



Solve M.E.

Pacing With Severe M.E.

Video Transcription

“I'm Hollis, and I'm entirely housebound and mostly bed and couchbound. And I'm able to join in this video forum today, but would otherwise be unable to participate in a live dialog.

I'm here to speak just from my own experience today, and I know that other clinical professionals on this [EmPOWER M.E. panel \(“Pacing: Power in Slowing Down”\)](#) have lots of very specific and useful ideas to share about pacing.

First, I want to recognize everyone who can't join us today to share their voices. The most severe cases are so often left out of research, recommendations, and community care. Pacing comes from a Latin root which means to stretch, and I think it's helpful to recognize that so often pacing is presented as stretching the limits of your physical capacity operating just below an anaerobic threshold. A threshold that crossing would cause PEM. I think we need to reframe this language of stretching.

Pacing is so often presented as incumbent on the patient, but pacing is really something that everyone around the patient needs to support and make possible. It's not something that can be done alone, and quite frankly, it's not fair that it's the main strategy or code treatment that we're given. Still, it's what we have.

As you can probably tell I'm taking breaks in this video. For me, the most useful phrase has been to do less than 50% of what you think you can. So, if you think you can sit up for ten minutes, sit up for less than five. If you think you can talk to a loved one for 20 minutes, speak to them for less than ten. That being said, for many of us, it's not always something within our control. PEM or worsening of baseline may be inevitable no matter how restrained we are.

Looking back, I understand now that I was in rolling PEM for years, and I needed to do much less than I or my care team realized. It's most important to have care teams read about the characteristics of PEM and rolling PEM, evaluate if this might be happening, and try to help the patient adjust accordingly.

I've found I need to stop any activity when my heart rate reaches 78, and any sustained activity over 80 beats per minute will lead to a crash. Please do not apply my numbers or anyone else's numbers to yourself, but find what works for you. You or your caregiver should track symptoms alongside exertion, medications, supplements, and changes. In something like [Solve Together](#)'s app. And you can put this alongside data from a wearable tracker if you have access to one.

So many resources exist about heart rate variability and heart rate that are useful for gauging your pacing. I'm sure the others on this panel will discuss those equations and various strategies, but ultimately, this is something you must figure out for yourself, and it's not always applicable. The equation doesn't always add up to PEM, or you might do something that you think wouldn't apply, and it does.

For me, additional tracking data points like overnight respiratory rate and oxygen in combination with my heart rate and heart rate variability are clearer indicators of big changes. But certain symptoms, like a sense of heat on the back of my neck, like I have now, muscle twitches and dystonic action in my neck, repetitive yawning, burning in my occipital lobe, or an increase in volume or change in tone of my tinnitus, are also important to watch.

So, for you, determine what those symptoms are and, with the care team, work together to identify these symptoms and watch for them. It's not just the patient again, but everyone who supports them.

I want to talk about several things that I didn't identify as triggers because they didn't cause heart rate or heart rate variability changes. Or perhaps I didn't consider it for other reasons, even though they were causing these changes.

First, I want to talk about emotion. For me, emotional exertion may or may not raise my heart rate, but more so than any other category, it causes PEM. This is both positive and negative emotions. Learning how to mediate emotional response is a challenge and can feel isolating. So, please work with loved ones and caregivers to help support you. Have signals and strategies for expressing when emotions feel intense. So, you don't have to verbalize that. And perhaps if you're able to tolerate screen engagement, a therapy app allows for shorter durations to process some of these emotions.

It took me a long time to realize how much cognitive exertion is causing PEM, and this varies so much from person to person. For me, I'm able to look at pictures and words together, like in a picture book or comic, but I can't easily read paragraphs.

Communication and finding strategies for sharing your thoughts--like dictation and setting that up on a computer or a phone for accessibility--can be really valuable. And, really importantly in PEM, have a plan for if you can't speak or don't feel that it would be helpful to do so. I know that Bateman Horne has communication cards, and I just want to point out again, this video and the amount of communication and complex thought involved is a huge exertion for me. I've had to pace around in the weeks leading up to it.

I want an aside here for social media. There's so much importance to finding community, and there's a really powerful, unique community on social media. Recently, I found that as my baseline has declined, I've needed to take away the emotional and cognitive exertion of social media, and stepping away has been extremely beneficial. So, please consider how you can set boundaries that work for you.

I want to talk about a not obvious aspect of physical exertion: please consider food and digestion. To digest, your body is working, not just in chewing and swallowing, but in processing and in bowel movements, and urination. Many who are more severe can't prepare their own food, but it's important to consider how hard it is for your body to digest. And again, this is going to differ from person to person,

especially in PEM. So, caregivers and care teams need to work to create meal plans that allow for digestion to also be paced, while simultaneously getting in appropriate calories.

For me, the most important thing, first and foremost, has been envisioning everything I do before I do it. This includes things I might say, such as evening conversations with my partner. I often plan talking points in my head. This includes things I might feel, reacting to anticipated news. This includes things like eating, imagining a meal before I eat it, and this includes how clothes that I wear might feel on my body, envisioning brushing my teeth or hair before I do so. Please note also that envisioning something in advance is cognitive exertion.

Pacing is more than a lifestyle change. It's a loss. It's constantly being meta, watching your body react to anything. And it's virtually impossible to stay fully present. There's so much grief about what you can't or don't do. Just to get through the next hour or next minute. It's not thriving, it's surviving, and we lose part of ourselves. Like any loss of a loved one, make sure that there are ways to mourn and grieve. And for me, part of pacing emotionally and not being overwhelmed by grief has meant making small moments and offering up moments of grief to mark those losses.

Finally, I want to offer that we might change the language of blame. Often, we say, "I crashed myself," or feel frustrated or blame ourselves for exceeding the threshold. I am the biggest culprit of this. But crashing is not always predictable. In a way, I've reframed this is that my body is having an unreasonable reaction to a reasonable action. Our bodies should be able to tolerate walking to the kitchen multiple times a day. We should be able to excitedly talk to our loved ones for however long we want, or to look out the window, or read multiple emails. It's not my fault that doing these things would cause my body to react with a litany of symptoms.

I wish I could say you could reach out to me with questions. I wish I could be there with each one of you, but I know I can't respond to your questions. The Bateman Horne Center and Solve M.E. are great places to turn for support. We are alone together in this."