MEAI
ME Advocates Ireland **ME Awareness Month Survey Feedback**

Post Exertional Response in Myalgic Encephalomyelitis

How do you avoid Post Exertional Neuroimmune Exhaustion (PENE)?

Pacing.

Try to rest regularly. Not overdo physical activity.

Try to operate within energy envelope, pacing, impossible to completely avoid as have to attend docs appointments etc.

Try not to overexert, pace jobs, limit activities.

Limit rather than avoid - stay within limits and limit exposure to triggers which always result in decrease in function.

Wish I knew.

Experience & self-education.

PLANNING. PACING. GOOD SLEEP.

Try to use pacing techniques as much as possible.

Pace, rest daily, don't over commit, break jobs down. Very hard to do when you want to do things and can't so I am inclined to overdo it and pay the price.

Reduce exertion, use wheelchair, rest a lot, watch reruns of non-stressful shows.

I try to be aware of my activity threshold/amount of energy expenditure which doesn't cause PEM, also use heart rate monitoring to help pacing however there are times I still don't manage to avoid PEM/PENE. It's important try work out where your energy level is. Any attempts to build it need to be done very very slowly.

Limit my mental stimulation.

Rest in bed as much as possible after exertion.

Pacing, cutting jobs down into parts to do over days weeks.

Try to limit activity, rest, but I’m not very good at avoiding it.

Pace and rest.

Pacing & using a HR monitor.

By sticking to the exact same routine everyday including same foods, eating at same time, avoiding too much talking or movement.

Trying to stay aware of my body’s responses. And not overdo activity beyond ability. But that is simply not always possible.

Limiting physical and mental strain where possible.

Working within limitations, not overexerting, pacing carefully, avoiding triggers.

Living within my energy limits.

Rest and trying to limit interactions with people, planning to limit any sudden issues.

Only way to avoid is to stay housebound, pacing can reduce it but doesn’t stop PEM.

Changed my lifestyle completely.

Controlling my activities.

Restrict what I do, hire help.

Become increasingly sedentary; mostly stay home; changed job.

Rest. Pace or accept.

Pacing.

Avoid exertion. I get groceries delivered and try to limit errands. If I have a doctor appointment I have to drive to, I need to plan for that several days in advance and do nothing in the days leading up to it. I try to do most appointments by Telemed if allowed. I don't have any kind of social life because I can't handle the lengthy flareups afterwards.

Try to pace where I can, which is very difficult being a single mum and full-time carer without any support or family.

Time limit.

Currently house/bedbound and avoid all triggers as much as possible.

Try to manage my activities but it isn't always possible.

Try to do things in very small chunks with lots of resting in between; d-ribose.

Break every task down smaller. Do the dishes over the day. Sit /lay down in between.

By staying within my energy limits, doing everything slow so my heart rate doesn’t increase too much.

Pacing, limiting activity.

Spend all my time in bed.

Haven't found a way. Alleviate by pacing, making sure I snack before walk etc.

I lie in bed all day doing nothing.

Try, to the best of my ability, to manage my day according to what's in my capacity. This of course isn't always possible, especially if you have caring responsibilities for others. The condition is unpredictable, and my energy often fluctuates throughout the day.

Pacing with a Heart Rate Monitor.

By not trying to do too much. Limiting exercise. Not going to social events. Not having visitors.

Pacing, resting after any activity.

Pacing. This means sitting or lying around every day, housebound. Have someone else do all cleaning, shopping, help with meals. I've set up an induction cooktop on my coffee table.

Going nowhere doing nothing, see no one. I also meditate, do VNS & Lymphatic massage, low inflammation diet.

Avoid those things if I can or just live with it if I can’t.

Pace, rest supine (I'm bedbound for about 23.5 hrs/day), break all tasks down into very short segments - and do them while supine if possible; figure out new minimal ways of doing everything; move slowly; keep elbows pinned to sides so as to not waste energy engaging chest and core muscles; have everything I need around me; have homecare and volunteer help for all the things I can't do; not get stressed/stay self-aware/a few seconds of breathwork as needed (I do this instead of meditating as it takes energy and this doesn’t); use a heart rate and hrv monitor; shower once a week or less.

Noticing cues and then stopping, really stopping - silence, darkness, lying still, until the cues clear up. Cues include internal tremor, icy burn on my skin, overall increase in pain.

Pacing.

Pacing and living a very limited life, supplements to feed my cells such as D Ribose.

Avoidance and counselling.

Pacing, getting to know my limits, [envelope of energy] and staying within my energy limits, mostly only going to areas or locations, i.e., shops etc, that I'm familiar with, where possible.

I try to pace, but I want so much to have some life that I'm not very good at it. It takes so little to cause PENE for me that it's hard to avoid. I'm probably in rolling PENE and my condition is gradually deteriorating.

Strict pacing, saying no to anything I don’t have to do in order to survive.

I am severe so I manage my life in a very strict way, adhering to my energy envelope. If I am able to do a little activity, such as sit up and do a few jigsaw pieces, I set alarms on my phone to stop and I have to stick to it. I also use heart rate monitoring and stop any activity if my HR goes above my baseline.

I try not to invoke an adrenaline surge which would carry me through what I couldn’t normally manage. I try to stay within my limits.

I do as little as possible, including but not limited to laying still in darkness with little to no sound, not moving to eat (often not eating), waiting to go to the bathroom until my body has recovered from the previous movement episode.

Don't overexert.

Avoid all kinds of exertion.

Living quietly with routine. Minimize outings. Keep heart rate below 100.

Pace, rest, avoid the triggers as much as possible.

Prioritise, plan, pace. However, this is not always possible.

I try not to move my body any more than absolutely necessary. This also applies to use of cognitive energy.

Limit cognitive work.

Avoid triggers and pacing.

Pace, rest. Spend majority of the day sitting or lying down. Sleep if I need to. Constantly checking in on myself.

I try to keep life quiet, getting better at saying I've had enough (family interactions), rest as much as possible.

Minimise sensory overload and environmental triggers, they pace and rest as much as possible. Make difficult decisions.

Trying to learn to pace. Trying to figure out what level of activity sets it off.

Try not to overdo it but sometimes I don’t have to do much.

Pacing and resting.

Rest as much as possible, sleep, drink more fluids.

Go to bed to sleep when I recognise PEM symptoms.

The only thing that helps me is resting heavily til it passes.

Myalgic Encephalomyelitis (ME) Awareness

Survey held & feedback collated during ME Awareness Month 2023

Thanks to the International ME community for your support.