MEAI
ME Advocates Ireland

ME Awareness Month Survey Feedback

Post Exertional Response in Myalgic Encephalomyelitis

What kind of exertion triggers your PENE/PEM?

Everything.

Stress, too many things to deal with/think about. Too much physical activity.

Too many senses stimulated at once for a time, foods, energy usage.

Too much of anything- housework, walking, late night, certain food, stress, emotion.

Anything beyond my current limits, limits which vary.

Being around kids, from their busy movement and noise..being out for too long...not enough resting.

Anything that changes my heart rate.

LONG day. UNEXPECTED events requiring immediate response. Mental STRESS. Mental ACTIVITY. Physical ACTIVITY.

Any basic exertion e.g., carers coming into my room & putting light on.

Physical, emotional, stress - usually physical exertion or prolonged social exertion.

Any physical exertion or mental exertion. Prolonged muscle use or short hard muscle use and cognitive strain.

Both mental and physical activity. If I go over my energy threshold in either e.g., too much reading or completing forms or admin needed causes exacerbation of symptoms, same way over exercising or too much physical activity. Find lifting anything weighty or attempting to walk uphill or attempting to hoover has huge payback compared to e.g., short walks on flat even surface.

Long conversation.

Any physical or mental exertion. Walking, standing, talking, laughing, laptop work, staring at screens, too much concentration.

Housework, walking to far, gardening.

Physical- walking too far, doing too much, driving, shopping, crowded places. Mental - Long conversations, learning something new, driving, anything that requires concentration and possibly memory.

Standing, walking, cognitive effort like studying, stressful events, driving.

Being upright too long. Too much talking, watching TV, computer time. Long phone calls, too long on social media!

Too much walking, being in a group of people even 3 or 4 people when everyone asks questions or having to follow and remember too many conversations.

Physical, mental and stress of not being understood.

Mild emotional stress, mild mental stress, surprises, mild physical activity.

Overdoing it in any way…. school work, long conversation, emotional stress, physical activity.

Physical, emotional, cognitive.

Sensory overload, listening and talking, concentrating on important matters, anything needing immediate unplanned reactions, other symptoms causing anxiety.

Any positive or negative stress, leaving the house for anything, not pacing.

Increased heart rate.

More exercise than usual; 3 hours of house chores or errands outside the house.

Housework, shopping, thinking too hard or too much.

Exercise, stress (even short term), grocery shopping, desk job, cooking.

Mental, prolonged.

Physical, mental, emotional, light/sound.

Anything can trigger it, just running errands, going to the grocery store. It doesn't take much. I recently moved to a new state. It took me about three months to get everything packed and shipped. I took four airline flights during that time. Six months later, I have not recovered from the move or the two airplane flights. I spent two full months in bed, and I have crashes and flareups all the time now.

Basic light chores, walking, bring upright, social, and mental exertion, stress.

Movement, exercise, concentration socialising, grocery shopping, being emotionally upset.

Visual/auditory overstimulation; physical activity; emotional distress; pain; mental activity/concentration.

Anything, emotional and physical.

Medical appointments, talking to anyone other than immediate family, standing, especially in one place, driving.

Mild exertion, standing in a line for 5 minutes, stress.

Physical, emotional, and mental.

Being around people or outside the house for more than half an hour, cleaning, cooking, showering.

Everything.

Most things. Shower, small reaction. Short walk, bigger reaction. Several bigger exertions or illness, much bigger reaction.

Reading, working, exercise, social activity.

Interacting with others is especially draining, in person or by phone. Anything that requires a fair amount of cognitive processing. Any slight physical exertion, sometimes just a shower.

Mental is marginally higher than physical exertion. I am very cautious to avoid big emotional swings, but they trigger PEM also.

Physical exercise, stress, rushing, social events, cleaning the house.

Over activity, lack of sleep, stress.

Being upright for more than 5 mins at a time. Emotional triggers, trying to use my brain for something new.

Visual speed or bright colours, physical movement, high pitch noise or constant noise e.g., lawn mowers, reading and concentrating.

Physical overdoing the most; trying to process and act on new info; conversations; sitting or standing up for a few minutes; negative stress, music; showers; mental exertion; on worse days eating and digesting food.

Any demands on my body, from noise/lights, infection, chemical hits, etc, as well as physical, mental, and emotional activity.

Almost everything. Talk for an hour, take a shower.

Physical, cognitive, and worst Is emotional exertion.

Stress/pressure/commitment and/or mental and/or physical activities.

Sensory overload, people moving around, or fluctuations in light, fluctuations in noise, any minimal physical activity that active for more than 20 mins, just being sociable with family or visitors for more 30-40 mins in a controlled environment.

Any kind! It fluctuates too, so something that is ok one day may cause PENE on another. Emotional/stress exertion will cause me to crash very badly. Any small amount of physical or cognitive exertion will cause a crash too. Anything from standing for a few minutes, to processing sound.

Being Upright, stress, doing mental tasks, emotional upset, socializing, traveling, catching a virus.

Both, mental exertion, and physical activity. The very worst trigger for me is talking on the phone or talking in general.

Anything sustained for too long (beyond my normal limits), whether physical or mental or emotion.

Physical, at the moment, moving from the sofa to the chair; mental, holding a conversation or trying to follow a storyline on the tv; emotional, happiness, sadness, excitement, planning something.

Any physical or mental exertion.

Everything- physical, mental, emotional.

Physical & cognitive.

Sensory, e.g., noise, light, smell, surrounding movements, extreme temperature or sudden change in temperature, emotional stress, mental stress, cognitive stress, physical stress, being upright.

Hoovering, walking, crowds, emotional upset e.g., parent having operation and needing support, child having additional needs.

Basic everyday tasks: brushing teeth, showering, getting dressed.

Mainly cognitive exertion.

People, noise, lights, fuss, movement in my peripheral vision, anything that creates the tiniest bit of stress, having to hurry.

Stress (emotional, cognitive, physical), noise, people, commotion.

Noise particularly high pitched, people around me talking, trying too hard to be normal in social encounters. Sometimes I just don't know what triggers it.

Physical, sensory, environmental, and emotional stress, talking while doing a task.

Physical movement, particularly walking, lifting, carrying, and bending. Emotional, such as anger or excitement.

Mental if I have to focus on thinking under pressure or following a plot. Can't read anymore due to brain fog.

Dinner with friends, showering, social event.

Overdoing activity.



Myalgic Encephalomyelitis (ME) Awareness

Survey held & feedback collated during ME Awareness Month 2023

Thanks to the International ME community for your support.