Pacing and Management Guide for ME/CFS and Long COVID

Summary

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an infection-associated chronic neurological disease (G93.32) that presents with symptoms across multiple systems. Post-exertional malaise (PEM) is the pathognomonic symptom of ME/CFS. PEM has also been commonly reported among people with Long COVID, an illness that develops after infection with SARS-CoV-2.
- PEM is a worsening of symptoms following physical or cognitive exertion, often presenting with a characteristic delay. Activities that precipitate PEM were previously tolerated before onset. Two-day cardiopulmonary exercise testing (2-day CPET) shows abnormalities associated with exertion in people who experience PEM.
- Pacing is an activity management strategy that balances rest with activity in order to prevent and mitigate PEM.
- By providing support and education on pacing, healthcare practitioners can play a critical role in improving health outcomes in patients with ME/CFS and Long COVID.
- Monitoring and documentation of both subjective and objective data can help clinicians identify common treatable comorbidities in people with ME/CFS and Long COVID.
- Consistent medical documentation can help patients access disability accommodations and protections.

What is ME/CFS?

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an infection-associated chronic neurological disease (G93.32).[1,2] In order to be diagnosed with ME/CFS, patients must experience substantial functional impairment for six months or more, and present with the following: 1) post-exertional malaise; 2) fatigue; 3) unrefreshing sleep; and 4) either cognitive impairment, presenting as impaired memory or ability to concentrate, or orthostatic intolerance.[1]

While these symptoms are all that is required for clinical diagnosis, the majority of patients experience a range of symptoms presenting in different systems. Other common symptoms include pain of new type or severity (including headaches), chills or night sweats, peripheral neuropathy, sensory sensitivity, allergies or sensitivities to previously-tolerated foods, odors, or medications, sore throat and/or swollen or tender lymph nodes, and gastrointestinal symptoms.[3,4]

ME/CFS occurs in people of all ages, genders, races and ethnicities, although it is more frequently reported in women.[5,6,7] The prevalence of ME/CFS among transgender and gender-diverse people has not been thoroughly studied.

People living with ME/CFS have lower quality of life than people with other severe chronic illnesses, including multiple sclerosis, congestive heart failure, and end-stage renal failure[8,9] with 25% of people with ME housebound or bedbound.[1]

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Severity of the disease may shift in the same patient, both short- and long-term. Patients well enough to engage in a clinical visit may have rested days beforehand and may require bedrest in the days following.

The pathognomonic symptom of ME/CFS is post-exertional malaise (PEM),[1,10] which is the worsening of symptoms and/or the appearance of new symptoms after physical or cognitive exertion. What constitutes overexertion differs in every person with ME/CFS, and will fluctuate in the same individual over time. Activities that precipitate PEM were previously tolerated before onset.

What is Long COVID?

Long COVID[11] (U09.9) is an illness that can develop in both children and adults after a probable or confirmed case of COVID-19, lasting months, years, or potentially be life-long. It can occur following infection of SARS-CoV-2 regardless of severity of acute presentation, including asymptomatic cases, and those who have been vaccinated.[12] In the United States, approximately one in five adults who had COVID-19 experience Long COVID symptoms.[13] Long COVID symptoms may also fluctuate in intensity and/or relapse over time.

Most people with Long COVID report having PEM,[14,15] and nearly half meet ME/CFS diagnostic criteria.[16,17] A survey of more than 3,700 people living with Long COVID in 56 countries showed that 89% reported having PEM within seven months of a suspected or confirmed SARS-CoV-2 infection.[14]

Understanding Post-Exertional Malaise (PEM)

Post-exertional malaise (PEM), sometimes called post-exertional symptom exacerbation (PESE), is the worsening of symptoms and/or the appearance of new symptoms after physical or cognitive exertion. Worsening of symptoms may develop during exertion, but is commonly delayed from several hours to several days. Recovery may take days, weeks, or even months.[18,19] Patients often call the sudden onset of debilitating fatigue, pain, and other PEM symptoms a ‘crash’.

PEM occurs in response to previously-tolerated exertion. Showering, cooking, having conversations, or reading are all things that could potentially trigger PEM in previously healthy individuals. Moreover, activity that is tolerated on one day may not be tolerated on a lower-energy day by the same individual.

Patients experiencing PEM may notice increased difficulty speaking, reading and communicating; increases in pain and neuropathy; flu-like symptoms such as fever or swollen lymph glands; and reactive sensory sensitivity. Patients may report that they feel “weighted down” and have trouble sitting up or even turning over in bed.

PEM is a unique set of symptoms, incongruent with experiences of fatigue after overexertion in healthy individuals.[19,20] Physical deconditioning is associated with reduced cardiac capacity as measured by diminished cardiac output at peak exercise in healthy individuals,[21,22] whereas people with ME/CFS show increased cardiac output at peak exercise.[23] In two-day cardiopulmonary exercise testing (2-day CPET), people with PEM demonstrate impaired response to exercise in comparison to healthy, deconditioned controls.[24] This impaired response includes diminished workload, and inability to increase oxygen consumption, heart rate, and systolic blood pressure during physical exertion.[24-28]

Graded exercise therapy (GET) is a clinician-supervised, gradual increase in physical activity over time. **While GET may be useful in the context of other diseases and disorders, it can lead to decreases in functioning in patients with PEM**. Multiple patient surveys indicate that people with PEM may deteriorate over time if managed with GET.[29] In one study (n=954), 74% of these patients reported deterioration;[30] in another, 81% of respondents reported worsening of symptoms or no change.[31] Most people with ME/CFS are eager to get back to their work, family and social lives, and need little encouragement to be more active; rather, they need the support to rest and pace their activity based on their symptoms.

While the pathophysiology of post-exertional malaise is not fully understood, there is increasing evidence linking symptomatology to metabolic dysfunction including bioenergetic dysfunction; anomalous endothelial response; changes in brain function and impaired cognition; orthostatic intolerance; shifts in methylation and acetylation with implications for gene expression and protein function; and changes to the gut microbiome.[20,32-37]

Recommending someone who has PEM to gradually increase exercise or activity levels causes harm, physical and emotional, sometimes irreversible, and may accelerate the progression of the illness.[29] It is important that clinicians understand that patients who experience PEM do not need to be pushed to increase activity levels; they need to be encouraged to stop, rest, and pace to increase their chances of slowing down disease progression and gaining quality of life.

What can trigger post-exertional malaise?

Identifying triggers for post-exertional malaise is an important aspect of disease management. However, some triggers are easier to avoid than others, and no trigger can be controlled all of the time. Therefore, the goal of pacing is to minimize post-exertional malaise rather than eliminate it. Keeping a daily activity and symptom diary can help patients learn to identify events and activities that trigger PEM. Potential triggers include but are not limited to:

- Physical (activities of daily living, work, exercise)
- Cognitive (reading/writing, long conversations)
- Sensory (loud, repetitive noises, bright or flashing lights)
- Emotional (challenging interactions, tragic events)
- Hormonal changes (e.g. changes during the menstrual cycle)
- Environmental (proximity to allergens, changes in weather, seasonal changes, temperature changes)

Pacing to prevent and mitigate post-exertional malaise

Currently, there is no cure for ME/CFS or Long COVID. Data demonstrate that people with PEM who are able to pace have fewer symptoms, better quality of life, and are more likely to improve physical functioning and fatigue severity.[38,39]

Pacing involves accurately assessing physical, mental, and emotional resources while making room for factors that cannot be controlled, iteratively adjusting rest and activity as needed. What constitutes a sustainable level of activity will differ person to person, and an individual's baseline will fluctuate over time. Patients who can pace well are active when able, and rest when tired. They may plan extra rest ahead of and after strenuous activities in order to prevent and mitigate PEM.[10]

Proper pacing involves building up awareness of the levels of daily activity that do not trigger relapse of symptoms through PEM. People with ME/CFS and Long COVID need encouragement and support to stop, rest, and pace, so they can adapt to daily living and avoid triggering PEM.

Note that 25% of patients with ME/CFS have a severe disease presentation, meaning they are housebound or bedbound.[1] Very severe patients may experience difficulty moving and communicating.[40] Activity management via pacing is unlikely to be useful in patients with very limited mobility.

Pacing is easier said than done, and the emotional toll of evaluating and accepting self boundaries of activity need to be acknowledged by clinicians. Moreover, pacing requires access to resources that allow people to take time off work to rest and adapt activities of daily living. Some people are unable to pace properly due to lack of access to paid sick leave, insufficient income, scarce social support for caretakers, inadequate housing, among other pervasive socio-economic problems that affect people with ME/CFS and Long COVID. Clinicians must work to understand what can be done within the context of each patient. Below are some ways clinicians can work with patients who present PEM in order to help them identify triggers, manage symptoms, and learn how to stop, rest, and pace.

Energy quotas

Terms like *energy budget* or *energy envelope* may help people conceptualize energy limitations in chronic illness. The spoon theory is an analogy frequently used among people with fatiguing illness to communicate their available energy, its finite nature, and that even everyday activities like eating, showering, and reading still use energy.

In spoon theory, a spoon represents a unit of energy. Each day a person has a limited number of spoons available. If a person with ME/CFS uses more than their allotted number of daily spoons, they may trigger post-exertional malaise.

Beyond pacing: specific activity management strategies

***Cutting activity in half*:**
Cutting daily activity in half can help a person with ME/CFS or Long COVID find a baseline level of activity where PEM is less likely to occur, with the understanding that the baseline may become better or worse over time.

***Preparing for anticipated exertion*:**
Encouraging patients to prepare for anticipated overexertion— such as attending a wedding, giving a lecture, or having guests in the house— can help them plan for worsened illness before it occurs. Pre-making meals, asking friends or family for additional help, and planning on soothing, low-energy activities can mitigate PEM after necessary exertion.

People with ME/CFS and Long COVID can still plan for unexpected post-exertional malaise due to factors out of their control by making sure medications are ordered promptly, well-tolerated snacks and electrolytes are on hand, and by clarifying expectations with others.

Some people with ME/CFS and Long COVID have found that being inactive before planned exertions, such as attending a wedding or giving a talk, can help mitigate the effects of post-exertional malaise. This strategy is called radical rest. Some patients benefit from spending their time or resting in a silent, dark or dimly-lit room, away from sensory stimuli.[41]

Documentation of ME/CFS and Long COVID

Document patient reported outcome measurements (PROMs):
PROMs that do not strain the respondent can help diagnose and document fatigue and PEM.[42] Proper documentation can assist patients in accessing disability protections and accommodations. PROMs that have reliably differentiated ME/CFS patients from healthy controls include the fatigue severity scale (FSS), and the DePaul Symptom Questionnaire for PEM (DSQ-PEM) and its pediatric version (DSQ-PSQ).[43]

***Monitor objective values*:**
Correlating information from the patient’s symptom diary and activity log with objective values such as heart rate, oxygen saturation, blood pressure, and heart rate variability (HRV) may be useful. Patients can access these data using wearable devices, finger oximeters, and blood pressure monitors.

Reducing activity to keep vitals within normal limits can help prevent or mitigate PEM. Some devices can be programmed to alert the wearer when their heart rate reaches a certain value. Encourage patients to program their devices to alert below the value identified as triggering PEM, so that they may stop or slow their activity.

Data collected by wearable devices can also help clinicians identify comorbid diseases and disorders of autonomic dysfunction, such as POTS[44] and orthostatic hypotension (OH).[45]

Additional resources

Pacing guides for people with energy-limiting illness:

- MEAction’s Pacing and Management Guides for ME/CFS (adult, pediatric, medical provider): https://www.meaction.net/resource/pacing-and-management-guide/;
- Bateman Horne Center’s The ME/CFS Crash Survival Guide: https://batemanhornecenter.org/education/mecfs-guidebook/

Post-exertional malaise:

Long COVID Physio:
https://longcovid.physio/post-exertional-malaise

Long COVID:

World Health Organization Q&A:
https://www.who.int/news-room/questions-and-answers/item/coronavirus-disease-(covid-19)-post-covid-19-condition

Dysautonomia management:

Peter Rowe, Chronic Fatigue Clinic, Johns Hopkins;
https://www.dysautonomiainternational.org/pdf/RoweOIsummary.pdf

Spoon Theory:

Spoon Theory on ME-pedia:
https://me-pedia.org/wiki/Spoon_theory

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