

## **Post-Exertional Malaise: Power to the People**

By Jennifer M. Spotila, J.D.

<http://www.cfids.org/cfidslink/2010/090103.asp>



*"It is not necessary to understand [PEM] before we respect it."*

This [four-part series](#) of articles about post-exertional malaise (PEM) in chronic fatigue syndrome (CFS) has reviewed the definition, experiences, measurement, and possible causes of PEM. This final installment of the series examines what patients can do to cope with and avoid this incapacitating symptom.

## When It Happens

People with CFS know that once PEM strikes, they are at the mercy of their symptoms.<sup>2</sup> Rest, good nutrition and patience are the only “remedies.” Dr. Cindy Bateman advises patients experiencing PEM, “to ‘pull back’ on all fronts (i.e., rest), focus on getting good sleep, reducing unnecessary stress, hydrating, replacing electrolytes, and generally tending all aspects of CFS until they pull out of the relapse.”

Esther says, “The unpredictable nature of it is a real hardship.” But it is possible to plan ahead for periods of PEM to a certain extent, says George. “I keep a little cache of quick lunches like tuna and crackers in the cupboard for just such times when I know that the PEM will strike. Since cooking or any other activity is completely out, having food and water become the major concerns.”

Coping with PEM is not just about managing physical symptoms and environment. It is common, especially when PEM lasts for days or longer, to struggle with the emotional consequences of the physical crash. Dr. Bateman tells her patients, “to remember that it will go away, eventually, and not to fall into despair about the relapse. While we all know that sometimes a severe relapse represents a setback that some may never fully recover from, I try to keep it positive. Sometimes the despair is more problematic than the relapse itself. So keeping a positive attitude and staying proactively focused on gradual recovery is imperative.”

George agrees, saying, “Meditation helps me see that the PEM period is a period of healing, a form of payment for engaging in activity that was more than my body could endure. . . . There is no cheating on the recovery times. Not giving adequate time for PEM recovery just costs me more time and more frustration.”

People with CFS do not have many alternatives once PEM has struck. But Dr. Bateman notes, “Treating PEM once it happens is much more difficult than preventing it.” If PEM can be prevented, CFS patients may not have to endure the misery of this disabling symptom.

## **Pace to Prevent**

Preventing PEM largely depends upon an individual's ability to limit activity to a safe level that will not exacerbate symptoms. People with CFS quickly learn that some activities, easily tolerated before becoming ill, are completely out of bounds for them. But patients also know that activity limits do not have clear, unchanging boundaries. Jane says, "When I'm housebound, [PEM] can be brought on by talking too much on the phone, being animated, being at the computer. When I'm feeling better, it can be brought on by walking too far."

Pacing is an approach to self-management that helps patients "remain as active as possible while avoiding overexertion."<sup>3</sup> Patients limit their energy expenditure to the energy they have available, engaging in activities and rest as needed. There is no single pacing strategy. Rather, a combination of practices can be applied by an individual in pursuit of the goal: to be as active as possible without experiencing PEM.

A few research studies have tested the efficacy of pacing, but the diversity of techniques and programs makes cross-study comparisons difficult. Patients enrolled in a multi-component program experienced significant improvement in fatigue, self-efficacy, and anxiety compared to controls.<sup>4</sup> A cognitive therapy treatment that emphasized pacing techniques produced better outcomes for patients in several areas, including PEM, than several other non-pharmacologic treatments.<sup>5</sup>

Dr. Leonard Jason has written extensively about the Energy Envelope Theory "which recommends that patients with ME/CFS pace their activity according to their available energy resources."<sup>6</sup> Patients were asked to rate their perceived energy (amount of energy available) and expended energy (total energy exerted). Expended energy can exceed perceived energy, especially when patients push themselves over their limits. Patients who exceeded their Energy Envelope limits experienced higher levels of symptoms, especially PEM.<sup>7</sup> Patients who stayed within their energy envelopes were more likely to experience improvements over time.<sup>8</sup>

Dr. Bruce Campbell is a pioneer of pacing in CFS, and offers courses and free materials through CFIDS & Fibromyalgia Self-Help Program, a non-profit organization. The goal of pacing is to live within one's limits, and "move gradually toward consistency in both activity and rest."<sup>9</sup> By moving away from the push-crash cycle so common in CFS patients, Campbell says that patients experience more predictability and control, while also giving their bodies a respite from PEM.

Pacing, according to Dr. Campbell, is a multi-layered process of adaptation. People can gain control by finding and staying within limits in four areas: physical activity, mental activity, social activity and physical sensitivities. Instead of one energy envelope, Campbell says that every type of activity (such as standing, talking, driving, or using a computer) has its own envelope or limit. "Chronic illness has different rules than acute illness," Campbell says. CFS cannot be pushed through or overcome because "the body will always win, and exact a punitive price for small mistakes." Just as overdrawing a checking account by \$2 can result in disproportionate bank fees, Campbell notes that exceeding one's energy limits by one hour could lead to a week or more of suffering and PEM.

Pacing offers a wide variety of practices and behaviors that can help patients learn to better manage their limitations and avoid that suffering. Pacing strategies include reducing activity level, taking daily planned rests, setting activity limits, switching among tasks, and keeping detailed records. Campbell points out that, "Pacing also includes making mental adjustments based on acceptance that life has changed. Acceptance is not resignation, but rather an acknowledgment of the need to live a different kind of life. Pacing is not a single action or strategy, but rather a way of living with CFS."

The first and most important strategy recommended by Dr. Campbell is pre-emptive rest according to a planned schedule rather than in reaction to symptoms.<sup>10</sup> Rest breaks are integrated into a person's daily routine, regardless of how the patient is feeling. By taking scheduled rest, lying down with eyes closed, patients have found that they can avoid PEM while still accomplishing the same tasks. The length and timing of rest breaks will vary from person to person, although severely ill patients may need many brief rests throughout the day (e.g., 15 minutes of rest every hour or two).

Pacing strategies can be customized and applied by patients at every point along the illness severity continuum. Moderately ill patients can use pacing strategies to manage activities like errands, household chores, and travel. The most severely ill and bedbound patients can benefit from the same techniques modified to their own circumstances. Activities of daily living (such as showering, dressing, or sitting upright for a brief period) can be managed with pacing techniques.<sup>11</sup> Dr. Campbell thinks pacing may be even more important for bedbound patients "because their cushion is so small and thus their vulnerability to PEM is greater."

It is not uncommon for patients to be overwhelmed by the complexity of pacing management. Rather than a linear process with a single end point, Campbell believes that pacing is a cyclical learning process. People with CFS, like people with diabetes and other chronic illnesses, must engage in a lifetime process of adjustment and change. Campbell emphasizes that each person needs a highly individual approach based on his or her own health and life circumstances. He encourages patients to choose their own starting points by asking, "what is the next thing I can do to improve my health?"

## **Power Over Post-exertional Malaise**

PEM is a disabling symptom for many CFS patients. There is no objective way to measure it, and no way to treat it once it occurs. But to some extent, it is possible for people with CFS to prevent PEM. Pacing can help patients avoid both overexertion and under-exertion, and may reduce the frequency and severity of PEM. Patients can choose from a wide variety of techniques and practices to create their own customized pacing program.

Pacing is not a cure for PEM, or for CFS. While some patients may be able to expand their energy envelope, other patients may not. The multiple body system impairments involved in CFS may create hard ceilings for activity capacity.<sup>12</sup> But pacing, and being able to prevent PEM to some degree, gives CFS patients some power over the illness. If a patient can predict the consequences of an activity, that patient is empowered to make informed choices.

Research has not yet discovered what causes PEM or how to treat it. It is up to people with CFS to apply their own strategies to minimize PEM and the suffering it causes. Although the medical system cannot yet offer much help to people with CFS, pacing to prevent PEM is one way that people with CFS can help themselves.

Jennifer M. Spotila, J.D., is a member of the Association's Board of Directors.

The author gratefully acknowledges the assistance provided by Lucinda Bateman, MD, Bruce Campbell, PhD, Lily Chu, MD, MSH, Todd Davenport PT, DPT, OCS, Tom Kindlon, Christopher Snell, PhD, Staci Stevens, MA, and the patients who shared their stories.

1. Bateman L. CFS and the exercise conundrum, <http://www.iacfsme.org/CFSandExercise/tabid/103/Default.aspx> accessed August 18, 2010.
2. See Part 1 of article series: <http://cfids.org/cfidslink/2010/060204.asp>
3. Goudsmit E. and Howes S. (2008) Pacing: A strategy to improve energy management in chronic fatigue syndrome. *Health Psychology Update*, 17(1): 46-52.
4. Goudsmit E., Ho-Yen D. and Dancey C. (2009) Learning to cope with chronic illness. Efficacy of a multi-component treatment for people with chronic fatigue syndrome. *Patient Education & Counseling*, 77: 231-236.
5. Jason L., Torres-Harding S., Friedberg F., et al. (2007) Non-pharmacologic Interventions for CFS: A Randomized Trial. *Journal of Clinical Psychology in Medical Settings*, 14: 275-296.
6. Jason L., Benton M., Torres-Harding S., et al. (2009) The impact of energy modulation on physical functioning and fatigue severity among patients with ME/CFS. *Patient Education & Counseling*, 77: 237-241.
7. Jason L. (2008) The energy envelope theory and myalgic encephalomyelitis/chronic fatigue syndrome. *American Association of Occupational Health Nurses Journal*, 56(5): 189-195.
8. Jason L. (2009)
9. Campbell B. The pacing lifestyle. <http://www.cfidselfhelp.org/library/10-pacing-lifestyle> accessed August 18, 2010.
10. Campbell B. Key 4: Nurture yourself with pre-emptive rest, <http://www.cfidselfhelp.org/library/4-nurture-yourself-with-pre-emptive-rest> accessed August 23, 2010.
11. Blackman G. How I gained hope and control: Pacing for the bedbound patient. <http://www.cfidselfhelp.org/library/how-i-gained-hope-and-control-pacing-bedbound-patient> accessed August 26, 2010.
12. Black C. and McCully K. (2005) Time course of exercise induced alterations in daily activity in chronic fatigue syndrome. *Dynamic Medicine*, 4:10.