PACING FOR PEM/PESE

Pacing for a dysfunctional metabolic system (e.g., ME/CFS and Long COVID (LC)) is a lifestyle strategy for managing exertion and recovery. It is more nuanced than traditional approaches for energy conservation and modifications as compared to other patient populations.

Successful pacing considers the multifaceted impacts of physical, cognitive, orthostatic, sensory, and the often neglected emotional domain. It must account for exertion prior to the task, during the task, and post-task. Pacing must be preemptively used to prevent dangerous energy expenditure.

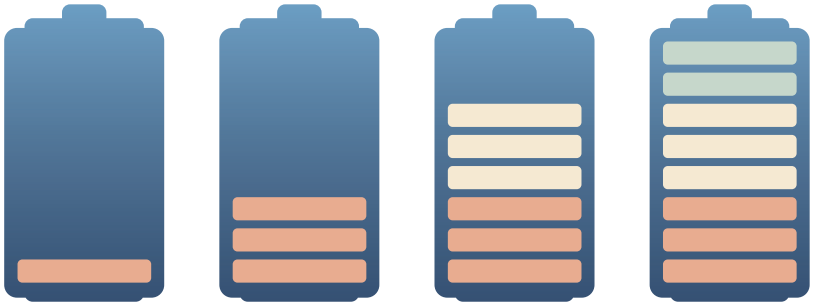
People with ME/CFS and LC have a premature ventilatory anaerobic threshold as identified on 2-day CPET (Cardiopulmonary Exercise Testing) which can further decrease post-exertion. In other words, these patients use the lactic acid system with minimal exertion or activity, and on "crash days", it takes even less effort before they move into the lactic acid system with activity. Pacing interrupts the push-crash cycle and protects against PEM/PESE.

REST

Resting is the single most important pacing strategy and mitigates further cellular damage.

BROKEN BATTERY METAPHOR

The energy systems in ME/CFS and LC are like a battery which never fully charges and drains very quickly. The body doesn't properly generate energy at a cellular level.



This impacts how much exertion people with ME/CFS and LC can tolerate on a daily basis. Patients may struggle with pacing due to personal, cultural or environmental expectations around pushing/striving, completion compulsion, perfectionism, grieving, etc.

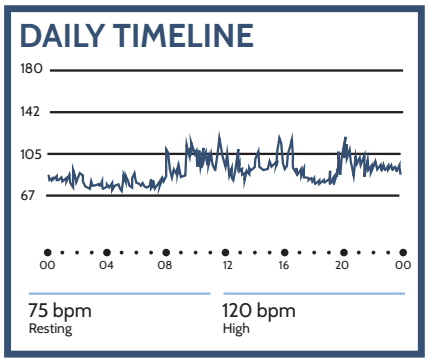
PACING FOR PEM/PESE

ME/CFS and LC exist on a severity scale from mild to very severe. It is critical to identify the individual's threshold and recharge rate before developing a plan of care. Any plan of care will continually evolve or adjust based on patient reports, symptom logs, and observation. The severity scale will dictate the appropriate exertion level.

The therapist should educate the patient and care providers to never fully drain the battery. Agreement between the patient, care providers, and therapist is essential to establish a safe and patient-centered treatment plan.

HEART RATE BIOFEEDBACK PACING (HRBP)

- Changes in heart rate can be a vital early warning sign to indicate when a patient has gone beyond their energy threshold. Early detection limits the PEM payback and can help the patient recognize the physical cues, prompting rest and behavior change.
- This provides objective and measurable feedback to encourage pacing (i.e., keeping the patient below the estimated/or known ventilatory anaerobic threshold).
- Workwell Foundation How To HRBP Guide



Optimally, the clinician will educate about RPE (rate of perceived exertion), symptom log, and Workwell PEM Timecourse to develop a customized heart rate biofeedback strategy.

Co-authored by professional ME/CFS rehabilitation clinicians.