

# Getting Ready to Talk about Long COVID with Your Child's Doctor

## What is Long COVID?

Long COVID is when someone has one or more new, ongoing, or worsening symptoms that last for at least three months after getting COVID-19. It is sometimes also called “Long Haul COVID” or “Post-Acute Sequelae of COVID-19 (PASC).”

Long COVID can happen to anyone, even if they had mild or no symptoms when they had COVID-19 or never had a positive test. Some children may have symptoms that do not go away after having COVID-19, and others may have symptoms that come and go over time.

If you think your child is experiencing symptoms of Long COVID, it can be hard to know where to start. This guide will go over what Long COVID can look like in children 5 years old and younger, and how to talk about it with your child's doctor.

## What are the symptoms of Long COVID?

There are more than 200 symptoms of Long COVID that can be different across age groups. Children who have Long COVID can have any mix of them. They can also have groups of symptoms across different parts of the body.

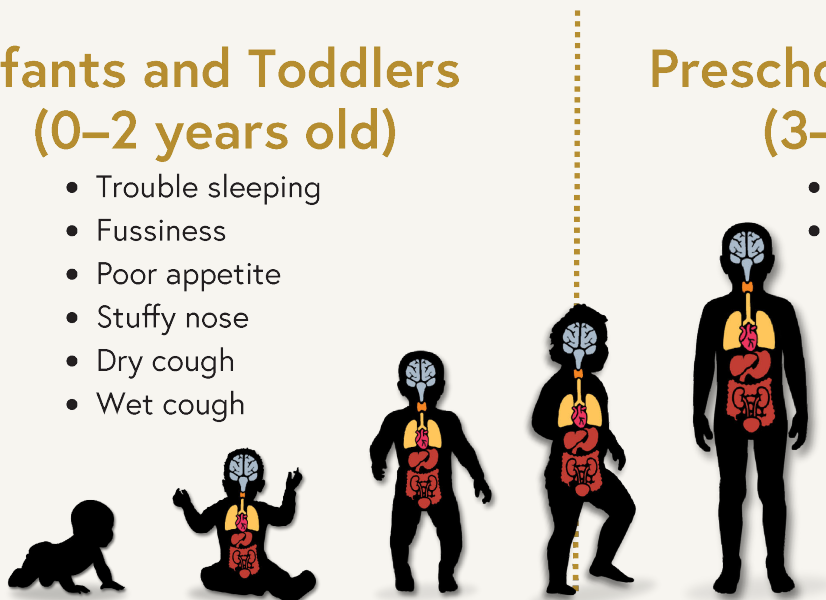
## Most common prolonged symptoms associated with a history of COVID-19 in young children

### Infants and Toddlers (0–2 years old)

- Trouble sleeping
- Fussiness
- Poor appetite
- Stuffy nose
- Dry cough
- Wet cough

### Preschool-Age Children (3–5 years old)

- Dry cough
- Daytime tiredness/sleepiness or low energy



### How else might Long COVID affect my child?

If your child has Long COVID, they may:

**Have trouble eating.** This may look like refusing meals or showing less interest in food.

**Become fussy.** Children under 3 years old may become more irritable and hard to comfort throughout the day.

**Have difficulty sleeping.** This may look like taking a long time to fall asleep at night, waking up throughout the night, or resisting naps. Children ages 3 to 5 years old may feel more tired during the day and play less.

## What should I do if I think my child has Long COVID?

If you think your child may have Long COVID, it is important to talk with their doctor. Make an appointment with your child's doctor to talk about what you are worried about, or talk about these issues during your child's regular doctor's visits.

## Right now, there is no cure for Long COVID

There is no treatment for Long COVID yet, but doctors can keep track of how your child is doing and give them medicine to help manage some symptoms.

For young children with Long COVID, regular rest can help their body and mind feel better. You can support rest for your child in these ways:

- Keep steady sleep routines, with consistent bedtime at night and naps during the day. Quiet time still helps, even if your child doesn't fall asleep.
- Build in breaks during playtime or shorten playtime by about half, especially if your child gets tired or fussy.
- Keep sounds gentle, such as lowering the TV or music volume and choosing quiet toys that don't cause too much excitement.
- Use soft lighting, and avoid bright or flashing lights, especially during screen time or before sleep.

## Before Your Child's Doctor's Appointment

Try your best to remember when your child had COVID-19 (once or multiple times) and what your child's experience was like during that time. Write down all of the symptoms they had, even if they went away.

Keep a journal for at least 1–2 weeks to write down:

- Symptoms, including when they start, how bad they are, if they happen more when doing certain activities, how long they last, and anything that makes them feel better or worse; write down any patterns and groups of symptoms you see
  - Try to do this at the same time of day over the 1–2 weeks
  - Try to do this when your child is changing from one activity to another because that is when symptoms could get worse

- What activities your child has been doing, like going to school or playing
- A list of all of the medications your child is taking
- Records of tests your child has done with other doctors, or a list of specialists your child has seen

## **During Your Child's Doctor's Appointment**

For appointments with your child's doctor, do the following:

- Bring a list of the five symptoms that bother your child the most; put them in order, starting with the most concerning ones
- Ask questions about your child's symptoms and how to manage them
- Be ready to talk about what your child's days are like, including what activities make their symptoms worse, and any medicines that seem to make their symptoms better or worse
- Make sure you understand the next steps in your child's care
- Ask for a summary of what you and your child's doctor talked about during your visit
- Ask your child's doctor to write down important instructions for you to bring home

## **After Your Child's Doctor's Appointment**

Follow the plan you talked about with your doctor. Remember that there is still a lot we are learning about Long COVID, and that different doctors may have different ways of working with families affected by Long COVID. If you still have questions, you can make an appointment with another doctor for a second opinion on how to care for your child's Long COVID symptoms.

If you want to learn more about what RECOVER has learned about Long COVID in children, read RECOVER publications at [recoverCOVID.info/peds-pubs](https://recoverCOVID.info/peds-pubs).