



# Whispers vs. Screams:

## Listening with Heart Rate Biofeedback Pacing for ME/CFS




 created by Sallie Rediske, MPT & Melinda Maxwell, PT MA

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### Post-exertional Malaise (PEM) Timecourse for ME/CFS

**What is Post-exertional Malaise Following Physical Activity?**  
 Post-exertional malaise (PEM) is considered the hallmark clinical feature of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). PEM is the worsening of symptoms and decreased function following physical, cognitive, or emotional effort. The onset may occur immediately after activity or be delayed.<sup>1,2</sup> Immediate, short-term and long-term PEM symptoms following physical activity can be explained in terms of the damaged energy systems found in ME/CFS.<sup>3,4,5</sup> Overload in other areas (cognitive, emotional, sensory, upright posture, etc) can also cause immediate and longer-term symptoms, but responses to these stressors are less well documented in the literature.<sup>6</sup>

**PEM Timecourse**

**Immediate**

Symptoms after physical activity are the direct result of exceeding the anaerobic threshold. Examples include fatigue, out of breath, dizziness and nausea. For healthy individuals, immediate symptoms from exercise stress resolve quickly but for people with ME/CFS they begin to worsen.<sup>7</sup>

**Short-term**

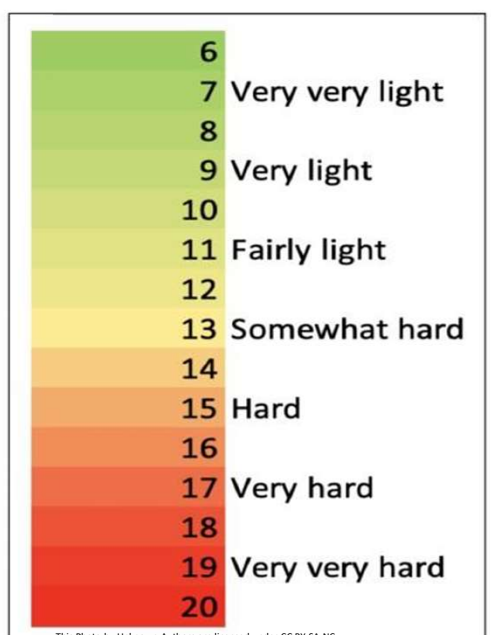
Lasts 2-4 days and reflects "overdoing activities" that exceed the anaerobic threshold for an extended period or multiple times per day exhausting the ability of the body to supply daily energy needs.<sup>8</sup> Symptoms of short-term PEM include muscle/joint pain, brain fog, headache and sleep disturbance. These symptoms reflect dysfunctional neurological and cardiopulmonary responses.<sup>9</sup>

**Long-term**


Lasts 7 days or more and reflects a sustained immune response consistent with a damaged aerobic energy system.<sup>4,9</sup> Signs may include weakness, a decrease in function, flu-like and cardiopulmonary symptoms.<sup>10,11</sup>

**Identifying PEM After Activity**  
 1. Do you experience severe fatigue with at least 3 symptoms in the categories below?  
 a. feel unwell b. feel weak c. don't sleep well d. have pain  
 2. Does it take a day or more to recover from exertion?<sup>10,11</sup>

**Preventing PEM**  
 1. What is your first symptom of PEM?<sup>2,12</sup>  
 2. How long does your PEM last?  
 3. Do your symptoms progress or change over the immediate/short-term/long-term?




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## ME/CFS Activity Management with a Heart Rate Monitor

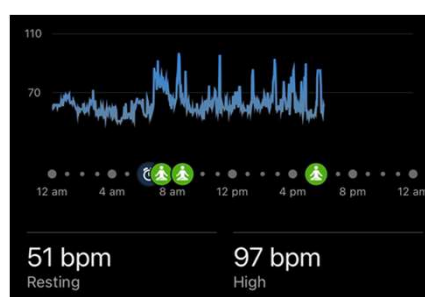


Heart rate monitoring during activity provides biofeedback that promotes symptom awareness and control. When heart rate is associated with symptoms and perceived exertion, it becomes a **powerful tool to manage post-exertional malaise (PEM)**, i.e., worsening of symptoms after activity (for more see our PEM Timecourse).

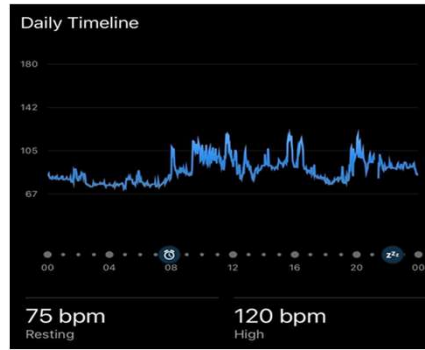
**Energy production is not normal in ME/CFS.** Even light/easy everyday tasks can exacerbate fatigue, cause dizziness and prolong recovery time. People with ME/CFS have a low anaerobic threshold which can **decrease further after activity**. Pacing with a heart rate monitor (HRM) interrupts the push-crash cycle and prevents PEM.

- Determine resting heart rate (RHR).** After waking, remain flat in bed and record resting heart rate with a HRM. Calculate the 7-day average RHR. Use this average heart rate as a baseline to evaluate recovery from daily activities. If morning RHR is 10 beats higher or lower than the normal average this indicates "overdoing" or lack of recovery from previous activities. When this occurs, it is recommended to **rest and decrease time spent doing activities**, including cognitive tasks.
- Use heart rate at the anaerobic threshold** from day two of cardiopulmonary exercise testing (CPET) to monitor daily activities. Identify those activities and body positions which put you over this HR. **Avoid spending more than 2 minutes above the anaerobic threshold.**
- Absent CPET, activity limits should be 15 beats per minute (bpm) above the average RHR.** Our research shows the anaerobic threshold is on average 15 bpm above resting heart rate.
- Identify PEM symptoms** for heart rates above the anaerobic threshold. Learn to recognize your symptoms when approaching and exceeding the HR threshold.
  - **Immediate symptoms** might include difficulty breathing, dizziness, and nausea.
  - **Short-term symptoms** of overdoing activity include muscle/joint pain, brain fog, headache, and sleep disturbance.
  - **Long-term symptoms** of PEM include weakness, a decrease in function, flu-like and cardiopulmonary symptoms.
  - **What is the first symptom** you experience when over your threshold? This, plus heart rate, is a **red light indicator** to stop activities before symptoms flare up.
- Stop activities if feeling immediate symptoms** of exceeding the anaerobic threshold and rest until heart rate returns to within 10 beats of the RHR. The time required to return to RHR can be longer for severe PEM and vary from minutes to hours.
- Tie activities to perceived exertion.** Activities above the anaerobic threshold should feel "hard." Activities below the anaerobic threshold should feel "light and easy." If an activity feels hard, stop and rest. If an activity feels light and easy with no symptoms of PEM, that activity can be continued safely.
- Stay below the RHR+15 bpm threshold and rest** when the immediate symptoms of exceeding the anaerobic threshold occur and, **over time, short-term and long-term PEM symptoms will resolve.**

1. Kurlin, V, et al. 2013. Discriminative validity of metabolic and workload measurements for identifying people with chronic fatigue syndrome. *Physical Therapy* 93:1888-93.  
 2. Maxwell, L, et al. 2020. *Workwell Foundation*. Not available symptoms (downloaded from) [www.workwellfoundation.org](https://www.workwellfoundation.org).  
 3. *Workwell Foundation*. A healthspan program of United Therapeutics, a registered 501(c)(3) non-profit organization 403-438852. [www.workwellfoundation.org](http://www.workwellfoundation.org)



51 bpm Resting  
97 bpm High



75 bpm Resting  
120 bpm High

Workwell Foundation  
A healthspan program of United Therapeutics, a registered 501(c)(3) non-profit organization 403-438852.  
[www.workwellfoundation.org](http://www.workwellfoundation.org)

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## Pulling It All Together

Activity Log

Name: \_\_\_\_\_ Date Commencing: 2.1.23

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<b>SLEEP:</b> Write number of hours you slept and the sleep quality. 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good	4	4	4	4	4	4	5
<b>Functional Capacity Scale:</b> 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good	1	1	1	1	1	1	1
<b>Record your activity during one work and your energy rating using the scale 1-10/10 every hour in each square.</b>							
<b>Activities:</b> (please specify)							
6 a.m.	Wake up	Wake up	Wake up	Wake up	Wake up	Wake up	Wake up
7 a.m.	Phone the doctor	Phone the doctor	Phone the doctor	Phone the doctor	Phone the doctor	Phone the doctor	Phone the doctor
8 a.m.	Computer work	Computer work	Computer work	Computer work	Computer work	Computer work	Computer work
9 a.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
10 a.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
11 a.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
12 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
1 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
2 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
3 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
4 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
5 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
6 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
7 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
8 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
9 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
10 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
11 p.m.	Supine	Supine	Supine	Supine	Supine	Supine	Supine
# of minutes walked							
# of walks per day	5	6	5	4	6	4	5


Dr. Alison Beaton ©  
Dr. Lynn Marshall and Dr. Rosemary Underhill

We encourage you to copy this log to use with your patients.

PEM Symptoms

6	Very very light
7	Very very light
8	Very very light
9	Very light
10	Fairly light
11	Fairly light

Wednesday Tracing (single day)



PEM Timecourse

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