

# Talking with your child's provider



**LONG COVID ESSENTIALS: A series by [The Sick Times](#) & [Long COVID Justice](#)**

[Long COVID](#) is a chronic condition that occurs after a SARS-CoV-2 infection and is present for at least three months. It includes a range of symptoms or conditions that may improve, worsen or be ongoing. [Children can develop Long COVID, too.](#)

## \* **If you think your child has Long COVID: Talk to your child's provider**

Right now, there is no cure. However, there are some medications and strategies that may help ease your child's symptoms. Your child's doctors can alert you to new treatments. They should also educate themselves and you about symptom management.

## \* **Other potential Long COVID symptoms:**

- Difficulty completing schoolwork
- Difficulty being active or playing
- Difficulty getting up or doing things in the morning
- Feeling isolated and misunderstood
- New sensitivities to certain foods
- Not wanting or being able to attend school or family activities



## **Children and young people may not have the language to explain how they're feeling.**

Therefore, they may explain their symptoms differently. Children may not understand that their Long COVID symptoms aren't a usual part of development:

- "My legs feel heavy," explaining fatigue.
- "I don't want to go to school," explaining post-exertional malaise.
- "I don't want to get out of bed," explaining fatigue.
- "My head hurts," explaining brain fog or headache.
- "I can't breathe," describing tachycardia or rapid heartbeat.
- "I don't want to eat that. It's gross," describing a change in taste or smell.
- "I can't do it," explaining cognitive dysfunction with school work.
- "My throat hurts," This can indicate pain in the neck or head, meaning a migraine.
- "It's hard to walk up the stairs," indicating POTS or dysautonomia.

## **\* 1-2 weeks before the appointment:**

*Start a journal and try to update it at the same time every single day – learn more in our [resource on tracking symptoms](#).*

If known, write down the dates of when your child had COVID-19. You should also list out:

- Your child's COVID-19 symptoms:
    - What were they?
    - How long did they last?
    - How did your child act?
  - When did your child's Long COVID symptoms begin?
    - What are they?
    - How long do they last?
    - Are the symptoms constant or fluctuating?
    - How does your child act?
    - Do they worsen after school, activity, or after doing homework?
- Be as specific as you can.



- Is your child still able to attend school, family events, sports, and other activities? Are they cognitively alert or drained afterward?
- How has their life changed? Are they still able to engage in hobbies and activities they used to enjoy before their COVID-19 case?
- Make a list of all the medications your child is taking, why they are taking it, and what they find helpful or not helpful for their symptoms.

## \* **During the appointment:**

*Bring your journal. If your provider is dismissive, you can ask to be seen by another medical provider.*

- Explain how this is affecting your child – be honest!
- Make sure your child's provider is clear about what the next steps are.
- Ask questions: What medications or symptom management strategies might help my child? What activities should they avoid?
- Ask for a summary of the appointment and ask your provider to write down instructions.
- Ask for your health care provider's support regarding your child's school, family and other activities.
- Consider seeing a functional medicine provider.
- Ask for a referral to a Long COVID clinic. Pediatric clinics are rare but some adult clinics may be able to help.



## \* **After the appointment:**

- Follow the provider's directions, but watch out for anything that does not help your child.
- Continue to track their symptoms.
- If something is not helping, contact your health care provider.
- Remember: There is still a lot we don't understand about Long COVID.
- Be patient and listen to your child.
- If you still have questions, make another appointment with your child's doctor or ask for a second opinion.

## \* **Resources:**

- [List of Long COVID clinics](#)
- [How children may explain their symptoms](#) – Long COVID Families
- [ME/CFS in Young People](#). Appendix E has a sample letter your health care provider can give to your child's school – *Frontiers in Pediatrics*
- [Kennedy Krieger Center Pediatric Post COVID-19 Rehabilitation Clinic](#) (DC/Baltimore-area clinic)
- [Spotting Long COVID Symptoms in Children](#) – Children's Hospital Los Angeles
- [Long COVID Kids](#) – Support groups
- [Long COVID Families](#) – Support and advocacy
- [New Report Raises Concerns About Long COVID in Children](#) – *The New York Times*

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**QUESTIONS?** [connect@s4hi.org](mailto: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.*