



# Solve M.E.

---

## MANAGEMENT AND TREATMENT OF ME/CFS

ME/CFS is a complex multi-systemic illness with a wide variety of symptoms that wax and wane unpredictably. While there is currently no targeted FDA-approved treatment for the disease, there are a number of medications and strategies that may help reduce your symptoms.

### PACING TO PREVENT POST-EXERTIONAL MALAISE

Post Exertional Malaise (PEM) is the worsening of symptoms after physical, cognitive or emotional exertion. Adopting strategies that help you avoid or reduce PEM is arguably one of the single most important things you can do to reduce your ME/CFS symptoms and improve the quality of your life.

Experts in the field consider “pacing” to be a key strategy for reducing the chance of a PEM crash. The goal of pacing is to be able to remain as active as your limited energy allows while taking proactive steps to avoid reaching your personal overexertion point and triggering the PEM response. Pacing (to avoid PEM) can and should be done regardless of other treatments you might pursue.

Learning to pace can be extremely frustrating. The threshold for triggering PEM varies from person to person and can change over time. Additionally, it’s difficult to accept that you are simply unable to get as much done as you did before you became ill. But if you’re living with ME/CFS, it’s important to adapt to this new reality. The following tactics can help and will be well worth it in the long run:

- ***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.*

The importance of pacing cannot be overstated. Patients who don't understand or accept the reality of PEM often find themselves in a "push-crash" cycle. When feeling better, they want to make up for lost time and try to get a lot done. The PEM response is triggered (usually unknowingly) and relapse occurs a day or two later. The cycle is then repeated – feel a bit better, do too much, relapse, and so on. This is harmful on many levels and should be avoided.

In 2017, a "Post Exertional Malaise Avoidance Toolkit" was drafted by the Stanford Medicine ME/CFS Initiative in order to help patients identify and monitor their own personal PEM triggers, avoid crashes, and understand their symptoms to enhance recovery. A link to the toolkit is provided below with the author's permission.

## **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 SMCI'S 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.

## **MEDICAL CARE**

ME/CFS experts generally suggest that patients focus on their most problematic symptoms first. Additionally, since patients with ME/CFS are often susceptible to infections, many experts believe that identifying and treating underlying infections should also be a priority. There is a growing body of evidence showing that antivirals, antifungals and antibiotics have a dramatic impact in some patient's lives.

**Sleep:** For unrefreshing sleep or insomnia, over-the-counter products and prescription medications may help. Make sure that you're practicing good "sleep hygiene" techniques as possible within the confines of the disease, and that you have no underlying sleep conditions (e.g. sleep apnea, narcolepsy) that should be addressed.

**Orthostatic Intolerance:** General recommendations for management of OI are to avoid prolonged standing, elevate your legs when sitting, try compression stockings, increase fluid and salt intake and consider prescription medication if needed. If your symptoms are moderate to severe, evaluation by a cardiologist and/or neurologist might be warranted.

**Cognitive Issues:** Brain fog and memory problems are common to many diseases, so there are a variety of memory aids and techniques to be tried (calendars, to-do lists, organizers). With ME/CFS, pacing strategies for any activity that requires mental effort can be helpful in reducing your cognitive symptoms as well. Some patients benefit from stimulant medication, although experts advise that caution is warranted due to potential worsening of symptoms or other adverse effects.

**Pain:** Pain is also a symptom that is common to many diseases and has a wide range of therapies to consider. Over-the-counter pain relievers and non-pharmacological pain management methods (e.g. massage, acupuncture, myofascial release, chiropractic care, hot or cold gel packs) are generally safe for people with ME/CFS. If pain is having a major impact on your life,

consider working with a pain management specialist. When considering prescription pain relief, experts recommend starting at the lowest possible dose since ME/CFS patients often develop new sensitivities to medications.

**PEM:** Unfortunately, there are no medications known to stop the PEM response or speed up the recovery period. The best way to get through a relapse is to stay hydrated and get plenty of rest (much as you'd be told if you have the flu). When needed, over-the-counter medications to reduce some of the symptoms of PEM (pain, flu-like symptoms, nausea) may be helpful.

**Experimental Medications:** There are two medications that purport to be effective in reducing symptoms for a subset of patients. Ampligen, a drug specifically designed to treat people with ME/CFS, has been used in clinical trials for decades. Although the drug has been endorsed by countries outside the USA, it does not have FDA-approval and is generally not covered by insurance in America due to its "experimental" designation. Another drug, Rituximab, recently made headlines for reducing symptoms in a percentage of ME/CFS patients in several small studies. A large clinical trial is currently underway in Europe. The American ME and CFS Society has published a comprehensive history on each of these promising drugs (see link below).

## MENTAL AND EMOTIONAL WELL-BEING

ME/CFS is not a psychiatric illness. However, it is common for people with serious medical issues to experience secondary anxiety and depression, and patients with ME/CFS are no exception. Feelings of anger, grief, hopelessness and guilt are common as well.

If you're having anxiety or depression, counseling and complementary therapies (mindfulness techniques such as yoga and meditation) may be of help. Be aware that "cognitive behavioral therapy" has not actually shown significant long-term improvement in patients with this disease despite the fact that it is often recommended by physicians.

Anti-depressants and anti-anxiety medication have been found to help some patients, while others report no benefit and/or harmful side effects. If you are considering a trial of medication, experts generally recommend that you start with the lowest dose possible and carefully monitor your results.

Also, while easier said than done, keep in mind that "stressing out" is a type of mental exertion and can potentially trigger PEM. Do what you can to reduce, minimize or avoid stressors whenever possible. Support groups exist to help patients share their experience and learn from others who truly understand the disease.

## DIET AND NUTRITION

Good nutrition is especially important when dealing with chronic illness, so try to eat foods that supply your body and brain with the nutrients they need. At the same time, keep in mind that you may have developed new allergies or sensitivities to both food and chemicals which can cause or exacerbate symptoms.

Given the challenges you face, ME/CFS experts often recommend that you learn what works best for your body, drink plenty of fluids, keep healthy snacks on hand and consider many small meals throughout the day. If willing, try to avoid or minimize dairy, gluten, and high carb/sugar foods to see if symptom severity is reduced. If you find that your food choices are very limited due to the disease, consider dietary supplements to get your RDA of vitamins and minerals. Other products that might help include Vitamin D, B complex, Essential fatty acids, and CoQ10. Just be sure to check with your doctor before adding any new supplements to your daily routine.

## ME/CFS EXPERTS

Although most ME/CFS patients work with a primary care physician and one or more specialists when needed, there are a number of ME/CFS specialists who see patients in the United States. For your convenience, SMCI has assembled a [list of clinicians](#) generally recognized to be experts in the field.

Whether you choose to meet with a specialist, find a new primary care doctor, or work with your current physician, check out our recommendations for working with your doctor at our "[Living with ME/CFS](#)" menu tab.

### Further Reading:

[International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis \(IACFSME\). ME/CFS Primer for Clinical](#)

Practitioners (2014 revision).

[http://iacfsme.org/portals/0/pdf/Primer\\_Post\\_2014\\_conference.pdf](http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf)

International Consensus Panel. Myalgic Encephalomyelitis – Adult and Paediatric, International Consensus Primer for Medical Practitioners

<http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf>

American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society “Experimental Treatments”

<https://ammes.org/experimental-treatments/>

Stanford Medicine ME/CFS Initiative ME / CFS Patient: Post Exertional Malaise Avoidance Toolkit

<https://solvecfs.org/wp-content/uploads/2019/01/PEM-Avoidance-Toolkit.pdf>

Medscape Medical News “New Findings Elucidate Potentially Treatable Aspects of ME/CFS”

<https://www.medscape.com/viewarticle/911666>

**Disclaimer:**

*The Solve ME/CFS Initiative Inc. serves as a clearinghouse for information on Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). Ideas expressed within the Solve ME/CFS Initiative website, print publications or materials, or monthly newsletters are strictly those of the authors or quoted individuals. The Solve ME/CFS Initiative assumes no liability for any medical treatment or other activity undertaken by individuals and encourages you to seek advice from a licensed health care professional before beginning any new medication, supplement, treatment, therapy, or exercise regime. The Solve ME/CFS Initiative does not recommend, endorse, make any warranties or representations with regard to any of the materials, products or services provided by companies or organizations referred to in this website, print publications or materials, or e-newsletters.*