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Using a Heart Rate Monitor To Prevent Post-Exertional Malaise in ME/CFS

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One of the identifying characteristics and key symptoms of ME/CFS (myalgic encephalomyelitis / chronic fatigue syndrome) is an intolerance to even mild exertion, known as Post-Exertional Malaise or PEM. In simple terms, this means that when people with ME/CFS engage in activity – even just walking to the bathroom or making a simple meal – they experience a sudden worsening of all chronic fatigue syndrome symptoms [1] (usually hours or days after the exertion), often aptly called a "crash" by patients. Fortunately, there are ways to quantify your limits and use a heart rate monitor to stay within those limits, thus greatly reducing post-exertional crashes.

What Exactly is Post-Exertional Malaise (PEM)?

In a study conducted by well-respected ME/CFS researcher Leonard Jason, more than 1500 adult patients from over 35 countries diagnosed with myalgic encephalomyelitis or chronic fatigue syndrome used a self-reported questionnaire to describe their experiences of PEM. Seventy-eight percent of respondents said that PEM occurred as the result of "basic activities of living," which makes it very difficult to avoid. Patients reported that their PEM symptoms lasted anywhere from one day to six months. Most patients in the study reported limited success with pacing (staying within your exertion limits), but only about 10% of those patients used a heart rate monitor to quantify their limits.

So, what's happening behind the scenes to cause PEM? One underlying issue is that the cells of people with ME/CFS don't process oxygen properly. In a healthy person (even one who is out of shape), exertion results in aerobic exercise, where the cells use oxygen to produce energy. Past a certain point, known as the Anaerobic Threshold or AT, the cells run out of adequate oxygen and switch to using glucose to create energy. During anaerobic metabolism, lactic acid, lactate, and carbon dioxide all increase in the cells and endurance is reduced. An elite athlete might switch to anaerobic exercise after running for many miles, indicating a very high AT, while those with heart disease typically have a lower-than-normal AT. For healthy people, AT is usually estimated simply by (220 – age), which is the heart rate at which they switch from aerobic to anaerobic metabolism.

For someone with ME/CFS, though, the AT is much lower, often just 50-60% that of a healthy person. This means that with minimal exertion, we switch from aerobic exercise to anaerobic exercise because there isn't enough oxygen available to our cells, thereby relying on energy

reserves we just don't have. This is why a short walk for us can cause a similar (or worse) reaction as an athlete running a marathon!

To makes matters worse, more than 97% of patients with myalgic encephalomyelitis or chronic fatigue syndrome have some form of Orthostatic Intolerance [2] (OI), which is an inability to hold heart rate and/or blood pressure steady while upright. For those with one type of OI, Postural Orthostatic Tachycardia Syndrome (POTS), heart rate jumps up considerably when standing or even just sitting up. This means that they will hit that reduced AT even faster.

How Do I Find Out What My Anaerobic Threshold (AT) Is?

The gold standard for measuring AT is to use gas exchange methods during exercise testing. Heart rate and blood pressure are measured during exertion, but the equipment also precisely measures how much oxygen is taken in and how much carbon dioxide is expelled. For those with ME/CFS, Workwell Foundation (formerly Pacific Fatigue Lab) developed 2-day Cardiopulmonary Exercise Testing (CPET) that measures AT and also shows clearly that PEM results after exertion, further dropping AT on the second day. This is the most accurate way to measure your AT (and also the best test to use in a disability case because it provides evidence of PEM).

Not all ME/CFS patients can afford or manage a 2-day exercise test, though. This is where a heart rate monitor (HRM) becomes useful. You can begin with an estimate of your AT using a modified formula and then use your HRM and observations to test whether it should be adjusted up or down. Since most people with ME/CFS have an AT that is usually 50-60% of healthy people, use this formula to estimate your own AT:

(220 – age) * 0.6 = estimated AT
(If you are more severely ill, use 50% or 0.5 instead of 0.6)

Alternatively, women can try:

(220 – (age * .88)) * 0.6 = estimated AT
(Or if severely ill, use 0.5 instead of 0.6)

Use the HRM to test how accurate your estimated AT is. Do you still crash when staying below it? Then adjust AT downward, until you find the point where you can prevent PEM by staying below your AT. Or, if you stay below your AT and never crash from over-exertion, you can carefully experiment with going higher than your estimated AT by a few beats per minute (bpm). Experience will help to fine-tune your estimated AT.

How Do I Use a Heart Rate Monitor to Prevent PEM?

Now that you have an estimate of your AT, the heart rate monitor can help you stay below that limit, thereby preventing post-exertional malaise. There are many choices available now for heart rate monitors, from those that only measure heart rate to wearable devices like Fitbits and smart watches that have other uses. Look for these features:

A customizable upper alarm for heart rate – you'll need to set an audible alarm at your AT.
A continuous and visible heart rate read-out – look for an HRM that shows a continuous heart rate that is easy to see without pressing a button.
A device that is comfortable – I personally prefer the wrist-only devices. I used to use a chest strap HRM, but I found it not only uncomfortable but awkward to put on, especially in public. Wrist-only devices seem to be more accurate and reliable for me, too.
Extra features – most HRMs can download data to your smart phone or computer. Some include stopwatches, calorie counters, step counters, heart rate variability measures (another way to manage ME/CFS), and more.
Once you have your HRM, set an alarm as the upper limit at your AT (or estimate) and try to stay below that limit. You will probably find, as I did at first, that almost everything puts you over your limit, even everyday activities in your own house. The first time I put mine on to try a short walk, I went over my AT just putting my shoes on! This can be discouraging at first, but studies show that staying within your limits – especially quantified limits like your AT – can help to reduce the number and severity of post-exertional crashes.

Use what you learn to make adjustments to your daily life. If certain activities, like climbing stairs or carrying things, send your heart rate over your AT, minimize those activities, find other ways, or ask for help. For instance, I sit at our kitchen counter to chop vegetables instead of standing, and I avoid carrying laundry or other things when my heart rate is higher.

What Kind of Improvements Are Possible from Using a Heart Rate Monitor?

Staci Stevens of the Workwell Foundation, one of the scientists that developed exercise testing for ME/CFS, reports on one patient who was tested using 2-day CPET initially and a year later. That first test gave her an accurate AT, and she used an HRM to stay below it. She also began a program of light strength exercises three times a week, lying down to keep her heart rate lower and using her heart rate monitor to stay below her AT. At the end of the year, the patient showed significant improvements and could manage daily activities better without crashing. The second CPET test showed a 75% improvement in time to recover from exercise (one week versus a full month before the study). Most striking, her AT actually increased by 20 bpm during that year! Staying within her limits and improving her fitness actually increased her limits, allowing her to do more without PEM.

My own results have been similar. Those first days of wearing my HRM were eye-opening. I discovered that carrying things increased my HR more than just moving and that I could lower my heart rate by sitting or lying down, crouching, flexing my leg muscles to keep blood flowing, and by taking slow, deep breaths. I, too, began some simple strength exercises while lying down,

using my HRM to stay below my AT.

I also noticed that my heart rate was higher the worse I felt; my body was telling me to rest more and do less. Dr. Nancy Klimas and Connie Sol of Nova Southeastern University Institute for Neuro Immune Medicine in Florida recommend tracking resting heart rate each morning upon waking, while lying down and before taking any caffeine or other stimulants. Keep records to see how your resting heart rate varies, as a measure of how you are feeling. Over-doing one day will result in a higher heart rate the next day (or for several days after), leaving less room for activity.

My heart rate was almost always over my AT, even with mild daily activities, sometimes just while lying on the couch! My next step was to treat my OI in order to lower my heart rate to more normal levels. In my case, low-dose extended-release beta blockers worked well and immediately lowered my heart rate by 30 bpm (it takes some trial and error for each person to find what works best). This was life-changing for me. Combined with using my heart rate monitor, the beta blockers allowed me to stay within my limits most of the time and even take walks again, go grocery shopping, and cook meals for my family [3] without crashing. As in Stevens' case study, my gains were additive over time; the more I was able to exercise and improve my fitness, the more my AT increased, allowing me to be even more active. PEM is rare for me now, and I live an active life. I can even walk for more than an hour (wearing my HRM and staying below my AT), with no PEM.

Using a heart rate monitor not only helps ME/CFS patients stay within their limits but also helps to increase those limits over time. By using a heart rate monitor to stay below your AT, you can prevent PEM. Many of us with ME/CFS are constantly overdoing and crashing, and using a heart rate monitor can help to stop that destructive cycle. It takes some time and patience, but by estimating your AT, using your HRM to stay below it, and possibly treating OI [4] to help, you can lead a more active life with more good days and fewer bad days.

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[7] @livewithmecfs.: **https://twitter.com/livewithmecfs**
[8] Pacing By Numbers: Using Your Heart Rate To Stay Inside the Energy Envelope: **http://www.cfsselfhelp.org/library/pacing-numbers-using-your-heart-rate-to-stay-inside-energy-envelope**
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[10] Heart Rate and Post-Exertional Crashes in ME/CFS: **http://livewithcfs.blogspot.com/2011/02/heart-rate-and-post-exertional-crashes.html**
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[12] Neurally Mediated Hypotension and Chronic Fatigue Syndrome: **https://link.springer.com/article/10.1007/BF02267785?no-access=true**
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[14] Discriminative Validity of Metabolic and Workload Measurements for Identifying People with Chronic Fatigue Syndrome: **https://www.ncbi.nlm.nih.gov/pubmed/23813081**
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