

COVID-19: Recommendations for People with Down Syndrome to Safely Re-enter into the Community

While the COVID-19 pandemic is subsiding, the virus is not yet gone, and a vaccine is not yet available. As people with Down syndrome make plans to re-enter and re-engage in their communities, our Down Syndrome Program at Massachusetts General Hospital offers the following information and resources so that caregivers can make informed decisions that are right for their families.

Where can I get more information about COVID-19 related to Down syndrome?

The national Down syndrome organizations collaborated with many physicians, including those from our MGH Down Syndrome Program, to write informational sheets ([abbreviated form](#) and [expanded form](#)) about COVID-19 considerations for people with Down syndrome. Dr. Kishore Vellody of Children's Hospital of Pittsburgh also [interviewed Dr. Andrew Nowalk on his podcast](#), about how caregivers can navigate a safe return for people with Down syndrome into their communities.

When is it safe for my loved one with Down syndrome to return into the community?

First, make sure that it is safe for the neurotypical population in your surrounding area to return to public areas. We recommend checking out your state's Department of Public Health for the latest recommendations (here is the [information for Massachusetts](#)). Next, we would recommend that you talk with your loved one's primary care physician to see they have any complex medical considerations that would necessitate additional caution. (The fact sheets listed in the answer above review these risk factors.) Your loved one's past experiences in fighting infections should be a good barometer for their ability to deal with COVID-19, should they become infected. So far, Down syndrome, in and of itself, does not appear to confer added risk for COVID-19 complications, but some of the co-occurring conditions (e.g., obesity) might.

When can my loved one visit grandparents or other close family members?

Two things are important to remember: (1) the elderly are among the most vulnerable to have serious complications from COVID-19, and (2) young persons are among the most

likely to be asymptomatic carriers. With this in mind, here is some guidance on visitations with grandparents as reported by the [New York Times](#) and [CNN](#).

My loved one with Down syndrome won't wear a mask. What can I do?

It is very possible that in some communities and situations (e.g., summer camps or schools), [wearing a mask](#) will be a requirement. For some people with Down syndrome who have facial sensitivities, this can be challenging. Here are some tips:

- Make it fun. Involve your loved one with Down syndrome in making their own mask. [Here's how](#). They can choose their own fabric or their favorite color. And, they can even help make masks for everyone in the family.
- Have everyone in your family practice wearing their masks during an enjoyable activity at home. Perhaps, you can wear it while playing a board game or watching a movie. Slowly increase the duration of wear, and then you can expand the wear to activities outside of the home.
- Read social stories together. Here is a [social story for children about wearing a mask](#) and about [why we wear masks for COVID-19](#). Here is [another example](#) that also includes wearing gloves. Also, here is a [video that you can watch together](#).
- Here is a [short video for caregivers](#) on how you can help your child get used to wearing a mask.
- If you are still stuck, consider a consultation from your local occupational therapist or behavioral therapist, who can help work on a personalized desensitization protocol for your loved one.

My loved one with Down syndrome is a hugger. He/She has a hard time understanding social distancing. What can I do?

The CIRCLES curriculum and [corresponding app](#) is a great way to teach people with Down syndrome about social boundaries. The app is an innovative way to teach children the degree of closeness they have with other people and how they touch them, depending on the kind of relationship you have with them. Dr. Skotko [recently talked to Leslie Walker-Hirsch](#), one of the co-creators, about how this curriculum can be adapted and used to teach social distancing.

How do I prepare my loved one with Down syndrome to get a COVID-19 test?

If your loved one with Down syndrome [has symptoms that might be associated with](#)

[COVID-19](#), contact their primary care physician to discuss [whether testing is appropriate](#). Some of these tests might involve a nasal swab; whereas others might be blood tests. We know that many people with Down syndrome have sensory issues.

Here are a few resources to help:

- Here are [some tips](#), including videos, for helping a person with Down syndrome tolerate testing
- Here is a [toolkit for caregivers](#) to explain and prepare their loved ones for testing (also [available in Spanish](#)).
- Use either this [simple](#) or [detailed](#) social story to prepare your loved one for COVID-19 testing. (Also available in Spanish: [simple](#) and [detailed](#).)

How can I prevent my loved one from getting COVID-19 during the next wave?

There are many pro-active steps that families can be taking:

- Good hand hygiene, wearing masks, and maintaining social distance are all important measures that are effective in reducing anyone's risk in getting COVID-19.
- People with obesity are known to have more serious complications from COVID-19. Know your loved one's [Body Mass Index](#). If he/she is in the overweight or obesity category, work with their primary care physician to develop a plan to help reduce their weight. We would recommend [locating a nutritionist](#) in your area to develop a personalized plan (available in [Spanish](#)). You can also check out the healthy eating recommendations from our [Wellness Wednesday e-newsletters](#) or the fitness tips from our [Movement Monday e-newsletters](#).
- This fall, be sure that your loved one with Down syndrome gets the flu vaccine. It is very possible that the flu season and second COVID-19 season will peak at the same time, and getting both viruses, at the same time, will be especially serious.
- Be sure that your child is caught up on all of their typical vaccines, as [recent studies](#) have shown that the COVID-19 pandemic has kept some families away from the primary care physician offices.

How should I discuss COVID-19 with my loved one with Down syndrome?

Provide factual information in a [calm, reassuring, and age-appropriate way](#). There are

[many resources, including social stories](#), to explain COVID-19 in an understandable way.

How do I explain a death in the family with my loved one with Down syndrome?

We have sadly lost grandparents, caregivers, close friends, and teachers during this COVID-19 pandemic. Here are [some resources](#) to help your loved one with Down syndrome grieve (also available in [Spanish](#)).

Is it safe for my loved one with Down syndrome to return to school in the fall?

The COVID-19 pandemic is a fluid one, and it is still too early to predict what the situation might look like this fall. The best decision for your family might not be the best decision for another family, and you should consider carefully the recommendations from your loved one's school, the guidance from your state's Department of Public Health, and consultation with your loved one's primary care physician.