Are people with Down syndrome more vulnerable to coronavirus disease 2019 (COVID-19)?

The simple answer is that the majority of people with Down syndrome are NOT considered immunocompromised patients. The nuanced answer is that people with Down syndrome can have slight disturbances in their immune system, making them more vulnerable to infections. We recommend using your loved one’s ability to handle past infections/viruses as a good barometer of his/her immune system and how they might respond, should they become infected with COVID-19. The CDC offers recommendations on what all families should be doing right now.

Some people with Down syndrome who have active, untreated, or chronic health conditions might be in a “high-risk” category, which means that they may experience more severe symptoms if infected with COVID-19. These would include patients with Down syndrome who are actively being treated for leukemia or other cancers, have untreated heart conditions, chronic, untreated respiratory diseases, and poorly controlled diabetes. The CDC has also indicated that older persons, in general, are more vulnerable to the virus. If your loved one with Down syndrome falls into one of these “high-risk” categories, the CDC offers recommendations on what you can be doing right now.

Here is a great podcast interview with Dr. Andrew Nowalk, an infectious disease expert, describing coronavirus in the context of Down syndrome.

How can I explain the coronavirus to my loved one with Down syndrome

- Phoenix Children’s Hospital offers what you need to know about coronavirus.
- Great article from the Child Mind Institute for adults to help with talking to kids about coronavirus
- Down Syndrome Medical Interest Group- USA (DSMIG-USA) joins an impressive national consortium to create a helpful Q&A on COVID-19 and Down Syndrome.
- Audio story from NPR for kids, plus printable comic strip
- Excellent list of videos, songs, and show segments from PBS, including segments from Daniel Tiger to Sesame Street helping with way to keep kids safe and healthy
- Free, printable social story by Amanda McGuinness about the coronavirus, which might be especially helpful for younger patients with Down syndrome, those with a dual diagnosis of autism, and those with complex medical needs

Should we be implementing social distancing for people with Down syndrome?

Social distancing would be wise for all of us. Social distancing means avoiding public spaces, generally limiting your movement outside of the home, and staying at least 6 feet away from non-family members. Social distancing has been shown to be one of the most effective ways to prevent the spread of the disease. What does this mean for your family? Here are some practical tips from health experts.

We recommend that your family also closely follow the directions of your local Department of Public Health, such as the one in Arizona.
How can I boost the immune system of my loved one with Down syndrome?
Here are some tips in an article from the New York Times.

Which hand sanitizers should we be using to protect against COVID-19?
Here is what to use—and not use—if your family is running low on supplies. In the end, soap is very effective.

What are the educational rights of students with Down syndrome if they are quarantined at home?
The U.S. Department of Education has developed this comprehensive fact sheet explaining what educational rights are maintained for students with disabilities who have Individual Education Plans (IEPs) during the COVID-19 outbreak.

Is it too late for the flu shot?
The flu season this year is also taking a toll this year. More than 180,000 American have been hospitalized so far from the influenza. We certainly don’t want people with Down syndrome getting the flu and coronavirus at the same time. It’s not too late to get the flu vaccine, which is the best way to protect your loved one with Down syndrome. Contact your primary care physician to make the arrangements.

How can you manage your own self-care as a caregiver during these stressful times?
Here are some excellent tips from the CDC on ways that you can take care of yourself and your family.

Are appointments at the Phoenix Children’s Hospital Down Syndrome Program being cancelled?
On March 30, 2020 all appointments have been changed to telehealth appointments. We have successfully held our first remote multidisciplinary clinic on April 21, 2020 which included Dr. Raz, Down Syndrome clinical director and our rehabilitation team (speech, occupational and physical therapists). We will evaluate the situation on a week-by-week basis, keeping the safety of our patients and families of paramount importance, and will continue telehealth visits as necessary. As our team is now working remotely, we thank you, in advance, for your patience and flexibility, as our response times might be slower than usual. If your loved one with Down syndrome has any symptoms of COVID-19, please contact his/her primary care physician by phone to inquire about your next best steps.

Where can I get more information?
LuMind IDSC Foundation is posting up-to-date information about COVID-19, as it relates to people with Down syndrome.