



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 common symptoms are
- 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" 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. Younger children may also have more risk of severe disease but most of them do recover.

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 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: 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 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.

Q5. 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:

- 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.
- 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.

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

Q6. Is travel safe for individuals with Down syndrome?

- A.** At this time, being out in public or any non-essential travel is strongly discouraged. Most states and communities have limited travel. 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.

Q7. 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:
- 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 the coronavirus.
- Stick to three balanced meals and two healthy snacks and be mindful of portion sizes. Avoid emotional eating, grazing, or eating when bored.
- If allowed, take walks outside, even for a short time. Always stay 6 feet away from other people and wear 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.

Q8. Should people with Down syndrome go to their school/work/day programs and other activities?

A. Many schools and programs have been closed at this time. Social distancing is recommended for all people. Activities with other people increases the spread of infection, and this is why many programs have been closed. For schools, programs, and activities that are open, it will be important to check what safety procedures have been put in place and to consider risk for infection at the activity. Any concerns about participating should be discussed with the person’s doctor.

Q9. 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.” 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, 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 new 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.*

Q10. 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.**

Q11. 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.

Q12. 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.

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 released a podcast with guest, Dr. Andrew Nowalk, a pediatric infection disease expert. You can listen to this two-episode podcast here: [Episode one](#) & [Episode two](#).
- For general information about the coronavirus and advice for direct support personnel, you can watch [this three part video](#) 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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References:

1. Malt EA, Dahl RC, Haugsand TM, et al. Health and disease in adults with Down syndrome. Tidsskr Nor Laegeforen. 2013;133(3):290-294.
2. Malt EA, Dahl RC, Haugsand TM, et al. Health and disease in adults with Down syndrome. Tidsskr Nor Laegeforen. 2013;133(3):290-294.



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