

Evidence Review E - Management Strategies Before Diagnosis

Review Question - What is the clinical and cost effectiveness of pre-diagnosis management strategies for people with symptoms consistent with ME/CFS but are not clinically diagnosed?

Only one study emerged for inclusion in the review in terms of clinical effectiveness, and seven in terms of cost effectiveness.

NICE therefore sent out a call for evidence. However the parameters of this were fairly strictly drawn, indeed such as not to differ markedly from the literature search already conducted;

We are looking for trials that compare different strategies or different methods of monitoring and review. Systematic reviews, randomised controlled trials, non-randomised trials that are prospective or retrospective cohort studies will be considered for inclusion in the guideline.

Predictably, nothing further came up *via* the call for evidence that was considered to meet the criteria for inclusion.

The core nugget of potential guidance that completely fails to emerge via this process is that patients have long reported that rest in the early stages is vital. Indeed, this used to be well recognised among professionals also. This theme repeatedly emerges in stakeholder comments, including on the draft scope, when several stakeholders sought to answer the proposed review questions rather than commenting on the value or otherwise of the proposed question. At this time NICE responded by indicating that the guideline in development would address this. For example, in response to a comment 'rest is best':

We have included a question on appropriate measures when ME/CFS is suspected which may include rest as you describe.

Patient feedback on this topic would be valuable, but was not sought.

The 25% ME Group

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