

# 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 ages 6–17 years old, 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 children

### Common Symptoms in School-Age Children (6–11 years)

- Feelings and behavior**
- Fear about specific things
  - Refusing to go to school

- Heart and lungs**
- Palpitations during exercise

- Skin, hair, and nails**
- Itchy skin or skin rash

### Common Symptoms In Both School-Age Children and Adolescents

- General symptoms**
- Trouble sleeping
  - Tired after walking
  - Poor appetite
  - Daytime tiredness/sleepiness or low energy

- Feelings and behavior**
- Feeling depressed
  - Feeling anxious
  - Fear of crowds or enclosed spaces

- Nerves and brain**
- Headache
  - Trouble with memory or focusing

- Heart and lungs**
- Feeling lightheaded or dizzy

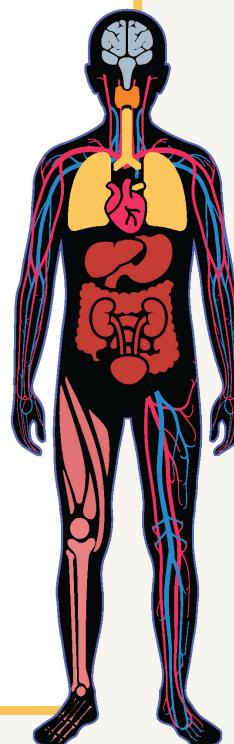
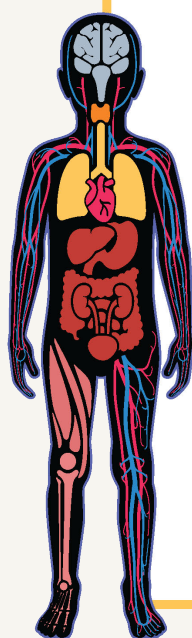
- Stomach and intestines**
- Stomach pain
  - Nausea or vomiting

- Muscles and bones**
- Body, muscle, or joint pain
  - Back or neck pain

### Common Symptoms in Adolescents (12–17 years)

- Feelings and behavior**
- Panic attacks

- Ears, eyes, nose, and throat**
- Change or loss of smell or taste
  - Stuffy nose



## How else might Long COVID affect my child?

If your child has Long COVID, they may:

**Have trouble playing or doing schoolwork.** This may look like trouble focusing, reading or thinking at a slower pace, needing to have things repeated multiple times to learn, or needing more breaks when reading or doing work in school or at home.

**Have trouble being active.** This may look like not being able to be part of sports teams like they used to, having trouble walking or standing, including walking up stairs, worsening of symptoms after being active, or needing to rest more.

**Have trouble getting things done in the morning.** This may look like having trouble sleeping, which may make early mornings an especially hard time for them, or needing extra time to do school tasks assigned in the morning.

Long COVID has many associated conditions, like post-exertional malaise (PEM) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). These conditions can make your child feel very tired after doing daily tasks that require mental or physical effort. Even small activities can cause a “crash,” where your child may need to rest for hours or days. The tiredness does not get better with regular rest. It’s important to let your child’s doctor know about any associated conditions your child may have, as their symptoms can overlap with Long COVID.

## **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 children with Long COVID, getting rest can help the body as well as the mind. It can also help symptoms get better and may keep symptoms from getting worse. Getting rest includes:

- Getting plenty of sleep at night
- Not doing things that make your child’s body work hard, like running fast
- Not doing things that make your child’s mind need to focus a lot or pay close attention
- Doing things that keep the mind calm and will not cause a lot of stress

## **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 hanging out with friends
- 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).