



# NTG & NDSS

## CAREGIVER NEWS

### COVID-19

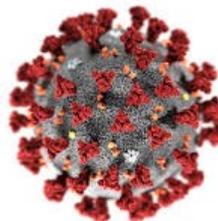
A Message from your Co-Editor

*Jadene S. Ransdell, B.S.*

What a strange time we are living in these days. A few months ago, many of us might have thought staying at home would be a wonderful treat. Now that we are practicing “safer at home,” it may not be the great escape we thought it would. I can say that focusing seems to be the hardest thing for me to do. I wander around the house, not sure just what to do next. Rachel and I speak frequently on the phone as we work to switch the NDSS Adult Summit from an incredible in-person event to an exciting virtual happening. She has expressed a similar problem with staying focused.

However, in one of our conversations, we thought it would be a good idea to put together some factual and timely information about the Corona Virus and our loved ones with Down syndrome or other intellectual disability. We are

#### COVID-19



Down Syndrome & Intellectual Disability

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### NDSS Adult Summit

The in-person Summit was cancelled due to the Corona Virus-19.

Watch for the announcement of the  
**NDSS Virtual Adult Summit**  
[Ndss.org](http://Ndss.org)

*“By staying calm,  
 you increase  
 your resistance against  
 any kind of storms.”*

*Mehmet Murat ildan*  
 Turkish playwright, novelist,  
 and thinker

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## COVID-19

hopeful that this issue of the newsletter will offer you some answers to questions you may have had. In this issue we have invited guest authors to share their insight on two topics that seem to be prevalent on Facebook lately. We reached out to Jeanne Kerwin, D.MH, HEC-C, a Medical Ethicist, who spoke at last year’s Adult Summit. We contacted Jeanne after seeing significant concerns from families about the potential for discrimination of our loved ones during this pandemic. In addition, we have noticed comments about changing behaviors of loved ones who do not understand why they no longer can attend their day program or do other activities that they have enjoyed. Routines have been upset and we all are trying to find ways to cope. Jennifer Phelps, a Board Certified Behavior Analyst (BCBA), experienced in working with people with dementia, provides some tips for success in this difficult time. Jennifer and I have had conversations about ways to adapt my son’s schedule so that he still has a sense of worth while he can no longer volunteer at our local Veterans’ Administration hospital and long-term care center.

We have also included the *Abbreviated Version of the Q & A on COVID-19 and Down Syndrome*, a new publication that was created through collaboration with several national organizations. If you would like to access the document online or would like to have the full document, it can be found on the NDSS (<https://www.ndss.org/covid-19-fact-sheet/>) and the NTG (<https://www.the-ntg.org/publications>) websites, as well as the websites of other organizations involved in the development of the Q & A.

It is our hope that this edition of the Family Caregiver News will provide you with some of the information you need to get through this uncharted territory. Know you are not alone. If you need to connect with another caregiver, feel free to email me (email address is on the back page of this newsletter).

## Share Your Story

We want to publish the stories of our readers, and we hope you will consider sharing your experiences related to caring for an individual with an intellectual or developmental disability who also has dementia.



We are now accepting stories for future issues of the *NTG NDSS Caregiver News*. Submit your story (between 500-1,000 words) in a Microsoft Word document file. Or, feel free to contact us with your story idea. We are always happy to work with you to write the story you would like to share. Write to us at [ntgfamilyadvocate@gmail.com](mailto:ntgfamilyadvocate@gmail.com) or [rgrimm@ndss.org](mailto:rgrimm@ndss.org). Include “NTG NDSS Caregiver News Submission” in the subject line of your email. Below are the topics which will be the focus of upcoming newsletters. Although we are interested in receiving pieces on other subjects, primary consideration will be given to articles related to these topics.

NTG CAREGIVER NEWS FOCUSED TOPICS		
ISSUE	SUBJECT	SUBMISSION DEADLINE / DISSEMINATION DATE
Summer 2020	Behavior Changes that Accompany Dementia	May 1, 2020 / June 21, 2020
Autumn 2020	Siblings	August 1, 2020 / September 21, 2020
Winter 2020	Arts & Dementia	November 1, 2020 / December 21, 2020
Spring 2021	Working with Health Care Providers	February 1, 2021 / March 21, 2021

# COVID-19 Information

## By and For People with Disabilities



### What is COVID-19?

It is a new illness spreading around the world.  
Its nickname is coronavirus.



### How do you get it?

Someone with COVID-19 gives you their germs.

When they cough or sneeze, their germs get in the air, on you, and on things.

Germs get into your body through your mouth, nose, and your eyes.

### What happens if you have it?



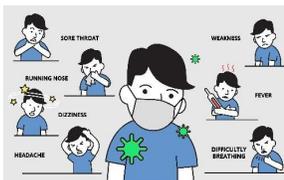
A fever of  
100.4 or higher



Coughing



Hard time  
breathing



If these things happen to you, it does not mean you have coronavirus.  
Lots of people get a fever or cough. You could just have a cold or the flu.

### If I am sick, when should I call a doctor?



Call if you have been out of the country.

Call if you have been with someone who has the virus.

Call if you have been at a place where people with COVID-19 got medical treatment.

**Call your doctor, do not go to the office.**

Adapted from COVID-19 Information By and For People with Disabilities, Green Mountain Self-Advocates [www.gmsavt.org](http://www.gmsavt.org)

To access the complete booklet visit the Green Mountain Self-Advocates website at this link:

<https://selfadvocacyinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf>



## Q&A on COVID-19 and Down Syndrome

Abbreviated 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

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

**We have tried to answer questions that are important:**

- **What may be unique about the virus in people with Down syndrome.**
- **How to help prevent the spread of the virus.**
- **What common symptoms are.**
- **What to think about when making decisions.**

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

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

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

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

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

**A. Yes. Information about COVID-19 is the same for people with Down syndrome. Good information is best found at central sources like websites that end with .gov:**

- **Centers for Disease Control:** [Coronavirus Disease 2019 \(COVID-19\) | CDC](#)
- **National Institutes of Health:** [Coronavirus \(COVID-19\) | NIH](#)
- **Your state health department website has advice about where you live.**

**Q2: Are individuals with Down syndrome at “high risk” with COVID-19?**

- A. The [Centers for Disease Control \(CDC\)](#), the [National Institutes of Health \(NIH\)](#), public health professionals and infectious disease experts have highlighted people who are more “at risk” or “high risk” for COVID-19. High risk means a person could be more likely to get the disease. They could also be more likely to have a severe illness. Experts say that people over age 60 and people with medical problems are at higher risk for getting severe COVID-19. Younger children may also have more risk of severe disease but most of them do recover.

**We do not know if people with Down syndrome are more likely to get sick with COVID-19. In general, people with Down syndrome are more likely to get infections. Also, many people with Down syndrome have other medical problems that could make them more at risk for severe illness from COVID-19. For these reasons, it is very important to follow the recommended precautions to prevent COVID-19 in people with Down syndrome.**

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

- A. **Children and adults with Down syndrome often have more than one health problem. If these problems are untreated or active, that person may be at higher risk for COVID-19. These can include:**
- Certain heart problems.
  - Chronic respiratory problems.
  - History of severe respiratory infections.
  - Asthma.
  - Obstructive sleep apnea.
  - People who may have lower immune function, such as:
    - » **People with diabetes.**
    - » **People receiving chemotherapy or undergoing active treatment for cancer.**
    - » **People on certain medications that lower the function of the immune system (such as for treatment of rheumatoid arthritis, lupus, or psoriasis).**

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

**Q4. What behaviors and functions in individuals 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. Some people with Down syndrome may need extra help to learn about “social distancing” and how to prevent the spread of infection.**

**People with Down syndrome may also have a hard time telling others when they don't feel well. They may have trouble knowing they have symptoms or how to describe them. For these reasons, they may not raise concerns or seek medical care quickly. Therefore, it is necessary to pay close attention and be watchful.**

**Q5. How can I help a person with Down syndrome understand about COVID-19 and how to stay healthy?**

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

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

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

**Q6. Is travel safe for individuals with Down syndrome?**

**A. At this time, being out in public or any non-essential travel is strongly discouraged. Some states and communities already limit travel. For information about travel both within and outside the United States, check [the CDC website](#).**

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

**Q7. What is useful in helping people with Down syndrome to reduce stress and stay well?**

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

- **Keep routines of getting dressed and ready for the day.**
- **Keep regular sleep schedules.**
- **Eat a healthy, balanced diet with whole grains, protein rich foods, fruits**

and vegetables, dairy (or substitutes) and healthy fats. There are no known foods or nutrients that prevent or treat **COVID-19**.

- **Stick to three balanced meals and two healthy snacks and be mindful of portion sizes. Avoid emotional eating, grazing, or eating when bored.**
- **If allowed, take walks outside, even for a short time. Always stay 6 feet away from other people. It may help to make a list of activities that are allowed both indoors and outdoors.**

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

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

**Q9. Are there special considerations for individuals with Down syndrome who are living in group homes or with roommates or support staff?**

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

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

**Q10. If sick, when should people with Down syndrome go to the doctor or the hospital?**

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

**Q11. What kind of a plan should I have if I am sick or test positive for COVID-19 or have to go into the hospital, and I am the only caregiver for a person with Down syndrome?**

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

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

**Q12. With Down syndrome, does having dementia or Alzheimer's disease increase the risk of COVID-19?**

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

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

### Other Useful Links:

- For more information on COVID-19 and people with Down syndrome, Dr. Kishore Vellody of the Down Syndrome Center at Children's Hospital of Pittsburgh released a podcast with guest, Dr. Andrew Nowalk, a pediatric infection disease expert. You can listen to [this 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.
- American Academy of Pediatrics [www.healthychildren.org](http://www.healthychildren.org) (Trending topics and quick links-English and Spanish).

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

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

[Global Down Syndrome Foundation GLOBAL](#)

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

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

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

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

The following individuals contributed their time and expertise to the content of this Q&A:

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# Medical Ethics in a Pandemic: What Does Resource Allocation Mean for the I/DD population?

*Jeanne Kerwin, D.MH, HEC-C*

In normal times (other than a pandemic such as we are experiencing today) patient care decisions in the US are made within the ethical framework of “patient-centered care,” focused on the individual patient’s needs, values, and preferences. In addition, consideration is given to the physician’s knowledge of interventions that would be most beneficial for the patient and interventions that would be more harmful and medically inappropriate.



In a pandemic situation that ethical framework must shift from patient-centered care to a public health focused duty to provide fair and equitable distribution of scarce resources. The goal of a public health focus is to save the most lives. This falls under the *ethical principle of utilitarianism* which tries to accomplish “the greatest good for the greatest number of people.”

The goals of medical care are always to provide optimal care for each patient. But, in a pandemic there may be increasingly severe shortages of staff, supplies, life support technologies and intensive care beds. It is this shortage, and with an overwhelming number of critically ill patients, that mandates health care leaders and governmental authorities to develop plans to safeguard the public, patients and staff. Additionally, there is a need to provide consistent, transparent and ethical guidance for the provision of medical care.

There is general consensus that any criteria used to triage patients for access to ICU beds and life-sustaining equipment such as ventilators must be developed through an ethical lens that maximizes benefits for the greatest number of people. Many of the protocols that were created after the SARS epidemic by experts in the fields of infectious disease, medical ethics, and pandemic planning serve as guidelines for this pandemic. The key points of agreement are:

1. All preparedness planners should use an ethical framework to deal with the host of difficult issues created by a pandemic. Those issues include:
  - Balancing individual freedoms against the common good
  - Balancing fears of personal safety against the duty to treat the sick
  - Balancing economic losses against the need to contain the spread of the virus
  - Using fair, consistent and transparent guidelines to allocate and prioritize scarce resources
  - Restricting freedoms through quarantine, travel restrictions and social isolation advisories
  - Providing fair allocation of benefits and burdens across populations
  - Protecting the vulnerable
2. The process for the development of protocols (with sound, ethical rationale) by local authorities and health care systems for use in a pandemic should be as inclusive as possible with input from key stakeholders in the community. Communication to the public should be consistent and transparent.



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3. Prioritizing patients for the allocation of ICU beds, ventilators and other scarce medical resources during a pandemic imposes limits on decision-making autonomy. Prioritization should be done based upon objective criteria that defines those with the greatest clinical need and the greatest likelihood of benefit. Methods of prioritizing (triage) all patients may include:

- a) *Inclusion criteria* (example: respiratory failure with a reasonable chance for recovery);
- b) *Exclusion criteria* (example: end stage underlying disease/condition with short term mortality and poor prognosis for recovery despite the use of a ventilator);
- c) *Underlying advanced illness* (those who are very sick and may not survive but if a ventilator is available should be given a time trial); and
- d) *Ability to survive* with general medical treatment and do not need ventilator or ICU.



Triage guidelines use objective clinical criteria and assessments to determine priority when there are limited resources, and should always include ethical oversight to prevent any bias or discrimination.

4. Triage and prioritization of patients for limited resources is done solely based upon objective clinical criteria assessing the needs of the patient and the clinical likelihood of benefit.
5. To sustain the traditional relationship between the patient and provider, it is recommended that health care systems appoint specialized triage officers or teams to use **objective clinical tools** to triage patients and to allocate resources when there are shortages during a pandemic. These triage teams should be blinded to other patient information unrelated to the clinical assessment tool. The physician taking care of the patient will not be the one making the triage decision. Patients who do not receive ventilators or ICU treatment are still under their physician’s care and should have access to alternative forms of medical treatment such as palliative care and symptom management.
6. *Important to note:* Triage of patients for scarce resources during a pandemic should only be implemented when the number of patients needing those resources outstrips the available ICU beds and ventilators. Hospitals may prepare and expand their surge capacities by reallocating space, staff and equipment in anticipation of scarcity, but an ethic of patient-centered care remains the primary model of care until such time as an influx of patients overwhelm the resources.
7. Respecting patient autonomy and preferences should always be a focus regardless of pandemic shortages and the need for triage. This can be done by increasing conversations before a medical crisis between care providers, surrogates and patients who belong to vulnerable populations (the very elderly, nursing home residents, those with chronic and terminal diseases and those who have strong preferences about what they would want under given circumstances). Having these conversations with loved ones before a medical crisis relieves stress and burden on families as well as health care providers who seek to provide the best care to all of their patients.



For those who worry about what will happen if their loved one gets sick during this pandemic and faces the possible restricting of hospitalization or

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life-supporting equipment, suggested resources to find out what plans have been developed in your area would be websites of the following organizations and agencies:

- The Department of Health in your state
- Developmental Disability Agency or Division in your state
- State Hospital Association
- Local hospital system
- Johns Hopkins Medical Center
- Center for Disease Control (CDC)

## How You Can Help Reduce COVID-19 Transmission



- **Social isolation**—This may be difficult for those with I/DD living in congregate homes and facilities. Check on staff requirements to assist with keeping residents isolated if needed. Create activities to keep safe distancing. (Think two times the distance of your outstretched arms.)



- **Hand washing**—Teach those who can sing some tricky 20 second songs or have them make up songs while washing hands. Here is a great video on handwashing. [https://www.youtube.com/watch?v=nEzJ\\_QKjT14](https://www.youtube.com/watch?v=nEzJ_QKjT14)



- **Keep hands away from your face**—Make a game about touching your face. First one to touch your face gets to wash the dishes (or some chore). If you don't touch your face all day you get a prize!



- **Cough or sneeze into your elbow joint**—not into your hand! Make fancy cloth face masks (instructions on YouTube) for those who sneeze and cough frequently. Whatever you can do...do it! We are in uncharted territory with this pandemic and creativity abounds!

**BE AWARE:** Scammers are out there promoting cures, prevention and products you need to protect yourself from COVID-19. ONLY GET ADVICE from reliable sources: CDC, State DOH website, local hospital website. Be wary of social media advice.

Jeanne Kerwin, D.MH, HEC-C, Consultant, Bioethics & Palliative Care, Atlantic Health System, Morristown, NJ  
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### OCR BULLETIN: CIVIL RIGHTS, HIPAA, AND THE CORONAVIRUS DISEASE 2019 (COVID-19)

OCR provided [this bulletin](#) to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, **disability**, age, sex, and exercise of conscience and religion in HHS-funded programs. The bulletin states that, "...persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient and his or her circumstances, based on the best available objective medical evidence."

# Set Yourself Up for Success During Difficult Times

Jennifer Phelps, M.S., BCBA, LifeTribe, LLC

Life can be downright difficult at times. How are we supposed to get through the tough times, especially when changes to routines are out of our control? It can be a monumental undertaking. The simplest change in routine can be very unsettling for our loved ones. *Set yourself and your family up for success with behavior reduction principles.*

## Your Daily Activity—Focus on YOU first!



- Develop a schedule for the following day the night before.



- Awaken early and have time for yourself.



- Write a list of three positive affirmations to set the tone for your day. Examples, “I live with courage and grace.” “I am patient and loving.” “I can have fun today.” *Notice your thoughts.* If you allow negative thoughts to run rampant first thing in the morning your loved one may pick up on your stress. Use your positive affirmations to help you change your mindset.



- Use mindfulness exercises to start and end your day. Reference article: *71 Mindfulness Exercises*: <https://www.developgoodhabits.com/mindfulness-exercises/>

## Preventive Strategies



- **REMEMBER, BEHAVIOR IS COMMUNICATION.** What messages are you sending?



- **CHALLENGING MOMENTS DON'T SPROUT WITHOUT ROOTS;** they are almost always warning signs that let you know when someone's behavior is starting to escalate. What are they trying to communicate to you?



- **ALLOW THE PERSON** the freedom to make their own decisions as much as possible.



- **PERMIT VERBAL VENTING WHEN POSSIBLE.** Allow the person to release as much energy as possible by venting verbally. If you cannot allow this, state directives and reasonable limits during lulls in the venting process. If needed, create a safe space where they can do this. You could include a picture of this space in their schedule and explain that is where they can go (anytime) to express those feelings.



- **IGNORE CHALLENGING (AND REPETITIVE) QUESTIONS.** When they challenge your rule, redirect their attention to the issue at hand without engaging in a conversation about the question.

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- **IGNORE NONSENSE BEHAVIORS.** Behaviors that are frustrating to you but do not interfere with the ability to complete daily tasks and do not put anyone at harm might be better off ignored and redirected to something else.



- **SET AND ENFORCE REASONABLE LIMITS.** If someone becomes belligerent, defensive, or disruptive, state limits and directives calmly, clearly and concisely. When setting limits, offer the person choices and consequences. Be mindful of your tone of voice, body language and facial expressions.



- **KEEP THEM CLOSE.** Being close allows you to intervene quickly, provides the individual with needed attention and less opportunities to engage in problem behaviors.



- **CATCH THEM BEING GOOD.** Provide positive comments, facial expressions and body language often.



- **KEEP EXPECTATIONS LOW.** When routines are disrupted and our stress levels increase, our tolerance levels for non-preferred or frustrating activities can be lowered.



- **ESTABLISH NEW DAILY ROUTINES.** Using pictures or a written schedule that is clearly displayed let them know what their new schedule is. When possible allow them to help you make the schedule or change the order of activities.



- **FILL THE DAY WITH SIMILAR ACTIVITIES** that include tasks that are like the ones they are used to. For example: If they worked at a job where they greeted people, go for a walk every morning and wave and say hello to people walking by or call family and friends and say good morning every day. If they sorted clothes at Goodwill, set-up a sorting station at home and start organizing closets.



- **AVOID ASKING THEM TO COMPLETE MULTIPLE NON-PREFERRED TASKS BACK TO BACK** when possible. For example: If tooth brushing and hair brushing are non-preferred tasks do something preferred in between. Brush teeth, read a book, then brush hair.



- **TAKE BREAKS.** Take breaks for yourself when needed. Time out for a caregiver is often the best response to a challenging situation.



- **USE TELEHEALTH.** There are many psychologist, counselors and behavior analysts available via telehealth for support and ideas during this time.



- **HAVE FUN! BE SILLY!** Focus on making new memories.

Some strategies presented in this article have been adapted from <https://educate.crisisprevention.com>

[www.lifetribe.us](http://www.lifetribe.us) At LifeTribe, the science of Applied Behavior Analysis is our foundation. To maximize treatment outcomes, we help you easily integrate these principles into your everyday life. We are honored to work with adults with intellectual disabilities, dementia and Alzheimer's disease. We recognize that you are the expert as it pertains to your loved one and family. We are the experts in behavior change. When we come together with mutual respect, and common goals, we can accomplish anything. The link between our combined expertise and passion for success will be woven together as we collaborate on behavior plan goals, recommendations, and family coaching plans. Jennifer is available for Telehealth consulting at: <https://jennifer.dobettermovement.us/en/e/coach-mentor/1>

# Five COVID-19 Facts

Stay Healthy

01

- ◆ Wash your hands
- ◆ Keep your hands off your face
- ◆ Wash your hands
- ◆ Sneeze or cough into your elbow (or a tissue you throw away)
- ◆ Wash your hands
- ◆ Stay at home

Know the Signs & Symptoms

02

- ◆ Fever
- ◆ Cough
- ◆ Shortness of breath

If you have symptoms, call your doctor. Do not go to the office unless told to do so.

For Most, the Risk is Low

03

The majority of people who get the virus recover at home. A small group will need to be hospitalized

Don't Panic

04

Many illnesses have similar symptoms. Stay in touch with friends and family to reduce anxiety.

Stay Informed

05

Visit websites of trusted sources like [Cdc.gov/COVID-19](https://www.cdc.gov/covid-19)

## Announcing New NTG Website

Matthew Janicki, PhD, and Seth Keller, MD, co-chairs of the National Task Group on Intellectual Disabilities and Dementia Practices recently announced the launch of our new website. With the increasing number of NTG Affiliated Trainers and other members, it is important to have a site that is dedicated to those who support individuals with intellectual disabilities and dementias. The new site is now available, and additional items are being added daily. You will soon be able to see the schedule of NTG workshops, current projects, publications such as the *COVID-19 Q & A*, *My Thinker's Not Working*, the *EDSD* and other items. If you missed any back issues of this newsletter, they will also be available. We hope you will like the ease of use and that you will check back often.



## Temple University Caregiver Research Project

Nearly four years ago Mary Hogan and Jadene Ransdell started the first national online support group for family caregivers of individuals with intellectual disabilities and dementia. One year later this newsletter was started as a way to provide additional information following the online meeting discussions. Supporting families in a caregiving roll is an important function of the NTG and we are always searching for ways to improve what we do. Conversations with NTG Steering Committee member, Philip McCallion, PhD, led us to an idea for research on the value of peer support and the needs of family members who provide both direct and indirect support to a loved one. We are excited to share that Philip and his colleague, Lisa Ferretti, LMSW, at Temple University have created a *Caregiver Questionnaire* that we believe will help us provide more effective support. It is our hope that other groups can use the research results to guide them in the development of additional support groups around the country.

*There is no requirement that you participate in the questionnaire but if you would like to respond, please know that no identifiable information on respondents will be collected.*

[The Caregiver's Questionnaire is available online – just click here.](#)

If you are looking at a hard copy of the newsletter and would like to be sent a link to the questionnaire just contact Philip McCallion at [philip.mccallion@temple.edu](mailto:philip.mccallion@temple.edu). You can also contact him with any questions. A summary of the findings from the questionnaire will be included in a future newsletter and will be posted to the NTG website. It is our hope that many of our readers who are family caregivers will participate.



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