



**Cymdeithas Cefnogi
ME & CFS Cymru**

**Welsh Association of
ME & CFS Support**

English CMO's report 2002: WAMES response

WAMES welcomes the publication of the report to the English CMO on CFS/ME. While the report has a number of shortcomings, we feel that it has made a creditable attempt to "bridge gaps in the understanding of CFS/ME and between concerned parties" and look for a "common ground". This can be considered a useful stage in the process of gaining much needed medical care for a neglected group of patients. We now wish to see money allocated, research instigated and health services planned.

1. SOME OF THE MAIN FINDINGS WHICH WE ENDORSE:

Nature of CFS/ME

- CFS/ME is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a very substantial impact on the individual and the family.
- Symptoms can be wide ranging but the prime indicator of the condition is the way in which symptoms behave after activity is increased beyond what the patient can tolerate. Such activity, whether physical or mental, has a characteristically delayed impact. The fatigue experienced is different to other types of fatigue and has a relapsing and remitting course over months or years.

Young People

- In children, the commonest age of onset is 13-15, but cases can occur as young as 5.
- A diagnosis in the young must be especially prompt, accurate and authoritative, and second opinions are needed if doubt exists.
- Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.
- In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court.
- It is important to listen to the child as well as to family members, to respect their experiences, and to give due weight to their views, especially the child's.

Severely Affected

- The severely affected, who may be house-bound or bed-bound, have a considerable level of need yet they face considerable barriers to accessing services.

Current medical services

- Patients and carers often encounter a lack of understanding from healthcare professionals

- It is difficult to obtain a diagnosis in a timely manner.

- There is evidence of under-provision of treatment and care, with patchy and inconsistent service delivery and planning across the country.

Proposed medical services

- Management should be undertaken as a partnership with the patient, should be adapted to their needs and circumstances, and should be applied flexibly in the light of the development of the illness.

- General Practitioners should usually be able to manage most cases in the community setting, but must be able to refer patients for specialist opinion and advice where appropriate (e.g. because of complexity in diagnosis and treatment). Training should be available.

- Sufficient tertiary level specialists in CFS/ME should be available to advise and support colleagues in primary and secondary care.

- Six months should be viewed as an endpoint for the diagnostic process, as patients will need help to manage the illness long before then.

- When a child or young person has symptoms affecting school attendance for at least four weeks, active steps should be undertaken to identify the cause from a list that includes CFS/ME.

- Ideally, services would be patient-centred, and adopt a holistic view of care. The general components of such a service are: Medical care; Support for adjustment and coping; Facilities for energy/activity management; Nursing and personal care.

- Support, care, and provision for patients' needs can be reached in their homes, by maintaining contact, and continually exploring potential options.

Research

- Overall, sufficient research evidence was lacking, and in many areas the quality of research was not optimal.

- A programme of research on all aspects of CFS/ME is required.

Benefits

- It is not appropriate that participation in a particular treatment regimen is made an absolute condition for continuation of sickness/disability payments.

2. PROBLEMS & CONTROVERSIES

The report acknowledges a number of problems and controversies that the Working Party encountered along the way, including: Criteria, Poor research, Name definition.

In spite of these controversies the report attempted to make various recommendations for treatment. Inevitably they are a compromise and include incompatible strands.

Research

WAMES is particularly concerned about the research evidence that the treatment conclusions were based on.

We believe that there is weighty research evidence for more than one sub group or possibly totally different illness groupings, which are currently gathered under the broad heading CFS/ME (or more recently ME/CFS). These include conditions that are primarily psychiatric and conditions that have organic abnormalities. All of this research was not included in the York Review, which the report is based upon. Dr Ellen Goudsmit's survey includes the missing research.

<http://freespace.virgin.net/david.axford/facts96.htm>

In addition, it would appear that the research that was surveyed was not always well assessed and that little attempt was made to compare like with like. Although acknowledging that there are different criteria for selecting patients for trials the report did not make it clear that the trials which found CBT and GET to be very helpful used a broad criteria with no attempt to exclude psychiatric conditions. The failure to mention the trials which found that GET was not helpful, and that counselling was as effective as CBT, leads to these treatments being given unwarranted prominence. Combined with patient experience of the dangers of GET in promoting relapse, especially in the early stages of the illness, we have reservations about GET as an option for patients with strict ME.

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