

Evidence Review G - non-pharmacological interventions for people with ME/CFS

Evidence Review H - Appendices for the management of ME/CFS

Review Question 1 - what is the clinical and cost effectiveness of non-pharmacological interventions for people with ME/CFS?

Regarding clinical effectiveness 74 papers covering 55 studies were included in the review. However it is not possible to get an overview on this as the Evidence Review references section stops at 110, while the studies identified as pertinent include: 111,113,115,116,119-123, 125-135, 138

Regarding cost-effectiveness, 5 studies are listed on page 192 as having been taken into account: 26, 58, 72, 90, 119. Again, number 119 is not on the references list and the coverage in the Evidence Review is inconsistent in this regard. We are advised that these are summarised in “the health economic evidence profiles below (Table 63 to Table 66)”. The studies featured in these Tables five completely different papers are as follows:

Ref 50. McCrone P, Sharpe M, Chalder T, Knapp M, Johnson AL, Goldsmith KA. *Adaptive pacing, cognitive behaviour therapy, graded exercise, and specialist medical care for chronic fatigue syndrome: A cost-effectiveness analysis*. PloS One. 2012; 41 7(8):e40808

Ref 61. O'Dowd H, Gladwell P, Rogers CA, Hollinghurst S, Gregory A. *Cognitive behavioural therapy in chronic fatigue syndrome: A randomised controlled trial of an outpatient group programme*. Health Technology Assessment. 2006; 10(37)

Refs 23. Crawley EM, Gaunt DM, Garfield K, Hollingworth W, Sterne JAC, Beasant L et al. *Clinical and cost-effectiveness of the Lightning Process in addition to specialist medical care for paediatric chronic fatigue syndrome: Randomised controlled trial*. Archives of Disease in Childhood. 2018; 103(2):155-164

Ref. 74 Richardson G, Epstein D, Chew-Graham C, Dowrick C, Bentall RP, Morriss RK et al. *Cost-effectiveness of supported self-management for CFS/ME patients in primary care*. BMC Family Practice. 2013; 14:12

Ref. 93 Vos-Vromans D, Evers S, Huijnen I, Koke A, Hitters M, Rijnders N et al. *Economic evaluation of multidisciplinary rehabilitation treatment versus cognitive behavioural therapy for patients with chronic fatigue syndrome: A randomized controlled trial*. PloS One. 2017; 12(6):e0177260

The main concern in terms of presentation of evidence in substance, as far as we can tell from the flaws in referencing, is that some review findings rest on a very narrow base, particularly in terms of CBT, and notably when considering the evidence on children and young people.

Review Question 2 - what are the experiences of people who have had interventions for ME/CFS?

In 2019 a call for evidence was made in respect of this question. NICE advised:

We are looking for evidence that explores and evaluates people's experience of interventions for ME/CFS. Qualitative studies evaluating focus groups and interviews and surveys will be considered for inclusion in the guideline.

Only 13 items were deemed to pass muster for consideration, but again it is hard to identify exactly which these are. The list provided on page 200: 3, 6, 12, 13, 27, 38, 54, 61, 67, 77, 79, 82, 101 [page 200] is not reflected in Table 68 summarising studies.¹

However, it is discouraging in the extreme to consider the evidence which was not taken on board and presented to the Guideline Committee following this call for evidence. To find the excluded items it is necessary to refer to Appendix F - 'Excluded Studies', beginning on page 626 of Evidence review H. It transpires, for example, that survey evidence is excluded on the grounds that it is not qualitative. This despite the call for evidence specifically stipulating that surveys would be considered.

This call for evidence had been signalled in advance by NICE, responding to repeated expressions of concern regarding the impact of graded exercise and cognitive behavioural therapy on patients, including expressions of concern recorded during consultations at the surveillance review and scoping stage.

For example, in response to surveillance review proposal comments, NICE advised:

Information obtained through the surveillance review, including feedback from stakeholders through this consultation, will be passed onto developers for consideration during the update of the guideline.

and the same assurance was given at the scope consultation stage, when the call for evidence was mooted:

To allow a robust analysis we also plan to review the published evidence on patient experience and conduct a call for evidence so that harms are identified and taken into account by the committee.

The (belated) strictly qualitative approach to delineating eligible evidence in connection with this call for evidence has ensured that considerable evidence of patient experience has not been taken on board.

The 25% ME Group
26th February 2021

¹ This Table also covers the 13 studies identified by NICE in this regard, separately from the call for evidence, however filtering those out still leaves anomalies.