

Evidence Review B - Information, Education and Support for Health and Social Care Professionals

Review Question 1: What information, education and support do health and social care professionals who provide care for people with ME/CFS need?

No issues identified.

Review Question 2: What are the barriers and facilitators to providing information, education and support for health and social care professionals?

Summary of the Qualitative Evidence: Table 7 [page 38]

A major issue emerging in respect of this section of the evidence review is straying from the topic.

Having established that there is an unmet need with regard to *Information, Education & Support for health and social care professionals* [Table 3 P18], the purpose of Table 7 [Page 38] is to summarise findings on ‘*the barriers and facilitators to providing information, education and support for health and social care professionals*’ However this Table is dominated by reports of findings pertinent to professionals providing information to and working with patients, with only 2 of the 12 ‘main findings’ listed pertaining to the subject of the Review Question. Others concern perceived barriers to health professionals providing information *to patients* or to meeting *patients’* need for information and support - i.e. the subject matter of Evidence Review A.

A tendency to assert a role for specialist services in a way that is not borne out by the evidence cited is evident here too - this overlaps with harking back to evidence relating to patients’ needs for information (i.e. the subject of Evidence Review A)

For example: “*Specialist services were seen as the best provider of information and support for people with ME/CFS, ...*” (properly the subject of evidence review A) is linked to studies 15, 24, and 37: ref. 15 concerned a GP education programme - at no point were the GPs asked what they saw as the best source of information to give to patients; neither can we find anything to support this finding in ref. 37; ref 24 looked at *patients’* views; these patients was asked to reflect on their time with a specialist service and reported that service had helped by providing info (this is same study as 25 in Evidence Review A).

Findings that rest on the flawed assumption that patients are manifesting de-conditioning or some other form of maladaptive behaviour / fundamentally psychological condition are presented without question

This is especially evident in terms of what is construed as a ‘barrier’ to professionals providing information to patients. For example: ‘Barrier - fear of negative reactions’ rests on two papers, only one of which is published. The published paper (ref. 13) is from 1999 and looked at patients’ perspectives. (So it is hard to see how it had been caught in the net of publications relevant to professionals’ requirements for information, education and support.) The authors state:

“Satisfaction with medical support, it seems, is strongly associated with beliefs about CFS, attributions as to its origin, and ways of managing it. Most sufferers believed that CFS is a predominantly physical disease for which increased rest is the most appropriate treatment, but they judged such a belief incompatible with the views expressed by many

physicians. This led to disagreements between the sufferers and their physicians and other health professionals, and to dissatisfaction with treatment and the medical establishment as a whole. ... Clearly, the uncertainties about the aetiology or chronicity of CFS strongly encourage sufferers to construct their own illness beliefs which may well lead to the adoption of inappropriate coping strategies. ...Likewise, those same uncertainties create difficulties for clinicians not only in deciding which treatments and coping strategies to recommend but also in adopting a manner that enables the patient to accept them."

The 25% ME Group
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