



# 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*

The unprecedented spread of the coronavirus (COVID-19) is presenting the world with a unique challenge. In our case, the pandemic calls for a united response to better understand its impact on the Down syndrome community.

Information in this Question and Answer (Q&A) document can be used to help you support your loved one with Down syndrome. It is our hope that this information will help us get through this health challenge. We encourage you to share the information in this document with your family, friends, doctors, nurses, therapists, teachers and others within the Down syndrome community.

In this version, we have done our best to update answers to questions that people are currently asking and to anticipate other important questions for our Down syndrome community. In this document, you will find information about:

- 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 Expanded Version and an Abbreviated Version of this Q&A are available. Many organizations and professionals have contributed to both versions by providing their expertise on Down syndrome and applying it to what we know about COVID-19 at this time. As we learn more about COVID-19, and about how it may affect people with Down syndrome, we will continue to update this Q&A.

To be clear, this Q&A is just informational. It is not medical advice. We hope the information is useful to you as you make decisions and look for medical, educational, or other recommendations. This Q&A should NOT be considered a substitute for the advice of a medical or related professional. You should speak with your own doctor or other healthcare professional(s) for medical advice.

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Please be sure that the information you receive is from reliable, trusted, and recognized sources. We recommend the Centers for Disease Control and Prevention (CDC) and websites ending with “.gov” in the United States. International, federal, and state health department websites should be the most reliable. Also, we encourage you to look to the websites of organizations who support the Down syndrome community, which are listed at the end of this Q&A.

## IMPORTANT REMINDERS

If you think you, a loved one, or someone in your care may have COVID-19, please call your healthcare professional as soon as possible. Calling first is strongly recommended before traveling to an office or hospital, as your time spent there may increase exposure to COVID-19 for you and others.

If you are a parent or caregiver, please remember to take care of yourself. It is hard and sometimes impossible to care for others if you are sick or too tired. It is also important not to spread your sickness. Stay healthy for the people who depend on you.

If you have the time and energy, we also encourage you to check in with your family and friends—especially those who may be struggling during this health emergency. A phone call or text message goes a long way to show someone you care. Finally, in the coming days and weeks, if possible, share resources and supplies with your family, friends and community members who are in need.

**In the event of an emergency, please call 911.**



## Basic Information about COVID-19

**Q1: Does general COVID-19 information about symptoms, transmission, protection, and supportive treatment apply to individuals with Down syndrome?**

- A.** The general information about COVID-19 (the illness that results from exposure to novel coronavirus) that applies to all individuals also applies to people with Down syndrome. This includes information on symptoms, how the disease is spread, protection, supportive treatment, and other insights regarding the virus. As far as experts know, people with Down syndrome get infected with the virus at the same rate, but some may be at greater risk of severe illness from COVID-19.<sup>1</sup>

## Q2. Are individuals with Down syndrome considered to be a “high risk” or “vulnerable” population in this coronavirus outbreak?

- A.** Based on what we know today, public health professionals and infectious disease experts warn that certain individuals are more likely to get severely ill and need to go to the hospital if they are sick with COVID-19. These include:
- People living in group homes or long-term care facilities.
  - “Older” people (individuals over 65 in the general population).
  - People with chronic (long-term) pre-existing conditions (like heart disease, kidney disease, or diabetes).
  - People with compromised immune systems (including those who are being treated for cancer, take immunosuppressant medications, or are on dialysis).
  - People with lung disease and/or respiratory (breathing) problems (including people who have asthma, and people who smoke).

As with all people, older people with Down syndrome are high risk. Also, since individuals with Down syndrome often have many of the underlying medical conditions mentioned above, people with Down syndrome and these co-occurring issues should also be considered high risk for COVID-19. In addition, because of living in close quarters, people with Down syndrome living in group homes or long-term care facilities are also at higher risk than the general population. We do not know whether just having Down syndrome means a person is at a higher risk of severe illness from COVID-19, but due to the factors mentioned above, the CDC has classified people with disabilities as “[people who need to take extra precautions](#)”<sup>2</sup>

## Q3. What are the medical conditions that individuals with Down syndrome could have that may put them at higher risk?

- A.** The CDC and the National Institutes of Health (NIH) say that people with certain medical conditions are “high risk.” These people are more likely to become severely ill and need to go to the hospital if they get COVID-19. As mentioned, the CDC also now classifies people with disabilities as “people who need to take extra precautions.”

People with Down syndrome are more likely to have one or more of these medical conditions that put them at higher risk than those without Down

syndrome.<sup>3</sup> However, to be clear, some people with Down syndrome will not have any of these medical conditions that cause higher risk of COVID-19.

Children and adults with Down syndrome are known to have several co-occurring conditions, that if untreated or active, may make that individual more likely to get COVID-19. These can include:

- **Ongoing heart defects (heart disease).**
  - » COVID-19 may cause a severe inflammatory response in the body which can also affect the heart.
  - » Based on what clinicians have seen so far, people with Down syndrome who were born with heart conditions (congenital heart conditions) which were fully repaired, or those whose hearts work fine, should follow general precautions for all individuals.
  - » Individuals who have heart failure or heart disease may be at higher risk and should consult with their health care provider about additional precautions that may be needed, especially if they also have other conditions like:
    - ✓ Diabetes
    - ✓ Obesity
    - ✓ Hypertension (high blood pressure)
    - ✓ Pulmonary hypertension
    - ✓ Chronic obstructive pulmonary disease (COPD)
    - ✓ Kidney disease
- **Chronic respiratory problems or lung disease or a history of severe respiratory infections.**
  - » People with Down syndrome are more likely to get respiratory infections like colds or flu.<sup>4</sup> Those who have had frequent or severe respiratory conditions in the past may have more serious health consequences if they are exposed to COVID-19.
  - » People with a history of previous serious respiratory conditions may be at especially high risk and should follow strict precautions.
  - » People with asthma are at higher risk and should continue their treatments during this time.

- **Sleep apnea.**
  - » Sleep apnea has been shown to be associated with increased respiratory infections.<sup>5</sup>
  - » Continuous Positive Airway Pressure (CPAP) machines with facial masks are often used to treat sleep apnea. It is important to properly clean the CPAP mask and machine, especially if the person using the equipment has a respiratory infection. A standard cleaning schedule includes changing the water nightly and replacing mask cushions 2 times monthly.<sup>6</sup> In the presence of a respiratory infection, these hygienic activities should be conducted more frequently.
  - » If a person with Down syndrome has symptoms of COVID-19 or has been diagnosed with COVID-19, CPAP (or BiPap) machines might aerosolize the virus (which means spread it in the air) and it might spread to others. In these situations, please check with your health professional or doctor for guidance.<sup>7</sup>
- **Lower immune function.**
  - » Some people with Down syndrome may have lower immune function and have more difficulty fighting infection. People who may have lower immune function include:
    - ✓ Those with diabetes.
    - ✓ Those receiving chemotherapy or undergoing active treatment for cancer, or those who have had a bone marrow transplant.
    - ✓ Those with autoimmune conditions, such as rheumatoid arthritis, lupus, or psoriasis, who are on certain medications that lower the function of the immune system.
- **Cancer/leukemia.** While children with Down syndrome have a 10 to 20 times greater risk of developing acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL), overall less than 1% of people with Down syndrome develop leukemia or other forms of cancer.<sup>8</sup> If a person with Down syndrome *is actively* being treated for cancer, they would be at higher risk for COVID-19. Families should work closely with their cancer specialists.

- **Diabetes.** Children and adults with Down syndrome who have diabetes are at risk for having lower immune function compared to people without diabetes.<sup>9</sup> People with Down syndrome who are effectively managing treatment for diabetes would not necessarily be at higher risk, and they should continue to take their medications during this time.

These medical conditions in children and adults with Down syndrome can make them “vulnerable” and at “high risk” for severe illness. Therefore, people with Down syndrome require closer monitoring, observation, and attention, especially when they are ill.

**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](#).<sup>10</sup>

**Q5: What can help people with Down syndrome reduce stress and stay well?**

- A.** Following a schedule can be helpful for all people. People with Down syndrome may be very sensitive to sudden changes to their routine and environment, which may cause stress. People with anxiety or depression will also likely need more help at this time. Reach out to health care providers with any concerns. Some ways to help stay well are to:
- If appropriate, take walks outside. Try to stay 6 feet away from other people and wear a mask.
  - 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.
  - » For more information visit [Dietary Guidelines for Americans](#).
- Stick to three balanced meals and two healthy snacks. Avoid emotional eating, grazing, or eating when bored.
- Drink plenty of fluids.
- Get outside as much as possible. It may help to make a list of activities that are allowed, both indoors and outdoors, such as activities like bike rides, or virtual dance parties where it is possible to stay physically distanced. Posting the list of activities around your home can also be a helpful reminder.
- Help connect the person with Down syndrome with their friends via video calls. If they are living in a group home, ensure that video apps are downloaded and available.
- 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.

## Q6. 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 [social distancing \(also called physical distancing\)](#).

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



## Q7. 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.

## Q8. Should adults with Down syndrome go to work, day programs, and other activities?

**A.** Going to work, day programs, or other group activities will likely put individuals with Down syndrome at greater risk for getting COVID-19, and if they have other medical issues, they are more likely to have severe complications. Some states and localities have asked places where people gather in groups to close or to limit entry, but recently some restrictions on this have been lifted in certain

states. Some businesses are still closed, and some are re-opening. If your adult with Down syndrome is employed at a business that is essential or has opened, the adult, the parent/caregiver, and the employer should confer about the risk for infection at the location and about the person with Down syndrome's specific risk to decide whether it is advisable to go to work.

For day programs, the program should have done a risk assessment and be implementing infection control practices (for example, requirement to wear masks, reduction in numbers, etc) and using surveillance (careful monitoring or watching) for symptoms of infection. Talk to the manager at the agency and ask what safety procedures they have started or are using. Also ask what safety procedures they are using for transport (drivers' training, disinfectants for the buses or vans, seat spacing, etc.) to help decide on participation. Additional considerations include whether staff are being screened for symptoms, getting temperature checks, or whether COVID-19 testing is readily available.

In any of the situations above, if the person with Down syndrome ends up at home, see if they can still do some of the activities that they often do at work or the day program. Creating a new schedule that they can depend on may also be helpful.

## Q9. 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.<sup>11</sup> 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](#).<sup>12</sup> 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.

#### **Q10. What educational rights is my child with Down syndrome guaranteed if our local school does not open or if the school does open but we decide it is not safe for our child to return?**

- A.** The COVID-19 pandemic has put a massive strain on students, families, educators, schools, and districts. The Individuals with Disabilities Education Act (IDEA) is still in place and schools must continue to ensure that students with disabilities are provided with a free and appropriate public education (FAPE) that includes challenging goals, while conducting remote learning. If a family does not feel comfortable with their child returning for in-person learning, they should discuss a virtual learning plan with the school. Council of Parent Attorneys and Advocates (COPAA) has issued a comprehensive collection of [frequently asked questions](#) and any family concerned about their child's educational rights may contact an advocate at their local chapter of The Arc or local Down syndrome organization.

The U.S. Department of Education has established a working group to provide information and resources to parents, students, teachers, schools, and school personnel related to the outbreak of COVID-19. They have developed a



[Fact Sheet: Addressing the Risk of COVID-19 in Schools While Protecting the Civil Rights of Students](#) and a [Supplemental Fact Sheet: Addressing the Risk of COVID-19 in Preschool, Elementary and Secondary Schools While Serving Children with Disabilities](#), to “offer guidance, technical assistance, and information on any available flexibility, within the confines of the law, to ensure that all students, including students with disabilities, continue receiving excellent education during this difficult time.”

#### Q11. Are there any data that have been published so far specific to people with Down syndrome and COVID-19?

- A. There is still so much we do not know about COVID-19 in people with and without Down syndrome and information continues to change rapidly. There have been four small studies specific to Down syndrome and COVID-19 that have been published at this time. These studies have looked at rates and risk factors for hospitalization and death, and the possible role of immune dysregulation in Down syndrome. It is important to understand that these study samples are very small and it is too soon to make any strong conclusions from these studies. These [studies are discussed here in this podcast](#) by Dr. Kishore Vellody and Dr. Andrew Nowalk.

#### Q12. Are there challenges in preventing or diagnosing COVID-19 in people with Down syndrome?

- A. The CDC has newly updated fact sheet outlining why [people with disabilities need to take extra precautions](#).<sup>13</sup> A lot will depend on the intellectual capabilities of the individual with Down syndrome and how much he/she can understand and communicate.
- **Intellectual disability.** Individuals with Down syndrome who have an incomplete understanding of their health (what is called, “health literacy level”) may need support to avoid being infected or managing the virus if they get it. They may not be able to take part in “self-management of the disease.” As a result, they may have problems and need help with medication, emotional self-regulation, following directions, self-isolation, hygiene, and following basic medical directions. In the case of COVID-19, it may be hard to help a person understand the need to maintain physical distancing to avoid handshakes and touching one’s face, and the need for handwashing.

- **Communication deficits.** Some individuals with Down syndrome may not be able to clearly express their pain, discomfort, or feeling upset. They may not be able to describe their symptoms or call out for immediate help. If they have fever, cough, and shortness of breath, it should be reported to a health care professional as soon as possible so that an early assessment can be made. People with Down syndrome may not be able to self-report such concerns and may need help from family members and/or caregivers who are able to recognize their symptoms better than others.



## Advice on Prevention

### Q13. What can be done to help individuals with Down syndrome stay healthy?

- A.** Experts at the CDC and NIH suggest “asymptomatic” (meaning they have no symptoms) individuals with COVID-19 may still spread the virus. There is currently no vaccine for COVID-19, however, there are some ways to stop the spread of this disease.

According to the [CDC](#), we can further reduce the spread of COVID-19 by 1) **staying home as much as possible**, 2) if you must go out, practice physical distancing by staying at least 6 feet away from other people and 3) [wear a mask covering your nose and mouth](#). Consider however, that certain situations, such as being in an elevator, on a plane, train, subway/tram/bus, or in crowds, may make it impossible to stay 6 feet away from others.

The CDC recommends that you:

- Wash your hands often with soap and water for at least 20 seconds, especially after being in public places; touching items or surfaces that have been touched by others; after going to the bathroom; before eating; after blowing your nose, coughing or sneezing; and when they are visibly dirty.
- If soap and water are not readily available, use an alcohol-based hand sanitizer with at least 60% alcohol.

- Stay home when you can and practice [physical distancing](#).
- If you go out, wear a mask or cloth face covering over your nose and mouth and still maintain physical distancing. Avoid other people who are not wearing a mask.
- Don't touch your eyes, nose, and mouth.
- Avoid close contact with people who are sick and stay home when you are sick.
- Cover your cough (cough/sneeze into the crook of your elbow), or sneeze into a tissue, then throw the tissue in the trash.
- Clean and disinfect objects and surfaces that you often touch using an [EPA approved household cleaning spray or wipe](#). The [CDC](#) recommends a cleaner made up of at least 70% alcohol or diluted bleach (i.e., 5 tablespoons of bleach in a gallon of water or 4 teaspoons of bleach in a quart of water).<sup>14</sup>
- Remember to follow basic health recommendations like maintaining healthy and balanced nutrition and hydration routines (eat healthy foods and drink plenty of water), exercising/movement, using stress management tips (especially those that worked in the past), getting rest, and maintaining a good sleep schedule.
- Look at other ways to stay socially connected using remote means, such as social media and telephone (and remember to clean your devices!).
- Keep yourself healthy which will make it more likely that your loved ones will stay healthy.

If someone in your home (who is not at high-risk) has mild symptoms and may have COVID-19, medical providers/doctors will likely advise them to get tested, stay home, and take care of their symptoms. It is very important to try as hard as possible to observe the CDC guidelines on isolation for that person in the home. Keep them at home and try to limit or stop contact between that person and anyone with Down syndrome in the home.

## Q14. How do I best explain what “physical distancing” is to my child or adult with Down syndrome?

- A.** The CDC defines physical distancing as “remaining out of congregate settings, avoiding mass gatherings, and maintaining distance (approximately 6 feet) from others when possible.”

A simple way of explaining this is to say that, “We should avoid places where there are a lot of people.” You might say, “When we go out, do not sit or stand or walk close to another person. Keep away from other people by two times as far as when you spread both your arms out.” Phrases they may already know include “staying in your bubble” or giving people “elbow room.” Using visual supports like holding out your own arms can be a great way to show what arm’s length means. For younger children, using a hula hoop can be a great way to show how to stay in their own personal space.

Smiling, waving, and socialization from a distance is fine, but avoid hugging, handshaking, and touching others.

## Q15. How can I help my child or adult with Down syndrome tolerate wearing a face covering or mask?

- A.** The CDC recommends wearing cloth face coverings in public settings, especially when physical distancing is difficult to maintain, but still try to maintain 6-foot distance from others. Some people with Down syndrome may have sensory issues that would make it difficult or uncomfortable to have something touching their face. Here are some things that may help your child or adult with Down syndrome tolerate a mask:

1. Allow the person to choose what covering they would like to use from a choice of 2 or 3 options. If you plan to make the coverings, allow them to pick the color or fabric design and even decorate it.
2. Use a first-then directive to tell the person that you will, “first practice wearing the covering and then (a preferred activity).”
3. Use a visual timer to help the person know how long they must wear the covering. Start with an amount of time that you know that the person can tolerate (even if it is just a few seconds) and end on a good note. Gradually increase the amount of time using the same visual timer while practicing at home.

4. Model wearing a face covering. During a family or group activity even at home, have everyone practice wearing their masks at the same time.
5. After the person reaches a certain amount of time that they can tolerate wearing the face covering, you can try going out with the covering. Still use first-then, but just say, “first go out for walk with mask, then come back and have lunch (or whatever the preferred activity is).”
6. [Easterseals](#) and the [Autism Services, Education, Resources and Training](#) have both created social stories specifically about wearing a mask you can watch together.

**Q16. What can I do to help my child or adult with Down syndrome wash their hands often and thoroughly? And how can I help my child or adult with Down syndrome to stop touching his/her face?**

**A.** For more practice, schedule times for handwashing throughout the day, in addition to the typical times hands are washed (after eating, after going to the bathroom, etc.). These scheduled times can be placed on a visual schedule as a reminder. Use a first-then directive to motivate the individual with Down syndrome to wash their hands. First wash hands, then (the preferred activity). Talk about proper handwashing. Using the chorus of a favorite song to help your child or adult with Down syndrome understand how long to wash their hands (about 20 seconds) can be helpful. Practice the procedure together. Practice not touching the face – include your child or adult in the task of checking that you don’t touch your face either. Praise your child or adult with Down syndrome when they have not touched their face—even if it has only been for a short time.

- Sunglasses or glasses may be worn to help the person not touch or rub their eyes.
- Gloves should only be used in a recommended way, including using single-use gloves, following proper removal and disposal protocols, and washing hands thoroughly after removal.<sup>15</sup>
  - » Keep in mind that while gloves may act as a barrier between your skin and germs, gloves can still spread the virus just like fingers can.<sup>16</sup>

- Fidget-toys or objects of interest can be used to help the person not touch things in the environment or touch the face. These may help during transportation or when a community outing is necessary.
  - » Keep in mind that these objects could carry infection themselves, so it is best if they are small and easy to clean quickly.



## Additional Advice

### Q17. Does having dementia or Alzheimer’s disease increase a person with Down syndrome’s risk of being infected by COVID-19?

- A.** [The Alzheimer’s Association](#) (in the United States) has noted that: “Most likely, dementia does not increase risk for COVID-19, the respiratory illness caused by the new coronavirus, just like dementia does not increase risk for flu. 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 and the flu may worsen cognitive impairment due to dementia.”<sup>17</sup>

Other factors that likely increase their risk for COVID-19 include group living arrangements in long-term care facilities and limitations on physical distancing due to increased reliance on staff or caregivers. Individuals with advanced Alzheimer’s disease have higher risk of swallowing problems and aspiration pneumonia (usually caused by accidentally inhaling food or liquids into the lungs). Adults with Down syndrome with Alzheimer’s disease who develop viral respiratory infections are likely to develop bacterial pneumonia on top of the viral infection. They may not be able to communicate if they begin to develop symptoms from the virus. They may be less likely to tell you that they have a fever or cough. Sometimes, signs of illness will include sudden change in behavior, such as increased confusion, agitation, or becoming completely inactive. 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 individuals with Alzheimer’s disease.

**Q18. How should families manage multiple family members who are considered “high risk” or vulnerable? For example, when a 65-year-old grandmother takes care of her grandchild with Down syndrome?**

- A.** A 65-year-old grandmother is considered “high risk” due to her age, and her grandchild might be, too, depending on whether they have any medical conditions associated with COVID-19. Consider your grandmother’s overall health and any possible exposure—for example, is she sheltering-in-place, or is she still going out and socializing?

You may want to assess the risk, your comfort with the risk, and the importance of your two high-risk family members being together. You may want to consider: Is the spread of COVID-19 in your community severe? Are your family members self-isolating (staying at home or in their room alone) most or all of the time? What other choices do I have? Make a decision that is right for you.

**Q19. If my child or adult with Down syndrome is hospitalized, will a parent or support staff be allowed to accompany them?**

- A.** Due to the spread of the virus, hospitals may restrict access to non-essential people visiting hospitalized patients. This policy is rightly meant to save lives and reduce further spread of COVID-19. However, as of June 2020, [Federal law requires](#) hospitals modify policies to ensure people with disabilities have access to support from a parent or caregiver while in the hospital if needed.<sup>18</sup> Under the new federal hospital accommodation law:

- Hospitals and other health care facilities are required to allow designated persons (family members, staff, or others) to support any patient that may need such support.
- Hospitals are required to provide available personal protective equipment (PPE) to support persons to keep them safe.
- Procedures for screening support persons for COVID-19 symptoms and for supporters to safely take breaks and leave and re-enter the hospital must be in place.
- Hospitals are encouraged to mitigate the risk associated with support persons supporting COVID-19-positive patients.

**Q20. What should I do if my child or adult with Down syndrome is hospitalized and my request for support accommodations is denied? Where can I find information or take action regarding equitable medical care and medical access rights for individuals with Down syndrome?**

**A.** Below are the websites for some relevant national organizations involved in this issue. Some have links directly to their complaint portal:

- [Administration for Community Living \(ACL\)](#)
  - » [State Protection & Advocacy Page; Resources for Older Adults & People with Disabilities](#)
- [American with Disabilities Act \(ADA\)](#)
  - » [ADA Complaint Submission](#)
- [Anti-Defamation League \(ADL\)](#)
  - » [ADL Discriminatory Report Submission](#)
- [The Arc](#)
  - » [COVID-19 Treatment Rationing Complaints](#)
- [Center for Public Representation \(CPR\)](#)
  - » [CPR Medical Rationing Page](#)
- [National Disability Rights Network \(NDRN\)](#)
  - » [NDRN Take Action Page](#)
- [Office of Civil Rights \(OCR\)](#)
  - » [OCR Complaint Portal](#)

**Q21. Is it safe for individuals with Down syndrome to travel?**

**A.** At this moment in time, non-essential travel is strongly discouraged. Like all people, individuals with Down syndrome should stay at home when they can and only travel when necessary.

For information about travel both within and outside the United States, we recommend reviewing [the website](#) of the CDC.

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. Some states have

instituted controls on visitors from states highly impacted by COVID-19, such as 14-day quarantine periods. Check the state's website to determine what controls may be in place. To travel you may have to carry a document showing you have had a COVID-19 test recently and tested negative. Try to use your personal vehicle or take transportation that is less likely to be crowded or during a time with fewer crowds. Remember to wash hands frequently or use hand sanitizer and wear a face covering or mask.

Some things to consider before traveling with an individual with Down syndrome:

- Has a “quarantine order” been issued where you are or where you are traveling to?
- Is this trip important enough to risk infection?
- How would I manage if I or my family member with Down syndrome became infected while traveling?
- What if one of us is hospitalized away from home (in the location we are traveling to)?
- What if one of us was quarantined in the place we are traveling to and not able to travel home for 14 days?
- If traveling and being potentially exposed would mean that one of us needed to self-isolate, i.e., be separated from family member for at least 14 days, what would happen?

## Q22. When should individuals with Down syndrome who may be sick go to the doctor or the hospital?

- A.** A child or adult with Down syndrome who has mild symptoms (like sniffles or congestion, but otherwise eating, drinking are normal, and the person is 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. You may ask if testing for COVID-19 is recommended or possible in your area. If there are more severe symptoms and seeing a doctor is needed, it is very important to call the doctor or hospital first.

**In the event of an emergency, please call 911.**

## Q23. How can I help a person with Down syndrome understand COVID-19 and how to stay healthy?

- A.** People with Down syndrome communicate, learn, and understand in different ways. People with Down syndrome also tend to be very sensitive to other people's feelings. Most people with Down syndrome will pick up that "something is going on." 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.

Here are some helpful resources you can use to better inform you about "having that conversation" about COVID-19:

- A useful PDF booklet created by the Self-Advocacy Resource and Technical Assistance Center (SARTAC) is titled, *COVID-19 Information By and For People with Disabilities*, and is available from: <https://selfadvocacyinfo.org/resource/plain-language-information-on-covid-19/>
- A useful article for adults to help with talking to kids about COVID-19 is available at: <https://childmind.org/article/talking-to-kids-about-the-coronavirus/>
- An audio story for kids, plus a printable comic strip is available at: <https://www.npr.org/sections/goatsandsoda/2020/02/28/809580453/just-for-kids-a-comic-exploring-the-new-coronavirus>
- An excellent list of videos, songs, and show segments from Daniel Tiger to Sesame Street, helping with ways to keep kids safe and healthy, is available at: <https://www.pbs.org/parents/thrive/how-to-talk-to-your-kids-about-coronavirus>
- A free printable social story about the coronavirus is available at: [https://theautismeducator.ie/wp-content/uploads/2020/03/The-Corona-Virus-Free-Printable-.pdf?fbclid=IwAR1ulf42\\_sHE6gejRqSA3l-1z6FFpRvVpliZXzggPDDGiKPn5LJgK0oWIXM](https://theautismeducator.ie/wp-content/uploads/2020/03/The-Corona-Virus-Free-Printable-.pdf?fbclid=IwAR1ulf42_sHE6gejRqSA3l-1z6FFpRvVpliZXzggPDDGiKPn5LJgK0oWIXM)

**Q24. What kind of plan should I have in place if I have symptoms or if I test positive for COVID-19 or must be hospitalized, and I am the sole caregiver of an individual with Down syndrome?**

- A.** Most people who are sick with symptoms or test positive for COVID-19 will not need to go to the hospital. However, they will need to isolate from others and practice physical distancing. In addition, they may need to have other people in the home tested for COVID-19, including those with Down syndrome. You will need a plan for someone else (a family member, a personal care worker, or a respite worker) to help provide any day-to-day care that you or your child or adult with Down syndrome may need.

If you are hospitalized, either someone else will need to be in the home to support your child or adult with Down syndrome or you will need out of home respite care for them. Contact a caregiver support worker at your local area agency on aging or a caseworker from the state or local developmental disabilities' agency. They may be able to arrange for respite and alternative housing while you are hospitalized. For yourself, connect with the office of your local area agency on aging or state department for elder affairs or local senior services (such as your council on aging).

See also the CDC advisory on homecare, "[Interim Guidance for Implementing Home Care of People Not Requiring Hospitalization for Coronavirus Disease 2019 \(COVID-19\)](#)."

**Q25. What kind of support is there for individuals with Down syndrome who have Alzheimer's disease and/or dementia and are diagnosed with COVID-19?**

- A.** If COVID-19 has been positively diagnosed in a person with Down syndrome who also has Alzheimer's disease and/or dementia, a medical provider should advise you whether the individual should stay in place or be admitted to a hospital or other health care facility. If the person should stay in place, the provider should advise you what to look for and if you should change any of your usual care routine.

[The Alzheimer's Association](#) recommends that all caregivers of individuals living with Alzheimer's disease and all other dementia should follow guidelines from the Centers for Disease Control (CDC), and should consider the following:



- For people living with dementia, increased confusion is often the first symptom of any illness. If a person living with dementia suddenly seems more confused, contact your health care provider for advice.
- People living with dementia may need extra reminders and support to remember important hygiene practices (like handwashing) from one day to the next.
- Consider placing signs or pictures in the bathroom and elsewhere to remind people with dementia to wash their hands with soap for 20 seconds. Also consider washing your hands together while singing a song that lasts for 20 seconds, for example the “Happy Birthday” song.
- Show them how to wash their hands carefully. Alcohol-based hand sanitizer with at least 60% alcohol can be a quick alternative to handwashing if the person with dementia cannot get to a sink or wash their hands easily.
- Ask your pharmacist or doctor about filling prescriptions for a greater number of days so you can go to the pharmacy less often.
- Think ahead and make other plans for the person with dementia in case the adult day care, respite, etc. is changed or cancelled in response to COVID-19.
- Think ahead and make other plans for care management if you (as the primary caregiver) become sick.

### **Q26. Are there any foods or nutrients that can prevent or treat COVID-19?**

- A.** No. You may read on the Internet that certain foods or nutrients can prevent or treat COVID-19; however, scientific evidence does not show that these foods or nutrients can prevent or cure the infection for anyone, including people with Down syndrome. That being said, it is useful in general to eat balanced and nutritious meals to stay healthy.

### **Q27. What advice is available about pets and service animals? They are an important part of many families.**

- A.** According to the CDC, there were a handful of reports of pets or companion animals who became sick with COVID-19. There is no evidence that such animals

can spread COVID-19 to humans. But the research is evolving, and we do know animals can spread other diseases, so people should wash their hands before and after touching or being around any animals.<sup>19</sup>

If you are sick with COVID-19, follow the same rules for your pets or service animals as you would with people. Ask someone to take care of your pet while you are sick, but if that is impossible, wash your hands before and after interactions with your pet, avoid petting or sharing bedding, and wear a face mask.<sup>20</sup>

## Q28. Are there special considerations or additional exposure risks for individuals with Down syndrome who are living in group homes or with roommates or support staff?

- A.** Staying in a group home with roommates or support staff may depend on several factors. As you consider this, please read the [CDC advisory on shared housing](#).
- First, know the extent of COVID-19 in your community and the group home’s community.
    - » If the infection rate is low around and within the group home, it may be best to let the agency handle risk factors.
    - » If the infection rate is higher than in your own community, you may want to bring the person with Down syndrome home and to shelter-in-place (to avoid contact with other people at risk).
    - » Consider that for some people with Down syndrome, a sudden change in their routine, roommates, and familiar environment will create significant stress.
  - Second, check how prepared the agency running the group home is. Are they following [Guidance for Direct Service Providers](#) established by the CDC? Has the agency running the group home begun using “respiratory protection program mitigation strategies” (strategies to stop COVID-19 from spreading) to make sure all residents and staff are safe?
    - » As a parent or family member, you must feel comfortable asking agency leadership what COVID-19 mitigation strategies they are using to make sure to keep all residents safe.
    - » It is important to ask specifically what **respiratory protection**

**mitigation strategies** are being used. A prepared agency will identify COVID-19 mitigation strategies such as:

- Identify and “red flag” all residents who are at high risk for COVID-19 (residents with repeated respiratory conditions, recently in the hospital, or who had pneumonia within the past year).
- Institute a “watch order” for high risk residents.
- Limit community social activities for those who are high risk residents.
- Start a training program for staff in all programs on recognizing symptoms, providing safe care, and using self-protection.
- Identify agency staff who are willing, competent, and capable to provide COVID-19 care once a resident tests positive.
- Do not allow visitors access to the group home (except medical personnel).
- Consult with the pharmacy and get a 2-months’ supply of medications for everyone.
- Update all consent information in case of sudden hospitalization.
- Update “individual health passport” (a hardcopy or digital document containing important medical and health information) for each resident.
- Identify healthcare professionals willing to provide in-home care.
- Plan for or create an isolation area in the home or dedicate one of their homes for the care of residents who have symptoms or who test positive for COVID-19.
- Order and make available protective supplies for use by staff and residents (such as masks, disinfectants, etc.).
- Set up infection control policies and procedures specific to COVID-19.
- Begin an incentive policy by increasing hourly wages for staff in homes where some residents are infected with COVID-19.
- Carefully monitor staff for illness at the beginning and end of each shift. For example, take temperatures and have staff complete a simple symptom check list.

- Have a plan in place for the referral and transfer of any residents needing hospital care.

If the agency is being proactive, it will have a procedure in place to reassure you of the safety of your child or adult with Down syndrome. If the agency has not taken any steps to prevent its residents and staff from being infected with COVID-19, then you may want to have your family member come to live with you until it is safe for that person to return to the group home.

Close contact with any individual who has COVID-19 symptoms is the greatest risk, especially in close quarters like a small home or with a roommate. Risk can be reduced by exercising caution such as thorough and frequent handwashing, keeping away from surfaces the person may have touched, and avoiding physical contact, but this will require close supervision by staff. Risk will be higher if roommates or support staff have had contact with an infected person other than someone living or working within the home and are not self-isolating. Check with the agency providing support services and ask what procedures they have in place to keep residents and staff safe and to stop the spread of COVID-19.

## Q29. What are some things to be aware of for people with Down syndrome who may be experiencing loss or grief during this time, including changing routines, missing school/work, or the death of a loved one?

**A.** Here are some common behaviors families/caregivers may see that could indicate a child or adult with Down syndrome is experiencing grief or loss:

- Behavioral changes or regression/loss of certain previous skills (e.g., incontinence when previously toilet trained, increase in self-talk, desire to be alone more often, rapid shifts in mood without an immediate reason why, tearfulness, no longer wanting to or being able to complete activities of daily living that they previously were able to do).
- “Delayed grieving” challenges with understanding the loss for weeks or even months after the loss has occurred.
- Statements about wanting to go be with person who passed (this does not mean that the person is suicidal, but they should be closely monitored).
- Repeatedly asking when they will see the person again.
- Self-talk with or about the person who has passed.

- Disruptive behaviors or angry reactions that were not present prior to the loss.
- Specific fears, anxieties, or phobias that were not present prior to the loss or change in routine.

Here are a few things families and/or caregivers can do to support a person with Down syndrome who is grieving:

- Maintain routines/structure as much as possible with visual schedules and checklists.
- Find approved ways to help the person with Down syndrome stay connected with family, friends, staff, caregivers as much as possible. Virtual dance parties are a great example!
- Put together a memory photo book about the people or activities that are missed.
- Use a social story explaining the situation in simple, first-person terms. Read the story often.
- Validate the person’s feelings, no matter what they are feeling.
- Use a visual showing different emotions to help the person articulate what they might be experiencing.
- Everyone grieves in different ways. People with Down syndrome may be more easily influenced by the emotions of others, so be mindful of how your own grieving process may be impacting the person with Down syndrome.
- Talk to a psychologist, therapist, or other professional familiar with your child or adult about how to help the individual with Down syndrome process the “new norm.”

### Q30. What precautions should be taken if an individual with Down syndrome needs urgent dental care?

- A.** During this challenging health crisis, if an individual with Down syndrome has an urgent dental problem (dental pain or swelling with fever), the problem needs to be addressed. Most dental offices are resuming care and you can call your dentist to seek care.

If you do not have a primary care dentist and the dental situation requires immediate attention, check with your primary care medical provider who may be able to offer advice or temporary treatment. As a last resort, you could seek evaluation and treatment in an urgent care or emergency room. However, the personnel there will most likely provide an antibiotic and/or pain medication, which will only be a temporary solution.

Be sure to tell the dental or emergency room personnel if there is a positive COVID-19 diagnosis. If you are unable to get urgent care, try contacting a community health clinic, which will generally have a dentist on staff, or your local dental school which will have a system in place to provide emergency care.

If the emergency is a traumatic injury to the face, teeth, or gums caused by an accident or fall, follow the same guideline. Call your dentist first, as most will have an emergency service set up. If they do not, follow the same course of action as noted above. It is important to get the pain, swelling, fever, and infection treated.

### **Q31. Could using CPAP after exposure to the coronavirus make a person with Down syndrome worse?**

- A.** Obstructive sleep apnea is very common in people with Down syndrome, affecting 50-90%,<sup>21</sup> CPAP is often used to treat it. Use of CPAP for those with sleep apnea is important for maintaining good health and is far more likely to benefit rather than harm a person with Down syndrome who has COVID-19. Some people find that it is less comfortable to use when congested and they prefer not to use it then. However, obstructive sleep apnea is often made worse when the tissues lining the nose and throat become swollen, as happens with infection. The air passages are then further narrowed, and they are already prone to collapse. Because of this, it may be that the discomfort they are experiencing is related to the CPAP not working as effectively as it usually does.

Two things can help make CPAP more comfortable to use when the upper airways are more swollen and congested: increasing the settings of the heated humidifier and raising the temperature of the heated air-hose. This may help reduce the swelling of the soft tissues of the upper airway and reduce the feeling of the air flowing through the nose, mouth, and throat.

Like other viruses that cause respiratory tract infections, coronavirus can cause severe inflammation of the lungs. However, it is important to recognize that

many people who develop respiratory disease are treated with CPAP, BiPAP, or mechanical ventilation to support their breathing while they recover. All these treatments have also been used in patients with COVID-19 whose inflamed lungs could not support the work of breathing during the acute phase of the disease. The fact that a CPAP machine is sometimes used to treat COVID-19 should help relieve concerns that the machine might increase risk if the person with sleep apnea is exposed to COVID-19.

However, if a person with Down syndrome has symptoms of COVID-19 or has been diagnosed with COVID-19, CPAP (or BiPap) machines might aerosolize the virus (which means spread it in the air) and it might spread to others. In these situations, please check with your health professional or doctor for guidance.



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**The following organizations contributed their time, resources, and expertise to this Q&A. You can download and access the Expanded Version and Abbreviated 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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