

## **Guidelines for Physical Therapy for Patients with Chronic Fatigue Syndrome (ME/CFS)**

Myalgic encephalomyelitis (ME) is also known, especially in the US, as chronic fatigue syndrome (CFS) and also as systemic exertion intolerance disease (SEID). It is most commonly referred to as ME/CFS.

ME/CFS is a serious and debilitating immune system disorder that causes dysfunction in almost every bodily system, especially the endocrine, immune, and autonomic nervous systems. There is a wide range in functionality of patients: some are bedridden, many are mostly housebound, and some can appear normal at times, though all patients are severely restricted in their activity levels.

The primary defining characteristic of ME/CFS is an intolerance to exercise (the CDC calls this post-exertional malaise or PEM). Even very mild exertion, physical or mental, can cause a relapse or “crash” anywhere from an hour to a couple of days afterward that can last for days, weeks, or even months. For this reason, it is absolutely essential for an ME/CFS patient in physical therapy to stay within his or her own individual limits (see below).

Another integral part of ME/CFS is an inability to maintain a steady blood pressure and/or heart rate when upright, referred to as orthostatic intolerance (OI). There are many kinds of OI, but the most common conditions in ME/CFS patients are where the BP drops when upright (orthostatic hypotension or neurally mediated hypotension) and where the HR goes very high when upright (postural orthostatic tachycardia syndrome). OI usually leaves the patient feeling very sick after being upright, often for days afterward, and sometimes even causes him or her to faint.

Patients with ME/CFS often have additional co-morbid conditions. Joint hypermobility and Ehlers-Danlos syndrome (EDS) are far more common in ME/CFS patients than in the general population.

NOTE: These guidelines are for treating an injury in a patient who also has ME/CFS, not for directly treating ME/CFS itself. Regular PT will make an ME/CFS patient worse, due to the exertion intolerance, and ME/CFS patients should never be forced to exercise past their limits (described below). A specialized form of manual PT that utilizes nerve gliding can be used to treat ME/CFS directly, and is most effective when used in combination with medication to treat orthostatic intolerance. Dr. Peter Rowe at Johns Hopkins is happy to explain these techniques over the phone or via e-mail to any physical therapist.

Here are general guidelines for working with ME/CFS patients:

**ME/CFS patients must stay within their individual activity restrictions or they will “crash” or relapse and be unable to continue PT. You can help ME/CFS patients stay within their limits with these guidelines:**

- Calculate their Anaerobic Threshold (which is very low in people with ME/CFS), if they don't already know it. You can estimate AT in someone with ME/CFS with this

formula:  $(220 - \text{patient's age}) * 0.6 = \text{anaerobic threshold}$  (that is, 60% of the maximum heart rate, though AT may be even lower for some severely ill patients).

- Have your patient wear a heart rate monitor, set a high-end alarm for their AT (or slightly below it), and make sure they keep their HR below that level. NOTE: For patients whose OI is not being treated with medication, they may not even be able to sit up without going over their AT.
- Because of the very low AT, most patients with ME/CFS are unable to manage aerobic exercise; their bodies quickly shift into anaerobic metabolism. This means, for instance, you should skip the usual warm-up on a bike or treadmill.
- Focus more on stretches and exercises that can be done lying down, especially lying on their back—this helps to keep HR lower and BP steady.
- Just staying below the patient's AT may not be enough to prevent a post-PT “crash” or relapse; stamina and time are important, too. The patient will probably know how much activity he or she can safely tolerate. They may even need to do PT exercises (lying down) in 5-minute increments, with 5-10 minutes of rest in between.
- Whatever you *think* is going slow and starting low ... go much slower and start even lower! People with ME/CFS have greatly reduced stamina because of PEM and OI.
- Listen carefully to the patient and stop if their ME/CFS symptoms flare up—pushing through when symptoms flare will only make someone with ME/CFS sicker.

#### **Be aware of OI and help to control it.**

- Always allow an ME/CFS patient to lie down when they need to.
- Avoid standing, especially standing still—that will bring on severe OI symptoms.
- Adjust PT exercises. If a standing exercise can be done sitting (or even better, lying down), then change it. Supine exercises are best.
- Never ask an ME/CFS patient to sit on the table with their feet dangling down—this hastens the blood pooling in the feet, worsening OI. Allow them to lie down, sit with legs up on the table, or provide a step stool for them to rest their feet on.
- Limit time spent standing or even sitting up and allow breaks in between for the patient to lie down.
- OI is characterized by blood pooling in the extremities, so avoid using heat on feet, lower legs, or hands—it will draw more blood away from the heart and brain.
- Encourage the patient to drink plenty of fluids. Gatorade, electrolyte drinks, and other sources of sodium are even better (as long as the patient doesn't have high blood pressure). These help to increase blood volume, thereby helping to stabilize HR and BP. Wearing compression garments, like knee socks, tights, or shorts, can also help.

#### **Timing, Planning, Scheduling & General Tips**

- ME/CFS patients will need more recovery time between visits.
- ME/CFS patients often have very strict scheduling needs—some need to nap in the afternoon, some can't get out of bed until later in the day, and some may only be able to handle appointments at a certain time of day when their OI medications are at their most effective.
- You will need to progress much more slowly with an ME/CFS patient.

- ME/CFS is a disease characterized by high levels of inflammation, so injuries usually take longer to heal. Standard expectations of time needed for PT and healing will probably be too short.
- Because of the inflammation, ice can be very helpful, often more so than heat in someone with ME/CFS.

It is possible for someone with ME/CFS to successfully complete PT and heal from an injury or surgery. However, it is a much slower process than it is for an otherwise healthy patient. The physical therapist must pay careful attention to the patient's limits and help him or her to stay within them, adapting typical protocols to the needs of the patient.

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## References

Campbell, Bruce. "[Pacing By Numbers: Using Your Heart Rate To Stay Inside the Energy Envelope.](#)" *ME/CFS & Fibromyalgia Self-Help* (July 30, 2018).

Johnson, Cort. "[Heart Rate Monitor Based Exercise Program Improves Heart Functioning in Chronic Fatigue Syndrome \(ME/CFS\).](#)" *Health Rising* website (August 13, 2013).

Rowe PC, Calkins H. "[Neurally Mediated Hypotension and Chronic Fatigue Syndrome.](#)" *The American Journal of Medicine* (September 28, 1998) Volume 105, Issue 3, Supplement 1, Pages 15S–21S.

Rowe PC. "[General Information Brochure on Orthostatic Intolerance and its Treatment.](#)" *Dysautonomia International* (March 2014) p. 4-5.

Saville, Jeryldine. "[Manual Therapy in CFS: Part 1 of 2.](#)" *Solve ME/CFS Initiative* blog/website (January 25, 2013).

Stewart JM, Gewitz MH, Weldon A, Arlievsky N, Li K, Munoz J. "[Orthostatic intolerance in adolescent chronic fatigue syndrome.](#)" *Pediatrics* (1999) 103(1):116–21.  
doi:10.1542/peds.103.1.116.