

Evidence Review A - Information, Education and Support for People with ME and their Families

Review Question: What information, education and support do people with ME/CFS and their families and carers need?

It is unclear how many of the many of the 15 included studies involved finding out from *patients* what their information, education, and support needs are and how they can best be met.

The papers considered relevant to this topic and to meet the criteria set for consideration appear to be heavily weighted towards publications by existing service providers. (Methodological limitations due to the role of the researcher not being discussed are considered only 'minor' in assessing quality of evidence.)

Also featuring prominently are publications by professionals who subscribed to the 'this illness is deconditioning' school of thought *i.e.* the very perspective that the GC have now recognised, in the draft guideline, is misplaced.

When reviewing pharmacological interventions a body of work has been excluded solely because recruitment did not include PEM as an essential criterion. When reviewing the evidence pertaining to this review question it would appear that no cognisance has been taken of the criteria used to diagnose (or suspect) 'ME/CFS' in the patients concerned - often patients attending an NHS clinic. This is inconsistent.

In reviewing this document, we have identified regarding Table 3 (page 17-18):

- **An instance of papers being cited that do not support the 'Main findings' listed**
Specifically, under the heading '*Support from specialists*' citing papers 15, 87, and 131 in support of "*those who ultimately were [referred to specialist services], had benefitted in ways including diagnosis, validation and information provision.*" (details of how we reached this conclusion may be found in comment number 114 from the 25% ME Group's submission to the consultation)
- **Selective Highlighting of Findings**
A fourth paper - no. 25 - was also cited in support of the above finding; this paper does provide some evidence, albeit thin, of a role or specialist services in this regard. However patients in this study advised that their general practitioner can play a valuable role; this is not recorded: indeed, the GP features not at all in summary of the qualitative evidence presented.

The 25% ME Group
Friday 26th February, 2021