

GUIDANCE ON POST-EXERTIONAL MALAISE (PEM) FOR CLINICIANS

WHAT IS IT? AND WHAT DOES IT MEAN FOR CLINICAL PRACTICE?

PEM is a defining feature of ME. The term was first recorded in 1994 but the phenomenon itself and its importance have been recognised since at least the 1950s. Sometimes the term Post-Exertional Neuro-immune Exhaustion (PENE) is also used.

PEM is an abnormal physiological response to normal activity. It presents as a significant and prolonged worsening of baseline ME symptoms, and as a reduction in the ability to function. Patients feel sicker, not just more fatigued. The impact of PEM can be reduced by careful pacing of activity.

WHY IS PEM IMPORTANT?

- ▶ Recent diagnostic criteria recommend no diagnosis of ME be made unless PEM is present.**
- ▶ The presence of PEM can help distinguish ME from other conditions presenting with fatigue such as idiopathic chronic fatigue, MS, and Major Depressive Disorder.
- ▶ Commonly prescribed exercise treatments for fatigue are contraindicated in patients with PEM.
- ▶ Patients severely affected by PEM may be unable to access health care and other services unless special accommodations are made for them.

** Note that some older criteria do not require PEM and select a different patient population.

THIS INFORMATION SHEET CONCERNS ME PATIENTS WHO EXPERIENCE PEM.

Disclaimer: The information in this pamphlet is not a substitute for medical advice.
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Also available to read online at www.m.e.awareness.nz/guidance-on-pem-for-clinicians

RECOGNISING PEM

PEM is an abnormal response to minimal exertion of any type. There are as yet no diagnostic tools that can differentiate reliably between PEM and other forms of exertion intolerance, and there is symptom overlap with other conditions. However, in many illnesses such as depression symptoms improve with exercise rather than worsen. Other conditions such as cardiovascular disease, overtraining syndrome, or delayed onset muscle soreness can be distinguished from PEM by paying careful attention to all three of the following questions in conjunction.

1 **Symptoms** : Ask about the type, range and severity of symptoms.

PEM has a wider range of symptoms than other forms of exertion intolerance (EI). While some common EI symptoms such as breathlessness or fatigue may be present, PEM also includes symptoms not usually associated with EI, such as sore throats, sleep problems, orthostatic intolerance, cognitive dysfunction, and more.

An individual patient's PEM symptom complex usually combines a worsening of baseline symptoms with additional symptoms only perceptible during PEM.

Functional ability may be significantly reduced during PEM and may leave severe patients bedbound and requiring care.

Significantly reduced stamina following exertion is a hallmark of PEM. ME studies consistently find an objective, measurable inability to reproduce a physical effort on day 2 of a repeat CPET. This finding distinguishes ME from deconditioning and some other conditions in the research setting, and it can demonstrate the presence of PEM. However, it remains to be elucidated to what degree the CPET findings reflect cause or consequence of PEM.

2 **Timing** : Ask about the timing of symptoms.

Symptoms starting and/or peaking during or directly following exertion, and which resolve within hours, are suggestive of EI.

Symptoms starting and/or peaking after significant delay - hours to days - and which take days to weeks (or even longer!) to resolve, are suggestive of PEM.

Tolerating an activity once but not on consecutive days is suggestive of PEM.

Note that the delayed onset of PEM means many patients may not have made the connection between symptom increase and preceding trigger - and some patients may be overdoing it to such an extent they are permanently in PEM.

3 Triggers : Ask about the types, range, intensity and frequency of triggers

PEM triggers include physical, cognitive and orthostatic exertion and, sometimes, strong emotions, excessive sensory input and environmental stressors.

Individual thresholds beyond which exertion provokes PEM vary greatly, can be very low and can be crossed by basic activities of daily living such as bathing, reading or talking. Severity of symptoms is often grossly out-of-proportion to the trigger.

Also, activities tolerated individually can cumulatively provoke PEM if too many are attempted at once and/or with insufficient rest between them.

Patients may not have made the connection between their symptoms and a preceding trigger as it is counter-intuitive that such minimal and varied triggers could have such disproportionate effects.

How to SUPPORT patients & minimise harm

A medical consultation exposes patients to several PEM triggers at once. To minimise harm from PEM:

- Consider home visits (especially for more severely affected patients).
- Offer a quiet, low-lit room with a bed for the patient to wait; ask the patient what other accommodations would be helpful.
- Keep appointments short and focussed on essential physical examinations - prepare and/or follow up by email.
- Because of PEM, standard exercise advice (e.g. for pain, sleep or mood) is contraindicated in ME. Instead, support the patient's efforts to pace their energy during the consultation. Refer to our Explanation of PEM for pwME and The Art and Science of Pacing resources.
- Document the patient's PEM for other service agencies.



The delayed onset of PEM can make the illness "invisible"; patients may appear relatively well in the clinic but suffer PEM - unseen - afterwards.

Research into the long-term effects of PEM is lacking. There is, however, some evidence that Graded Exercise Therapy not only causes PEM and significant short-term distress, but that it may also lead to long-lasting, possibly even permanent, PEM symptom exacerbation and a reduction in function and quality of life.

Resources

- **Medscape article:** Postexertion 'Crash,' not Fatigue per se, Marks Syndrome by Miriam E. Tucker (2016) www.medscape.com/viewarticle/871482
- **Dialogues for ME/CFS videos** (5-15 minutes) introducing ME, PEM and the problems with GET <http://www.dialogues-mecfs.co.uk/videos>
- **Video animation on ME and PEM** (3 minutes) provides insight into PEM and how it impacts the lives of those living with ME. www.youtube.com/watch?v=TGIo1v7KVJQ
- **Extensive resources on physical therapy** - what is useful and what is harmful: Workwell Foundation <https://workwellfoundation.org/resources>
- **Patient survey on the harms of overexertion:** NICE Patient Survey Outcomes CBT and GET <https://www.meassociation.org.uk/wp-content/uploads/NICE-Patient-Survey-Outcomes-CBT-and-GET-Final-Consolidated-Report-03.04.19.pdf>
 - Summary of results also discussed here: ME Action summary of survey results www.meaction.net/2019/04/03/get-and-cbt-are-not-safe-for-me-summary-of-survey-results
- **Journal article:** Friedberg, F., Sunnquist, M. & Nacul, L. Rethinking the Standard of Care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *J GEN INTERN MED* (2019). <https://doi.org/10.1007/s11606-019-05375-y>

Sources

- Chu L, Valencia IJ, Garvert DW, Montoya JG. (2018). Deconstructing post-exertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: A patient-centered, cross-sectional survey. *PLoS One*. 13(6):e0197811. www.ncbi.nlm.nih.gov/pmc/articles/PMC5983853
- Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Redefining an Illness, Washington (DC): National Academies Press (US); 2015 Feb 10.
 - Full report: www.ncbi.nlm.nih.gov/books/NBK274235
 - PEM section: www.ncbi.nlm.nih.gov/books/NBK284902/#sec_073



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M.E. Awareness NZ is a national collective of People with ME and our carers and supporters. We exist to increase awareness of this debilitating disease and to improve the lives of those affected by it.



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