

To Whom It May Concern

### **Scottish Good Practice Statement on ME-CFS – May 2009**

This document is dated May 2009 and it is published by Action for ME and NHS Scotland both of whom have their logos on it. Its production was led by a GP called Dr Purdie who practices in NHS Dumfries and Galloway.

The views expressed in this letter are my own and not necessarily representative of any organisation that I am associated with.

#### **Summary**

In summary, my opinion is that this document takes an extremely partisan review of the scientific evidence. Throughout there is confusion of terms and what conditions the guidelines apply to CFS or ME or both. It appears to have been driven largely by the view of one GP and a small number of individuals rather than a properly constituted procedure for reviewing evidence. In my view, following these guidelines risks harm to patients. The fact that NHS Scotland appears to have endorsed it is worrying and represents a major departure from evidence based medicine.

#### Chapter 1

The introduction presents a very negative picture of the illness as neurological and permanent. This does not apply to the vast majority of people seen in medical practice with chronic fatigue syndrome and is likely to lead to alarm and therapeutic nihilism. Even more worrying the guide refers to and even seems to partially endorse fringe investigations run by private practitioners with no accepted scientific basis, such as mitochondrial testing.

#### Chapter 2

This refers to clinical presentation. It not only endorses unproven precipitants for the illness such as pesticide exposure but goes on to use 'Canadian diagnostic criteria'. These are marginal in the scientific area and have been produced by a small group of clinicians in a low impact journal. The internationally accepted criteria published by the US Centres for Disease Control are ignored. Almost all the literature on chronic fatigue syndrome is written according to the CDC International criteria. Not only are the Canadian criteria marginal and unused in research they are in places odd. For example, they list ataxia, muscle weakness, and fasciculation as common symptoms of this illness. These are symptoms which should lead to a serious search for alternative neurological diagnoses. Furthermore, they list symptoms according to bodily systems (for example autonomic neuroendocrine and immune when it is not at all clear that the symptoms do relate to abnormal function in these bodily systems. At the end of the section on the diagnostic criteria there is a phrase, which appears to dismiss the NICE guidelines in Scotland. NICE guidelines are based on rigorous metanalysis.

#### Chapter 3

This refers to clinical assessment and diagnosis. It states correctly that fatigue may be a symptom of many conditions. However, rather than discuss the differential diagnosis based on the symptoms the chapter moves straight into investigations and specialist referrals. There is no consideration given that the fact that by far the commonest differential diagnosis is with depression and anxiety. Some of the tests listed are specialist and have little diagnostic value in CFS, such as fat biopsy for volatile organic compounds, gastric biopsy and SPECT scans. There is a lack of clinical perspective in this section. Similarly the section on children does not consider the differential diagnosis in a balanced fashion. There are a large range of reasons for non-attendance at school of which (aside from one unreplicated minor study) "ME-CFS" and does not figure prominently in. Removing children from school unnecessarily (and arranging home tuition) as is advocated in the document may on occasion be necessary but it is potentially damaging to the child's development and requires careful assessment and consideration before it is implemented.

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This section moves into child protection and concludes that graded exercise and CBT are 'controversial treatments'. These are the treatments for which are the most evidence supported by systematic reviews and meta-analysis and clearly advocating the NICE guidance. Statements like this remove this document from the area of scientific medicine. There is the next section which claims that a quarter of people with this diagnosis are confined to bed. That is a statement without real evidence.

### Chapter 4

This refers to symptom management. This section again emphasises "the debate and controversy" around graded exercise and cognitive behaviour therapy. These treatments have far more evidence than almost the entire remaining guidelines document. The section on symptom management starts with drug treatments for which there is very little evidence. The section on non-drug treatment starts with an apparent attempt to dismiss a Cochrane collaboration systematic review in the light of a questionnaire survey undertaken within the members of the charity concerned. The consensus approach to this condition which is acceptance of the problem and collaborative rehabilitation using graded increases in activity and cognitive behavioural techniques does not emerge from this document whereas lots of non-evidence base approaches such as various drug treatments for symptoms do. This is unhelpful and potentially harmful for patients.

### Chapter 5

This is about research. It includes a selection of studies with no apparent logic about which have been selected. Finally the websites quoted are exclusively those of advocacy organisations and not mainstream information provided by other bodies such as the NHS.

### Chapter 6

This chapter is on support for patients and considers welfare benefits and social care.

Finally the appendices include information including details of the Canadian definition a made up severity scale and is a highly selected list of references.

Sincerely yours,



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