



## **Solve M.E. Patient and Caregiver Resource Guide: Post Exertional Malaise (PEM) and Rest**

As defined by the [Centers for Disease Control](#), “post-exertional malaise (PEM) is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.” PEM is the topic of multiple studies – many of them currently ongoing. Unusual, undeniable, crushing life-altering fatigue. Fatigue that dictates the terms of a person’s lifestyle. Fatigue that demands to be recognized. Fatigue that must be planned for and planned around. It is real and measurable and being aggressively studied in clinical research.

Prior to a person being afflicted with ME/CFS or Long Covid, recovery from physical or mental or emotional stress could easily and reasonably be taken for granted. Recovery from all sorts of exertion could be expected and assumed to be on its way after an appropriate period of rest. A “good night’s sleep” usually did the trick. Before becoming ill, people with ME/CFS or Long Covid often report having worked forty hours per week; many report working well more than forty hours, plus maintaining a regular active exercise routine. All the while juggling children, home life and social commitments, as well as engaging in a whole range of activities that were soaked in physical, mental and emotional stress. Normal daily life, while not always easy, was manageable with reasonable amounts of rest.

With ME/CFS or Long Covid, quick easy recovery cannot be taken for granted. Often crushing fatigue – even after minor everyday exertions – is a major concern for people living with these diseases. The kind of fatigue we’re considering is well beyond being reactively tired after vigorous exertion. The

kind of fatigue being considered is a relentless flu-like fatigue that can persist for days, even weeks and perhaps months after exertion. These episodes are recently referred to as “crashes.”

Far too often, people who are dealing with ME/CFS or Long Covid are encouraged by well-meaning friends, family, and even doctors to engage in a program of physical exercise. It seems folks unknowingly mistake the uncommon persistent fatigue for physical weakness. Of course, being persistently in a state of exhaustion can be expected to result in physical weakness. However, PEM is:

- NOT a condition of being weak or a result of deconditioning
- NOT laziness
- NOT an aversion to exercise

PEM is the ongoing failure to recover. When people with ME/CFS or Long Covid do accept the misguided advice to exercise their way back to full strength, the most common outcome is even longer and more severe periods of exhaustion. Physical exertion beyond what is referred to as an “energy envelope” can leave a person with ME/CFS or Long Covid so exhausted, they may spend days, weeks or months in bed attempting to recover. Read more about exercise and pacing below.

One of the great frustrations of those living with ME/CFS or Long Covid is that even the most ordinary daily tasks can trigger a severe PEM reaction. The mental exertion of reading instructions, studying, reading a good book or balancing a checkbook (or the computerized equivalent), can ignite an unexpected PEM response.

Worry and stress, when allowed to gather too much momentum, trigger PEM as well. Sudden fatigue to the point of exhaustion is even more frequent when

dealing with common emotionally tense situations; disagreements between family members, financial demands, and a contentious political conversation are all possible scenarios that are likely to produce a “crash.”

Most people with ME/CFS or Long Covid have learned to plan step-by-step for taking a shower so they can complete a normally simple task with enough energy to re-dress and dry their hair before needing to lie down, or before collapsing on the floor. Some people with ME/CFS or Long Covid report only being able to shower every five days or longer. For people with ME/CFS or Long Covid, preparing meals is an ordeal. This task can also become a major undertaking that must be completed in stages with resting periods between chopping, stirring and cooking.

Careful planning is a must for any travel, holidays, or even normal family celebrations. As a result of both physical and emotional exertion, people with ME/CFS or Long Covid can either miss family holidays, or end up “crashing” during the visit. Unfortunately, “crashing” immediately after returning home is far too frequently the outcome of having fun. Often even the most pleasant events can result in spending days or weeks bed-bound during recovery.

It is extremely important to learn to “listen to your body.” To get a picture of the extent to which PEM can impact your daily activities, visit the [You + ME Impact Tool](#).

Thankfully, PEM can be reasonably controlled by “activity management,” also called pacing. Your main goal must be to avoid PEM flare-ups and illness relapses, by balancing your activity and rest.

You can also take control of other environmental factors that can limit PEM. With ME/CFS your sensitivity to environmental conditions are magnified, and need to be managed with as much precision as your resources and circumstances allow. A healthy diet is, of course, an important factor to monitor. Too much heat and humidity can worsen PEM and you can choose to avoid conditions that particularly impact you. Loud sonic environments and too many too bright lights can be unexpectedly exhausting. Mindfulness or meditation practice have been shown to be helpful and are worth exploring. Just being out in nature can be a boost – if not too hot and humid or too loud and bright. In the end, the one main help for the “crashes” and the crushing fatigue of PEM is Rest! Rest! Rest!

### **Pacing and Resting**

As a person with ME/CFS or Long Covid, you need to determine your individual limits for physical and mental activity, and plan your day accordingly. Through trial and error and tracking your symptoms after differing types of activities, you can find your rhythm to avoid “crashes.” Rest is the main ingredient for reinstating your physical equilibrium.

Rest can be done prophylactically. Rest, prior to an event, can help prevent a “crash.” Resting does not equate to “being lazy.” Rest is a course of action to prevent PEM.

Limitations may be different for each person. By utilizing personal daily diaries and charting, you will be able to discover different patterns of symptom improvement and/or regression. With any chronic illness you need all the advantages you can garner to improve your daily life.

### **Pacing Tactics**

- Prioritize your activities and delay, delegate or eliminate non-essential items.
- Minimize sustained physical or cognitive exertion by dividing and spreading out your activities into small segments with planned rest periods in between. For moderate to severely ill patients, even normal activities of daily living (eating, bathing, dressing) should be modified to avoid triggering PEM.
- Immediately stop and rest if you start to feel dizzy or short-of-breath, notice your heart rate increasing, or sense other PEM warning signs that might be unique to you. Don't try to "push through" when you feel sick or tired. Although the concept is lauded in today's society, doing so with ME/CFS will only exacerbate your symptoms and potentially worsen your illness.
- Schedule rest time (even if you don't think you need it) to relax your body and allow for potential healing. When anticipating the need for extra energy (e.g. trip to the doctor, night out with friends, special occasion), plan extended rest time before and after the event.
- Learn to recognize emotional PEM triggers and take steps to avoid or minimize their impact. If a stressful situation is primarily beyond your control (e.g. the actions of others, world events, lack of understanding about this disease) try to take the emotion out of your thought process. Worrying or holding on to anger when you can't do anything about a situation rarely accomplishes anything for anyone, but if you're living with ME/CFS, it can use up your energy and cause you harm.
- Difficult as it may be, avoid the temptation to do too much when you're feeling a bit better. It is rarely worth the consequences when living with ME/CFS.

## **IMPORTANT WARNING: “GRADED EXERCISE THERAPY (GET)” CAN CAUSE YOU HARM**

Graded Exercise Therapy is NOT the same as pacing. GET requires you to increase your activity over time, potentially pushing you to repeatedly trigger the PEM response. GET has been reported by many patients to be harmful and has left some patients significantly worse than they were before they started. In 2011, a study done in the UK claimed that Graded Exercise Therapy could benefit people with ME/CFS. As a result, the CDC listed GET on their website and health providers began to recommend GET to patients.

The Solve ME/CFS Initiative (then called The CFIDS Association of America) recognized several flaws in the study, most importantly that study participants might not have even had the disease! Participants only needed to have six months of fatigue, but PEM and other core ME/CFS criteria weren't even considered. Additionally, the study excluded severely ill patients and anyone who had been living with the illness for more than six years. Despite our analysis, GET became a “go-to” therapy prescribed by doctors for people with ME/CFS.

Since then, patients and advocates have taken up the call to discredit the study. At the same time, newer studies have found that GET can actually have a negative impact on people with ME/CFS. GET can repeatedly push a patient to the point where the PEM response is triggered, resulting in an overall (possibly permanent) worsening of symptoms.

The CDC recently removed GET from its website. However, far too many physicians are unaware of the new information and still recommend potentially harmful GET to their patients today.

## **Identifying Triggers**

Along with management of your optimal “rest time,” it is also wise to explore other possibilities that may affect your health. Diet is important to even the healthiest of bodies, so of course it can make a huge difference in attempting to reinstate health from the effects of this illness. If you are not sure where to turn with food choices for your health, ask your physician for a referral to a trusted dietitian.

Alcohol and smoking are both contributors to increased symptomatology. They can slow your recovery and increase the severity of your illness. Heat and humidity are environmental contributors that can also increase symptoms of ME/CFS.

The next step is to take charge, and move in ways that feel encouraging and supportive to yourself. You can control what you put in your mouth, you can control the type and amount of physical exercise when you are able to tolerate it (slow walking is usually advised), and you can control the temperature and humidity in your daily environment. These are the steps to take charge of your symptoms.

**Types of Stress That Intensify Your Symptoms (PEM)**

<b>Type of Stress</b>	<b>Specify Aftermath Symptom (PEM)</b>
Example: Financial Stress Example: Physical Stress	Example: Resulted in 2 Bed Days Example: Resulted in 5 Bed Days



**Foods that Affect Your Functioning**

<b>Food</b>	<b>Aftermath Symptom</b>
Example: Pancakes and Syrup	Example: Fatigue