Pacing and management: Tips for parents and caregivers



LONG COVID ESSENTIALS: A series by <u>The Sick Times</u> & <u>Long COVID Justice</u>

Scientists are working to understand and find treatments for Long COVID. But with support from their parents/caregivers and other trusted adults, kids and teenagers with Long COVID can take steps to help manage their symptoms.

* Long COVID terms:

- **Pacing**: Pacing is about keeping daily activities at a safe level. The goal is to stop your child's symptoms from getting worse while saving energy for things they enjoy or that are most important to do.
- PEM: Many people with Long COVID get <u>Post-Exertional Malaise (PEM)</u>. It is also known as post-exertional neuroimmune exhaustion (PENE) or post-exertional Symptom Exacerbation (PESE). This means their symptoms get worse after physical, emotional, or mental activity. Some people call this a "crash."
- Crashes can happen hours or days after activity. They can be brief or last for weeks
 or more. Possible triggers can include exercise, stress, excitement, hot weather, noisy
 places, or "overload." They can also be triggered by normal daily activities like doing
 homework or spending time with friends.
- **Baseline**: The overall state of your child's health. This includes how much daily activity their body and brain can handle.
- Trigger: An activity, event, or situation that makes their symptoms worse.

★ Pacing: Tips for managing Long COVID

Pacing is a way to help manage your child's Long COVID symptoms. Pacing means saving energy, resting when tired, spacing out activities, and encouraging them not to push themselves too hard. The goal is to minimize symptoms and save energy.



Pacing can mean building "rest stops" into your child's day, saying "no" to some activities, helping them to set limits, planning ahead, making time to recover, breaking tasks into smaller parts, and other steps.

Here are some pacing tips for caregivers of children and teens living with Long COVID.

- People with Long COVID need lots of rest. When your child feels tired, encourage
 them to rest. Help them to identify and express when they feel tired, or other common
 symptoms like cognitive issues or dizziness. Provide a quiet place for them to lie
 down and close their eyes, switch to low-energy activities, or suggest sitting down for
 a while and taking a break.
- Keep track of your child's activity levels and symptoms. This can help you to identify
 what causes crashes and better understand their baseline.
- Once you understand things that trigger your child's PEM, aim to avoid, plan around, or space out those activities. Let them know it's okay to say "no" to activities that will make them crash.
- Make time for low-key fun. Set time aside to do things your child enjoys, especially activities that don't use up a lot of energy. Try to avoid things that cause them stress.
- Take steps to protect your child from catching COVID-19 again. Repeated infections can lead to worse symptoms.
- Let them know it's okay to talk about how they're feeling.
- "Radical rest" means resting before your child feels tired, so they have more energy later. Resting before a big event can help to "recharge their batteries."
- **Plan ahead:** when your child has a big event or busy day coming up, set aside some "rest time" beforehand, and some "recovery time" afterward.

See our <u>resource about fatigue and PEM</u> and our <u>resource about the importance of being</u> <u>cautious with activity and exercise</u> for more recommendations.



*** Supports at school:**

Talk to your child's school about how Long COVID affects them and any accommodations that will support their learning and wellbeing. This might include having a quiet space where they can lie down, allowing a flexible schedule, adjusting their workload, getting lesson outlines, skipping gym class, granting extra time to complete tasks, or other accommodations. During a crash, your child may need to miss school and stay home. This resource has more information about potential accommodations.

*** Resources:**

- Pacing guide for children and parents, and one for doctors #MEAction
- Guide to share with friends and family Bateman Horne Centre
- Tips for parents supporting a child with Long COVID The Conversation
- Video: Supporting Kids with Long COVID in the Classroom Long COVID Kids
- Online peer support for people aged 13–18 Long COVID Kids
- <u>Educational Toolkit</u> for teachers and parents Long COVID Kids
- <u>Video: Understanding PEM/PESE</u> Long COVID Physio
- <u>Letter to share if a doctor recommends exercise</u> Workwell Foundation
- "Pacing Penguins" poster (pacing tips for children) Long Covid Kids
- Resources for children and families Johns Hopkins Children's Center

FULL SERIES OF FACTSHEETS WITH LINKED RESOURCES + MORE:

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QUESTIONS? connect@s4hi.org

This series was designed by people living with Long COVID and associated diseases. Each resource sheet has been reviewed by patient and medical experts. This is an informational resource, not medical advice. Publication date: 12/13/2024.