

Risks of graded exercise therapy (GET)

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Introduction

Please note, the information we share about graded exercise therapy (GET) is not a recommendation.

Action for ME is very clear that, in line with the 2021 NICE guideline for ME/CFS, GET should NOT be offered as a treatment to people with ME.

The October 2021 NICE guideline for ME/CFS advises health professionals as follows (section 1.11.14):

"Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a cure for ME/CFS
- generalised physical activity or exercise programmes this includes programmes developed for healthy people or people with other illnesses
- any programme that does not follow the approach in recommendation 1.11.13 [see below] or that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy (GET)
- physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS."

What is GET?

The NICE guideline for ME/CFS defines GET as follows (page 32):

"Graded exercise therapy is a term used in varying ways by different services supporting people with ME/CFS. In this guideline, graded exercise therapy is defined as first establishing an individual's baseline of achievable exercise or physical activity, then making fixed incremental increases in the time spent being physically active.

"This definition of graded exercise therapy reflects the descriptions given in the evidence that was reviewed, and it is this approach that the guideline says should not be undertaken. An individualised approach that should be taken for people with ME/CFS who choose to undertake a physical activity or exercise programme is described in recommendations 1.11.10 to 1.11.13."

We recommend looking at sections 1.11.10 to 1.11.13 which give advice on how to ensure physical activity is personalised and led by the person with ME/CFS, the need to understand the risks and benefits, and that activity should be overseen by a physiotherapist in a specialist ME/CFS team.

The NICE guideline recommend that patients manage their activities to stay within their "energy envelope" to prevent crashes and possible long-term worsening from post-exertional malaise, i.e. pacing.

Action for ME's physiotherapists take a holistic, individualised approach to help people stay within energy limitations.

This is the symptom management approach that the majority of people with ME consistently tell us offers them the most benefit.

Why was GET removed from the **NICE** guideline?

In its comprehensive evidence review for the updated 2021 guideline, the NICE guideline committee reports (page 368):

"Evidence from 12 randomised controlled trials were identified for graded exercise therapy. Six studies compared graded exercise therapy to usual care, two studies to flexibility/relaxation, and single studies compared graded exercise therapy to heart rate variability feedback, adaptive pacing, intermittent exercise, and activity dairies.

"The quality of the evidence ranged from low to very low quality. No evidence was identified for mortality, care needs and impact on families and carers. The severity of ME/CFS was mixed or unclear in all of the studies and one study included young people and adults."

One of the studies they looked at was the 2011 PACE trial - see more on this below.

Regarding other types of exercise interventions, the review continues: "Evidence from 3 randomised controlled trials compared types of exercise (intermittent exercise, orthostatic training and gigong) to non-active controls (usual care, sham, no treatment) and 1 randomised controlled trial compared anaerobic activity therapy to cognitive therapy or relaxation.

"The quality of the evidence was very low quality. No evidence was identified for mortality, cognitive function, psychological status, pain, sleep quality, treatmentrelated adverse events, activity levels, care needs and impact on families and carers."

The PACE trial

The results of a large-scale study published in 2011, of adaptive pacing therapy, GET and CBT, called the PACE trial, found that some people with mild or moderate ME experienced a small degree of improvement after undertaking CBT and GET, and no significant improvement after adaptive pacing therapy.

However, the PACE trial was based on a flawed hypothesis that ME "was largely being maintained by abnormal illness beliefs and behaviours, along with inactivity and deconditioning" (Shepherd, 2017).

Repeated questions have been raised about the methodology of this trial, and the reliability of its results, including potential harm caused by GET.



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