



Q&A on COVID-19 and Down Syndrome

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ORGANIZERS:



SUPPORTING ORGANIZATIONS:

Down Syndrome Affiliates in Action, Exceptional Parenting Magazine, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, Matthew Foundation, T21 Research Society

Information in this Question and Answer (Q&A) document is here to help you care for your loved one with Down syndrome during the coronavirus disease 2019 (COVID-19) pandemic. Please share this information freely.

We have tried to answer questions that are important:

- What may be unique about the virus in people with Down syndrome
- How to help stop the spread of the virus
- What to think about when making decisions.

This Abbreviated Version and an Expanded Version of this Q&A are available. Many experts have worked together to provide this information. As we learn more about COVID-19, we will update this Q&A - check our websites for updated versions.

This Q&A is not a substitute for the advice of your medical professional. You should speak with your doctor or other healthcare professional(s) for medical advice.

If you think you or anyone in your care may have COVID-19, call your doctor or other health professional immediately. Calling first is important. Going to an office or a hospital makes your risk of possibly catching or spreading the virus greater. If you call first, the office or hospital will be prepared for you. If you have an emergency, please call 911.

It's important to take care of yourself. If you are sick or too tired, you cannot care for others. Stay healthy! Others depend on you. When you can, check in with family and friends. They may have problems with this health emergency and could use your help.

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Q1: Is general COVID-19 information about symptoms, spreading and preventing the virus, and treatment the same for people with Down syndrome?

- A.** Yes. Information about COVID-19 is the same for people with Down syndrome. Good information is best found at central sources like websites that end with **.gov**:
- Centers for Disease Control and Prevention (CDC): [Coronavirus Disease 2019 \(COVID-19\) | CDC](#)
 - National Institutes of Health (NIH): [Coronavirus \(COVID-19\) | National Institutes of Health](#)
 - Your state health department website has advice about where you live.

Q2. Are individuals with Down syndrome at "high risk" for COVID-19?

- A.** The CDC, the NIH, public health professionals and infectious disease experts have highlighted people who are more “at risk” or “high risk” for COVID-19. High risk means a person could be more likely to get the disease. They could also be more likely to have a severe illness. Experts say that people over age 65 and people with medical problems are at higher risk for getting severe COVID-19.

We do not know if people with Down syndrome are more likely to get sick with COVID-19. In general, people with Down syndrome are more likely to get infections.¹ Also, many people with Down syndrome have other medical problems that could make them more at risk for severe illness from COVID-19.² In addition, the CDC has recently classified people with disabilities as “people who need to take extra precaution.”³ For these reasons, it is very important to follow the recommended precautions to prevent COVID-19 in people with Down syndrome.

Q3. What are the medical problems that people with Down syndrome may have that put them at high risk?

- A.** Children and adults with Down syndrome often have more than one health problem. If these problems are untreated or active, that person may be at higher risk for COVID-19. These can include:
- **Certain heart problems.**
 - **Chronic respiratory problems.**
 - **History of severe respiratory infections.**
 - **Asthma.**

- **Obstructive sleep apnea.**
- **People who may have lower immune function, such as:**
 - » People with *diabetes*.
 - » People receiving chemotherapy or undergoing *active treatment for cancer*.
 - » People on *certain medications* that lower the function of the immune system (such as for treatment of rheumatoid arthritis, lupus, or psoriasis).

**More detailed information about Down syndrome and the underlying medical conditions considered high risk for COVID-19 is available in the Expanded Version of this Q&A.*

Q4: The CDC notes that people who are “older” (loosely defined as 65 or over) are at “high risk” for severe illness from COVID-19. At what age are individuals with Down syndrome considered “high risk” since there is “accelerated aging” in this population?

A. We do not have enough data about COVID-19 and people with Down syndrome to know for sure, but limited published findings suggest that adults with Down syndrome younger than 65 years of age are more likely to become severely ill if infected by COVID-19. They may also have increased mortality from COVID-19, but we do not yet know how many people have been infected by COVID-19 to know this for sure. We also do not yet know exactly what underlying risk factors may be more likely to result in severe illness or death. Unpublished, early reports from an international survey currently being undertaken by the Trisomy 21 Research Society (T21RS) COVID-19 Taskforce may provide us with more insight into this question. You can [find information from the survey here](#).⁴

Q5. Are there challenges in preventing or diagnosing COVID-19 in people with Down syndrome?

A. People with Down syndrome communicate, learn, and understand in different ways. They may have trouble understanding how to keep themselves healthy or knowing if they are ill. Some people with Down syndrome may need extra help to learn about “[social distancing](#)” (also called physical distancing) and how to prevent the spread of infection.

People with Down syndrome may also have a hard time telling others when they don’t feel well. They may have trouble knowing they have symptoms or how to



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describe them. For these reasons, they may not raise concerns or seek medical care quickly. Therefore, it is necessary to pay close attention and be watchful.

Q6. How can I help a person with Down syndrome understand COVID-19 and how to stay healthy?

A. People with Down syndrome tend to be very sensitive to other people's feelings. Most people with Down syndrome will pick up that "something is going on." Try to avoid too much exposure to the news. We suggest you share information and answer questions about COVID-19. Be calm and give facts. Use simple words and pictures. Try to follow the same daily schedule as much as possible. Many strategies can help:

- Practice handwashing using the chorus of a favorite song or the "ABCs" or "Happy Birthday." Handwashing should be for about 20 seconds.
- When in public spaces, wear a face covering or mask that covers your mouth and nose.
- Use social stories, words like "staying in your bubble," and visual supports to show what keeping a safe distance looks like.
- Explain that smiling, waving, and socialization from a distance is fine, but avoid hugging, handshaking, and touching others.

**Additional resources and links are available in the Expanded Version of this Q&A.*

Q7. Is travel safe for individuals with Down syndrome?

A. At this time non-essential travel is strongly discouraged. States and communities may have different travel and quarantine policies in place. For example, some locations may require a self-isolation period of 14-days for travelers. For information about travel both within and outside the United States, check the CDC website.

If it is necessary for an individual with Down syndrome to travel, follow the local rules, which may vary from city to city and state to state, try to take transportation that is less likely to be crowded or during a time with fewer crowds, and remember to wash hands frequently or use hand sanitizer, and wear masks or face coverings.

Q8. What is useful in helping people with Down syndrome to reduce stress and stay well?

A. Following a regular schedule at home can be helpful. Follow a similar routine every day as much as you can. People with Down syndrome may be very sensitive to sudden changes to their routine and environment. They may also become anxious if they notice others are anxious or upset. Try to avoid keeping the news on. People with anxiety or depression will also likely need more help at this time. You can use calming strategies to help people relax, such as deep breathing and exercising. Reach out to health care providers with significant concerns. Some ways to help stay well are to:

- If allowed, take walks outside, even for a short time. Try to stay 6 feet away from other people and wear a face covering or mask over your nose and mouth. It may help to make a list of activities that are allowed both indoors and outdoors.
- Keep routines of getting dressed and ready for the day.
- Keep regular sleep schedules.
- Eat a healthy, balanced diet with whole grains, protein rich foods, fruits and vegetables, dairy (or substitutes) and healthy fats. There are no known foods or nutrients that prevent or treat COVID-19.
- Stick to three balanced meals and two healthy snacks and be mindful of portion sizes. Avoid emotional eating, grazing, or eating when bored.
- There are many resources available online to help find safe activities. Consider checking your local Down syndrome clinic or local Down syndrome organization's website.

Q9. How will we know when it is safe for people with Down syndrome to return to activities outside the home such as school, work or visiting with friends and family?

A. Given that some people with Down syndrome may be at high risk for COVID-19 and may have other unique challenges, a minimum precaution is to return to activities outside the home only when government guidance allows for such activities for the general population.

Anyone with Down syndrome who has significant health issues should take extra precautions and should discuss returning to activities outside the home with family members/agency caregivers and a physician and/or health professional first.

In addition, consideration should be given as to whether a person with Down syndrome can follow the rules (or has support to follow the rules) associated with activities outside the home, like physical distancing.

Family members and agency caregivers should understand the risks, take appropriate precautions, and use their best judgment.

Q10. What are some factors I should consider when choosing what activities may be safe for a person with Down syndrome?

A. As states have begun lifting shelter-at-home orders and more spaces and activities are opening, families and caregivers are struggling to find a balance between maintaining health and safety, and supporting mental wellness. There is no single answer to this question and the decision will be different for every person. Determining what activities may be safe for your child or adult should be made with consideration for your individual child or adult in mind and in consultation with their medical provider. There is no way to ensure complete safety for any activity, but there are ways to reduce risk and harm. It may be helpful to consider these factors when considering different activities:

1. Personal / Individual. Specific risk factors- Consider your child or adult's health history, including any factors that may make them higher risk, like older age or certain medical conditions. Consider whether they are able to follow safety precautions such as maintaining a safe distance, wearing a mask and not touching their face. Discuss personal factors with your loved one's health care professional.
2. Factors specific to the activity. Some activities are considered more high risk than others. For example, large crowds indoors without masks would be considered higher risk, while outdoor activities in which people can wear masks or stay 6 feet away would be considered lower risk.
3. Public health factors. Consider the COVID-19 health trends in your state and community. Check with your state's Department of Public Health. Consider whether the number of new infections is increasing or decreasing, and what your community's capacity is for monitoring and testing.

Q11. Is it safe to send my child with Down syndrome to school when they open in my community?

- A.** At this moment in time, there are many discussions happening on the local, state, and national level about schools opening in the fall. In-person learning, remote learning and hybrid models are all being considered. Decisions about schools re-opening will likely depend on where you live.

The CDC and American Academy of Pediatrics (AAP) have both acknowledged that students receiving special education services may be more negatively affected by distance-learning. Because most children with Down syndrome greatly benefit from the structured learning environment of school, their special education services, and individual therapies, remote learning may be especially difficult for children with Down syndrome.

The AAP has acknowledged the importance of in-person learning and has strongly advocated for in-person learning.⁵ This is based on the current information that suggests that serious illness from COVID-19 remains rare in school-aged children, with and without Down syndrome. It is important to note that we do not have a lot of data regarding the risk of COVID-19 in children with Down syndrome because many children with Down syndrome may be staying physically distanced from other people and have very low exposure to COVID-19 at this time.

When your school discusses re-opening plans, you should make sure that they align with the American Academy of Pediatrics (AAP)/CDC guidelines on school re-opening.⁶ Talk to school officials about these guidelines and what policies and practices are being put into place, especially to protect people who may be more vulnerable. Consider your child's specific risk and discuss with school officials what accommodations the school will provide. You can request written safety plans from your school to review with your child's medical provider.

For more information, you can also listen to the following podcast about school re-opening and considerations for children with Down syndrome by Dr. Kishore Vellody, Medical Director of the Down Syndrome Center at Children's Hospital of Pittsburgh, and Dr. Andrew Nowalk, a pediatric infectious disease expert.

**Information about consideration for safety and schooling are available in the Expanded Version of this Q&A.*



Q12. Are there special considerations for individuals with Down syndrome who are living in group homes or with roommates or support staff?

- A.** Agencies and group homes should have plans in place to protect people with Down syndrome – “Respiratory Protection Program Mitigation Strategies.” [CDC has also issued a new advisory on shared housing](#). It is important to ask about this. Decisions should depend on the extent of COVID-19 in a home community compared to where adults are living in a group. Close contact with anyone who has COVID-19 symptoms can pose a greater risk. Thorough and frequent handwashing, wearing masks, staying away from things a sick person may have touched, and not touching a sick person is important. The risk may be increased if roommates or support staff have had contact with a person who has symptoms or has tested positive for COVID-19 and are not self-isolating. Check with the agency providing support services and ask about what procedures they have in place to prevent infection with COVID-19. Many states have limits on visitors to any care or residential facilities.

**Information about “Respiratory Protection Program Mitigation Strategies” and sample questions to ask group home managers are available in the Expanded Version of this Q&A.*

Q13. If sick, when should people with Down syndrome go to the doctor or the hospital?

- A.** People with mild symptoms (like sniffles or congestion, but otherwise the person is regularly eating, drinking, and having no trouble breathing) should stay at home and **NOT** go to the doctor’s office or hospital. If there are mild symptoms, you should call the doctor for advice. If you are worried, you should ask if testing for COVID-19 is recommended or available in your area. If you see severe symptoms, do not delay and call your doctor or hospital to get advice on where to go. **In the case of a medical emergency, call 911.**

Q14. What kind of a plan should I have if I am sick or test positive for COVID-19 or have to go into the hospital, and I am the only caregiver for a person with Down syndrome?

- A.** Most people who are sick or who test positive for COVID-19 will not require hospitalization, but will need to maintain social isolation from others. The CDC has issued an advisory on [homecare](#). Anyone who has symptoms or tests positive for COVID-19 will need to maintain social isolation and stay away from others. Close contacts of that individual may also be tested for COVID-19.

It is important to plan for someone else (a family member, personal care worker, respite worker) to provide care for your loved one with Down syndrome. If you are hospitalized, someone else will need to be in the home to provide support, or out of home respite will be necessary. Contact a caregiver support worker at your local area agency on aging, local senior services, or state department for elder affairs, or a caseworker from the state or local developmental disabilities' agency who may be able to arrange for respite and alternative housing.

Q15. With Down syndrome, does having dementia or Alzheimer's disease increase the risk of COVID-19?

- A.** [The Alzheimer's Association](#) (in the United States) has noted that “most likely, dementia does not increase risk for COVID-19.” However, dementia-related behaviors, increased age, and common health conditions that often accompany dementia may increase risk. For example, people with Alzheimer's disease and other causes of dementia may forget to wash their hands or take other recommended precautions to prevent illness. In addition, diseases like COVID-19 may worsen cognitive impairment and confusion due to dementia or could increase delirium.

Other factors that likely increase their risk for contracting COVID-19 include group living arrangements in long-term care facilities and limitations on physical distancing due to increased reliance on staff or caregivers. Additionally, people with advanced Alzheimer's disease may be at increased risk due to a higher risk of swallowing problems and aspiration pneumonia. Adults with Down syndrome who have Alzheimer's disease who develop viral respiratory infections appear to be particularly susceptible to developing secondary bacterial pneumonia. Also, they may not be able to communicate if they begin to develop symptoms from the virus. They may be less likely to have a fever or cough, but sometimes the signs of illness will include a sudden change in behavior, such as increased confusion, agitation, or becoming completely inactive. Therefore, watching out for signs of the infection or any of these significant behavioral changes is very important. Preventing exposure to anyone who may have COVID-19 is key. [The Alzheimer's Association](#) also provides recommendations for all people with Alzheimer's disease.

Other Useful Links:

- For more information on COVID-19 and people with Down syndrome, Dr. Kishore Vellody of the Down Syndrome Center at Children's Hospital of Pittsburgh has released a series of podcasts with guest, Dr. Andrew Nowalk, a pediatric infectious disease expert. You can listen to their new episodes here: [Episode four](#) & [Episode five](#).
- For general information about the coronavirus and advice for direct support personnel, you can watch [this video series](#) by Dr. Rick Rader, of the American Academy of Developmental Medicine and Dentistry.
- American Academy of Pediatrics www.healthychildren.org (Trending topics and quick links-English and Spanish).

The following organizations contributed their time, resources and expertise to this Q&A. You can download and access the Expanded Version of this Q&A from their websites:

[Down Syndrome Medical Interest Group-USA](#) (DSMIG-USA)

[Global Down Syndrome Foundation](#) (GLOBAL)

[LuMind IDSC Down Syndrome Foundation](#) (LuMind IDSC)

[National Down Syndrome Congress](#) (NDSC)

[National Down Syndrome Society](#) (NDSS)

[National Task Group on Intellectual Disabilities and Dementia Practices](#) (NTG)

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