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## The Dos and Don'ts of Physical Therapy when You Have Chronic Fatigue Syndrome

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Like everyone else, there are times when someone with ME/CFS might need physical therapy (PT), for an injury, strain, or after surgery. The problem is that one of the primary characteristics of ME/CFS is an intolerance to exercise. So, how can you possibly manage physical therapy with chronic fatigue syndrome or myalgic encephalomyelitis [1]? The downloadable document below is designed to give to your physical therapist so that you can safely recover from an injury and get the physical therapy you need, without making your underlying illness worse.

I wrote these guidelines when I myself needed physical therapy for a shoulder injury, and then I needed them again the following year when I injured my other arm. Both times, I printed this brief document and gave copies to any physical therapist who worked with me. In all cases, it was well-received, and the physical therapists all appreciated having the information and learning something new. Every one of them followed the guidelines and was very kind and caring toward me, helping me to stay within my limits to avoid <u>post-exertional crashes</u> [2].

## Is Physical Therapy an ME/CFS Treatment?

Please note that standard physical therapy is **not** an <u>ME/CFS treatment</u> [3] and that using physical therapy for chronic fatigue syndrome without these kinds of guidelines and limits in place can worsen your condition. The studies that resulted in recommending exercise as a "treatment" for ME/CFS have been debunked and proven to be flawed. If your doctor tries to send you to PT (without an injury) for Graded Exercise Therapy (GET) to treat your ME/CFS, you can also print this document to share with your doctor, to help educate him or her about why exercise can be harmful for those with ME/CFS.

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One <u>specialized form of manual PT that utilizes nerve gliding</u> <sup>[4]</sup> can be used to treat ME/CFS directly. Manual PT means that the patient is entirely passive (and in this case, lying down), while the physical therapist gently moves parts of the body. Nerve gliding uses manual PT to help release injured or "stuck" nerves that may be causing pain and reducing mobility. Many patients, especially those who are also hypermobile and/or have Ehlers-Danlos syndrome, report that this specialized type of manual PT with nerve gliding has helped to reduce pain and improve their

physical condition. It is most effective when used in combination with medication to <u>treat</u> orthostatic intolerance <sup>[5]</sup> (OI), which helps to make some mild exercise possible, without a post-exertional crash afterward. Dr. Peter Rowe at Johns Hopkins helped to develop this protocol, and he is happy to explain these techniques over the phone or via e-mail to any physical therapist.

The thought of attempting physical therapy can be terrifying for patients with ME/CFS, especially if a short walk to the mailbox or going up a flight of stairs typically causes a relapse. It is possible, though, to manage PT safely, in order to heal from an injury or surgery, without crashing from over-exertion. With some basic knowledge, your physical therapist can learn how to help you stay within your limits and support you through a slow, steady process of recovery. Happy Healing!

Download your printable pdf copy of "Guidelines for Physical Therapy for Patients with Chronic Fatique Syndrome (ME/CFS) [6]."



Suzan Jackson is a freelance writer who has had ME/CFS since 2002 and also has Lyme disease. Both of her sons also got ME/CFS, in 2004, but one is now fully recovered after 10 years of mild illness and the other just graduated from college, with ME/CFS plus three tick-borne infections. Sue writes two blogs, Live with ME/CFS at <a href="http://bivewithcfs.blogspot.com">http://bivewithcfs.blogspot.com</a> [7] and Book By Book at <a href="http://bookbybook.blogspot.com">http://bookbybook.blogspot.com</a> [8], and wrote an upcoming book, Finding a

New Normal: Living with Chronic Illness. You can follow her on Twitter at @livewithmecfs.

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- [2] post-exertional crashes: https://www.prohealth.com/library/using-heart-rate-monitor-prevent-post-exertional-malaise-cfs-91620
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- [4] specialized form of manual PT that utilizes nerve gliding: https://solvecfs.org/manual-therapy-in-cfs-part-1-of-2/
- [5] treat orthostatic intolerance: https://www.prohealth.com/me-cfs/library/orthostatic-intolerance-part-2-treating-oi-82949
- [6] Guidelines for Physical Therapy for Patients with Chronic Fatigue Syndrome (ME/CFS): https://www.prohealth.com/wp-content/uploads/2019/11/Physical-Therapy-for-ME-CFS.pdf

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