

PERMISSION TO REPOST

Campaigning for Research into Myalgic Encephalomyelitis

APPG Chair supports use of Oxford Criteria

On Dec. 9 2004, Tony Wright, Chair of the All Party Parliamentary Group on ME, said:

.... Regarding the PACE trials... I support the use of the Oxford Criteria ... as I similarly support the use of the Fukuda and London Criteria for them. Such trials will prove an excellent way to test such criteria.

Criteria such as the Oxford and Fukuda do not describe the pattern of symptoms people with ME experience i.e. Ramsay, below. Let's look at one of them:

The CFS Oxford Criteria was set out in the Oxford Guidelines - MC Sharpe et al. A Report - Chronic Fatigue Syndrome: Guidelines for Research, JRSM Vol.84, Feb. 1991, pp 118-21.

Of the 21 clinical and scientific researchers who wrote the Oxford Guidelines, eight were in psychiatry or psychology, another six were research scientists, non-psychiatric clinicians were few (see BM Hyde, The Clinical and Scientific Basis of ME/CFS, 1992, 12). Notable exclusions were DS Bell, EG Dowsett, BM Hyde, AM Ramsay and JS Richardson, experts on ME and its epidemiology.

OXFORD CRITERIA (1991)

Chronic Fatigue Syndrome (CFS)

a:- A syndrome characterised by fatigue as the principal symptom

b:- A syndrome of definite onset that is not life long

c:- The fatigue is severe, disabling, and affects physical and mental functioning

d:- The symptom of fatigue should have been present for a minimum of 6 months during which it was present for more than 50% of the time

e:- Other symptoms may be present, particularly myalgia, mood and sleep disturbance

f:- Certain patients should be excluded from the definition. They include:

i:- Patients with established medical conditions known to produce chronic fatigue (eg severe anaemia). Such patients should be excluded whether the medical condition is diagnosed at presentation or only subsequently. All patients should have a history and physical examination performed by a competent physician

ii:- Patients with a current diagnosis of schizophrenia, manic depressive illness, substance abuse, eating disorder or proven organic brain disease. Other psychiatric disorders (including depressive illness, anxiety disorders and hyperventilation syndrome) are not necessarily reasons for exclusion.

The Oxford Criteria is too inclusive. A number of different types of illness including ME are being lumped together under the single banner 'CFS'. In the words of Dr Dowsett 'CFS' is a 'facile euphemism for ME... which enmeshes this serious and potentially life long neurological illness in a web of trivial fatiguing sub entities... '

The Royal Colleges Report on CFS 1996 used the Oxford Criteria and claimed up to 1.4 million people in the UK had CFS. Estimates of ME incidence are much lower. **People with ME fear the results of the PACE trials, as they do those associated with the new 'CFS/ME' NHS centres and satellites: The all inclusive, onesize fits all approach will mean the results will most probably be successful for the majority of participants listed under the 'CFS/ME' banner but then used as an excuse to set back the case for physical research into G93.3 ME.**

The above feel the Chair of the APPG should not have made such a brash and definitive statement without having consulted more widely.

They wonder if he, as a member of the ruling party, is simply endorsing what has already been decided for the sake of convenience and political expediency.

What is scary is that politicians can make public statements like this which are against the interests of vulnerable people; and that they are being allowed to get away with it.

If you are concerned, please take the matter up with Tony Wright via your MP. And please send us copies of your correspondence.

**Tony Wright MP, House of Commons Westminster SW1A 0AA
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Action for ME?

Please remember, also, that Action for ME - an organisation which was set up originally by ME people for ME people is supporting the PACE trials. It would seem reasonable to conclude, therefore, that it also supports the use of the Oxford Criteria.

They have been claiming credit for clarifying that ME is listed as neurological disorder by WHO. Given this fact, shouldn't they be pushing for a strict an ME criteria as is possible?

They appear more interested in pleasing the Govt/'Wessely psychiatrists' than listening to/representing people with ME.

If you are concerned, then take the matter up with:

**Chris Clark, 4 Deans Court St Paul's Churchyard EC4V 5HH
afme@afmeuk-demon.co.uk**

**Paul Davis, RiME, 10 Carters Hill Close, Mottingham SE9 4RS
rimexx@btinternet.com**

The following is taken from AM Ramsay, ME and Post Viral Fatigue States, 1988, Chapter 3 'The endemic form of the disease'.

The clinical features of myalgic encephalomyelitis

The onset of the disease is similar to those described in the various recorded outbreaks. Thus it may be sudden and without apparent cause, as in cases where the first intimation of illness is an alarming attack of acute vertigo, but usually there is a history of infection of the upper respiratory tract or, occasionally, the gastrointestinal tract with nausea and/or vomiting. Instead of an uneventful recovery the patient is dogged by persistent and profound fatigue accompanied by a medley of

symptoms such as headache, giddiness, muscle pain, cramps or twitchings, muscle tenderness and weakness, paraesthesiae, frequency of micturition, blurred vision and/or diplopia, hyperacusis (sometimes alternating with deafness or normal hearing), tinnitus and a general sense of 'feeling awful'. Some patients report the occurrence of fainting attacks relieved by a small meal or just eating a biscuit; these attacks are the result of hypoglycaemia and we are reminded of the three young women in the outbreak in Finchley who were admitted to hospital in an unconscious state, the result of acute hypoglycaemia. All cases run a low-grade pyrexia, seldom exceeding 100F and usually subsiding within a week. A very thorough examination of the central nervous system should be made and this should be accompanied by a careful estimation of muscle power, especially in the limbs and neck. A search for enlarged lymph nodes should never be omitted. If muscle power is found to be satisfactory, a re-examination should be made after exercise; a walk of half a mile is sufficient, as very few ME cases can manage more.

Once the syndrome is fully established the patient presents a multiplicity of symptoms which can most conveniently be described in three groups.

1. Muscle phenomena

Muscle fatigability whereby, even after a minor degree of physical effort, three, four or five days, or longer, elapse before full muscle power is restored is unique and constitutes the sheet anchor of diagnosis. Without it I would be unwilling to diagnose a patient as suffering from ME, but it is most important to stress the fact that cases of ME of mild or even moderate severity may have normal muscle power in a remission. In such cases, tests for muscle power should be repeated after exercise. In severe cases of ME, muscle spasms and twitchings are a prominent feature and give rise to swollen bands of muscle which are acutely tender. In less severe cases, muscle tenderness may not be so readily elicited but careful palpation of the trapezii and gastrocnemii (the muscle groups most commonly involved) with the tip of the forefinger should enable the examiner to detect minute foci of exquisite tenderness. It is interesting to note that Dr Garnet Simpson in Sydney, Australia (1986), without any prior knowledge of my writings devised the identical technique and found that detection of these of these foci 'will make the patient yelp'. In the aftermath of the disease patients frequently fumble with relatively simple manoeuvres such as turning a key in a lock or taking the cork out of a bottle.

2. Circulatory impairment

Most cases of ME complain of cold extremities and hypersensitivity to climatic change, but the most striking illustration of this condition is the observation by relatives or friends of an ashen-grey facial pallor, some twenty or thirty minutes before the patient complains of feeling ill.

3. Cerebral Dysfunction

Impairment of memory, impairment of powers of concentration and emotional lability are the cardinal features. Failure to recall recent or past events, difficulty in completing a line of thought, thus becoming tongue-tied in the middle of a sentence, and a strong inclination to use wrong words saying 'door' when they mean 'table' or 'hot' when they mean 'cold' (two doctors have testified to this) are all common deviations from normal cerebral function. A complete inability to comprehend a paragraph even after re-reading is a further example of this defect. This may be accompanied by bouts of uncontrollable weeping which can prove very embarrassing to those who pride themselves on a stoical temperament. Alterations of sleep rhythm or vivid dreams, or both, are common and occurred in patients with no previous experience of such phenomena. In a very tragic case, complete reversal of sleep rhythm in a young university student led to suicide.

Frequency of micturition and hyperacusis are an almost invariable accompaniment of the cerebral features and together with episodic sweating and orthostatic tachycardia they can only be attributed to involvement of the autonomic nervous system. Though less frequently encountered, and usually in severe cases episodic, sweating is a very striking event. I encountered this phenomenon fifteen years ago in a patient who used to waken in the night to find himself lying in a pool of water. His wife is a nurse and reports that his temperature in these episodes is 94 or 95F. His condition remains unchanged and the sweating episodes are still occurring.

Variability and fluctuation of both symptoms and physical findings in the course of a day is a constant feature in the clinical picture of myalgic encephalomyelitis.

MEActionUK - it does exactly what it says on the tin
<http://www.meactionuk.org.uk>
<http://health.groups.yahoo.com/group/MEActionUK/>