



START HERE

First Steps for Families

If your child is still unwell weeks or months after having COVID-19, you're not alone. Many families are navigating pediatric Long COVID, sometimes called "post-COVID conditions." This guide is designed to help you take the first steps with confidence and support.

1. TRACK SYMPTOMS

When symptoms are unpredictable or vague, tracking them can help make sense of what's going on. This is one of the most helpful first steps you can take.

Why symptom tracking matters

- It helps you identify patterns and triggers
- It supports conversations with your child's doctor, school, or therapists
- It builds a record you can refer back to over time

What to track

When symptoms are unpredictable or vague, tracking them can help make sense of what's going on. This is one of the most helpful first steps you can take.

What symptoms are showing up

Include physical (fatigue, dizziness, headaches), cognitive (brain fog, memory issues), and emotional symptoms (anxiety, mood swings)

When symptoms appear

Note what time of day they show up

Track what happens before or after symptoms start

Look for delayed effects, like feeling worse the day after an activity



WRITE DOWN EVEN SMALL CHANGES. PATTERNS OFTEN EMERGE OVER TIME.

What to track, continued

What makes symptoms better or worse

- Record anything that seems to help, like rest or quiet time
- Note triggers, like screen time, loud noise, heat, stress, or physical activity
- How your child feels before and after activity
- Are they tired or energized beforehand
- Do they feel worse after a walk, school, or socializing
- How long does it take them to recover

2. PRACTICE ENERGY PACING

Many children with Long COVID feel worse after physical or mental effort. This is called post-exertional symptom worsening (PEM). It can happen hours or even a day or two after an activity.

What pacing can do

- Helps your child avoid crashes or flare-ups
- Balances activity with rest to protect recovery
- Gives your child a sense of control over their energy

How to pace daily life

- Write down symptoms to share with the doctor at a later time.
- If medical appointments feel overwhelming, consider rescheduling non-urgent ones.
- Follow your child's care plan and reach out to their clinician if you are concerned about new or severe symptoms.

Use our Pacing Guide for age-appropriate examples and tips.

3. TALK TO YOUR CHILD'S DOCTOR

You may need to guide the conversation. Some providers are still learning about Long COVID in kids. Coming prepared helps you advocate for the care your child needs.

Bring helpful information

- A symptom log that shows patterns over time
- A timeline of when symptoms started and how they've changed
- Notes about what helps or worsens your child's condition.

If your doctor is unfamiliar with Long COVID

- Share trusted information from longcovidfamilies.org
- Ask if they can consult with a specialist or refer you to one
- You can also request a second opinion if needed

See our How to Talk to Your Doctor Guide for scripts and printable prep sheets.

4. SUPPORT MENTAL HEALTH

Long COVID can affect emotions and behavior, not just the body. Your child may feel frustrated, anxious, isolated, or overwhelmed. These feelings are valid and common among children managing ongoing illness.

How you can support your child

Listen with Patience

- Give your child space to share their feelings without rushing to fix them.
- Validate their emotions so they know what they feel is real and matters.

Create Predictability

- Stick to a regular routine to help your child feel safe and calm.
- Build in small rituals like bedtime reading or morning check-ins to give stability.

Offer Rest and Breaks

- Encourage quiet time or gentle activities when your child feels overwhelmed.
- Normalize breaks so your child does not feel guilty for needing them.

Build a Support Team

- Seek out a therapist or counselor who understands chronic illness.
- Partner with teachers, school staff, and trusted adults who can provide extra support.

Check In Regularly

- Ask open-ended questions such as “What felt hard today?” or “What helped you feel okay?”
- Keep check-ins simple and consistent. Even short conversations can make a lasting difference.

5. WORK WITH THE SCHOOL

Children with Long COVID may struggle in school even when symptoms aren’t visible. They may qualify for school accommodations under U.S. federal law.

Ask about support options

- A 504 Plan for things like flexible attendance, reduced workload, or rest breaks
- An IEP if your child’s learning is significantly affected
- A health plan with the school nurse to manage symptoms during the day
- Keep communication open with teachers and staff.
- You are your child’s best advocate.

YOU ARE NOT ALONE

Many families are walking this same path. Long COVID can feel unpredictable and isolating, but what you see is real. Your persistence and advocacy matter.

- Keep asking questions
- Keep tracking symptoms
- Keep reaching out for support



YOU ARE DOING A GREAT JOB. AND YOU ARE NOT ALONE.