

PACING AND MANAGEMENT GUIDE FOR PEDIATRIC ME/CFS AND LONG COVID



What is PEM?

Post-exertional malaise (PEM) is the cardinal symptom of ME/CFS, and is a symptom that has been reported in children with Long COVID. PEM is a flare of symptoms and/or the appearance of new symptoms after exertion, often presenting 24 hours after the triggering event. Physical activity, cognitive overexertion, and sensory overload can all trigger PEM.

Post-exertional malaise is a unique symptom, incongruent with experiences of fatigue after overexertion in healthy children. It is not the same as being more tired than normal after activity, or second-day muscle soreness after activity.

What is pacing?

Pacing is an **activity management** strategy. Pacing means being active when able, and resting when tired. Parents or guardians may need to plan extra rest for children ahead of activities.

The goal of pacing is to prevent worsening of symptoms rather than to do more each day.

ME/CFS

Myalgic encephalomyelitis/chronic fatigue syndrome, is a neurological disease triggered by an infection in the majority of people. It is a complex chronic disease with symptoms in multiple body systems, including neurological, immunological, endocrine, and metabolic.

Long COVID

Long COVID may refer to several post-infectious illnesses that can develop after having COVID-19. Many—but not all—people with Long COVID have symptoms consistent with ME/CFS and go on to acquire an ME/CFS diagnosis.

A note on graded exercise therapy

Graded exercise therapy (GET) is a gradual increase in activity over time as directed by a clinician, under the assumption this will help return the patient to a healthy activity level. Because post-exertional malaise is the hallmark symptom of ME/CFS, **programs that gradually increase exercise** may do **more harm than good**.

A recent, large-scale survey found that ~80% of people with ME/CFS **found no benefit** or **significantly worsened** on graded exercise regimens.

The core symptoms of ME/CFS and Long COVID are not due to deconditioning. Children with less severe disease presentation may have activity levels similar to that of healthy children, but still experience post-exertional malaise when they overexert.

EXERTION ≠ EXERCISE

Exertion is defined here as anything that **stresses or strains the system**. Some stressors can be controlled for and some cannot. Identifying triggers for post-exertional malaise is vital to a child's physical and psychological well-being. Potential triggers include:

- **Physical** (running, walking, bathing, brushing hair/teeth)
- **Orthostatic** (standing or sitting upright)
- **Cognitive** (conversations, doing homework, learning in class)
- **Sensory** (sudden or repetitive noises, bright or flashing lights)
- **Emotional** (challenging interactions or events)
- **Environmental** (allergens, changes in weather, poor air quality)

Post-exertional malaise may be delayed for hours or days after the exertion, often appearing after 24 hours. This is an important consideration when connecting PEM to a triggering event.

Note: No trigger can be controlled all of the time. The goal of pacing is to **minimize** post-exertional malaise, rather than eliminate it. Keeping an activity and symptom diary with your child can help identify triggering events.

Beyond pacing: activity management

Radical rest

Some people who experience post-exertional malaise have found that being **inactive before planned activities**, like going to the movies or having a sleepover with friends, can help minimize or prevent PEM symptoms. This strategy is called **radical rest**.

Make room for recovery time

Knowing that an activity is coming can also help you and your child **plan for worsened symptoms** should they occur. Plan very low-energy activities for your child, like reading aloud, watching their favorite show, or soothing art projects. Stock up on snacks that your child tolerates even on their worst symptom days, and keep plenty of water on hand.

Cut activity in half

Decreasing activity by half to start with can help your child find a baseline -- with the understanding that the baseline can become better or worse over time. While some people who experience PEM have a progressive disease course, many may increase their baseline by avoiding overexertion.

Learn your child's limits

A **symptom diary** can help you and your child keep track of symptoms and activities each day, making it easier to identify triggers that lead to PEM. You can download an app for this purpose, or keep track on paper. In addition, a wearable device can ensure your child's heart rate is recorded when engaged in an activity that turns out to trigger PEM.

Ensuring your child's heart rate stays **below that value** can help prevent or mitigate PEM.

Some devices can be programmed to **alert the wearer** when their heart rate reaches a certain value. Programming your child's device to alert them before their heart rate goes too high can help them learn to gear down before their activity worsens symptoms.

Good pacing practice requires that your child is encouraged to **listen to their body** and is given the opportunity to **adjust their activities** accordingly. If your child continues to develop PEM, they may have to decrease their activity. Likewise, they may be able to increase their 'safe' heart rate if they do not experience PEM at those values.

Break necessary activities into manageable tasks

Encourage your child to avoid trying to 'perform' as if they are healthy. They should be encouraged to sit down wherever they need to, stop activities whenever they like, and speak up for themselves

when they are with others. Above all, avoid pushing them to engage when they are exhausted or overwhelmed. Both children and adults may be inclined to push through their symptoms to participate in enjoyable activities rather than to shirk the games, projects, and social engagements they love.

However, most activities can be adapted for your child.

- Keeping supplies for a project-in-progress in its own container can help make it easy to stop and resume an activity whenever your child is ready. Purchase some cheap multi-pack scissors and glue sticks so all the supplies for each project are kept together.
- Instead of cleaning their whole room at once, you can help your child break the room up into sections or 'quadrants' to tidy at a time. This can also help if your child feels overwhelmed or unsure where to start.
- Talk to your child's teachers about reducing their homework by answering every other question on worksheets geared to practicing a skill– in math, for example. Periods of deliberate relaxation to break up homework may be helpful.

Prioritize Activities

When faced with a challenging activity, consider its:

→ **Importance:**

How necessary is this activity? What would happen if your child left it undone? Does it contribute to a balance of life activities (e.g. learning, health, hygiene, play, relationship) for your child?

→ **Difficulty:**

How challenging would it be for your child to do each step of this activity on their own? Can the steps be modified or spread out? Can they do it less frequently or for a shorter amount of time?

→ **Specificity:**

Could someone else do the activity for them or does it need to be the child? Can steps in the activity be alternated between your child and a helper?

After considering each, you may choose to:

- Drop this activity if it isn't necessary or isn't helpful
- Ask for accommodations for your child, either temporarily or for good
- Delay doing this activity and allow your child time to rest
- Do this activity, but less often than before, or only when absolutely necessary
- Do this activity, but adapt/change how you do it to support your current well-being

Example: participating in an after-school art club

1. **Importance** - It's important for your child to have healthy social interactions when they can. If participation is stressful, or requires a long recovery period rather than a positive social experience, it may be time to drop the activity.
2. **Difficulty** - It may be challenging to engage in additional activity after a long schoolday.
3. **Specificity** - Your child is the only one who can do this activity for themselves.

Adapting Activities

1. Could your child participate in a weekend art class, instead?
2. Can your child participate for shorter periods and observe for the remainder? Can they attend less frequently?
3. Have a 'hard stop' after a certain period of time?

Ideas for School Accommodations

Work with your child's school for accommodations that are specific to your child's current limitations. Many of the well-known accommodations for other conditions, such as traumatic brain injury or ADHD, can be helpful for children with ME/CFS or Long COVID. Here are some accommodations that you may consider to help your child succeed in school.

Changes to the environment

- Taking tests in a quiet space
- Use of mobility aids like a wheelchair or scooter
- Rest periods where the child can lay down in a quiet, dim environment
- Ability to elevate legs
- Allow water & electrolyte drinks in the classroom at all times
- Allow bathroom breaks without dismissal

- Allow sunglasses or headphones
- Late start / early dismissal
- Allow flexible schedule
- Homebound instruction

Changes to instruction

- Checking in frequently on key concepts
- Getting outlines of lessons
- Self-paced workload
- Modified gym class or substitute health class

For more information check out Long Covid Families' [resource page on school accommodations and modifications](#) for students with Long COVID. Topics covered include 504 plans, Individualized Education Plans and more.