4 packet confused chronic fatigue with chronic fatigue syndrome; the two are not the same. We regret the error and any confusion it may have caused”.
6. In the section “Rigid preconceptions” the Report states: “A question that patient organisations are again and again confronted with is whether CFS is a neurological or a psychiatric disorder. This is, in fact, a spurious question”. It is far from a “spurious” question: “spurious” means “false” or “not legitimate”: the correct answer to this question is fundamental to the existence and even to the very survival of most patients with ME/ICD-CFS because it

impinges so directly and so extensively on their ability to obtain appropriate medical care (as opposed to inappropriate and indeed damaging psychiatric interventions) and necessary financial support (which, due to the misperception by some of ME/ICD-CFS as a psychiatric disorder, is often denied or inappropriately reduced, thereby condemning those with ME/ICD-CFS to a state that is barely compatible with survival).

7. The Report states “CFS is one of the many syndromes with physically unexplained symptoms, other examples being irritable bowel syndrome”. Why are the authors of this Report not aware that the cause of IBS is no longer “physically unexplained”? IBS has been demonstrated to be due not to psychosocial distress as used to be asserted, but to previously unknown mechanisms involving a molecular defect in the gut, with dysregulation of serotonin receptors (key elements of serotonin signalling have been demonstrated to be changed in IBS -- as Professor Michael Gershon from the Department of Anatomy and Cell Biology at the College of Physicians and Surgeons at Columbia University, New York, has pointed out: “IBS is now associated with a very real abnormality in the gut and one that is as biochemical as any other”). It is surely incumbent upon authors of Government Reports such as this to ensure attention to medical and scientific accuracy and not to make facile and demonstrably erroneous statements that are inexcusably misleading. Could the reason the authors do not refer to this advancement of medical knowledge be because to admit to it would weaken their preferred stance on what they expediently choose to call ‘unexplained physical’ symptoms?
8. The section on cognitive behavioural therapy is misleading in the extreme. The authors state “The systematic reviews that have been conducted of interventions for CFS reveal CBT to be an effective treatment”, but this is grossly misleading because those systematic reviews reveal that there are only five (5) studies of appropriate design that claim some (but not universal) efficacy for CBT. Where is the evidence upon which the Report authors claim a 70% success rate for CBT in CFS? Importantly, the entry criteria for most of those studies used either the Oxford (1991) or the CDC (1994) criteria, and both of these exclude by definition those with ME/ICD-CFS. To date, there have been NO studies of CBT on those with ICD-classified ME, only upon those with loosely-defined “CFS” (which by definition expressly includes those with long-term fatigue due to psychiatric disorders).

In conclusion, this Report seems to represent a travesty in that it fails to acknowledge or even to be aware of the abundance of peer-reviewed medical and scientific evidence of biological abnormalities in ME/ICD-CFS that involve all the major systems of the body, most notably the cardiovascular system, the immune system, the nervous system (particularly the autonomic nervous system), the endocrine system, the respiratory system, the gastrointestinal system and the musculoskeletal system.

Without doubt, the Report is clearly biased and appears to be designed to uphold the psychiatric paradigm of “CFS” and thereby to support the medical insurance industry, to which the Report defers: “It is the responsibility of occupational physicians and insurance physicians to explain that the assessment of fitness for work hinges on three

issues”. The authors then proceed to proffer more erroneous information as though it were established fact (there is no credible evidence to support the notion that if a person with ME/ICD-CFS “is able to function to some extent, then certain forms of work will also soon be possible”). Further, it is not applicable in ME/ICD-CFS to state: “an insight into the psychosocial context plays an essential role when forming an opinion on an individual’s fitness for work”. Such unsupported assertions are little short of scandalous.

Dutch ME sufferers may wish to quote from Dr Vicky Ripperé’s salient observation made in 1992: **“It is worrying that many neurological patients may be relegated to the disadvantaged status of ascribed mental illness because of systematic abuse of the doctor’s diagnostic authority”** (see JRSM 1992:85:59). It is deeply disturbing that, especially in The Netherlands, such abuse remains so prevalent over thirteen years later.