

Post-Exertional Malaise (PEM) in ME/CFS **a brief guide to a hallmark symptom**

Transcript for a video from Dialogues for a Neglected Illness
www.dialogues-mecfs.co.uk

Dr. Luis Nacul: A problem with ME and differential diagnosis particularly compared to some mental illness or depression in particular, is that some of the symptoms are overlapping. So people with depression will have fatigue, will have cognitive changes, which happen in ME/CFS, but there are some key differences. For example post-exertional malaise is typical of ME/CFS, people with depression tend to improve with exercise. This is one of the differences.

Dr. Charles Shepherd: If patients exceed their very limited limitations, in relation to physical activity or mental activity they pay for that and they get this post-exertion exacerbation of these symptoms

Dr Luis Nacul: People may overdo it lets say now and they seem to be OK but in about one day or a few hours they will feel much worse.

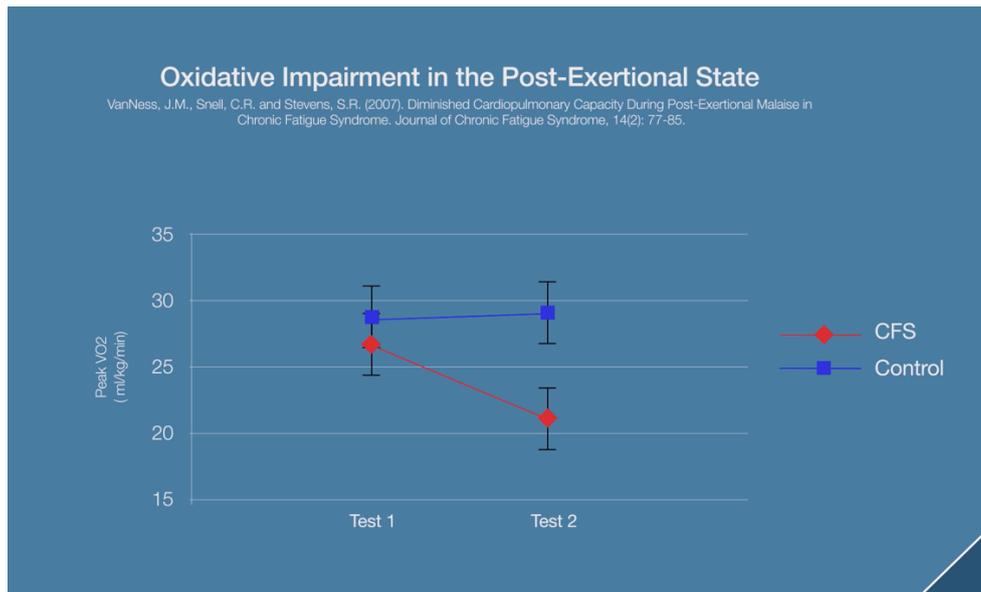
What is post-exertional malaise?

Dr Chris Snell: It's the symptom that's most recognisable and probably unique to the illness. It consists of a decreased function and an exacerbation of symptoms usually following a physical event, but it can also follow a cognitive or mental event and even an emotional event. Recovery time is highly variable, there can also be some delay in when it first appears, even two days after the triggering event.

PEM can be measured objectively!

Dr Chris Snell: We pioneered the use of the 2 day exercise test, where we have people do a test on day one, then we have them come back 24 hours later and do a second test. A large number of our patients, were unable to repeat their performance from day one on day two.

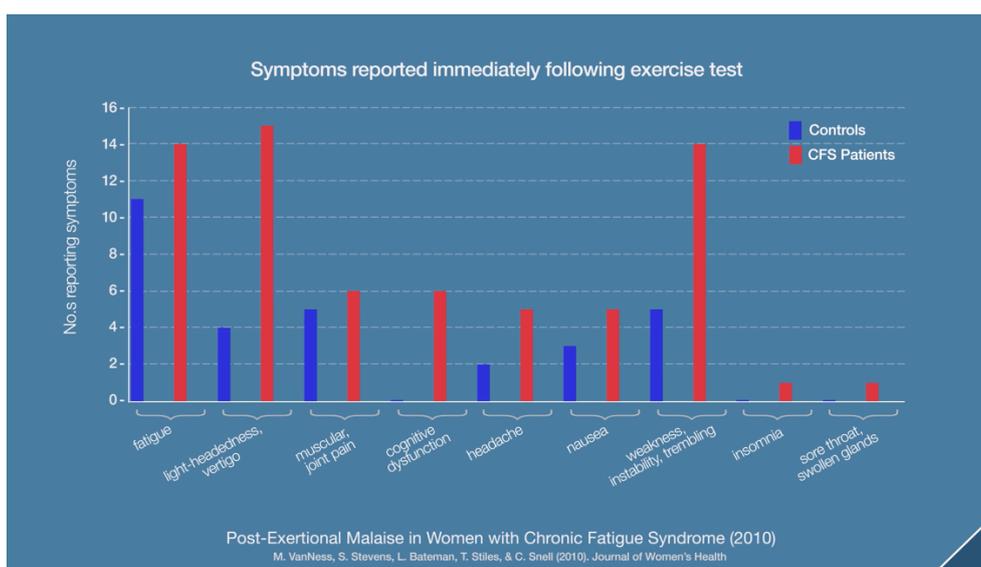
Prof Mark VanNess: The results of the exercise testing, especially the two day cardio pulmonary test provide more objective evidence of post-exertional malaise: cardiovascular, respiratory and metabolic abnormalities. The capability of the systems are diminished in the post exertional state



Is PEM different and unique in ME/CFS?

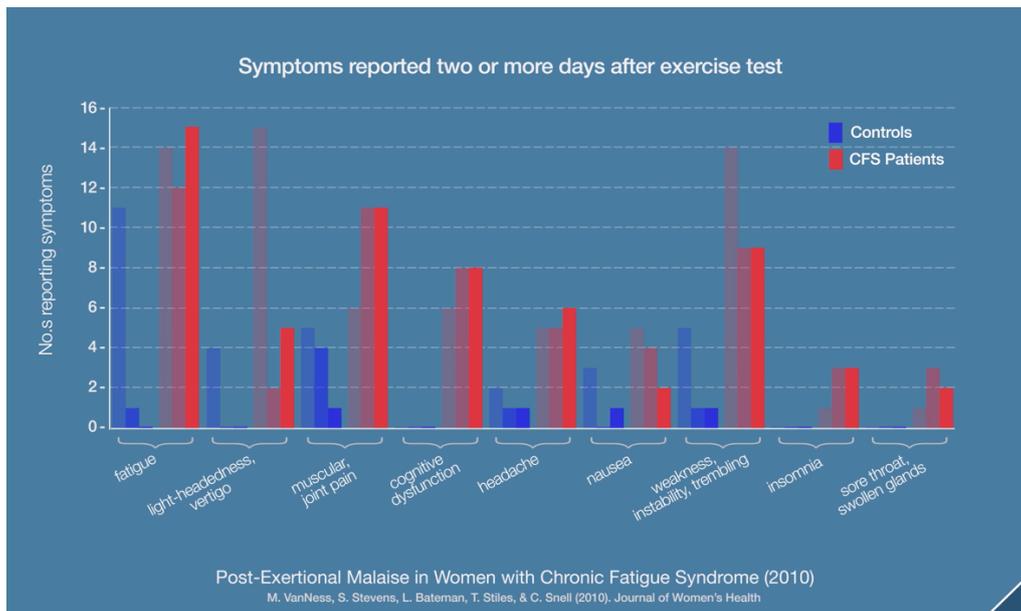
Dr Chris Snell: We would suggest this is unique. It's not been documented in any other illness or even in normal populations even with very deconditioned individuals.

Staci Stevens: PEM is distinctly different in ME than in patients with heart disease, or lung disease or HIV. So we'll test our heart failure patients and they'll say that they're fatigued for a couple of days. We'll test a healthy individual and they may have some delayed onset muscle soreness, but it resolves.



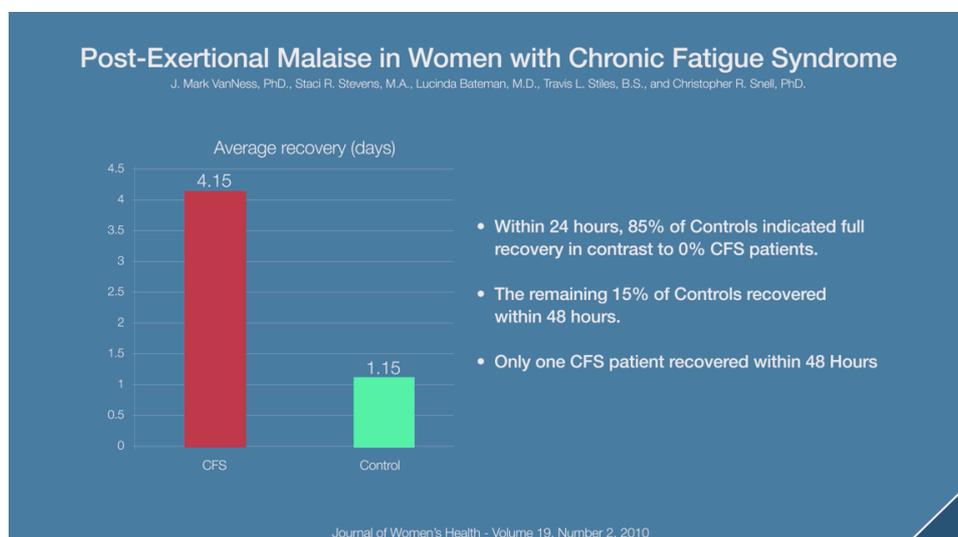
For ME patients, we test them, and there's a whole laundry list of symptoms that are atypical and abnormal. They have flu like symptoms,

they have cognitive problems, they can't sleep, they get sick. And that's completely different from what we see in other conditions.



Dr Nina Muirhead: Post exertional malaise can often start with headaches or a sore throat coming on, feeling like I'm getting flulike or coming down with something and then a couple of days later it really hits me and I literally can't get out of bed and I feel as though I am concussed, I can't concentrate.

Prof Todd Davenport: Fatigue, sleep abnormalities, cognitive abnormalities, immune abnormalities, shook out as being most significantly predictive of ME/CFS. And all of these are sort of very abnormal symptom responses to physical exertion. This is the kind of thing that, just by listening to your patient, can actually be the million dollar work up.



Staci Stevens: Does recovery take 24 hours or longer? If patients aren't recovering in a day and they're expressing three or more symptoms. Chances are they have PEM!

The importance of pacing

Dr Chris Snell: One of the keys to managing ME/CFS is to avoid symptoms of PEM. We recommend an activity called pacing.

Prof Mark VanNess: A successful pacing strategy means learning how much activity produces a post-exertional response and it can be something very benign, walking up and down stairs, standing to do dishes or carry on a conversation, and those can be above what a patient can tolerate.

Dr Nina Muirhead: It can literally be just concentrating for a hour on something, can be enough to trigger it.

Prof Todd Davenport: The act of thinking, reading, using a computer, bed mobility, these are all things that can exacerbate symptoms in I think all patients with ME/CFS but in particular in very sensitive folks who are housebound and bed bound.

Dr Luis Nacul: So it's very important that people understand this concept and pacing can be incorporated into their daily life and daily routines.

Dr Charles Shepherd: there's a big need for education and training of health professionals that could have a very important input here with what is probably the most important aspect of management at the moment.

Post-Exertional Malaise (PEM) is an abnormal response to exertion. It involves both an exacerbation of symptoms and a loss of stamina and/or reduction in functional capacity.

It can be caused by any activities beyond those normally tolerated, whether a single event or a period of slightly 'overdoing'. These could involve –

- **Physical stressors such as exercise, activities of daily living, orthostatic stress.**
- **Cognitive or mental activities and social interactions.**
- **Environmental and sensory stressors such as light, sounds, movement, temperature extremes, chemicals**
- **Emotional stress**

PEM is typically delayed by a day or two and recovery time is abnormally prolonged, whether days, weeks, months or much longer. Overexertion can cause lasting relapse, with patients never returning to their preceding level of activity.

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