



25% M.E. Group

Support for Severe M.E.

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

25% ME Group stance on exercise

We are the **25% ME Group Charity**, the only charity concerned specifically with the needs of those most **severely affected by myalgic encephalomyelitis (ME)**. We were formed 25 years ago and have a wealth of experience. As such we are generally seen as **an authority on severe 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 International Consensus Criteria (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**. [1]

We are extremely concerned that some medical/care professionals and sports/exercise specialists **are still recommending exercise programmes and/or graded exercise therapy (GET) to people who suffer from ME** without even adding very prominent warnings about **the harm that exercise can cause to ME sufferers - especially those with severe ME**

Many patients, ME charities (including ourselves), and some dedicated researchers have campaigned to highlight how **exercise has made many ME sufferers many times worse**. As one of our members says, "I was originally mild/moderate and struggled to work part time. My doctor recommended pushing myself more and suggested I undertake an exercise programme. The gym manager said he understood my condition, and said he knew how to design a programme for me. His life no doubt continued as normal afterwards. My doctor's life also continued as normal. But my life was destroyed. The **post exertional neuro-immune exhaustion (PENE** - sometimes referred to as **PEM** - post exertional malaise) - was unbelievable. I felt like I'd been in a car crash. I **never recovered from that exercise programme**. I was ill before but I was able to work part time. After the "carefully thought out" exercise programme I was unable to work, unable to care for myself: I needed carers to help with my daily living needs".

Why did her doctor get it so wrong? Sadly, she is not alone, yet health, medical, care, and exercise professionals still all-too-often encourage/pressure people with ME to follow exercise programmes.

We believe that professionals who claim knowledge of ME should check their understanding. ME is a World Health Organisation (WHO) classified neurological disease with multi-system dysfunction and yet **too many people still wrongly believe that it is a psychological illness**. Indeed in one small study at a UK training event for doctors only 27%

reported having had formal teaching on ME; 89% believed ME to be in part psychological or psychomatic, instead of the devastating physical illness that it really is. [2]

Correct diagnosis is vital. To avoid confusing ME with the many illnesses where fatigue is a symptom, **25% ME Group recommended the use of ICC to diagnose ME.** To diagnose ME a very detailed primer for medical professionals has been drawn up by a panel of respected experts to help understand and diagnose the illness. [3]. **According to ICC guidelines PENE is a prerequisite of ME.** Some others talk of PEM. Patients often describe getting “**payback**” **from undertaking activity, often with a delayed onset.** This payback can last days, weeks, or longer. Our members have found that pushing themselves into a payback situation can lead to **permanent deterioration in their health.** 86% of members of 25% ME Group who responded to our questions about exercise told us that graded exercise made their condition worse. [4]

Here are some of the research findings which show the harm caused by exercise to people who suffer from ME:

- ❖ The **exertion intolerance** suffered by people suffering from ME have been measured using a procedure **2-day Cardio Pulmonary Exercise Testing (2-day CPET)** which illustrate how people with ME have delayed recovery compared to control groups [5]. (People with severe ME are advised not to undertake this test as it may be too harmful to their health).
- ❖ **Muscle function** of ME sufferers has also been studied and it has been found that muscle recovery is greatly delayed following seemingly trivial tasks, caused by an impaired oxygen uptake by the muscle cells or their mitochondria. [6]
- ❖ **GET** doesn't restore the ability to work in ME/CFS. Rethinking of a Cochrane review. When researchers reviewed the amended Cochrane exercise review they found that: *“GET not only fails to objectively improve function significantly or to restore the ability to work, but it is also detrimental to the health of ≥50% of patients, according to a multitude of patient surveys. Consequently, it should not be recommended.”* [7]

25% ME Group is extremely concerned about people recommending exercise programmes to people with ME. We would expect any exercise professional who claims to have sufficient knowledge of ME to recommend a particular exercise programme to be aware of these issues and to draw the ME sufferer's attention to them so that they can make an informed decision regarding the potential risks. We have included end-notes so that readers can view the full details of the information we have mentioned.

Jan Johnson
August 2020

ABBREVIATIONS

CPET cardio pulmonary exercise testing

GET graded exercise therapy

ICC international consensus criteria

ME myalgic encephalomyelitis

PEM post-exertional malaise

PENE post exertional neuro-immune exhaustion

WHO World Health Organisation

BIBLIOGRAPHY

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

[2]. <https://drive.google.com/file/d/1R6MgsNuEjdj1fsfJds5bJ2MAACSogOXn/view?usp=drivesdk>

[3]. <http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf>

[4]. <https://25megroup.org/download/1796/?v=3065>

[5]. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6131594/>

[6]. https://www.researchgate.net/profile/Mark_Vink/publication/282133390_The_Aerobic_Energy_Production_and_the_Lactic_Acid_Excretion_are_both_Impeded_in_Myalgic_EncephalomyelitisChronic_Fatigue_Syndrome/links/5604342508aea25fce30bd1d/The-Aerobic-Energy-Production-and-the-Lactic-Acid-Excretion-are-both-Impeded-in-Myalgic-Encephalomyelitis-Chronic-Fatigue-Syndrome.pdf?origin=publication_detail

[7]. <https://content.iospress.com/articles/work/wor203174>