

# PEM: It's Time to Retire the Term

## by Pete Hanauer




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A guest editorial by ME/CFS advocate Pete Hanauer. Mr. Hanauer was a law book editor for 35 years, after which he joined the staff at Americans for Nonsmokers' Rights, an organization he co-founded in 1976. He worked there for 16 years, analyzing thousands of tobacco control laws for a national database, until his chronic fatigue forced him to retire last summer. He lives in Berkeley, CA.

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**FOR MANY YEARS**, people who suffered the pain and disruption to their lives caused by ME/CFS also suffered the indignity of being thought, even by many doctors, to have a mental disorder or worse yet, to be malingerers. Fortunately, the medical community is now nearly unanimous in realizing that ME/CFS is very much a physical disease, with very severe consequences.

And yet, a remnant of the past remains in the terms still used to describe the primary symptom of the disease, namely the sheer exhaustion experienced by patients following even slight physical or mental exertion. The term, Post Exertional Malaise, or PEM, not only fails to accurately describe what happens to patients, but actually reinforces the idea that they have a mental or psychological condition.

According to Merriam Webster, there are two definitions of the word "malaise":

1. An indefinite feeling of debility or lack of health often indicative of or accompanying the onset of an illness
2. A vague sense of mental or moral ill-being

The first definition describes a "feeling" accompanying the onset of a disease—not the effect of the disease. The second relates totally to a mental condition. Moreover, a list of synonyms for the word "malaise" includes "unhappiness, uneasiness, unease, discomfort, melancholy, depression, despondency, dejection, angst, ennui; lassitude, listlessness, languor, weariness; indisposition, ailment, infirmity, illness, sickness, disease," all but the last few of which are mental or psychological conditions. In short, the term currently used to describe the principal symptom of ME/CFS strongly points to a mental or psychological illness rather than a physical one.

It is long past time to retire the term PEM and replace it with something that accurately reflects what happens to ME/CFS patients after physical or mental exertion and that respects their dignity. We suggest the term Post Exertional Disability, or PED. When patients must sit down or lie down after the slightest exertion, or are confined to bed or home, because they lack the energy to perform even routine tasks, they are, in a very real sense, disabled. ■