



25% M.E. Group

Support for Severe M.E.

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<https://25megroup.org/about-us>

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We are **25% ME Group Charity**, the only charity concerned specifically with the needs of those **most severely affected by ME**: being formed 25 years ago and having a wealth of experience. As such we are generally seen as **an authority on Severe ME** <https://25megroup.org/me>. We are active in campaigning for better diagnosis, treatment and care of people with Severe ME, for example we are a stakeholder in the NICE review, we support the use of ICC, we undertake surveys about various aspects of Severe ME, we disseminate information, etc, and we are a respected voice for people who are the most affected by ME are writing to you about NICE Graded exercise therapy guidelines for ME

In the light of NICE guidance to post Covid 19 patients regarding exercise we feel that NICE should not delay any further regarding its guidelines for ME and should remove any advice regarding GET immediately. Too many people have suffered already. We believe NICE must act now to prevent any more harm to the ME patient community

Please act NOW. Please give us something to celebrate on **8 August – Severe ME Awareness and Remembrance Day**. We would be delighted (and so very relieved) if you **remove any advice regarding exercise and GET from your ME Guidance**.

Many of our members were **made more ill by undertaking GET** (a staggering **86% of those surveyed were made worse by GET** and 41% were made worse by CBT) this information has already been submitted to NICE on your call for evidence forms submitted last year. It is well known that the GET advice was based on the severely flawed PACE trials.

We feel we should point out that it is not ok to claim that patients can refuse treatments. Patients are not usually aware of this. They consult their doctors and put their trust in those doctors. The doctors, in their turn, are not aware of this. They put their trust in NICE guidelines, but they often miss the small print

In 2017, after years of resisting pleas from patients, advocates, and clinicians, the American CDC quietly dropped the treatment recommendations from its website. This change represents a major victory for the patient community — and for science.

Patients with the debilitating disease Myalgic Encephalomyelitis can't miraculously improve by exercising.

Exercise and psychotherapy might sound like the most benign of recommendations. But the hallmark symptom of Myalgic Encephalomyelitis is that overexertion triggers relapses that can leave patients much sicker, as pointed out in the International Consensus Criteria (ICC-2011) and the ICPrimer of 2012. In fact a steady increase in activity can easily trigger a complex neurological central nervous system into an exacerbation of dysfunctions though out neurological, immunological, gastrointestinal, cardiovascular and musculoskeletal issues along with severe forms of paresis, seizures, intractable savage headaches and life threatening complications.

The theory underlying the two discarded treatments arose in earlier decades when the medical and scientific communities largely dismissed the devastating illness as illusory or psychological. According to that misguided theory, such patients harbor mistaken beliefs that they suffer from an actual physical disease. As a result, they remain sedentary out of a misguided fear that activity will make them worse. They then develop severe deconditioning, perpetuating their symptoms.

Not only has the science always been available to prove the permanent damage caused by treating a biophysical disease with psychological therapy, but the patients themselves have spoken, cried and pleaded for help until the only way out of enforced exercise was suicide. It's time to listen to the patients.

NICE has demonstrated that it is capable of acting quickly and decisively to prevent further harm to post Covid 19 patients which could be caused by exercise. **We applaud that NICE acted quickly and decisively in that regard.** We now ask NICE to act equally quickly to prevent any further unnecessary harm to ME sufferers. Please remove recommendations for GET from your ME guidelines now.

Thank you for caring

Simon Lawrence
Chair