



## Starzl Network Patient & Family Voice FAQ

Acknowledgement to Drs. Mike Green, Marian Michaels, and Zachary Aldewereld

UPMC Children's Hospital of Pittsburgh

### How long should transplant patients remain in isolation?

- Any COVID-19 positive patients should remain in isolation until we have negative tests and are clinically better or if no repeat testing available clinically better (no fever for at least three days without antipyretics and improved respiratory symptoms) and at least 14 days from start of illness
- For general transplant patient who is not symptomatic - avoidance strategy is recommended while COVID-19 is circulating in the community, which is for the foreseeable future

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

- Depends on reason for visit
  - If ill, call **first** so that we can get a mask on the patient right away before being seen
  - If routine visit, would check with coordinators **first** to determine if it can be delayed or if telemedicine and getting labs locally will be enough
  - While masking when not sick is not routinely recommended it may help keep the child from touching their nose or mouth with unwashed hands, similar to what we do for children with fever and neutropenia

### How has infection with COVID-19 affected pediatric transplant recipients?

- There are very few reported cases in pediatric transplant recipients
- Anecdotally we are not seeing greater problems, but it is still early in the pandemic and too early to know if they are at increased risk for severe disease. There are 3 reported cases of children with transplants in Italy who tested positive for COVID-19 who did not develop lung disease. However, 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. At least one very young child in the United States did require ICU care.

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

- Again, there have been limited numbers of immunosuppressed children being infected with COVID-19 and here again it is still too early to tell.

**When media says immunocompromised are a high at 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.*

**How is COVID-19 affecting the ability to be transplanted?**

- *At this time, we are considering transplant needs individually on a case-by-case basis. It is based on urgency of the transplant, the potential donor risks, and ability to be tested*

**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 COVID-19 differently from how we would treat other children. The mainstay of treatment is supportive. If sick and requiring hospitalization, we would try to find a study to use for treatment that is applicable to pediatric patients, if no study available then we would use off label or compassionate release medications.*

**Is it recommended they go to their transplant center if they test positive even if we live out of state?**

- *Recipients with a positive test should contact their transplant center for discussion and to help decide on 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 is possible that interstate travel will become more restricted as time goes on. In addition, if very sick, getting to the nearest medical center may be more important.*

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

- *It is very natural to be anxious during this period of a novel infection going across the world. However, many people including some transplant recipients have handled this infection similar to people without transplants. At this point in time 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 around the house as much as possible, and excellent attention to handwashing. We also recommend social distancing as much as possible and avoid touching things that other people have touched.*

**What is the recommendation on the isolation of immediate family members (those that live in the house) of transplant recipients when it comes to work/school?**

- *We would recommend that other children stay home from school. This is because children are more likely to have no symptoms or mild symptoms with the virus but could still transmit it to others. Similarly, if it is possible for working family members to work from home, this is preferred. If this is not possible, they should adhere to the following practices for trying to avoid infection: frequent hand washing/hand sanitization, don't touch your face, and maintaining 6 feet between themselves and others. It might also be prudent to change into fresh clothes when you get home and put the ones you were wearing into the laundry.*

**Should we be asking about 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. You can be assured that if/when your child with a transplant develops an infection, your transplant doctors will consider whether they need to decrease the dose of immunosuppressive medications on a case-by-case basis.*

**Should the kids return to school when the province/states say? Or keep home?**

- *This may need to be on a case-by-case basis depending on when children begin returning to schools. For the time being, we encourage you to touch base with your transplant team if this question comes up.*

**Should they wear masks in public, when not in self isolation?**

- *We would encourage you to stay in self-isolation as much as possible. If you are going to be outside and able to maintain your distance from other people, a mask is not necessary. However, if they are going into a building, wearing a mask is advisable. We strongly recommend avoiding locations that are likely to be crowded though, such as grocery stores.*



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**Can transplant children go for walks (leave the house)? If so, what should they wear?**

- ❖ Yes, but need to be careful to maintain social distancing guidelines where at all possible. A facemask (or equivalent) should ideally be worn.

**Should transplant children wear a mask all the time when outside, even if they are not around others?**

- ❖ Yes

**Are transplant children showing delayed symptoms of COVID-19 due to immunosuppression?**

- ❖ There are not data to suggest that delayed or occult COVID-19 infections are occurring more frequently in immunosuppressed patients. There are reports of transplant (and other immunosuppressed) patient populations contracting the virus, but overall incidence does not appear to place these populations at increased risk of contracting the disease.

**Should high risk individuals get priority for antibody testing?**

- ❖ Given that transplant patients do not appear to be 'high risk' for and other populations (older, co-morbid conditions such as heart disease, diabetes, etc.) appear more at risk, there will likely need to be further data to help answer.

**When we transition back to "normal", should transplant children follow different guidelines/timeline? Can they return to daycare with others?**

- ❖ As above, more data may be required to best answer this question. It is too early to determine the timeline children should follow.

**Is there a treatment protocol for COVID-19 in immunosuppressed children?**

- ❖ No specific treatments (other than supportive therapy) are currently in place and strategies will need to be somewhat tailored to the individual as it relates to strategies, such as immunosuppression reduction etc. Regarding many of the clinical trials and reported therapies that may be beneficial, I think it is critical to stress the importance of working with healthcare team and to, where possible, be enrolled into a clinical trial that is designed to assess for efficacy of any potential treatment that may be available. Please note very few transplanted children, less than 10-15, in the US have been reported to test positive as of 4/13/20.

COVID-19 information for parents for returning to school, discussing the virus with your children, and how to relax. This has been prepared by Dr. Diana A. Shellmer, Associate Professor of Surgery and Psychiatry, University of Pittsburgh School of Medicine, Hillman Center for Pediatric Transplantation, UPMC Children's Hospital of Pittsburgh.

### **1. Returning to school**

- a. As noted during the panel discussion it will be important to follow the guidance of your individual transplant team, the state health department, the school board and your individual school
- b. I believe that most transplant teams will likely provide their patients with guidance regarding school re-entry. The guidance will likely provide the same level of detail provided to you and your child soon after initial transplantation
- c. For those children/adolescents and young adults who have a 504 Plan (this is within the US) you can work with your school to make changes to the plan that may allow more latitude in regards to when to return to school and yet provide your child with support to continue their education
- d. Schools typically do communicate to their community when there is an outbreak within the school. If that has not been your experience, please work through the school system to alert them of your need to be aware of any cases of COVID-19 in order to make appropriate choices for your family.

### **2. Discussing the virus with your children**

- a. It would be ideal if parents had a chance to review the shared resources and perhaps pick one of the written resources (there were comics on NPR, a young child's book about COVID-19, etc included in the links provided) as a way to help them guide a talk with their children
- b. Prior to the discussion it may be helpful to run through what you would like your main message to be regarding this virus and to consider how comfortable you may be in sharing the information. Sometimes as parents we need time to feel comfortable with what we will be discussing and confident in what we want to share before feeling calm enough to proceed with the discussion.
- c. For younger children you can focus on the big points:
  - i. What the virus is
  - ii. Why we are social distancing and how it is helping
  - iii. The many people who are working to fix the problem
  - iv. Acknowledging the fears that may go along with the situation
  - v. The strength we can find in helping each other (e.g., sending cards to friends we miss, saying thank you to the mailman/garbage collector)
  - vi. Doing our part (e.g., wearing our masks when we go for walks, washing our hands, etc)
  - vii. \*Keep in mind that many young children will be more than satisfied with a simple direct answer. Take your lead from them.
- d. For older children still think through the above, but making it more of a conversation during which they can ask questions and you can look up information together may be beneficial (please of course stick to trusted sources such as the Centers for Disease

- Control). In addition, highlighting the important role that your children have in supporting the steps being taken to limit the spread of the virus can be rather helpful.
- e. Overall, letting your children feel they can talk to you about any of their concerns and that you will honestly (within reason based on your knowledge of your child and preexisting mental health concerns such as high levels of anxiety) answer them, listen, reflect and seek answers together if needed will go a long way in helping them calm

### **3. Relaxing**

- a. This is an unprecedented time and it is difficult to fully relax. However, most people can reach a state of calm when they are able to consider the situation from an “active coping” stance—meaning taking active steps whether through thought or action to mitigate the effects of what is happening in the community.
  - i. The above can mean being aware of the role you are playing in your family to keep yourself and those within your family safe
  - ii. The steps you are taking to educate yourself
  - iii. The role you are playing daily in supporting the larger community efforts (e.g., limiting your trips out, wearing a mask while being out)
  - iv. Reminding yourself that you are contributing and helping can provide a sense of purpose and help individuals regain a sense of control even in an unpredictable environment
- b. I would then strongly suggest considering doing the following to decrease your own and your child’s stress level:
  - i. Limit your own and your child’s exposure to the news
  - ii. Limit information sources to trusted sources such as the CDC
  - iii. If parents are at home set some time aside for quiet activities/soothing activities that include a distraction component such as reading/coloring for the kids
  - iv. Help children focus on what they can control (e.g., what to wear that day, which board game/video game they play with the parent)
  - v. Maintain a schedule that is flexible but includes anchors (e.g., consistent breakfast/lunch times, outside breaks)
  - vi. Maintain a bedtime routine that helps both you and your children decompress from the day
- c. There are some excellent mindfulness apps and meditation apps on the market that could be of significant help when aiming to decrease stress and relax

Hope the above is helpful. Please note that your individual transplant teams likely have wonderful social workers and/or psychologists working with them and you are always encouraged to reach out to them for more specific support.