



People with Myalgic Encephalomyelitis Show Deleterious Effects following GET and CBT

Myalgic encephalomyelitis (ME) is a neurological disease with changes in energy metabolism, immune function, and endocrine function. It is explicitly stated to not be a psychological or psychosomatic disease by the US Centers for Disease Control and the National Academies of Medicine. As a metabolic disease, it is inappropriate -- and potentially damaging -- to treat people with ME with talk therapy and exercise.

Studies show that activity may exacerbate symptoms and worsen disease course in people with ME, and that activity cannot be curative.

- **Standard biomedical studies compare people with ME to deconditioned/sedentary controls;** differences in responses to exercise persist despite similar activity levels in both groups. For example, [Vermeulen et al. \(2014\)](#) compared sedentary controls (active less than 1 hour / week) to people with ME in exercise testing. Oxygen extraction in people with ME was still found to be less than half that of these controls during activity. **These differences are still present in minor-presenting people with ME who are active as the average healthy individual** but who manage the intensity and duration of activity carefully through pacing. If people with ME with an average activity level still experience debilitating symptoms, activity cannot be curative.
- Multiple studies have shown that GET and CBT don't improve the well-being of people with ME. [Wiborg et al. \(2010\)](#) set out to show that CBT improved fatigue, but found that **people with ME experienced no change in physical functioning after CBT**. [Stordeur et al. \(2008\)](#) analysed the effectiveness of CBT and GET in the Belgian CFS Knowledge Centers. They found **no objective improvements after CBT and GET using exercise testing (VO2 max)**. They also found that **fewer people were able to work and more people were receiving illness benefits after undertaking these therapies**, implying a loss of physical functioning. Note that these two studies were reliant on objective rather than subjective data (oxygen extraction during exercise and employment status).

Numerous studies have found **paradoxical reactions to prolonged or intense activity** in people with ME, including but not limited to:

- Reduced blood flow to the brain and heart (Neary et al., 2008; Peterson et al., 1994)
- Reduced oxygen uptake in hemoglobin (Miller et al., 2015)
- Reduced oxygen use (VO₂ max) on second-day exercise testing ([Jones et al., 2012](#); [Keller, Pryor, & Giloteaux, 2014](#)) not caused by deconditioning ([Vermeulen, & Vermeulen van Eck, 2014](#)).
- Differences in oxygen use (VO₂) on two-day cardiopulmonary exercise testing in people with multiple sclerosis, people with ME, and healthy controls ([Hodges, Nielsen & Baken, 2017](#)).
- Decreased absolute heart rate recovery after single-day cardiopulmonary exercise testing was found in people with ME ([Moneghetti et al., 2018](#))
- Abnormalities on MRI – [Cook et al. \(2017\)](#) found that people with ME performed significantly worse in difficult mental tasks post-exercise; this impairment correlated to changes on fMRI. [Staud \(2018\)](#) found that, while people with ME showed no differences in cerebral perfusion (blood flow to the brain) from healthy controls at rest, they showed a significant decrease in perfusion following a strenuous task.
- [Snell et al. \(2013\)](#) found that, while a single exercise test showed no noticeable differences between CFS patients and controls, a second test performed 24 hours later showed significant abnormalities in oxygen use and how hard patients were able to work. This is known as a two-day CPET.

There are numerous metabolic, endocrine, and neurological abnormalities in people with ME. [See the research review](#) for more information: <http://bit.ly/MEActionResearchSummary>.

Recent, large-scale survey shows damage caused by graded exercise

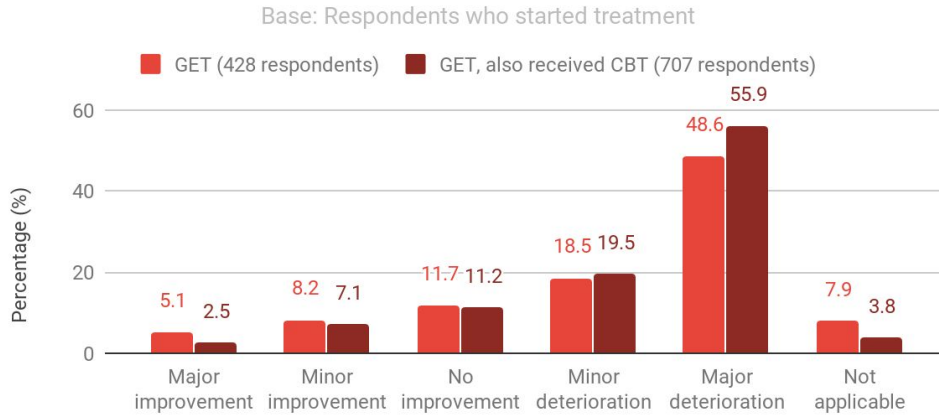
Over 2,000 people with ME responded to a recent survey of their experiences with cognitive behavioural therapy (CBT) and graded exercise therapy (GET) for myalgic encephalomyelitis/chronic fatigue syndrome (ME/cfs). Overwhelmingly, people with ME experienced harm from GET and no improvement from CBT.

To be eligible respondents needed to have a diagnosis of either ME, CFS or PVFS; and to have received or been offered CBT or GET in the UK since 2007.

98.5% of responders reported experiencing **post-exertional malaise (PEM)**. Post-exertional malaise is a **worsening of symptoms and/or the appearance of additional symptoms after physical or cognitive exertion**. The effects of PEM are not necessarily proportional to the original exertion and it may take days, weeks, or months for the person with ME to return to their previous baseline. Post-exertional malaise is not tiredness after exercise as experienced by healthy people and is characteristic enough to be considered a hallmark symptom of ME ([Carruthers et al., 2003](#); [Carruthers et al., 2011](#); [Chu et al., 2018](#)).

Following treatment, **over two thirds (67.1%) of those who underwent GET alone reported deterioration in their physical health.** Three quarters (75.4%) of those who underwent GET as well as CBT reported deterioration in physical health, and **this was a serious, major deterioration for the majority of responders.**

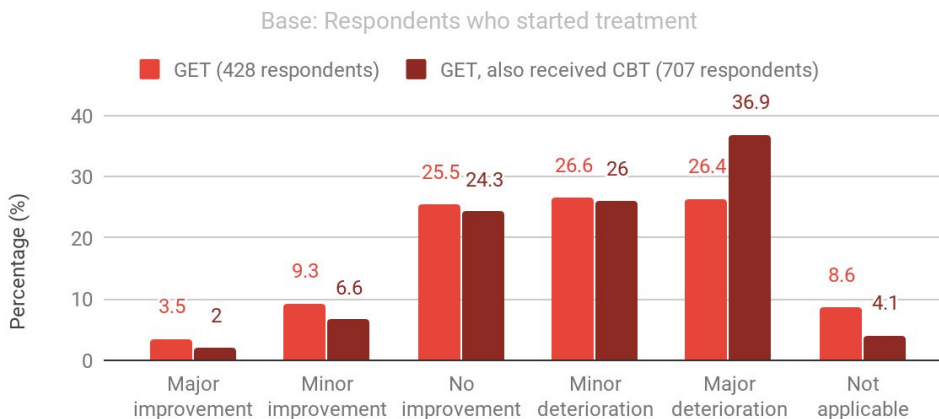
Impact of graded exercise therapy on the physical health of people with ME



Source: 2019 Forward ME Group CBT & GET Survey.

Following roughly the same pattern as impact on physical health, **a majority (53%) of those undergoing GET experienced a deterioration in their mental health.** This increased to 62.9% when the respondent had also undergone CBT.

Impact of graded exercise therapy on the mental health of people with ME

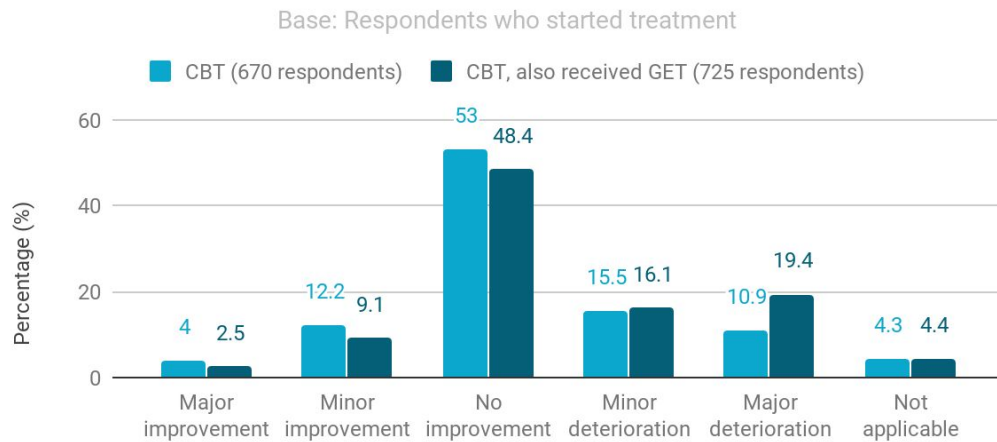


Source: 2019 Forward ME Group CBT & GET Survey.

Impact of cognitive behavioural therapy

Most respondents (53%) reported no change in their physical health after CBT. Whether or not they had received GET as well, **more respondents experienced deterioration than improvement in their physical health after CBT.**

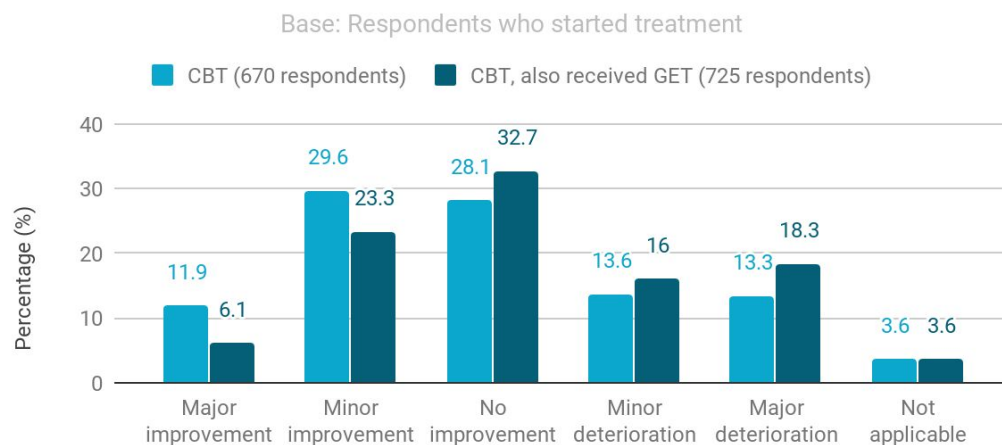
Impact of cognitive behavioural therapy on the physical health of people with ME



Source: 2019 Forward ME Group CBT & GET Survey.

For those who received CBT alone, 41.5% reported an improvement in their mental health whilst 55% reported no change (28.1%) or a deterioration (26.9%). **When GET was received as well as CBT, rates of improvement after CBT decreased significantly (26.9%).**

Impact of cognitive behavioural therapy on the mental health of people with ME



Source: 2019 Forward ME Group CBT & GET Survey.

Impact of CBT and GET on symptoms

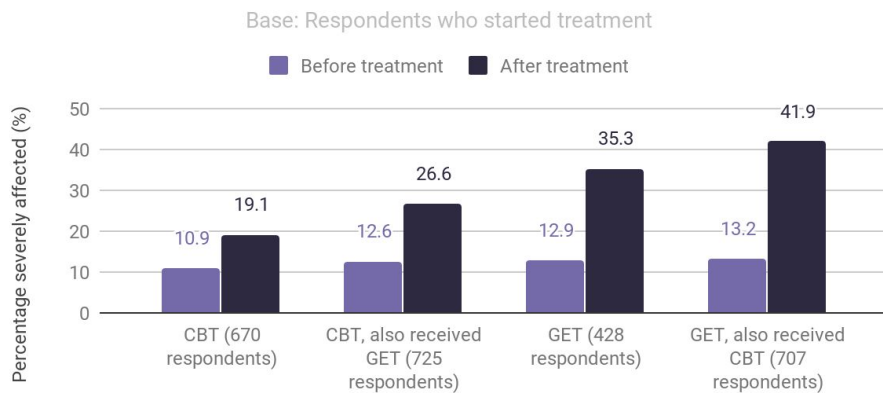
Separately to overall impact on health, respondents were asked if any of their symptoms worsened.

- **GET led to a worsening of symptoms for 81.1% of those who received GET alone and 85.9% of those who received both GET and CBT.**
- **CBT led to a worsening of symptoms for 46.6% of those who received CBT alone and 58.3% of those who received both CBT and GET.**

Severe illness

All respondents were asked to report the severity of their illness before treatment and after treatment. The precoded answers of mild, moderate and severe were defined as per the current NICE guidance (NICE, 2007b). Independent of treatment course, more respondents reported being severely affected after treatment than before. **The numbers of those reporting severe illness after GET was over three times higher in comparison to before treatment. That is, more than three times as many individuals reported severe illness after GET. After CBT, almost twice as many reported severe illness than before.**

Comparison of those accessing CBT and/or GET who are severely affected before and after treatment



Source: 2019 Forward ME Group CBT & GET Survey

If these data were attached to a drug to treat ME, it would be pulled from the shelves.

By definition, people with ME are intolerant to overexertion and experience direct harm as a result. Modern clinical practice can and must rely on evidence. Insistence on exercise and talk therapy for ME flies in the face of the available evidence and directly harms people with ME.

Read more about the current scientific research on ME: <http://bit.ly/MEActionResearchSummary>

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