



**Cymdeithas Cefnogi
ME & CFS Cymru**

**Welsh Association of
ME & CFS Support**

CFS/ME and FM services in Wales: The Health Minister decides!

On 8th June the Health Minister Edwina Hart, accepted the recommendations of the CFS/ME Task & Finish Group Report, which were:

1. The Welsh Assembly Government should formally endorse the existing 'International Status' Map of Medicine Care Pathway for CFS/ME
2. The Welsh Assembly Government should task Informing Healthcare as procurer of the Map of Medicine in Wales to adapt and develop the existing 'International status' Map of Medicine care pathway for CFS/ME into a 'NHS Wales status' care pathway. This process must be led by clinicians in consultation with patient groups and supported by planners.
3. The Welsh Assembly Government should task Local Health Boards as follows:
 - With immediate effect – to develop primary, community, secondary and tertiary services in line with the existing 'International Status' Map of Medicine care pathway
 - Overtime, to develop services further in line with the proposed 'NHS Wales status' Map of Medicine care pathway and to adapt the 'NHS Wales status' care pathway at LHB level to reflect local protocols and referral pathways.
4. In recognition of the specific needs of people with or suspected of having fibromyalgia, the Welsh Assembly Government should mirror the recommendations set out above for CFS/ME separately for fibromyalgia. A separate 'NHS Wales status' care pathway can be created on Map of Medicine to reflect this.

The Task & Finish Group

The Task & Finish Group met during 2009 and early 2010 and based their deliberations on:

- a Review of the evidence for guidelines and care pathways for CFS compiled by the National Public Health Service;
- a survey of service provision in each of the Local Health Boards;
- questionnaires received from NHS stakeholders and WAMES (Welsh Association of ME & CFS Support), the ME Association, the Young ME Sufferers Trust and Cerebra;
- a presentation and Q&A session with WAMES.

The Report contains edited responses from representatives of the Local Health Boards, a WAG advisory committee, individual health professionals, the National Public Health Service and patient groups, and illustrates the lack of evidence and consensus on the appropriate assessment and treatment of patients with suspected CFS, ME and Fibromyalgia. The T&F Group has chosen to endorse a care pathway based on the psychosocial approach of the NICE guidelines. The Report can be read at <http://tiny.cc/Ofsb9>

WAMES' response

WAMES contributed 2 questionnaire responses and attended a meeting of the Task & Finish Group outlining our concerns and recommendations:

- There is no published care pathway which fully meets the needs of people with neurological ME.
- The NICE guidelines are inadequate and inaccurate – not 'fit for purpose'
- There are no existing services which cater specifically for adults, children or young people with neurological ME.
- There are no domiciliary services. Severely affected patients and those with mobility problems or who are in relapse are often even refused home visits by the GP or nurse when they are unable to attend the surgery. There are no diagnostic services.
- A new approach needs to be developed which will give early diagnosis, management advice to patients close to home and long term monitoring. It needs to be underpinned by thorough and ongoing education of the participating GPs, district and community nurses and therapists in order to avoid the current situation where incorrect diagnoses are being given, inappropriate advice is being given about rest, exercise, education etc. and accusations of abuse or neglect are still being made about parents of ill children.
- CBT and GET are neither appropriate nor cost effective treatment options how care for people with ME fits into the Chronic Conditions Model and the role that individualised management plans, GPwSI (GPs with Special Interest) and specialist neurological nurses could play.
- How the Map of Medicine could be adapted for ME.

WAMES believes that the Map of Medicine has much to recommend it and it could be modified to become a useful tool to help doctors diagnose new patients, but it has serious failings when recommending treatments and should not be used for people with neurological ME in its current form. WAMES is pleased that the Health Minister has acknowledged that the management of CFS/ME is a high priority for the NHS in Wales and that they should, as they do for other chronic diseases, "*put appropriate measures in place to ensure prompt diagnosis and appropriate treatment, care and support in the right setting by the right professional*".

We do not believe that this can be achieved by using CBT and GET as the main treatments. As no money has been provided for the development of services at a national or local level, it remains to be seen whether Local Health Boards will be able to provide the services recommended by the NICE guidelines and care pathway. We will, however, be expecting to see an improvement in the standard of care offered to the thousands of existing patients.

WAMES will continue to take part in all consultations and discussions highlighting the patient experience and biomedical research results. We will be launching a major awareness campaign in the autumn. In order to monitor how effectively services are improving we would also like to hear people's healthcare experiences.

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