

This document outlines some of the lessons I have learned about pacing and avoiding PEM. I've also learned that everyone truly is different and although many of the details below may not apply to everyone, the framework I use could be very helpful for people like me who struggled to get on top of PEM.

1. **Scheduling in rest periods did not work for me**, even when I set alarms and timers. The temptation was to continue going as long as I felt well enough to carry on in the moment. The problem with PEM is that an activity may feel like it is OK in any given moment, but there is almost always a price to pay later.
2. **I needed a real-time way to guide my pacing – enter heart rate (HR) monitoring.** I started to make considerable progress with minimizing PEM when I started tracking with a HR rate monitor. This has been eye-opening.
3. **HR and symptom monitoring combined helped me to clarify my illness.** Since starting to monitor 2 months ago, I learned I have mild POTS. I never knew this, but in hindsight everything is falling into place. I have long been unable to stand for more than a minute or two before I start feeling very uncomfortable – shortness of breath, light headed, and nauseous. Knowing that I have POTS is essential for pacing – it requires a whole different level of aggressive rest and many behavioral modifications. My POTS is far worse when I am in PEM.
4. **Resting heart rate (RHR) is the most valuable predictive tool I have found.** I measure my RHR each morning. If it is lower than my average, I know PEM is on the way and I know to stay in bed. When it exceeds my average, trouble has arrived and I need to stay in bed.
5. **Simple behavioral modifications can really help!** I learned that there are many routine activities that spike my HR and have made the following modifications:
 - Hot showers (and especially baths) and weather cause my HR to increase: I now bathe in cooler water sitting on the shower floor with my knees raised to my chest. Raising my arms also increases HR so I now stop and rest with my arms by my side every few minutes.
 - Tasks need to be broken down:
 - *Bathing/ablutions:* I make sure I have a towel ready to grab so I can dry off while sitting down in the shower. Before getting dressed, I have to rest in bed for about 20 minutes until my core temp cools and HR settles; I now sit in a chair to brush my teeth and hair;
 - *Cooking:* I have stools positioned around the kitchen and mats on the floor for when my HR starts to spike;
 - *Driving:* I have my seat reclined back as far as possible (while still remaining safe). I use a handicap placard, too;
 - *Mobility:* I use a rollator mobility device – not so much for stability, but to have a seat when I need to rest; I also keep a wheel chair, pillow, jackets, water, etc. in my car at all times. I'm going to get a light-weight electric wheel chair.
6. **Avoiding Anaerobic Threshold (AT) is key:** I have learned how the anaerobic system is largely broken in ME/CFS patients and that crossing it must be avoided at all costs. Based on a back of the envelope calculation, my AT is around 102 bpm. I surpass this easily just walking around for a few minutes. But AT isn't everything with my PEM, I've learned.

7. HR zones are key for knowing how much time is spent in rest, recovery, or overdoing it.

After monitoring for a month, I set HR zones that correspond to the following categories:

- a. Within 10% of RHR – this is the only range in which I feel ok (ish) and corresponds to bed rest mostly. I find that on most days I need to very little in bed to stay within 10% of RHR. I aim to spend as much of the day in this range, especially in PEM.
- b. Within 11-20% of RHR – this zone corresponds to me resting in bed and working on my computer, reading the news, watching Netflix, etc. I can also sit on a stool and do some meal prep in the kitchen if I'm not deep into PEM.
- c. Within 21-30% of RHR - this zone corresponds to me being upright and doing something, like preparing a meal, driving, walking to from point A to B, socializing, all while still trying to sit in a reclining position.
- d. Within 31-50% of RHR- in this zone I am most certainly over-doing it. This happens when I walk up the stairs, don't stop to break up tasks with brief resting periods, bathing, and many of the activities in part c above. When I'm in PEM, much of my day can be spent in this zone, even with rest. I try to limit activity in this zone to 2 minutes followed by rest until RHR is reached.
- e. Within 51% - AT (102 bpm) – this is the danger zone. This happens when I ignore my HR or am unable to rest when it is starting to rise.

8. Some emotions are more draining than others. Through HR monitoring, I have been able to understand which emotional states are linked with adrenaline and corresponding spikes in HR. Anxiety, fear, and shame can lead to a rapid rise in HR in me. Deep breaths help to bring HR down.

9. Variable heart rate (HRV) gives me some predictive power. Each morning I measure my HRV and morning readiness score. HRV provides a snap-shot into the status of the autonomic nervous system. When I am showing an imbalance toward the sympathetic nervous system I know I need to rest and minimize stress. When I am tending more toward parasympathetic dominance I likewise re-evaluate the day ahead and try to rest as much as possible.

10. Monitoring has shown me my core symptoms and which symptoms are worse in PEM.

Before I started monitoring, I felt like my symptoms were very chaotic and noisy. Now I'm seeing some patterns. Fatigue, weakness, OI, insomnia, migraines, and GI symptoms are my main symptoms. Light sensitivity, neuropathic pain, muscular/skeletal pain, temperature intolerance, shortness of breath/air hunger, Raynaud fingers, abdominal pain, hair loss, etc. are more prevalent during PEM.

Conclusion: I have learned so much in the last two months. HR monitoring is the retractable lead that I've been needing. Using the zones described above, RHR, and ANS snapshots, have given me targets to aim for and some predictive power. HR monitoring has brought more awareness to my movements and how I can better stay in my energy envelope.

Finally, I had an essay published in the Mighty that many people found helpful:

<https://themighty.com/2017/04/importance-of-avoiding-post-exertional-malaise-with-mecfs/>

Please feel free to share with other patients if helpful. Thanks!