

COVID-19 FAQs

For Children with Solid Organ Transplant or Heart failure

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COVID-19 and Children

Is there any published data about pediatric patients with COVID-19?

A very [important study of over 2143 pediatric patients](#) that tested positive for COVID-19 in China was recently published in the journal, *Pediatrics*.

Can children get COVID-19?

Children of all ages can get COVID-19. Boys and girls are equally likely to get it. The symptoms of COVID-19 are similar in children and adults, but children tend to have milder cases or no symptoms at all. Children with symptoms tend to have fever, runny nose, cough and sometimes vomiting and diarrhea ([CDC](#)). Because children with COVID-19 often have no symptoms, they [may play a major role in spreading the virus](#).

What symptoms do children experience?

In a [study of over 2000 pediatric patients](#) that tested positive for COVID-19 in China, more than 90% of the children either had no symptoms or mild/moderate cases.

Are children in general at risk of becoming very sick or dying from COVID-19?

Based on what we know so far, children are much less likely than adults to get severely ill from COVID-19. In a [study of over 2000 pediatric patients](#) that tested positive for COVID-19 in China, only one child died. Most cases were mild, with far fewer severe and critical cases in children (5.9%) compared to adults (18.5%). Very few had difficulty breathing or low blood oxygen levels (0.5%). Very few experienced ARDS or multiorgan system dysfunction (0.6%).

Why does it seem that children do better with the virus?

We do not fully understand why children do not get as sick as adults. The data that is emerging from China, Italy, Europe and Seattle are reassuring. Children are not being admitted to the hospital or developing severe disease nearly as often as adults.

Are children with transplants at higher risk?

There is still much more to be learned about how the disease impacts children, especially those with underlying medical conditions. For children with transplants, we do not have specific information on whether COVID-19 infection will be more severe. However, other viruses often cause more severe disease in people whose immune system is low, such as transplant recipients. The limited existing reports in the pediatric transplant population provide some cautious optimism that transplant children have a similar disease course as non-transplant children.

Are there any pediatric transplant cases that we know of?

There are very few reported cases in pediatric transplant recipients. But it is still too early to know for sure if children with transplants are at increased risk for severe disease. There are 3 reported cases of children with transplants in Italy who tested positive for COVID-19. None of those children developed lung disease. At least one very young child in the United States required ICU care but this is not yet published. It is unclear whether the small number of cases reported is because they are not severely affected, or because the families have been more rigorous about self-isolation.

[A study of 87 mostly adult heart transplant recipients in China](#) found that prevention and quarantine efforts led to a low rate of COVID-19. Even though most resided in Hubei and many had recently traveled to Wuhan, the center of the COVID-19 outbreak, all cases were mild, especially thanks to five prevention/quarantine efforts:

- Self-quarantining at home for more than 1 week
- Wearing a mask
- Washing hands
- Sanitizing
- Monitoring body temperature and symptoms daily

Until we know more, we strongly recommend good hand hygiene and social distancing for the families of children with transplants. [Teach your children to become health heroes by reading our “Wanna be a Health Hero” handout!](#)

How do children spread COVID-19?

Since most children have no symptoms or mild cases of COVID-19, children may play a major role in spreading COVID-19. Sneezes, coughs, and poop can spread COVID-19. It's important to know that children who are not toilet-trained could possibly spread the disease to people who change their diapers.

How to Protect Yourself and Your Family

What should I do to keep my child and family safe?

As the parent or caregiver of a child with a transplant, your family should already be careful about protecting yourselves from germs and infections. It's important to continue healthy habits and take extra precautions.

Encourage your family to be health heroes!

- Ensure your child takes all of their normal medicines. Because pharmacies might get crowded during this time, make sure you have 4 weeks of medication on hand.
 - *Please use mail-order pharmacies, if possible. You can also contact your local pharmacist to discuss and understand the local supply for medications.*
- Stay at home to slow down the spread of the coronavirus. If you need to leave your home, use “social distancing.” That means keeping more distance—at least 6 feet—between yourself and other people. When you get back home, change your clothes and wash your hands.
- Don't touch your face or rub your eyes.
- Wash your hands for 20 seconds while singing “Happy Birthday!”
- Encourage your family to be more careful than normal to prevent unnecessary injuries and doctor visits.

Why social distancing?

Social distancing is a very important way to slow down the spread of the coronavirus and “flatten the curve.” We recommend staying home. If you must leave your home, use “social distancing.” That means keeping more distance—at least 6 feet—between yourself and others.

What is “flattening the curve”?

If too many people get sick with COVID-19 too quickly, the healthcare system will not have enough medical staff, hospital beds, or equipment to properly care for them or others with different medical issues. Flattening the curve means reducing the number of people who get sick at the same time. This is the way we make sure that the healthcare system has enough capacity to care for sick people. We can't stop the coronavirus, but we can slow it from spreading too fast. Flattening the curve will help our healthcare system deal with the strain of the outbreak.

If schools open in 2 weeks, should we send our children back?

Until there is a better understanding of how immunocompromised children are affected by COVID-19, we recommend that all children with transplants avoid large gatherings, including school, if there is an ongoing outbreak in your community. We recommend that other children living in your home also stay away from school and other group settings. Since children overall are more likely to have no symptoms or mild symptoms, they could transmit it to others unknowingly and potentially place immunocompromised children at greater risk of getting COVID-19.

How much medication/prescriptions should we keep on hand?

If possible have at least 4 weeks of your medications (if insurance allows) remaining at all times. Check to see if your insurance will allow for a 90-day supply. Try having medications mailed to your home, delivered or picked up by a caregiver so your family can avoid crowded places.

Should parents wear masks and gloves if still going to work?

We would encourage you to stay at home in self-isolation as much as possible. If you are going to be outside and able to maintain a 6-foot distance from other people. Using a mask depends on where you live and the recommendation of your team. With the shortage of masks it may not be possible. Masks are also not as protective as they may appear. We strongly recommend that you avoid crowded places, like grocery stores. Try to have your groceries delivered or a friend or family drop them off for you. Some stores have also started having special hours for the elderly and the immunocompromised. Check with your local grocery store. Try to spray deliveries with disinfectant and wipe them down before bringing them into your home. Don't forget to wipe down the cart when you arrive at the store.

Other than self-quarantining and wiping down deliveries, what else can we be doing?

To help keep your child from getting infected, we recommend avoiding crowds, avoiding people who are sick, staying around the house as much as possible, and washing hands vigilantly. We also recommend social distancing as much as possible and avoiding touching things that other people have touched.

When shopping should we be using gloves? Could items at store be contaminated?

Gloves are not recommended at this time when shopping. If possible, avoid taking your child with you to the store to limit potential exposures. Wash or disinfect your hands as soon as possible after being in a public place like the grocery store. Remember to try to avoid touching your face, mouth and eyes while you are shopping.

If we must report to work for an essential service (like healthcare or grocery store operations), what should we do when arriving at home?

If it is possible for working family members to work from home, this is preferred. If this is not possible, you should adhere to the following practices for trying to avoid infection:

- Frequently wash or sanitize your hands.
- Don't touch your face or rub your eyes.
- Maintain 6 feet between yourself and others.
- When you get home, it might also be smart to put your clothes in the laundry and change into fresh clothes. You could also spray disinfectant like Lysol spray on your shoes and leave them outside your door or in a separate plastic container.

Should my children and family members wear masks if we need to go out in public?

We would encourage you to stay at home in self-isolation as much as possible. If you are going to be outside and able to maintain a 6-foot distance from other people, it's not necessary to wear a mask. We strongly recommend that you avoid crowded places, like grocery stores. Try to have your groceries delivered by friends and family, and try to spray deliveries with disinfectant and wipe them down before bringing them into your home.

If I am a single parent and must take my children out with me to the grocery store or another public place, how can I protect my family?

Stay home as much as possible. We strongly recommend avoiding locations that are likely to be crowded, such as grocery stores. Try to have your groceries delivered or ask for help with errands from other family members or community members.

What type of mask should we wear if we want to wear a mask?

If you plan on wearing a mask - Before putting on a mask, clean your hands with hand sanitizer with 60% or more alcohol or wash your hands with soap and water. Try not to touch the mask while using it. Replace the mask with a new one if it becomes damp. Don't reuse single-use masks.

The [CDC](#) currently recommends that NIOSH-approved N95 respirator masks be reserved for healthcare professionals working on the front-lines of the coronavirus pandemic. There is a shortage of N95 respirators in the U.S., and it's important that hospital workers can get access to these more protective masks, which filter out 95% of very small bacteria and virus particles.

Remember unlike N95s, face masks are loose-fitting and provide only barrier protection against bacteria and virus droplets. Facemasks don't require fit testing or seal checking. Most facemasks can filter out large respiratory particles, but don't effectively filter small particles from the air and do not prevent leakage around the edge of the mask.

What if they run out of masks? Is it ok to go out without mask?

If you run out of masks, you should do your best to limit contacts and use careful social distancing.

How can I help my children cope mentally?

ACTION and PHTS have created a printable handout for children. It shows them how to be "[health heroes](#)" during the coronavirus pandemic. Be sure to [download the handout](#) and go over it with your children.

Share truthful information with your child based on their age and try to avoid overwhelming them. UNICEF suggests: "Children have a right to truthful information about what's going on in the world, but adults also have a responsibility to keep them safe from distress. Use age-appropriate language, watch their reactions, and be sensitive to their level of anxiety. If you can't answer their questions, don't guess. Use it as an opportunity to explore the answers together. Websites of international organizations like [UNICEF](#) and the [World Health Organization](#) are great sources of information. Explain that some information online isn't accurate, and that it's best to trust the experts."

Adjust the information you share based on the age of your child:

Early elementary

- Basic information about what germs are and how to stay healthy
- Helpful things to remember about health and lots of simple examples.

Upper elementary/early middle school

- Real facts of the sickness to help them separate truth from other false information they may see on the internet
- Talk about what their schools and other groups are doing to help
- More detailed information on what they can do

Upper middle/High school

- Can discuss it more in depth
- Share more resources for them to review; which sites can be trust/helpful (help them feel like they have some control).
- Understand the real importance of healthy habits and social distancing

How can I help my children cope emotionally?

Remind your children that it is okay to feel sad, worried, angry, or even happy with all the changes happening. All of us need to practice patience and understanding during these changes. Here are some great ways you can support your child during this time:

- Validate or give “names” to feelings, but do not dwell on things too much.
- Engage in healthy routines. Develop daily schedules together.
- Help your child to find positive, distracting activities when negative feelings take over. Limit news/media exposure. Together as a family, think of something good that happened each day.
- Encourage relaxation strategies, like deep breathing, mindfulness exercises, and yoga.
- Challenge those negative thoughts! Ask: Is this thought true? Is it helpful? Is there a more helpful thought I can focus on?
- Model healthy coping and take time to address your own feelings.

How can I cope?

Before talking with your child, talk with a friend, family member, coworker, or healthcare provider over the phone about your own anxieties so that you avoid increasing fear in your child by sharing all of your worries with them. Try to maintain routines, even if you're at home. If you have any concerns, reach out to your primary care or mental health provider.

In Case of an Outbreak

If someone in our home contracts COVID-19, is there any hope of preventing the spread?

How do we do that?

We understand that having someone in the home diagnosed with COVID-19 will be stressful. Start by reading the [CDC's recommendations for cleaning your home](#) if someone gets COVID-19. There are several ways to help prevent spread to other family members within the household.

The infected household member must:

- Stay home except to get medical care. Do not use public transportation. Do not go to work or school.
- Distance yourself, or self-quarantine, as much as possible. Sleep in a separate room and try to stay in that room and eat your meals there.
- Designate a bathroom for the infected person, if possible. Do not let any other family members use that bathroom.
- Keep your child in a separate room and bathroom from the sick family member.
- Avoid sharing personal household items (cups, forks, towels, blankets etc.) with other people in the home.
- Clean and disinfect objects and surfaces that you touch during the day. Use household cleaner or wipes. Then use disinfectant spray. Be sure to follow instructions on the disinfectant and make sure you allow the spray to sit on counters and objects as long as the package recommends to ensure you are fully disinfecting.
- If you do have a mask available the infected family member should wear a mask if they need to interact with others in the household. Masks can help contain droplets from the infected individual.

Everyone in the home can:

- Frequently wash your hands throughout the day and before you eat.
- Wash for 20 seconds with soap and water.
- If hands are not visibly dirty, you can use hand sanitizer.
- Avoid touching your face.
- Clean and disinfect objects and surfaces that are frequently touched during the day using household cleaners or wipes.

How long should transplant patients remain in isolation?

For general transplant patients who do not show symptoms of COVID-19, we recommend staying at home and avoiding contact with any sick persons.

For anyone who has tested positive for COVID-19, they must remain in isolation until they have negative tests and are clinically better. If no repeat testing is available, they should remain in isolation until they are clinically better. “Clinically better” means no fever without medications and resolution of all symptoms for at least 3 days.

If my husband got exposed on Monday to one of his workmates who showed signs of COVID-19 but did not yet test positive, should he proactively isolate himself in another room at home?

The plan should depend on the exposure. How long was he around the person? How close was he to the infected person? There are many ways to approach this situation. The most conservative approach, if possible, would be to have the person who was exposed self-isolate while awaiting the test results. This is not always possible. There may be no tests available in your city or you may not be able to isolate yourself from your family. Each family is going to handle it differently. If you need guidance your local healthcare team may be able to help assess the risk.

Symptoms and Testing

When should we call PCP and when should we call transplant team?

If you or your child experiences a cough, sore throat, runny nose, shortness of breath, or fever above 99.6° F, call your primary care provider (PCP) and your transplant team before going into the Emergency Department (ED).

Primary care providers can play different roles in a transplant patient’s healthcare after surgery. Their role varies by institution, the location of your child from the transplant center, and even the PCP’s familiarity with transplant-related issues. If you have any doubt about who to call, we always encourage you to talk to your transplant team for guidance. We know this is a time of great uncertainty. We are always here for you.

Should we still call the transplant team just like we would before coronavirus?

You should still call your transplant team for symptoms like fever, elevated blood pressure, and vomiting—just like you would before coronavirus. These guidelines will differ between institutions. We suggest you touch base with your transplant team about their specific guidelines and recommendations.

For those who live 1 to 3 hours away from our transplant center, should we triage at a local hospital or PCP or head straight for the transplant center if our child experiences symptoms of COVID-19 or if they have troubling signs for transplant?

Always call before heading into an Emergency Department (ED), primary care office, or urgent care center. Recipients with a positive COVID-19 test should contact their transplant center to discuss where to go for evaluation, management or even whether to stay home. Based on early adult data, not all transplant recipients will require hospitalization. It's important to know that if your child is very sick, getting to the nearest medical center may be more important than traveling to your transplant center.

Are children's hospitals being allotted enough testing kits for COVID-19?

This is variable at this time. It depends on where you live in the country. Everyone is working to have tests available for the most at-risk patients.

Higher Risk

When the media says that people who are immunocompromised are at a higher risk, does that definitely include liver transplant children by virtue of being on immunosuppressants or no since doctors can technically control amount of immunosuppression?

The blanket term "immunocompromised" does include those with liver transplants. However, this statement is based on observations in **adult patients**. To date, there simply is not enough data to know whether immunocompromised children are at similarly increased risk. Because we do not know, out of caution, we recommend strict adherence to self-isolation.

Should we change our child's immunosuppressant dosage?

Do not change your immunosuppressant medication without your transplant doctor's instruction. Decreasing your child's medication could lead to rejection, which itself could lead to hospitalization and potential exposure to COVID-19. You can be assured that if your child with a transplant develops COVID-19, your transplant doctors will consider whether to decrease the dose of immunosuppressive medications on a case-by-case basis.

Does having multiple comorbidities (i.e. post-transplant, hypertension, ESRD) put them at exponentially higher risk?

Older adult patients with existing comorbidities are at [the highest risk](#) of becoming very sick from COVID-19. There is not enough data to know whether **children** with comorbidities are at increased risk. Out of caution, we recommend that you strictly adhere to self-isolation until more is understood.

Are there cases of other types of immune-suppressed kids being affected yet?

There have been very limited numbers of immunosuppressed children being infected with COVID-19.

My daughter had a liver transplant and has asthma. We are concerned how she would handle this virus.

It is very natural to be anxious about this global pandemic. However, many people, including some transplant recipients, have handled this infection similar to people without transplants. At this point, it is not clear if **children** with transplants will have more trouble than other children without immunosuppression or without asthma.

To help keep your child from getting infected, we recommend avoiding crowds, avoiding people who are sick, staying healthy at home as much as possible, and washing your hands frequently. We strongly recommend social distancing and avoiding touching things that other people have touched.

Treatment and Vaccination

If our transplant kids test positive, is there a different treatment for them compared to other kids?

Currently, we would not treat transplant children with mild COVID-19 differently from how we would treat other children. Most children with COVID-19 have mild symptoms that can be treated at home. If hospitalization is required, the current approach is to provide supportive treatments such as fluids to reduce dehydration, medication to reduce fever, and supplemental oxygen in more severe cases. Many centers are considering treatment based on ongoing studies and/or off-label or compassionate use.

Are there any proposed COVID-19 treatment medications (such as Chloroquine or Remdesivir) that are viable for transplant patients? Would any of the above interfere with Prograf or Cellcept? And are there other risks in taking those meds for transplant patients?

Currently, we would not treat transplant children with COVID-19 differently from how we would treat other children.

Some medications that may be used to treat COVID-19 can interact with immunosuppressive medications. Many of these can be anticipated, and modifications can be made if needed. You can ask your healthcare team how they are working together to ensure that drug-drug interactions and other potential side effects are minimized.

I have heard that COVID-19 could cause complications if you are on ACE Inhibitors?

There has been much speculation on whether ACE inhibitors, Angiotensin blockers or ibuprofen might have an effect on COVID-19 infections. At this time, there is no basis for a recommendation on this issue because some experts have speculated a protective effect from ACE inhibitors, while others think the opposite. We therefore recommend continuing your current treatment for now and discussing this issue with your provider at regular intervals as additional information becomes available.

I have heard that COVID-19 could cause complications if you are getting Ibuprofen?

Several physicians in the news have recommended avoiding ibuprofen (and other NSAIDs like naproxen) based upon the observation that some patients who were taking ibuprofen experienced severe forms of COVID-19 pneumonia. However, this is not supported by any reliable information and the observations may or may not indicate a real risk.

At the same time, since acetaminophen (Tylenol) is felt to be safe for COVID-19 infections, it is recommended that people use acetaminophen to relieve symptoms if they are able to do so, and only use ibuprofen if they do not obtain relief from acetaminophen. Children with transplants or VADs do not take NSAIDs anyway due to the effects on the kidneys and the coagulation system.

Parents want to know if we will get vaccine sooner than Feb 2021. Will it be a “dead” vaccine that our transplant kids can receive?

There is currently no vaccine for COVID-19. It is too early to tell which vaccine-candidates will make it through the clinical trials process and be effective. However, vaccines currently in development are “dead” vaccines. Public health officials have indicated that a vaccine will not be publicly available until 12-18 months from now.

Changes in Healthcare

Why did my clinic appointment get canceled?

Many clinic visits and elective procedures are now cancelled or postponed to protect you, your family, our communities, and the healthcare system. We all need to work together to slow down the spread of the coronavirus. Your appointments may change or happen in new ways, like telehealth.

What is telehealth?

Just like FaceTime calls or phone calls to your family and friends, now you get to virtually meet with your doctor online too. Talking with your doctor and healthcare team on the phone or computer is called “telehealth.” It’s a great way for us to stay connected and have our usual appointments and conversations without risking the spread of the coronavirus.

How might things be different in the hospital at this time?

If you need to visit the hospital during the coronavirus outbreak, there are some differences you should expect.

- When you enter the hospital, you might be screened for illness.
- The Emergency Department (ED) may be more crowded. Always call your healthcare team before going into your ED.
- You may notice different masks and gowns worn by healthcare team members.
- You might be in a different area or unit of the hospital than you are normally.
- Food offerings may be different and cafeterias may be closed.
- There may be different visitor policies.

If transplant patients require a hospital visit, do we do anything different?

This depends on the reason for your visit:

- If your child is ill, call your Transplant Team first before going to the Emergency Department.
- If your child has a routine visit, check with coordinators first to determine if it can be delayed or if telehealth or getting labs locally will be enough.

Are transplants deemed essential surgeries and will they still be done during this pandemic despite the change in the hospital systems?

As of March 24, 2020, CMS has deemed transplant surgeries as essential care. According to this guidance, transplant surgeries should be considered high priority and should not be postponed during the COVID 19 pandemic. The situation is being continually assessed both at the program level and also at the national level. Each case will be reviewed closely with consideration of urgency and the risk to the patient.

With elective surgeries being held off, what does this mean for catheterizations and biopsies?

The definition of elective procedures will vary by institution. In most centers, the decision to cancel patients is reviewed with key team members to determine if there is an immediate urgency for the procedure or if it can be delayed safely. Delaying procedures is helpful for supporting social distancing and reducing the risk of coming into contact with the virus. It is important to realize the catheterization/biopsy techniques vary greatly between institutions and that many routine procedures can be delayed safely without impacting the health of your child.

Are we exposing our child when we go to get labs? How can we protect them? Is delaying ok?

Laboratory blood draws do represent a potential risk of exposure to coronavirus. You can contact your transplant team to determine whether it's possible to decrease or delay your lab visits at this time. However, this decision has to be balanced against maintaining good medical management of your child's transplant care or heart care.

If you do need to go to the lab, we recommend calling your lab ahead of time to find out which times are the quietest. Try to go during the quietest times of day. When you go to the lab, bring only the people who must be there and not any extra family members.

Here's what you can do to protect yourself and your child while at the lab:

- Wear face masks if available.
- Stay at least 6 feet away from other individuals waiting.
- Wipe the armrests of chairs you or your child are using.
- Avoid touching doorknobs or other objects if possible.
- Wash your hands frequently.

Are clinical trials like TEAMMATE going to be affected by this outbreak?

In many centers, patient-related research has been placed on hold both for the safety of the patients and the research staff. New patients will not be enrolled. The impact of this will be study-dependent and will vary by institution.

Is the hospital isolating specific rooms for transplant patients or other immune suppressed patients?

This will vary hospital to hospital depending on the amount of virus circulating in the community and the number of patients in the hospital.

Should my healthcare providers be wearing gowns, masks and gloves?

The CDC is only recommending Personal Protective Equipment (PPE) be worn when seeing a patient that has symptoms consistent with COVID-19. This is hospital-dependent and in some hospitals, masks are being worn for all patient encounters. At this point, it is variable and may change as more equipment is made available.

How is the shortage of masks affecting care in the pandemic?

The shortage of Personal Protective Equipment (PPE) is putting healthcare workers and patients at risk. This is one of the reasons that all elective visits and surgeries have been canceled. We are hopeful that more PPE is on the way to your hospitals soon. Many individuals are donating PPE and private companies are ramping up production.

Are they currently trying to get more ventilators/respirators in areas with shortages like NYC?

This is an area of significant concern nationwide, and every hospital is working to ensure they will have enough medical supplies to support their local areas through this pandemic. Efforts are being made to find creative ways to increase equipment and medical supplies, including companies shifting production to hand sanitizers, private clinics donating respirators, and other companies donating extra supplies. However, all these efforts will only be successful if our communities continue social distancing to slow down the ongoing spread of the virus.

How is the pediatric heart failure and transplant community coming together during this pandemic?

Our medical societies are actively working together to come up with answers to all of your questions. We are using weekly calls and message boards to share our learnings. We are also collectively accumulating data to learn in real time, since the coronavirus pandemic changes rapidly day-to-day. We have contacts in the states and in the countries that have been the epicenters of the pandemic. We are learning from many of the providers and families that have been through the worst of this weeks to months before us. The societies working together to bring these Questions & Answers together are ACTION, PHTS, and the Starzl Network.

Have a question?

Is there something you are concerned about that hasn't been answered? Send your questions to:

✉ info@actionlearningnetwork.org

Special thanks to the following for providing answers:

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