



**Cymdeithas Cefnogi
ME & CFS Cymru**

**Welsh Association of
ME & CFS Support**

NICE guideline on diagnosis & management of CFS/ME in adults and children - WAMES statement September 2007

The clinical guidelines for CFS/ME were published by NICE in August 2007, a year after the draft guidelines were distributed for consultation. WAMES contributed to the original consultation by taking into account the views of patients and their families in Wales, and concluded that the guidelines were 'unfit for purpose' and failed to meet NICE's own standards of producing objective 'evidence-based and 'cost-effective' guidance. They made many unjustified claims, included inconsistencies in terminology, failures of logic and huge gaps.

We acknowledge that improvements have been made to the final version and a consensus has been reached on many aspects of general care. Unfortunately this remains a document which not only fails to grasp the full nature of neurological ME and the implications for management, but also fails to provide adequate guidance for diagnosis. It also recommends widespread use of the psychosocial rehabilitative treatments of CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) in spite of reports of harm from ME patients. At best this means that the main thrust of the guidelines are irrelevant for most people with ME, at worst, dangerous.

Major concerns:

1. **Failure to acknowledge the WHO classification** of ME/CFS as being a neurological disorder (in section G93.3 of ICD 10).
2. **The remit was limited and skewed** – thousands of biomedical studies were not investigated and the remit NICE was given highlighted rehabilitation approaches: To prepare for the NHS in England and Wales, *guidance on the assessment, diagnosis, management of adjustment and coping, symptom management, and the use of rehabilitation strategies geared towards optimising functioning and achieving greater independence for adults and children of CFS/ME.*
3. **All current definitions of the illness have been rejected** and a new one has been devised that is too broad and doesn't contain the biomedical abnormalities which could help doctors distinguish ME from other illnesses with a fatigue element, as the excellent Canadian guidelines do. It acknowledges the existence of sub-groups but gives no advice on distinguishing between them. The illness definition in the patient's guide is even broader and weaker.
4. **Guidance for assessment and investigations is inadequate** and fails to mention promising and potentially useful research about SPECT scans, orthostatic intolerance, elevated choline levels, post-exertional oxidative stress etc.
5. **It fails to give sufficient weight to the experiences of patients and clinicians** familiar with neurological ME in matters of management and treatment where there is insufficient research evidence e.g. harmful exercise therapy, sensitivity to drugs, the need to sleep during the day, the value of pacing, supplements and alternative therapies
6. **CBT and GET are named as the treatments of first choice** although the research evidence does not support this. The type of Cognitive Behavioural Therapy recommended is not the same as that

used with other illnesses such as cancer and diabetes and Graded Exercise Therapy is not used for other chronic illnesses. The few studies supporting the use of CBT and GET have many problems relating to the broad diagnostic criteria, the small samples, high drop out rates in some, and the lack of long term monitoring of subjects in some. Surveys of patients have also found exercise therapies to be a major cause of relapse.

7. **The guidance relating to the severely affected is inadequate.** There is a need for more information about the severe symptoms experienced and potential management approaches. The decision to recommend parts of CBT, GET and Activity Management for this group although it is accepted that there is no research evidence to support, it is foolhardy, and could leave doctors open to legal action.
8. **Implementation in Wales would be difficult, costly and time consuming.** Unlike England there is no existing network of CFS clinics or transition guidance. Providing CBT and GET for the estimated 11,700 people with CFS and ME in Wales would be prohibitive even if sufficient trained therapists were available.

WAMES welcomes the following points:

- that the illness can be as disabling as many other chronic conditions and be a severe burden to patients and families;
- the need for early diagnosis (4 months in adult and 3 months in children) and advice on symptom management while waiting for confirmation of diagnosis;
- the post-exertional nature of the fatigue/malaise, that it is unlike everyday fatigue and can be triggered by minimal activity;
- that symptoms fluctuate in severity, may change over time, that relapses can be expected and that some may remain severely affected;
- that there is a need for health professionals to consider patient preference, the right of the patient to refuse treatment without detriment to the rest of care, and to engage in collaborative decision making;
- there is no cure and different combinations of management approaches will be helpful for different people;
- carers and relatives should have the opportunity to be involved in the decision making if the patient wishes and should also receive support and information;
- the need for the severely affected to be able to access healthcare - the need for domiciliary community services;
- the need for cooperation between adult and paediatric services and smooth transition;
- the need for good communication and information in a variety of formats;
- the role of health professionals in recommending flexible adjustments or adaptations to work or studies to help people with CFS/ME to return to them when they are ready and fit enough.
- the need for specialist diagnostic and treatment services;
- a named healthcare professional should be responsible for coordinating a patient's care;
- the need for training of healthcare professionals;
- every patient should be able to access help to develop an individualised management plan if they wish, with regular reviews;
- warns against therapists with no experience of CFS/ME and unstructured vigorous exercise (e.g. going to gym) as this may worsen symptoms;
- that patients should be given information about local and national self-help and support groups;
- there is a need for research into the cause/s and prevalence of the illness.

The NICE guideline, Quick Reference Guide, Full guideline and information for patients on 'Understanding NICE guidance' can be downloaded from www.nice.org.uk/CG053

Jan Russell enquiries@wames.org.uk
www.wames.org.uk

Secretary / Ysgrifennydd
01970 636515