

# Staying Below Your Energy Limits

by Whitney Dafoe, severe ME/CFS patient and advocate

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My number one piece of health advice for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis patients, more important than any current medication or treatment, is to never exceed your energy limit. But let me explain to be clear. The most unique, best identifying symptom of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (ME/CFS) is Post-Exertional Malaise. Healthy people can exercise way past the point of exhaustion. They can continue when their bodies scream to stop and later that day, they recover and feel fine, if not euphoric. I know this feeling well, I ran cross country in high school. ME/CFS patients have an energy limit and if we exceed that limit, we get Post-Exertional Malaise which means we get physically sick afterward and any ME/CFS symptoms we have get worse. This can last for days, weeks, months or be a permanent worsening of the illness. But the most important part is that when we exceed our energy limit, the limit goes down so next time we have to stop sooner or the whole process repeats itself as a vicious cycle.

Patients with mild ME/CFS usually reach their limit only with anaerobic exercise but a more severe patient's limit can be brushing their teeth for too long a time and for even worse patients like me, the limit is for example being touched by another person, being in the same room with someone else, looking at something for too long or even thinking about something for too long or thinking of something that requires too much mental energy. Especially when someone is in the room which already puts me over my limit, the combination of also thinking at the same time is extremely overwhelming. I have to meditate on a couple simple ideas or memories and if my mind strays even for a moment it can be devastating.

Most people are completely out of touch with their bodies. ME/CFS patients have to learn to be keenly aware of our bodies and exactly where our limit is. We have to make a choice to stop when we feel ourselves reaching our limit before we go above it. This choice is part of the reason we are judged so harshly by friends, family and even loved ones. Because we have to choose to stop activities or refrain from activities before we are symptomatic from them. So people don't see

us getting Post-Exertional Malaise and due to the lack of awareness, they never understand the connection.

It's also extremely difficult for us because it's pleasure first, negative consequences later and our minds are famously bad at negotiating this. Think of how hard it is to stop using drugs. It's a similar pleasure first, negative consequences later situation. But with ME/CFS it is life itself we are having to refrain from not a high from life (no slight intended to the difficulty faced by people addicted to drugs/alcohol).

A good way to control the urge to indulge the pleasure center of the mind is to think about how you will feel afterward. If you exceed your energy limit pushing yourself to continue engaging in an activity - mental or physical - your limit will go down, you may never be able to do that activity again, and in the future you'll have to do even less just to stay below your new limit. It helps to bring the negative consequences into the present and hopefully make it easier for you to stop within your limits.

This happens to be Superman's number one piece of health advice as well, arrived at independent of me. Genius minds think alike.

But please understand, getting worse DOES NOT mean it is your fault. For one thing ME/CFS is an extremely complicated illness and its mechanisms are mostly as of yet unexplained. Some people (like me) get worse without exceeding energy limits. I went from mild to severe ME/CFS overnight while traveling in India. Then slowly recovered and back to severe over and over until I came home and got better but remained worse than before India. No one knows what caused that. The world is also full of chaos and we can't always accurately predict how much energy something will take. We often get stuck in situations we can't just stop and we have to push ourselves past our limits. This is why a predictable routine becomes important- the less unexpected energy expenditure the less likely we are to wind up in one of these situations and overdo it. It's also really hard to know your limit and body well enough to feel it coming on and stop. It takes years of experience.

So don't blame yourself. Just do your best and let go of the rest. And prepare for the very real likelihood that you could get worse.