

COVID-19 and Down Syndrome Resource

Updated February 1, 2021

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

It has been over a year since the unprecedented spread of the coronavirus (COVID-19) presented the world with unique and on-going challenges. In our case, the pandemic called for a united response to better understand its impact on the Down syndrome community. To date, our organizations have developed a series of Q&As on this topic. Much of the information from these prior Q&As is still relevant and correct and can be located on any of the 6 supporting organizations' websites. This document emphasizes important updates and contains new information in the era of access to COVID-19 vaccinations.

Information in this resource document can be used to help you support your loved one with Down syndrome. 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.

At the time of this update, many areas of the United States are experiencing high levels of community spread and hospitalizations. We are also seeing the first COVID-19 vaccines becoming available. We have done our best to answer questions that are currently being asked and to anticipate other important questions from our Down syndrome community. In this document, you will find information about:

- What to think about when considering the COVID-19 vaccine
- How to support mental health challenges during the ongoing pandemic
- What we have learned about the virus that may be unique in people with Down syndrome
- How to help stop the spread of the virus and stay safe
- What to think about when making decisions to participate in activities.

Many organizations and professionals have contributed to this document by providing their expertise on Down syndrome and applying it to what we know about COVID-19. As we learn more about COVID-19, its prevention and treatment, and about how it may affect people with Down syndrome, we will continue to update this resource.

To be clear, this document 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 document should NOT be considered a substitute for the advice of a medical or related professional with whom you are directly working. You should speak 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 \(CDC\)](#), the [Food and Drug Administration \(FDA\)](#) 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 resource.

Copying or posting of this document is prohibited. However, providing a link to the website of any of the six organizations who published this document is permissible. Free individual downloads and printing from the websites of any of the six organizations is also permissible.

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. Keep in mind that people react differently to the COVID-19 virus. Keep in touch with your physician and seek advice as to how proceed in either case.

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, U.S. residents contact 911.

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1. Basic Information

- 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 and vaccinations, supportive treatment, and other insights regarding the virus.
- 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 be hospitalized if they get sick with COVID-19. These individuals are considered “high risk.”
- As of December 2020, Down syndrome has been added to the CDC’s list of conditions that increase a person’s risk of becoming severely ill and needing to go to the hospital if they are sick with COVID-19.
- In addition, people with Down syndrome often have many of the underlying medical conditions that “are at increased risk” or “may be at increased risk” for severe illness from COVID-19 according to the CDC, including:
 - *Cancer*
 - *Overweight and Obesity*
 - *Heart conditions*
 - *Immunocompromised state (weakened immune system) from bone transplant, immune deficiencies, or use of other immune weakening medications*
 - *Type 1 & 2 Diabetes*
 - Neurological conditions, such as dementia

2. Research Updates about COVID-19 and Down syndrome

- More data about COVID-19 and people with Down syndrome is needed, but limited published findings so far suggest that:
 - Individuals with Down syndrome over the age of 40 infected with COVID-19 are hospitalized at a higher rate and are more likely to become have serious illness or die from COVID-19 compared to the general population of the same age.
 - Individuals with Down syndrome infected with COVID-19 exhibit many symptoms similar to those seen in the general population (fever and cough), but people with Down syndrome seem more likely to have breathing and respiratory related complications in addition to confusion.
 - Children with or without Down syndrome do not seem to get as severely sick from the virus.
 - Immune dysregulation in people with Down syndrome may put them at increased risk for poor outcomes.
- For additional information, review the following websites and podcasts:
 - Preliminary results from the Trisomy 21 Research Society (T21RS) COVID-19 Taskforce Survey and Report: <https://www.t21rs.org/results-from-covid-19-and-down-syndrome-survey/>
 - “Does Having Down syndrome lead to higher risk in COVID?” a podcast 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.
 - “[Update: COVID & Down Syndrome, January 8, 2021](#),” a Matthew Foundation webinar featuring Dr Brian Chicoine, Medical Director of Advocate Medical Group Adult Down Syndrome Center, and Dr Andre Strydom, President of the Trisomy 21 Research Society.

3. COVID-19 Vaccine

a. General Information

- For the most recent information about the COVID-19 vaccine, please visit the [CDC's COVID-19 vaccination resource](#) and the [FDA's COVID-19 vaccination review](#).
- Because there is a limited supply of vaccines, people will be vaccinated in shifts. Some people will be prioritized to receive the first vaccine. The first people to receive the vaccine have been health care workers. Who is eligible to receive the vaccine in each of the phases is being decided on a state-by-state basis. You can review your state's vaccine distribution plan on your [state department of health website](#).
- If you previously had COVID-19 and recovered, it is still recommended to receive the COVID-19 vaccine.
- It is recommended that no other vaccine (for example flu vaccine, or shingles vaccine) be given two weeks before or after receiving either COVID vaccine doses. Review where people with Down syndrome fit into your state's vaccination plan and when they may be able to be vaccinated for COVID-19. Other vaccines should be planned accordingly.

b. How They Work

- Currently, two vaccines are available in the United States:
 1. **Pfizer COVID-19 vaccine:**
 - Recommended for individuals 16 years and older
 - 95% effective at preventing the infection by coronavirus
 - Requires two doses given 21 days apart.
 2. **Moderna COVID-19 vaccine:**
 - Recommended for individuals 18 years and older
 - 94% effective at preventing the infection by coronavirus
 - Requires two doses given 28 days apart.
- You must receive the same vaccine for both doses, and the full effect of the vaccine is not achieved until after several weeks after you have received the second dose.
- Both the Moderna and the Pfizer vaccine are mRNA vaccines, which cause your cells to make a harmless piece of the "spike protein" of the COVID-19 virus. The immune system then develops immunity against the protein. They do not use live virus and they do not change or interact with your genes or DNA.
- Whether asymptomatic individuals are able to spread the virus after they have been vaccinated is still currently being studied.

- Even after you are vaccinated, it is still very important to follow prevention measures like maintaining 6 feet social distance, wearing masks, and washing hands after being out in public.
- There have been multiple new variants of the coronavirus that have been discovered, for example the UK variant and the South African variant. Early research indicates that the vaccine may be effective against multiple virus mutations, including these more contagious variants.

c. Safety

- The COVID-19 vaccine has been recommended for almost all people. While vaccination is recommended for nearly everyone, if you have specific concerns consult your medical professional for more information.
- As far as we know, people with Down syndrome were not specifically included in the vaccine trials, but it has been recommended that they receive the vaccine (except for children and/or individuals with a history of severe allergic reaction).
- The vaccines were tested on many thousands of people and have been deemed by the FDA to be safe and effective for individuals age 16 years and over (Moderna) or age 18 years and over (Pfizer). These ages were determined based on the ages of the individuals included in the trials (i.e., no one under these ages was included in either trial). The vaccine is now being studied in younger individuals.
- Side effects reported by some individuals have been mild and temporary, including arm pain, swelling, fever, and tiredness. To help researchers learn more about the vaccine, we encourage family members, caregivers, and self-advocates to register any side effects they may experience at the [Vaccine Adverse Event Reporting System \(VAERS\) website](#) co-managed by the CDC and FDA.
- If an adult with Down syndrome lives in a group home or a long-term living situation, consider if essential staff at the home have been vaccinated and what controls are in place to mitigate infections.
- For additional information on safety and people with Down syndrome, you can review the [DSMIG-USA IDD COVID-19 Vaccination Position Statement](#).

d. Additional Resources on COVID-19 Vaccination

- For additional information, review the following websites and articles:
 -

4. Testing

- Testing is generally accessible in the U.S., although wait times, type of tests available, and turn around period for results may differ city-by-city and state-by-state. You can find your nearest testing site by visiting your [State Health Department](#) or calling your medical provider.
- Current guidelines from the CDC recommend people should be tested for COVID-19 if **they**:
 - Are experiencing COVID-19 symptoms
 - Have been in close contact (defined by the CDC as within 6 feet for 15 or more minutes) with a person with confirmed positive for COVID-19
 - Are referred for testing by their doctor or state department
- To determine if you have a **current** infection (meaning you currently are positive for COVID-19) the following tests can be performed:
 - Viral Test: Also called a PCR test. This is a **Nose Swab** that will tell you if you are currently infected with the coronavirus. Results typically take 2-3 days.
 - Rapid Test: Also called an antigen test. This is a **Nose Swab** that can tell you if you are currently infected with the coronavirus. Results typically take 15-30 minutes, but it may provide less accurate results (meaning you may be infected with COVID and receive a negative test result).
- To determine if you had a **past** infection (meaning you previously had COVID and have since recovered), the following test can be performed:
 - Anti-Body Test- This is a **blood test** that will tell you if you have antibodies, which may mean you had a **past** infection. It is still not known if having antibodies will protect you from future infections or how long any possible immunity may last. Preventative measures are still important to protect yourself and others.
- The most common COVID-19 test is performed using a nasal swab, where a long Q-tip is inserted into both nostrils by a medical professional. This may cause momentary discomfort, but it may be especially distressing for people with Down syndrome who may be anxious about how the test is performed or have sensory issues. Here are some things that may help your child or adult with Down syndrome tolerate a COVID nasal swab:
 - Talk about the process, how it is done and what they should expect. Allow them to ask questions or express concerns.
 - Watch videos of the test being done
 - Allow them to watch you or a loved one have the test performed first.
- You may hear about schools, hospitals, airlines, or other organizations who are either using random testing as a prevention measure or require a negative test before participating. They are referring to the Viral or PCR Test, not an antibody test.


- Individuals with or without Down syndrome may test positive for anti-bodies related to COVID-19 and have had symptoms that were mild or went unnoticed.
- It is possible to be infected with COVID and receive a negative test result. This is called a “false negative.” This can happen if you are tested before there was enough infection to be detected. It is also possible to become infected after taking a test while waiting for your results. For this and other reasons, a negative COVID test result should not be the only factor to consider when making important health decisions, like visiting high-risk relatives or traveling.

5. Ways to Stay Safe

a. Basics

- Experts at the CDC and NIH suggest “asymptomatic” (meaning there are no symptoms) individuals with COVID-19 may still spread the virus.
- Vaccines for COVID-19 are currently being administered, however, it is likely they will not be widely available to the general public until summer 2021. In the meantime, according to the [CDC](#), we can reduce the spread of this disease by:
 - **Staying home as much as possible**
 - If you must go out, [wear a mask covering your nose and mouth](#). Avoid other people who are not wearing a mask.
 - Practice physical distancing by staying at least 6 feet away from other people.
 - Wash your hands often with soap and water for at least 20 seconds after being out in public
 - If soap and water are not readily available, use an *alcohol-based hand sanitizer* with at least 60% alcohol.
 - Try to avoid touching your eyes, nose, and mouth.
 - Avoid close contact with people who are sick and stay home when you are sick.

b. What to do if someone gets sick

- 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 to observe the CDC guidelines on isolation for that person in the home. Try to limit or stop contact between that person and anyone with Down syndrome in the home. See also the CDC advisory, [“Caring for Someone Sick at Home: Advice for Caregivers in non-healthcare settings \(2020\)”](#). 
- Make 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 in case you are hospitalized.
- 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) contact your doctor as soon as possible for guidance. 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.

c. Precautions for Travel and Returning to Activities

- At this time, non-essential travel is strongly discouraged. Specific regulations may differ state-by-state. For information about travel both within and outside the United States, we recommend reviewing [the website](#) of the CDC.
- Like all people, individuals with Down syndrome should stay at home when they can and only travel when necessary. If it is necessary for an individual with Down syndrome to travel, follow the local rules, 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 with 60% alcohol base and wear a mask.
- *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.
- 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:
 - *Personal/Individual 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 can follow safety precautions such as maintaining a safe distance and wearing a mask. Discuss personal factors with your loved one's healthcare professional.
 - *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. Many communities are now requiring everyone to wear masks in any indoor area. Comply with these requirements to keep everyone safe.
 - *Public health factors*- Consider the COVID-19 health trends in your state and community. Consider whether the number of new infections is increasing or decreasing, and what your community's capacity is for monitoring and testing.

d. Mask Wearing & Handwashing

- The CDC recommends wearing masks in public settings and maintaining 6-feet of distance from others. While the science now reports that virus pick-up is low from surfaces, handwashing is still important. Ensure that handwashing is completed immediately upon returning home from a trip outside or in public.
- Review the CDC's [Your Guide to Masks](#) for guidance on fit, fabric type and more.

- 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:
 - Allow the person to choose what mask they would like from a choice of 2 or 3 options. If you plan to make the masks, allow them to pick the design and even decorate it.
 - Use a first-then directive to tell the person that you will, “first practice wearing the covering and then (a preferred activity).”
 - Model wearing a face covering. During a family or group activity even at home, have everyone practice wearing their masks at the same time.
 - [Easterseals](#) and the [Autism Services, Education, Resources and Training](#) have both created social stories specifically about wearing a mask you can watch together.
- Here are some things that may help your child or adult with Down syndrome maintain proper handwashing hygiene:
 - Scheduled 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.

6. Mental Health

- The ongoing pandemic has led to increases in anxiety, depression, and other mental health challenges for many people, including families, caregivers, and people with Down syndrome.
- People with Down syndrome can be very sensitive to sudden changes to their routine and environment, which may cause stress and anxiety. Here are some common behaviors families/caregivers may see that could indicate a child or adult with Down syndrome is experiencing stress during the pandemic:
 - Behavioral changes or regression/loss of certain previous skills (e.g., incontinence when previously toilet trained or no longer wanting to or being able to complete activities of daily living that they previously were able to do).
 - Increase in self-talk.
 - Increased isolation or desire to be alone.
 - Rapid shifts in mood or tearfulness.
 - Disruptive behaviors or angry reactions that were not present prior to COVID.
 - Specific fears, anxieties, or phobias that were not present prior to COVID
- Here are a few things families and/or caregivers can do to support a person with Down syndrome during the challenges presented by COVID:
 - Maintain routines/structure as much as possible with visual schedules and checklists.
 - Find approved ways to help the person with Down syndrome stay connected. Video chat, texting, phone calls, letters, etc.
 - Make a list of activities that *are* allowed, both indoors and outdoors, such as 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.
 - 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.
 - Validate the person's feelings, no matter what they are feeling.
 - People with Down syndrome may be more easily influenced by the emotions of others, so be mindful of how your own emotions 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".
- It is important to note that the pandemic has created incredible stress and challenges for parents and caregivers as well. It has been a very difficult year trying to balance employment, general uncertainty, remote learning, and more. Make sure to take time for yourself, reach out to your social networks for support, and identify respite care if needed.

7. Advocacy Matters

a. Hospital Visitation and Access to Care


- Due to the spread of the virus, many hospitals restricted access to non-essential people visiting hospitalized patients. This policy was meant to save lives and reduce further spread of COVID-19. However, as of June 2020, [Federal law requires](#) that hospitals modify policies to ensure people with disabilities have access to support from a parent or caregiver while in the hospital if needed. 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, and to provide personal protective equipment (PPE) to support persons to keep them safe.
- Medical care rationing (often called “triage care”) may discriminate against people with disabilities. If you feel your child or adult with Down syndrome is experiencing discriminatory care, please contact any of the organizations listed on this document or contact the relevant national organizations involved in this issue below:
 - [American with Disabilities Act \(ADA\)](#)
 - [The Arc](#)
 - [Center for Public Representation \(CPR\)](#)
 - [National Disability Rights Network \(NDRN\)](#)
 - [Office of Civil Rights \(OCR\)](#)

b. Education

- During the COVID-19 pandemic 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.
- Remote learning has been challenging transition for some students with disabilities. A common concern among caregivers is that their child with Down syndrome will lose academic progress. Try to be patient, give yourself grace, and know your child is still learning every day. Consider this an opportunity to teach them valuable life skills that can be taught more easily at home or spend time specifically on one task they want to learn.
- If your child is attending school in-person make sure the school is meeting the [American Academy of Pediatrics \(AAP\)/CDC guidelines on school re-opening](#).¹² 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.
- 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.

8. International Updates

- Vaccine brands, availability, access, and recommendations vary by country. If you are outside of the United States or its territories, contact your local health authority for local rules and policies.
- In December 2020, a new variant of the coronavirus was detected in the United Kingdom and in the Republic of South Africa. Both have been spreading within Europe. This new variant is generally considered more contagious (that is they spread more quickly), but not more severe or deadly. Since then, this variant has been detected in multiple other countries, including the United States. The vaccines currently available appear to also provide protection against these variants.
- Limitations on international travel, community spread rates, and hospitalization rates differ country to country. Consult the CDC or a Ministry of Health website for the country in question to learn more about their specific data.
- For additional international update or information, review the following resources:
 - UK Statement on Down syndrome prioritization 



9. Contributors

The following organizations contributed their time, resources, and expertise to this resource. You can download and access this document 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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10. References: