



GET and CBT for people with M.E.

Action for M.E.'s Big Survey: two-page explainer

What are GET and CBT?

- Graded exercise therapy (GET) and Cognitive behaviour therapy (CBT) are symptom management approaches recommended by the 2007 National Institute of Health and Care Excellence (NICE) guideline for M.E./CFS (undergoing extensive review, with a new guideline expected in December 2020).
- There is much debate and discussion about these approaches – and the published evidence for them – as to whether or not they work, and whether they may cause harm.
- Our response to NICE's October 2019 call for evidence made it clear that we do not support the current guideline's view that CBT and GET "are the interventions for which there is the clearest research evidence of benefit" because of the legitimate questions raised about their safety and effectiveness.

What is M.E.?

- Myalgic Encephalomyelitis (M.E.) is a long-term, fluctuating, neurological condition affecting many body systems.
- Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or M.E./CFS is often given.
- Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time. One in four people with M.E. are severely affected, ie. house and/or bed-bound.
- People with M.E. experience debilitating pain, fatigue and a range of other symptoms linked to post-exertional malaise.

What did our Big Survey find?

- One in three (33%) respondents who completed our survey had tried GET in the past five years.
- More respondents (40%) had tried CBT in the past five years.
- See next page for more detailed results.

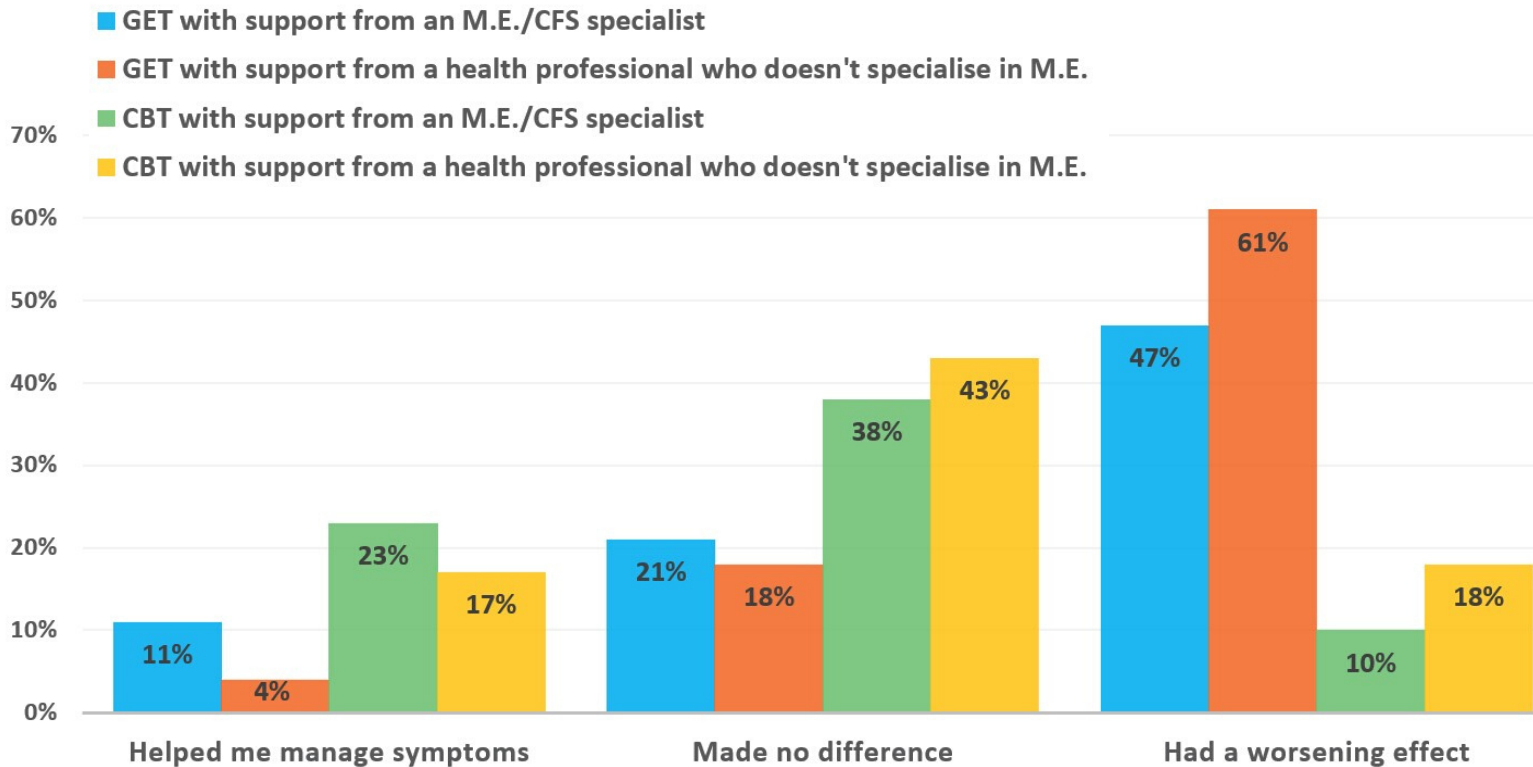
"I did CBT and found it to be very helpful with depression and anxiety caused by M.E. Both myself and the professional I was working with agreed it would be futile to try and use it to try and deal with the physical symptoms of M.E."
Male, 32, Bournemouth

"I did GET and after 3 months it left me severely affected, house-bound, bed-bound half the day and unable to have visitors. All my symptoms worsened and I have lots of new symptoms too." Female, 39, Liverpool

What is Action for M.E.'s Big Survey?

- Between May and August 2019, UK charity Action for M.E. surveyed more than 4,000 young people and adults with M.E.
- We asked about diagnosis, education and employment, health and social care, symptom management and Universal Credit.
- Nearly two thirds of respondents were 40 years or older; 5% were under 18.
- There was a ratio of one to five male to female respondents; nearly 90% had been ill for four years or more.
- 99% said they experience post-exertional malaise either always, usually or sometimes.
- 96% were White British, Irish or other. 82% of respondents were from England, 12% from Scotland, 5% from Wales and 2% from Northern Ireland.

We asked survey respondents who tried GET and CBT to select a series of statements they agreed with including:
Who supported you to try it and what effect did it have on your symptoms?



Even when people are supported by an M.E. specialist, only one in 10 reported that GET helped manage symptoms, while nearly half reported a worsening effect. CBT makes no difference in almost half of cases and had a worsening effect for one in five.

Our Big Survey showed that treatment outcomes are most likely to have a worsening effect:

- when people are supported by a healthcare professional who does not specialise in M.E.
- when people do not feel like an equal partner in their treatment
- for those respondents (almost one in four) who said that the professional they worked with did not understand how M.E. affects them.

The symptom management approach that the majority of people with M.E. consistently tell us offers them the most benefit is pacing.

Pacing is a way of carefully managing physical, mental and emotional activity and rest to avoid post-exertional malaise. Find out more at www.actionforme.org.uk/pacing

Action for M.E. takes action to end the ignorance, injustice and neglect faced by people with M.E.
 We meet need now to improve lives while taking action to secure change for the future.

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