



Hope 4 ME & Fibro Northern Ireland
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FAO: Health Care Professionals

Please note the following when considering advising "exercise" for ME & fibromyalgia* patients:

1. NICE guidelines for CFS/ME include using a heart-rate monitor to keep exertion levels to within a range of 50-70% of age-calculated maximum heart rate. Patients who have monitored their heart rate often report that even gently-paced activities of daily life can be enough to exceed this threshold. Thus, the conventional understanding of the word "exercise" is inappropriate.

<https://www.nice.org.uk/guidance/cg53/chapter/1-Guidance> (See section 1.6.2.19.)

Further thoughts from one of our Trustees here:

<http://www.slideshare.net/SallyBurch/heart-rate-monitoring-and-nice-guideline-for-me>

2. Patient surveys demonstrate that graded exercise therapy (GET) can be harmful: The ME Association survey from 2015 shows that 74% of patients doing GET report a worsening of their symptoms. Some of the anecdotal stories at the end the survey make harrowing reading. E.g. "GET made me significantly worse. Before I didn't use a wheelchair, now I use one full time. It caused harm." Thus, the risks of giving exercise advice need to be carefully considered.

Survey can be downloaded here:

<http://www.meassociation.org.uk/2015/05/23959/>

3. The PACE trial, which has been used to underpin GET as a recommended treatment, has now been academically challenged, and a re-analysis of the PACE data using the original protocols has shown that both GET and CBT are ineffective.

<http://www.virology.ws/wp-content/uploads/2016/09/preliminary-analysis.pdf>

4. Questions have also been raised in Parliament about possible fraud with regards to the PACE trial. Seven questions relating ME (or CFS) were asked by Kelvin Hopkins MP in November 2016.

Shortened link directly to questions here:

<http://tiny.cc/gjp9qy>

The NICE guidelines for ME are coming up for review in 2017. We sincerely hope that GET will at last be removed from NICE recommendations, and that CBT will no longer be used to promote increased activity to this vulnerable patient group. In our experience, patients who rest, and carefully pace their activities, have the fewest long-term health problems.

Trustees for Hope 4 ME & Fibro Northern Ireland.

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*We include fibromyalgia in this note of caution because of the significant symptom overlap between ME and fibromyalgia, and our concern that some patients diagnosed with fibromyalgia may also have ME.