

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

What is Long COVID?

Long COVID is when a child still has 1 or more new symptoms of COVID-19 that last for at least 4 weeks after first getting an infection. It is sometimes also called “Long Haul COVID” or “Post-Acute Sequelae of COVID-19 (PASC).” Note that some children may have no symptoms when they first get an infection, and some may never have had a positive test.

Long COVID affects what a child is able to do during a day, like how they play or if they are able to go to school.

Long COVID can happen to any child, even if they had mild or no symptoms during their COVID infection. Some children may have symptoms that do not go away after their COVID infection. Some children may start to feel better and then start having symptoms.

There are more than 60 symptoms of Long COVID. Children who have Long COVID can have any mix of them. Children can have symptoms that come and go. They can also have groups of symptoms across different parts of the body.

What are the symptoms of Long COVID-19?

Symptoms may include:

- Feeling very tired (fatigue)
- Feeling weak or struggling to carry out daily activities
- Feeling nauseous, wanting to throw up, or not wanting to eat

Symptoms may affect different parts of the body:

- Lungs or heart
 - Trouble breathing
 - Coughing or feeling short of breath
 - Chest pain
 - Feeling like the heart is beating fast (heart palpitations)
- Stomach and other parts of the body that help digest food
 - Stomach pain
 - Loose poop (diarrhea)
- Head, brain, or nerves
 - Trouble sleeping
 - Feeling like you can't think clearly, also known as "brain fog"
 - Trouble remembering things or following directions
- Mood changes, including feeling sad, worried, angry, or easily upset
- Headache
- Lightheadedness when standing up
- Loss of smell or change in taste (may make a child more fussy or not want to eat)
- Joints or muscles
 - Joint or muscle pain
- Skin or hair
 - Hair loss
 - Skin rashes
 - Mottled skin (a red or dark pattern on the skin)

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.

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

Doctors can give your child medicines to help with some symptoms. They can help keep track of how your child is doing and let you know about new treatments.

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 the Doctor's Appointment

Try your best to remember when your child had a COVID infection 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 1-2 weeks to write down:
 - Symptoms, including when they start, how bad they are, if they are related to an activity, 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
 - Try to also do this when your child is changing from one activity to another, when symptoms might be more likely to worsen
 - What activities your child has been doing, like if your child is going to school or other activities.
- Make a list of all of the medications your child is taking.

During the Doctor's Appointment

- Bring a list of your child's symptoms; put them in order, starting with the most concerning ones
- Ask questions, including about symptoms and how to manage them, starting with what worries you and your child most
- Be ready to talk about how your child's day is, 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 was talked about during your visit
- Ask your doctor to write down important instructions for you to bring home

After the Doctor's Appointment

Follow the plan you talked about with your doctor. Remember that there is still a lot we don't know 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 with Long COVID symptoms.