

Health Care Needs Assessment

Hot on the heels of the ‘Scottish Good Practice Statement’, a ‘Health Care Needs Assessment for People Living with ME-CFS’ (HCNA) was published. You can download a copy of this and related documents at:

http://www.scotphn.net/projects/current_projects/care_needs_for_those_experiencing_cfs_me/

(Arrangements for obtaining paper copies are unclear at time of writing – but if you would like to see the report and don’t have the on-line option please contact the office and we’ll see what we can do).

Recommendations

The range of recommendations certainly provides plenty of scope for voluntary groups representing patients to become involved in implementation. We will aim to influence this process towards the inclusion of appropriate responses to the needs of people with severe M.E. in the NHS in Scotland at all levels. However, we will have to decide on priorities since we are not a highly resourced organization. Recommendations include:-

DEFINING ME AND CFS

It is recommended that the clinical, symptomatic definition of ME outlined in the Canadian Guideline be adopted in Scotland. It is further recommended that a symptomatic definition of CFS based on that proposed in the NICE guideline be adopted in Scotland.

It is hoped that this pragmatic approach will allow clinicians to adopt an approach to diagnosis that can ensure that all those individuals for whom CFS exists are identified as rapidly as possible and also allow for more focused assessment and review to confirm a diagnosis of ME, where appropriate. This is more fully explored in the Scottish Good Practice Statement on ME-CFS (SGPS).

Comment: We discuss this potentially valuable distinction under the heading ‘What is meant by ME-CFS?’ below.

EPIDEMIOLOGY

There is an urgent need for a sound epidemiological study of ME and CFS in Scotland; in which regard consideration should be given to including ME and CFS within the Scottish Health Survey.

A PROPOSED MODEL OF CARE FOR SCOTLAND

NHS Health Boards / NHS Regional Planning Groups should prioritise the development of consultant led services, supported by a Tier 3 Multidisciplinary Team for ME-CFS.

Comment: Three ‘multi disciplinary teams’ are proposed: this would translate to one team per Regional Planning Area (West of Scotland, North of Scotland, and South East & Tayside). Unfortunately the Needs Assessment hasn’t managed to rescue M.E. from the ‘CFS’ diagnostic dustbin as the composition of the proposed teams suggests that what is envisaged is a ‘fatigue’ service.

INFRASTRUCTURE ISSUES

NHS Quality Improvement Scotland should work with all interested parties to develop service standards for ME-CFS services in Scotland. NHS Education Scotland should work with independent ME-CFS organisations to develop solutions to ME-CFS issues which would be included within education packages. These should be fed into undergraduate, foundation and professional training of health care staff across Scotland. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist's Office and a new strategy developed, aimed at broadening the evidence base for ME-CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a Centre for Research Excellence and Dissemination.

What is meant by 'ME-CFS?'

Both the Scottish GP guidance and the Needs Assessment introduce a new term to describe the disorder(s) in question. What is meant by 'ME-CFS'? Here is what the Needs Assessment has to say (our emphasis):

Any formal assessment of health care needs in relation to **Myalgic Encephalomyelitis – or Encephalopathy – (ME) and the broader spectrum of conditions that have been grouped together under the term Chronic Fatigue Syndrome (CFS)** is a challenging exercise. The cause – or causes – of ME remains the subject of ongoing research; however, it can be defined symptomatically by characteristic features that include the incapacitating exhaustion and general, debilitating illness that occurs even after minimal exertion, neurological signs, cognitive and visual impairment, pain and the very real disabilities that are associated with the condition. Historically in the UK, this has given rise commonly to linking ME with CFS under the identifier CFS/ME. However, there are some who argue **it should more usefully and appropriately be described ME-CFS, to reflect "ME and CFS"**. In the light of this, this health care needs assessment (HCNA) uses the acronym ME-CFS to reflect this distinction.

The Scottish Good Practice Statement also refers to 'ME-CFS'. However, it makes no distinction between ME and CFS:

ME-CFS is an illness characterised by persistent and fluctuating symptoms of fatigue, pain and loss of endurance to normal activities associated with conspicuous deterioration after exercise. **It has been referred to as ME (Myalgic Encephalomyelitis/Encephalitis*/Encephalopathy), CFS (Chronic Fatigue Syndrome) and sometimes as PVFS (Post Viral Fatigue Syndrome).**

**the HNCA doesn't include 'myalgic encephalitis' as a possible meaning for 'ME'*

So, on the one hand, we have the recommendation in the Needs Assessment that ME and CFS patient groups should be differentiated, with the 'Canadian' definition adopted to identify people with M.E. This could be of paramount importance for appropriate service development. At the same time, the Needs Assessment appears to vest responsibility for implementing these recommendations in the Scottish Good Practice Statement, which doesn't endorse the Canadian definition - nor any other definition, for that matter - and doesn't attempt to differentiate people with M.E. from other people who may be diagnosed with 'CFS'. So the outcome could be to solidify a sleight of hand that links all the various uses that have been made of the term 'CFS' to the illness that is 'ME' - via the term 'ME-CFS'. In short - there's work to be done if the recommendations of the Needs Assessment on defining ME and CFS are to translate into improved diagnostic practice, and improved patient care.