



# Q&A on COVID-19 and Down Syndrome

Expanded Version • From March 26, 2020

## ORGANIZERS:



## SUPPORTING ORGANIZATIONS:

*Down Syndrome Affiliates in Action, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Lejeune Foundation, T21 Research Society*

The unprecedented spread of the Coronavirus Disease 2019 (COVID-19) is presenting the world with a unique challenge and, in our case, 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, educational and medical providers, and others within the Down syndrome community.

We have done our best to answer questions that are currently being asked and anticipate other important questions relevant to our Down syndrome community. In this document you'll find information about:

- What may be unique about the virus in people with Down syndrome.
- How to help prevent the spread of the virus.
- What some common symptoms are.
- 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 in general, and about how it may or may not affect people with Down syndrome, we will continue to update this Q&A.

To be clear, this Q&A is informational only and not intended to provide medical advice or related advice. It is intended to provide information that we hope is useful as you confront decisions and consider seeking 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 consult with your own doctor or other healthcare professional(s) for medical advice.

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 suspect 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/from 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 difficult 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 sake of those 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, modes of transmission, protection, supportive treatment, and other insights regarding the virus. As far as experts know, individuals with Down syndrome get infected with the virus at the same rate, but some may be at greater risk of developing more severe illness from COVID-19.

## 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 hospitalization when infected with COVID-19. These include very young children, “older” people (individuals over 60 in the general population), people with compromised immune systems (including those undergoing treatment for cancer or dialysis), people with chronic pre-existing conditions (such as heart disease, kidney disease, diabetes), people with lung disease and/or respiratory difficulties (including asthma and obstructive sleep apnea, and people who smoke), and people living in nursing homes or long-term facilities.

As with all people, individuals with Down syndrome who are older are considered high risk. In addition, since individuals with Down syndrome are highly predisposed to many of the underlying medical conditions mentioned above, those individuals with Down syndrome should also be considered high risk or more vulnerable to COVID-19. In addition, because of living in close quarters, people with Down syndrome living in group homes or long-term facilities are also at higher risk than in the general population. It is not known whether having Down syndrome in and of itself equates to a higher risk of more severe illness from COVID-19.

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

- A.** The Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) have identified people with certain underlying medical conditions as “high risk,” meaning these individuals are more likely to become severely ill and need hospitalization when infected with COVID-19.

Individuals with Down syndrome are among this “high risk” group, as they are much more likely to have one or more of these underlying medical conditions compared to those without Down syndrome. However, to be clear, some people with Down syndrome will not have any of these underlying medical conditions.

Children and adults with Down syndrome are known to have several co-occurring conditions, that if are untreated or active, may make that individual more vulnerable to 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.
  - » People with Down syndrome who were born with congenital heart conditions which were fully repaired, or those with normally functioning hearts, 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)
    - ✓ 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 susceptible to respiratory infections. 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.
  - » CPAP machines with facial masks are often used for treatment of sleep apnea. Proper cleaning of the CPAP mask and machine are needed, especially in the presence of a respiratory infection. This includes establishing a regular cleaning schedule, changing of

water nightly, and replacing mask cushions 1-2 times monthly. In the presence of a respiratory infection, these hygienic activities should be conducted frequently.

» If a person with Down syndrome is suspected of having, or has COVID-19, the use of CPAP (or BiPap) machines could theoretically aerosolize the virus and increase the spread to others. In these situations, please consult with your health professional or doctor for guidance.

- **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.
- ✓ 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 10-20 fold elevated 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. If an individual with Down syndrome *is actively* being treated for cancer, they would be considered a higher risk. 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. Persons 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 underlying medical conditions, associated with both children and adults with Down syndrome, can contribute to identifying them as being “vulnerable,” and at “high risk.” Therefore, persons with Down syndrome require closer

monitoring, observation, and attention, especially when they are experiencing an illness.

#### Q4: 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:

- 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.
- If allowed, take walks outside. Always stay 6 feet away from other people.
- It may help to make a list of activities that are allowed, both indoors and outdoors. Posting the list of activities around your home can also be a helpful reminder.

#### Q5. Are there any videos or other media that I can listen to or watch that explains this to me?

**A.** For more information on COVID-19 and individuals with Down syndrome, Dr. Kishore Vellody, the President of the Board of the National Down Syndrome Congress and Medical Director 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 podcast](#).

For general information about the coronavirus and advice for direct support personnel, you can watch [this video](#) by Dr. Rick Rader, of the American Academy of Developmental Medicine and Dentistry.

## Q6. What are some of the behavioral and functional factors in people with Down syndrome that may complicate identifying or preventing illness?

A. A lot will depend on the intellectual capabilities of the individual with Down syndrome and to what degree 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 effectively participate 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 adherence to basic medical protocols. In the case of COVID-19, it may therefore be difficult to help a person understand the need to maintain [social distancing](#), to avoid handshakes and touching of one’s own face, and the necessity for handwashing.
- **Communication deficits.** Some individuals with Down syndrome may not be able to clearly express their pain, discomfort, or agitation and are at greater risk by not being able to describe their symptoms or calling out for immediate medical attention. Guidance for COVID-19 recommends that concerns of fever, coughing and shortness of breath should be reported 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 assistance from family members and/or caregivers who are able to recognize their symptoms better than others.

## Q7. Would the Centers for Disease Control and Prevention (CDC) recommendations differ depending on whether the person with Down syndrome is a child, an adult, or an older adult?

A. The general information about COVID-19 will always apply to people with Down syndrome regardless of age (such as symptoms, modes of transmission, protection, supportive treatment, and other insights regarding the virus) as it will to people without Down syndrome. These suggestions, precautions and strategies should be followed and adhered to.



## Advice on Prevention

### Q8. What can be done to help individuals with Down syndrome stay healthy?

- A.** There is currently no available vaccine for COVID-19. However, there are some ways to stop the spread of this disease.

According to the [Centers of Disease Control and Prevention \(CDC\)](#), we can further reduce the spread of COVID-19 by **staying home as much as possible** and if you must go out, practice social distancing; that is, staying at least 6 feet away from other people. Consider however, that certain situations, such as being on a plane, train, subway/tram/bus, or in crowds, make it impossible to stay 6 feet away from others.

The CDC recommends that you:

- Stay home when you can and practice social distancing.
- Avoid close contact with people who are sick.
- Avoid touching your eyes, nose, and mouth.
- 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 frequently touched objects and surfaces using a regular household cleaning spray or wipe ([Per the CDC](#), use a cleaner made up of 60% alcohol, or mix your own bleach diluted solution — i.e., 5 Tablespoons (TBSP) bleach/gallon water or 4 TBSP bleach/quart water).
- Wash your hands often with soap and water for at least 20 seconds, especially 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.
- Wash clothes worn in public places in hot water and sanitize your laundry basket and washing machine surfaces.



- Remember to follow the basic health recommendations, such as maintaining healthy and balanced nutrition and hydration routines, exercising/movement, using stress management interventions (especially those which have 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 (remember to clean your devices!).
- Keep yourself healthy which will increase the chance that your loved ones will stay healthy.

If someone in your home (who is not at high-risk) is suspected or proven to have COVID-19, medical providers/doctors will likely advise them to stay home and tend to symptoms of a mild illness. It is very important to try as hard as possible to observe the CDC guidelines on isolation for that person in the home, including preventing contact between that person and anyone with Down syndrome in the home.

### Q9. How do I best explain what ‘social distancing’ is to my child or adult with Down syndrome?

- A.** The CDC defines social 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/stand/walk close to another person; keep away from the other people by how far you can spread both your arms out.”* Phrases for younger kids that may already be used in other settings include *“staying in your bubble”* or *“elbow room.”* Using visual supports like holding out your own arms, can be a great way to show arm’s length.

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

### Q10. What can I do to help my child or adult with Down syndrome be more diligent about washing hands and keeping hands from his/her face?

- A.** Discuss proper handwashing. Using the chorus of a favorite song to help your child or adult with Down syndrome to understand how long to wash their hands (approximately 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. Give positive praise when they do not touch their face, even if it has only been for a short time.

- Sunglasses or glasses may be worn to help reduce the number of times an individual touches or rubs his/her eyes.
- Gloves of any kind can also help reduce touching of the mouth, eyes, and nose.
  - » Latex or surgical gloves are not needed to serve this purpose; any tolerated gloves can help.
  - » Keep in mind that gloves can transmit coronavirus just like fingers can.
- Fidget-toys or objects of interest can be utilized to temporarily reduce the risk of touching things in the environment and the face and may be useful in reducing risk during transportation or when a community outing is necessary.
  - » Keep in mind that these objects could carry infection themselves, so ideally such objects should be small and easy to clean quickly.



## Minimizing Risk of Contracting COVID-19

**Q11. Does having dementia or Alzheimer's disease for someone with Down syndrome increase the 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."

Additionally, individuals 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 with 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. 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.

**Q12. The Centers for Disease Control and Prevention (CDC) refers to people who are “older” (loosely defined as over 60) as being at “high risk” for COVID-19. At what age are individuals with Down syndrome considered “high risk” since there is “accelerated aging” in this population?**

**A.** We know that individuals with Down syndrome may have early aging, which might suggest that people with Down syndrome younger than 60 years of age are also more likely to be affected more severely. However, we do not have enough data about COVID-19 and people with Down syndrome to know this for sure.

**Q13. How should families manage multiple family members who are considered “high risk” or vulnerable? For example, when a 60-year-old grandmother takes care of her grandchild with Down syndrome?**

**A.** A 60-year-old grandmother is considered “high risk” due to her age, and her grandchild might be, too, depending on whether there are any underlying 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 vulnerable 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 most or all of the time? What alternatives do I have? Make a decision that is right for you.



## Additional Advice

### Q14. Is it safe for individuals with Down syndrome to travel?

- A.** At this moment in time, non-essential travel is not recommended. 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 Centers for Disease Control and Prevention (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. Try to 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.

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

- Has a “shelter-in-place” 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?

### Q15. When should individuals with Down syndrome who may be sick go to the doctor or the hospital?

- A.** Individuals with mild symptoms should stay at home and **NOT** go to the doctor’s office or hospital. If there are mild symptoms (like sniffles or congestion, but

otherwise eating, drinking are normal, and the person is having no trouble breathing), 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.**

**Q16. Where can I find information or take action regarding equitable medical care and medical access rights for individuals with Down syndrome?**

**A.** Below are some relevant national organizations and links to their websites:

- [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](#)
- [National Disability Rights Network \(NDRN\); NDRN Take Action Page](#)

**Q17. What behavioral and functional factors in people with Down syndrome require special consideration?**

**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. Individuals with Down syndrome may need extra help to learn about “social distancing” and how to prevent the spread of infection. Individuals 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 seek medical care quickly, so close attention and support from caregivers is needed.

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.

There are some helpful resources you can access to better inform you about having that ‘conversation’ about COVID-19:

- Useful [PDF booklet](#) created by the Self-Advocacy Resource and Technical Assistance Center (SARTAC) titled, *COVID-19 Information By and For People with Disabilities*
- [Useful article](#) for adults to help with talking to kids about coronavirus
- [Audio story](#) for kids, plus printable comic strip
- [Excellent list](#) of videos, songs, and show segments from Daniel Tiger to Sesame Street helping with way to keep kids safe and healthy
- [Free printable social story](#) about the coronavirus

**Q18. What kind of a 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 necessarily require hospitalization. However, they will need to isolate from others, and exercise social distancing. In addition, they will likely 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, 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 out of home respite will be necessary. Contact a caregiver support worker at your local area agency on aging or a caseworker from the state or local developmental disabilities’ agency, as 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 Centers for Disease Control and Prevention (CDC) advisory on homecare, [“Interim Guidance for Implementing Home Care of People Not Requiring Hospitalization for Coronavirus Disease 2019 \(COVID-19\).”](#)

**Q19. With “stay and shelter” directives, and cancellations and closures of schools and events, should individuals with Down syndrome still go to work/school/day program and other activities?**

- A.** Going to work, school, day programs or other group activities will likely put individuals with Down syndrome at greater risk for getting infected with COVID-19, and if there are other medical issues, it may raise the risk for severe complications. Localities are increasingly asking places where people congregate to close or restrict entry. Some businesses are closing and some are remaining open. If your child or adult with Down syndrome is employed at a business that is remaining open, you and the employer should confer about risk for infection and susceptibility and then decide whether it is advisable to continue going to work.

Schools are currently temporarily closed across the United States. When they open, you should have a conversation with school officials teachers about risk for infection and susceptibility that will help you decide on when your child can return to school.

In the case of day programs, the agency involved should be doing a risk assessment and may decide to close for a period or stay open after introducing infection control and surveillance for symptoms of infection. Confer with the manager at the agency for what safety procedures they have instituted and check as to what safety procedures they have put in place for transport (drivers’ training, disinfectants for the busses or vans, seat spacing, etc.) to help decide participation.

In either situation, if individuals with Down syndrome end up at home, try to engage them in some of the activities that are similar to a work, school or day program environment. Creating a reliable, consistent new schedule may also be beneficial.

**Q20. 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 an individual with Down syndrome who also has Alzheimer’s disease and/or dementia, a medical provider should provide advice as to whether the individual should stay in place or if admission to a hospital or other health care facility is required immediately or over time.

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 shows rapidly increased confusion, contact your health care provider for advice.
- People living with dementia may need extra and/or oral reminders and support to remember important hygienic practices 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. Wash your hands together while singing the “Happy Birthday” song.
- Demonstrate thorough handwashing. 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 his/her hands easily.
- Ask your pharmacist or doctor about filling prescriptions for a greater number of days to reduce your trips to the pharmacy.
- Think ahead and make alternative plans for the person with dementia should adult day care, respite, etc. be modified or cancelled in response to COVID-19.
- Think ahead and make alternative plans for care management if you (as the primary caregiver) should become sick.

### **Q21. Are there any foods or nutrients that can prevent or treat COVID-19?**

- A.** No. There is information on the Internet promoting certain foods or nutrients that can prevent or treat the coronavirus infection; however, there is no scientific evidence to support that these foods or nutrients prevent or cure the infection for anyone including those with Down syndrome.

### **Q22. What advice is available about pets and service animals? They are an important part of many families.**

- A.** According to the Centers for Disease Control and Prevention (CDC), at this time there are no reports of pets or companion animals becoming sick with COVID-19, and there is no evidence that such animals can spread COVID-19. However, since animals can spread other diseases, it is always recommended that



everyone wash hands before and after touching or being around any animals. If you are sick with COVID-19, follow the same rules as you would with people. Ask someone to provide care for your pet while you are sick, but if impossible, wash your hands before and after interactions with your pet and wear a face mask. For more information, [check the advisories](#) of the American Veterinary Medical Association.

**Q23. What educational rights is my child with Down syndrome guaranteed if we are quarantined at home?**

- A.** The U.S. Department of Education has developed a [5 page resource](#), *Supplemental Fact Sheet: Addressing the Risk of COVID-19 in Preschool, Elementary and Secondary Schools While Serving Children with Disabilities*, that explains what you need to know about getting services for children with disabilities during the coronavirus outbreak.

**Q24. Are there special considerations or additional 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 group living](#).
- First, know the extent of COVID-19 in your community and the group home's community.
    - » If it is low around and within the group home, it may be best to let the agency handle risk factors.
    - » If it is higher than your own community, you may want to bring the individual with Down syndrome home and shelter-in-place (to avoid contact with other people at risk).
    - » Consider also, that for some people with Down syndrome, a sudden change in their routine, roommates, and familiar environment will create significant stress.
  - Second, assess the extent of preparedness by checking with the agency running the group home. Has the agency running the group home implemented "Respiratory Protection Program Mitigation Strategies" to ensure the safety of all residents and staff?
    - » You as a parent or family member must feel comfortable asking agency leadership what COVID-19 Mitigation Strategies have been implemented to ensure the safety of all residents.

- » It is crucial to ask specifically what **respiratory protection mitigation strategies** have been implemented. A prepared agency will identify COVID-19 mitigation strategies such as:
- ✓ Identify and “red flag” all residents that pose significant risk for COVID-19 (recurrent respiratory conditions, recently hospitalized, pneumonia within past year).
  - ✓ Institute a “watch order” for those vulnerable and at-risk residents.
  - ✓ Restrict community social activities for those “red flagged.”
  - ✓ Institute a training program for staff in all programs on recognizing symptoms, providing safe care, and instituting self-protection.
  - ✓ Identify agency staff who are willing, competent, and capable to provide COVID-19 care once a resident tests positive.
  - ✓ Restrict all visitor access to the home (except medical personnel).
  - ✓ Consult with the pharmacy and acquired 2-months’ supply of medications for everyone.
  - ✓ Update all consent information in case of sudden hospitalization.
  - ✓ Update “individual health passport” 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 infected residents.
  - ✓ Order and make available protective materials for use by staff and residents (such as masks, disinfectants, etc.).
  - ✓ Institute infection control policy and procedures specific to COVID-19.
  - ✓ Institute an incentive policy for increased hourly wages for staff in homes with some residents infected with COVID-19.
  - ✓ Provide for testing, of staff in homes with a resident with COVID-19, at the beginning and end of each shift.

- ✓ 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 implement preventive measures against its clientele 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 individual to return to the group home.

Close contact with any individual who has COVID-19 symptoms can pose the greatest risk, especially if living in close quarters in a small home or with a roommate. It can be reduced by exercising caution such as stringent and frequent handwashing, keeping away from surfaces the person may have touched, and avoiding physical contact, but this will require close supervision by staff. There will be an elevated risk 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 about what procedures they have in place to minimize contamination and potential spread of COVID-19.

## **Q25. 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 experiences dental urgency (dental pain or swelling with fever), the problem needs to be addressed. Call your dentist to confer and explain the symptoms and seek his or her advice. Most dental practices will have emergency coverage or a service that will direct you to care.

If you do not have a primary care dentist and the dental situation requires immediate attention, your local hospital emergency room is a safety net. However, the personnel there will most likely provide an antibiotic and/or pain medication, which will only be a temporary solution.

Be sure to inform the dental personnel or emergency room personnel if there is a positive COVID-19 diagnosis. If you are unable to obtain urgent care, try contacting a Public Health Center, which will generally have a dentist on staff, or your local dental school which will have a system in place to provide emergency care. The State Dental Society should have a hotline for sourcing referrals as well.

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 that the pain, swelling, fever, and infection be treated. All health care professionals will be working together to provide interdisciplinary care to persons with special needs.

For up-to-date advisories check the [American Dental Association](#) website and that of the [CDC](#).

## Q26. Could using CPAP after exposure to the coronavirus make it worse?

- A.** Obstructive sleep apnea is very common in people with Down syndrome, affecting between 30-60%, and 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 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, further narrowing down the air passages that 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 which can help make CPAP more comfortable to use when the upper airways are more swollen and congested are increasing the settings of the heated humidifier and raising the temperature of the heated air-hose. Doing so may help reduce the swelling of the soft tissues of the upper airway and reduce the sensation of the air flowing through the nose, mouth, and throat.

Similar to other viruses which cause respiratory tract infections, COVID-19 can cause severe inflammation of 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 have also been used in patients with COVID-19 whose inflamed lungs were unable to 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 allay any concerns that the machine may somehow increase risk if exposed to COVID-19.

**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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**Note:**

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We are very thankful for the input received from the many experts who contributed and reviewed the Q&A. We acknowledge the contribution of the lead author Dr. Matthew P. Janicki, PhD, co-chair of the US National Task Group on Intellectual Disabilities and Dementia Practices.