

The UK National Service Framework and ME/CFS

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In 2001, during the deliberations by the Chief Medical Officer's so-called "independent" Working Group on "CFS/ME" --all drafts of which made it obvious that the only model to be countenanced was to be the psychosocial model -- Professor Malcolm Hooper et al pointed out that such a model was in contempt of the available evidence of the organic nature of the disorder and that ME/CFS was likely to be included in the then-forthcoming UK National Service Framework for chronic neurological disorders.

To support this, they quoted from a letter dated 30th May 2001 from Linda Percival at the Department of Health, who had written: "To improve services for people with long-term illnesses, the Government recently announced a National Service Framework (NSF). The NSF will have a particular focus on the needs of people with neurological disease, as well as developing generic standards of care for people with long-term/chronic illness. **It is very likely that chronic conditions such as ME/CFS will be included.** The NSF will ensure that services are better organised and more focused towards the needs of people with long term health conditions" (ref: TO 2001/15353).

Hooper et al were immediately denounced by Chris Clark, CEO of Action for ME who, on 8th June 2001 wrote to someone saying: "I had been told ME was definitely NOT to be included in the neurological NSF. If this message is true it is sensational".

Who told Clark that ME/CFS was not to be included or accepted as a neurological disorder? Was it the psychiatric lobby, with whom he closely co-operates? Was it because the psychiatric lobby would not tolerate any departure from their own well-publicised agenda to re-classify ME/CFS as a behavioural disorder?

Whatever the answer, it is immaterial, since the evidence that ME/CFS **is** included in the NSF as a chronic neurological disorder is now irrefutable.

The NSF was launched on 10th March 2005 and it sets standards of treatment, care and support across health and social services, focusing particularly on long-term neurological conditions. The Convenor of the Cambridgeshire Neurological Alliance (ME Association Trustee Diane Newman) commented at the time: "**This particular NSF focuses on neurological conditions and ME/CFS falls in that remit**" (ref: ME Essential: Issue 94: Spring 2005: page 21).

The National Service Framework for Long Term Conditions currently being developed will set out the generic standards which will benefit people with a wide range of chronic illness **including people with CFS/ME** (see:

http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/HealthAndSocialCareArticle/fs/en?CONTENT_ID=4098128&chk=bXJnLS

In case further confirmation is needed, it is provided in Hansard for 6th March 2006 (HC: Column 1200W), where the Under Secretary of State for Health, Liam Byrne MP, stated categorically: “National Health Service organisations are expected to demonstrate that they are making progress towards achieving the level of service quality described in the National Service Framework (NSF) for long-term conditions. The NSF sets out a clear vision of how health and social care organisations can improve the quality, consistency and responsiveness of their services and help improve the lives of people with neurological conditions, **including CFS/ME**”.

Nothing could be more unequivocal than Hansard, so for the avoidance of doubt, members of the ME community may wish to draw this evidence of fact to the attention of their Member of Parliament, including those MPs who are members of the Gibson Parliamentary Inquiry.