



PEM Template

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1. What is PEM/PENE/PESE?

There is one condition that has 3 acronyms that it is vital that HCPs are familiar with when treating Long Covid and ME/CFS patients.

PEM - Post Exertional Malaise

PENE- Post Exertional Neuroimmune Exhaustion

PESE -Post Exertional Symptom Exacerbation

Research shows that up to 89% of Long Covid patients have PEM and it is one of the most prominent symptoms reported anecdotally in the Long Covid community. It is also devastating and can lead to profound lack of functional ability in patients. It is important to realise that Exertion does not just mean exercise or activity - it can be any exertion, like sitting up, reading or sensorily engaging with the world.

Within the scientific literature that studies PEM in ME/CFS we can see measurable negative effects on the body that lead to a deterioration of health. These include patient abnormalities in endogenous pain inhibition (Meeus et al., 2010); cognitive functioning (Blackwood et al., 1998); altered immune response; altered gene expression (Light et al., 2012); & affected microbiome (Shukla et al., 2015). An excellent and comprehensive examination of PEM can be found on the [MePedia](#) site which is important reading.

It is also important to listen to patient testimony on the effects of PEM. It is unlike what most people have ever experienced and goes far beyond the normal experience of tiredness, fatigue, or malaise. It is more like a multi-system body shut down on intense suffering that can lead to a permanent worsening of symptoms and disability. This is what you are risking by going ahead with this study.

Testimony from Exercise and Rehab programs in Germany (Treat Long Covid [[@TreatLongCovid](#)], 2022)

“Max, 27 years old Symptoms: Fatigue, PEM, sleep disorders, brain fog ... Therapy: Swimming and long walks
Result: Bedridden and no longer able to use his smartphone.

Bettina, 35 years old Symptoms: Fatigue, PEM, muscle twitching, headache. Therapy: Walking with weights on her feet
Result: Housebound and unable to care for her kids

Rob, 24 years old Symptoms: Muscle pain, fatigue, PEM, sleep disturbances Therapy: Running on a treadmill
Result: Bed bound and unable to communicate via smartphone.”



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Many won't even know what PEM is due to the lack of medical education or public awareness. Stating that the patient can stop at any time and even adopting a collaborative approach where the patient is in 'control' is strewn with difficulties and risk; the patient might be unaware of PEM, PEM is notoriously difficult to predict and can be variable, there is no effective and easy way to monitor the risk zone of when the patient enters PEM, by its very nature the effect is delayed so there are not always immediate physical signals as the deterioration comes 24, 48 or even weeks later.

2. Importance of familiarity of the relevant scientific literature in Long Covid and ME/CFS

So we have established that a significant subset of Long Covid patients experience PEM (89%) & that exercise can be harmful (74%). It is therefore vital that the Clinicians, Physiotherapists and Consultants treating those with Long

Covid are familiar with the recent and historical scientific literature of the use of exercise as a treatment in Long Covid and in the other disease that has PEM – ME/CFS.

It is becoming apparent in the Long Covid Scientific literature that there is a significant crossover of Long Covid with ME/CFS. Multiple sources are confirming that c. 50% of those with Long Covid are meeting the criteria for ME/CFS: 46 % in the Mancini paper (Mancini et al., 2021); 50% in a German study (Kedor et al., 2021); 50% in a study in the Journal of Translational Medicine (Haffke et al., 2022) and 58.7% met the PEM scoring thresholds used in people living with ME/CFS in a study released in April 2022 (Twomey et al., 2022). Therefore, it is imperative to understand that a significant subset of the Long Covid study will meet an ME/CFS diagnosis. We know the historical harm that giving exercise to ME has and this must be considered.

Firstly in Long Covid a key paper that addresses these concerns of Exercise therapy is: 'Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome'. (Décary et al., 2021)

"We observed a growing number of patients with long COVID who experienced adverse effects from exercise therapy and symptoms strikingly similar to those of myalgic encephalomyelitis (ME). Community-based physical therapists, including those in private practice, unaware of safety issues, are preparing to help an influx of patients with long COVID. In this editorial, we expose growing concerns about long COVID and ME...Clinicians may be promoting a dangerous message that could lead people with long COVID down a path of endless cycles of overexertion and relapse"

Another key read is: "The evidence base for physiotherapy in myalgic encephalomyelitis/chronic fatigue syndrome when considering post-exertional malaise: a systematic review and narrative synthesis' (Wormgoor & Rodenburg, 2021) This collates and critiques the field for physiotherapy interventions when PEM is involved and the issues of what criteria (Oxford, Fukuda, IOM/NAM, ICC, Canadian) is used to define MECFS. Any positive intervention effects were diminished significantly when the criteria became more specific and included PEM.

"Conclusion Currently, there is no scientific evidence when it comes to effective physiotherapy for ME patients. Applying treatment that seems effective for CF or CFS patients may have adverse consequences for ME patients and should be avoided."

Recently before the current MECFS Guideline change NICE formed a committee to conduct a rigorous and thorough review (*Evidence-Review-7.Pdf*, n.d.) (*No More Mr NICE Guy... - The Science Bit*, n.d.) of the research in favour of the findings for exercise therapy and CBT for MECFS. There were 64 Exercise studies for MECFS and they were all ranked of a 'low' (19%) or 'very low' (81%) research status. This shows that in the recent and historical research literature there is not sufficient evidence to claim that exercise is effective in helping a disorder that has PEM –



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MECFS. In light of this exercise as a treatment has been dropped from the new MECFS NICE Guidelines. (*Overview | Myalgic Encephalomyelitis (or Encephalopathy)/Chronic Fatigue Syndrome*, n.d.)

In summary, upon an adequate review of the literature ([summary](#) provided) regarding PEM, Long Covid, ME/CFS and exercise therapy it is very clear that exercise leads to measurable physical abnormalities, is harmful to the patient and there is no reliable evidence that exercise is a beneficial treatment. This has been attempted to be proven for decades and still there is no scientific evidence or patient testimony. It is an old, outdated paradigm that needs to be abandoned for the sake of patients and researchers' reputation.

“If anyone deserves an apology it is the people with ME/CFS, many of whom have experienced years of being told that their symptoms are “all in the mind” and given no meaningful medical management – mainly as a result /of the dominance of the psychosocial model of causation. As a result, progress involving biomedical research into the underlying cause of ME/CFS has been severely hampered.” (*Charities, Patients and Researchers Are All Working Together to Find the Cause and Effective Treatments for ME/CFS*, 2022)

It is important to note that the WHO Guidelines for the ‘Clinical Management Covid 19 Patients’ (*MAG/Capp - Making GRADE the Irresistible Choice - Guidelines and Evidence Summaries*, n.d.) it has very clear guidance for patients with PEM/PESE:

“For the clinical rehabilitation management of PESE in adults with post COVID-19 condition we suggest using education and skills training on energy conservation techniques such as pacing approaches. The provision and training in the use of assistive products and environmental modifications may be useful for people experiencing moderate to severe PESE”

And with fatigue:

“For the clinical rehabilitation management of fatigue in adults with post COVID-19 condition we suggest using a combination of education, skills-training on energy conservation techniques such as pacing approaches and, in the absence of PESE, a cautious return to symptom-titrated physical exercise training”

Therefore this clarifies that energy conservation techniques are paramount and that physical exercise should not be given.