

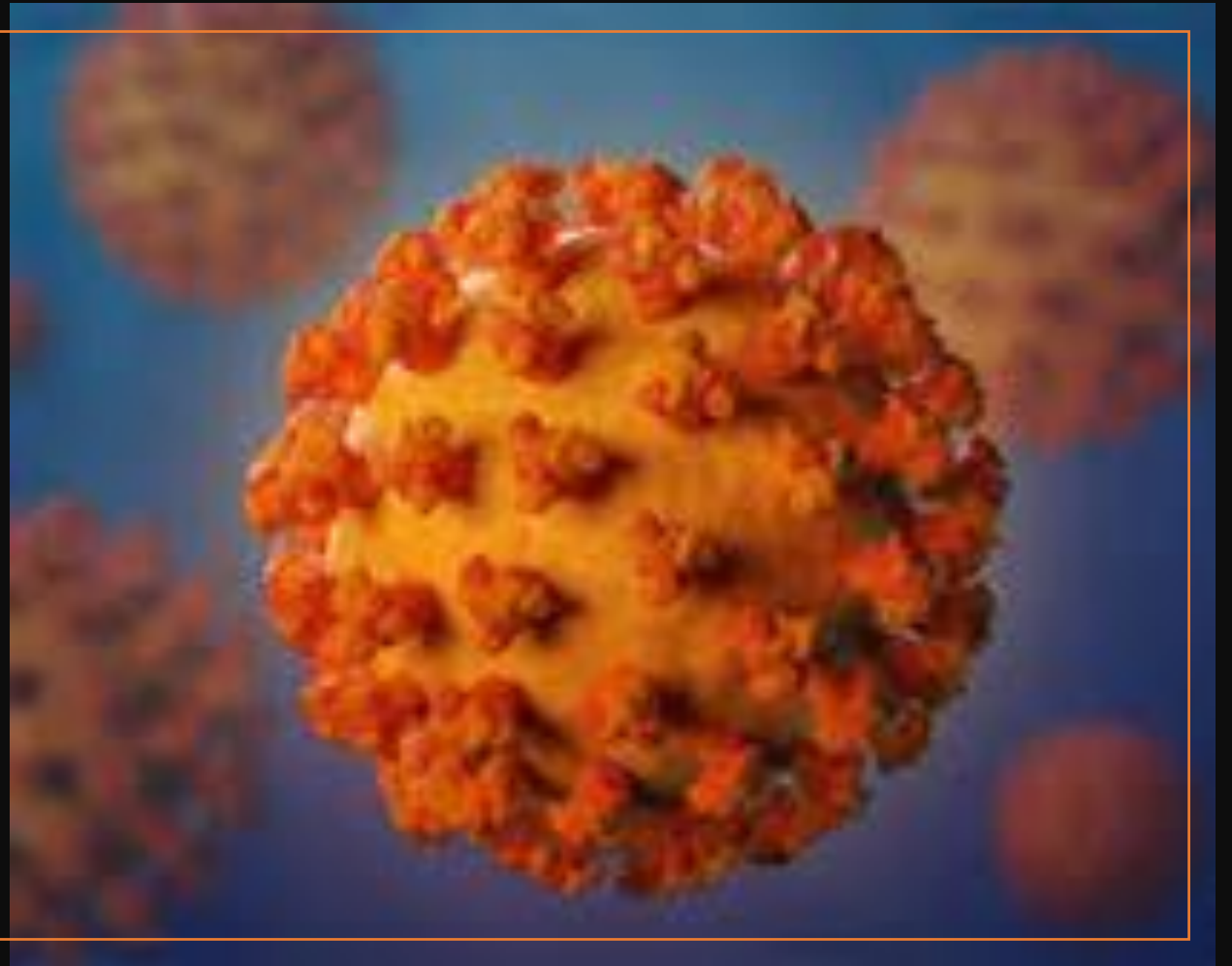
# COVID-19 and IDD for Professionals

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April 7, 2020



### Projects

**Covid-19 & Down Syndrome Q & A**

**NTG Joins National Groups in Issuing Q&A on COVID-19 and Down Syndrome**

With the constantly changing status of the COVID-19 pandemic in the United States, the NTG joined in with an effort by national organizations to produce and issue a Q&A on COVID-19 and Down Syndrome. The Q&A has two versions, one a brief series of content answers, and another longer version covering numerous questions that have arisen. The Q&A is directed toward families and others concerned with impact of COVID-19 upon persons of all ages with Down syndrome.



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<https://www.the-ntg.org/projects>

# Long and Short Versions



**Q&A on COVID-19 and Down Syndrome**  
Expanded Version • From March 26, 2020

**ORGANIZERS:**  
MIG-USA, GLOBAL, Lumind, ndcss, ntg

**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.

Q&A on COVID-19 and Down Syndrome Page 1 of 21



**Q&A on COVID-19 and Down Syndrome**  
Abbreviated Version • From March 26, 2020

**ORGANIZERS:**  
MIG-USA, GLOBAL, Lumind, ndcss, ntg

**SUPPORTING ORGANIZATIONS:**  
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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.

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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.


**Q: 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.

Q&A on COVID-19 and Down Syndrome Page 1 of 6

# English and Spanish Versions

 **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 Leguane Foundation, T21 Research Society*

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Q&A on COVID-19 and Down Syndrome Page 1 of 21

 **P&R sobre COVID-19 y el Síndrome de Down**

Versión Ampliada • 26 de Marzo de 2020

**ORGANIZADORES:**  
     

**ORGANIZACIONES DE APOYO:**  
*Down Syndrome Affiliates in Action, GiGi's Playhouse, International Mosaic Down Syndrome Association, Jerome Leguane Foundation, T21 Research Society*

**Traducción española:** Fundación Iberoamericana Down21 (España)

La difusión sin precedentes de la Enfermedad por Coronavirus 2019 (COVID-19) está ofreciendo al mundo un desafío especial y, en nuestro caso, nos apela para dar una respuesta unida con el fin de comprender mejor su impacto sobre la comunidad síndrome de Down.

Se puede usar la información contenida en este documento Preguntas y Respuestas (P&R) para ayudarnos a apoyar a nuestro ser querido con síndrome de Down. Esperamos que esta información os ayude a superar este reto de salud. Os animamos a compartir esta información con vuestra familia, amigos, educadores, personal sanitario y demás personas perteneciente a la comunidad síndrome de Down.

Hemos puesto lo mejor para responder a cuestiones que están ahora siendo planteadas y para anticipar otras cuestiones importantes de interés para nuestra comunidad. En este documento encontraréis información sobre:

- Qué puede ser lo peculiar de este virus en el síndrome de Down
- Cómo ayudar a impedir la extensión del virus
- Cuáles son los síntomas más frecuentes
- Qué reflexionar al ir tomando decisiones

Están disponibles esta Versión Ampliada y una Versión Abreviada de este documento P&R. Muchas organizaciones y profesionales han contribuido a ambas versiones ofreciendo su conocimiento sobre el síndrome de Down y aplicándolo a lo que actualmente sabemos sobre COVID-19. Conforme aprendamos más sobre el COVID-19 en general, y sobre cómo puede afectar, o no, a las personas con síndrome de Down, seguiremos actualizándolo.

Para dejarlo claro, el P&R es sólo informativo y no pretende ofrecer consejos médicos u otros relacionados. Su intención es la de dar información que esperamos os sea útil al confrontaros con decisiones y consideréis buscar recomendaciones médicas, educativas o de otra naturaleza. Este P&R no debe ser considerado como sustituto de los consejos de los profesionales médicos y otros profesionales. Habráis de consultar con vuestro propio

P&R sobre COVID-19 y el Síndrome de Down 1/23

## Partner Organizations



## 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 following organizations contributed their time, resources and expertise to the Q&A***

- 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)

*(You can download and access the Q&A from their websites)*

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

- Content areas
  - Focus on Down syndrome, but applicable to all intellectual disability
  - Covers all ages - from school age to older adults
  - Covers range of risk issues
  - Covers exposure and care issues
  - Covers quarantining and staying at home (recommended actions)
  - Covers contingencies when moving around outdoors (travelling)
  - Covers miscellaneous issues (e.g., pets)
  - Covers activities when idled at home
  - Covers group home and workplace situations
  - Covers civil rights and accessing COVID-19 treatment

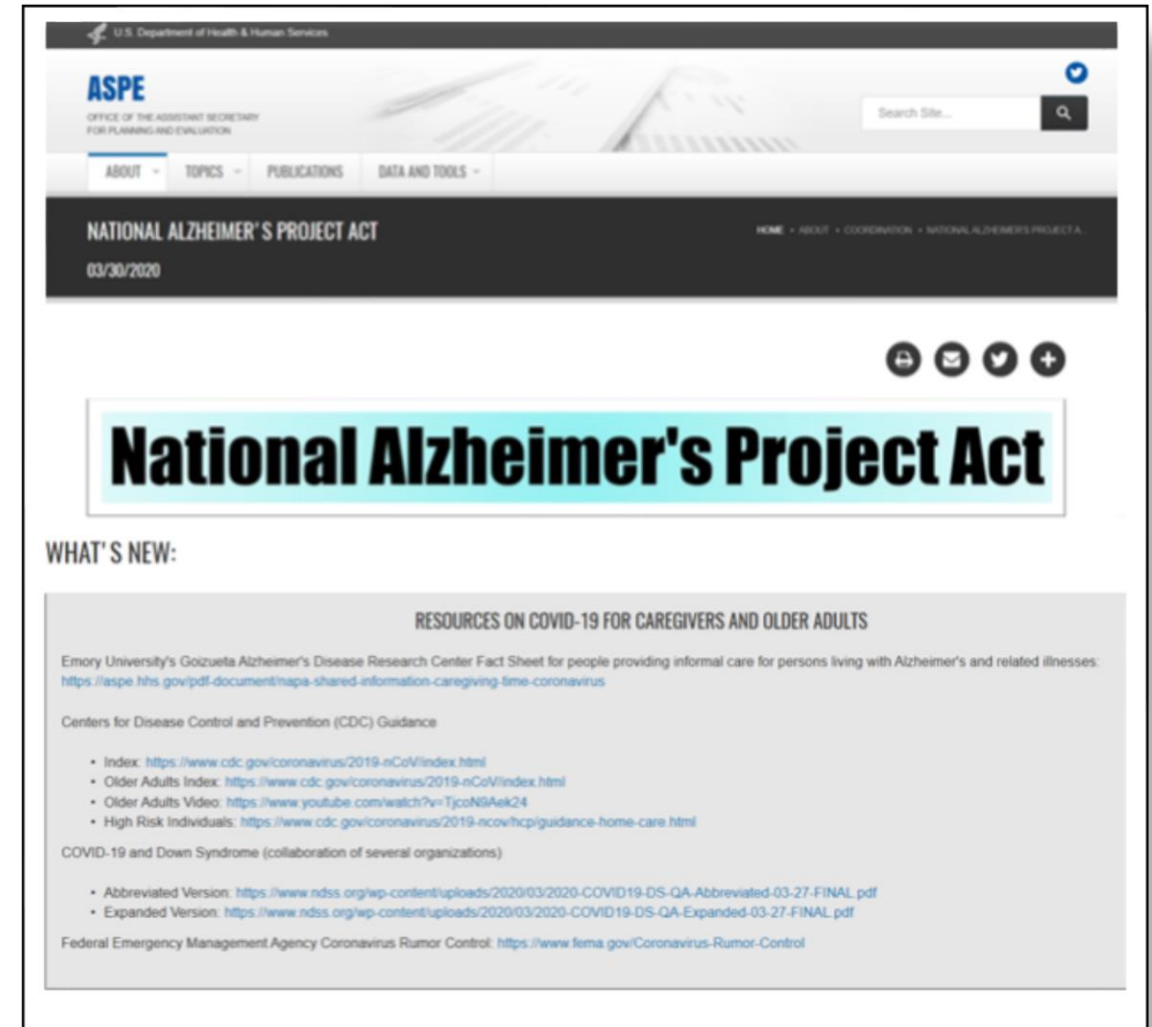
## Q&As related to Alzheimer's/Dementia

Q11. Does having dementia or Alzheimer's disease for someone with Down syndrome increase the risk of being infected by COVID-19?

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?

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?

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..."*




The screenshot shows the ASPE (Office of the Assistant Secretary for Planning and Evaluation) website. The header includes the ASPE logo and navigation links for ABOUT, TOPICS, PUBLICATIONS, and DATA AND TOOLS. Below the header, the main heading reads "NATIONAL ALZHEIMER'S PROJECT ACT" with a date of "03/30/2020". A large teal banner contains the text "National Alzheimer's Project Act". Underneath, a "WHAT'S NEW:" section highlights "RESOURCES ON COVID-19 FOR CAREGIVERS AND OLDER ADULTS". This section lists several resources, including a fact sheet from Emory University, CDC guidance, and a document from the National Dementia Service (NDS) regarding COVID-19 and Down Syndrome. The URL for the NDS document is <https://www.ndss.org/wp-content/uploads/2020/03/2020-COVID19-DS-QA-Abbreviated-03-27-FINAL.pdf>.

<https://aspe.hhs.gov/national-alzheimers-project-act>

# ID organizations and COVID-19

NDSJ joins National Consortium to Create COVID-19 & Down Syndrome Resource





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NDSJ > NEWSROOM > COVID-19

## COVID-19

A message from NDSJ about COVID-19:

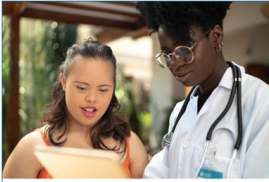
NDSJ believes that health is the most critical human right. The NDSJ Team has been monitoring current events surrounding COVID-19. The health and safety of our community is a top priority. We have developed a COVID-19 one pager with



Programs & Resources

## COVID-19 and Down syndrome

Misinformation about COVID-19 is reaching infodemic levels, perhaps even more so for people wanting to know how it may affect individuals with Down syndrome. The unprecedented spread of COVID-19 presents the world with a unique challenge and calls for a united response to better understand its impact on the Down syndrome community.




We're proud to work with other Down syndrome organizations to provide useful information surrounding COVID-19. We hope you find this Q&A an important resource for individuals with Down syndrome and their families, and we will continue to update these documents as we learn more. We have also sent a joint [press release](#) to national media sources.

[Abbreviated Version](#)  
[Expanded Version](#)

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LuMind IDSC and other Down syndrome organizations have received inquiries from families about COVID-19 and their concerns for their loved one with Down syndrome. The information is currently evolving and we are closely monitoring current and accurate information surrounding COVID-19.

### LuMind IDSC joins National Consortium to Create Important Covid-19/Down Syndrome Resource

The unprecedented spread of Coronavirus (COVID-19) presents the world with a unique challenge and calls for a united response to better understand its impact on the Down syndrome community. LuMind IDSC Foundation (LuMind IDSC) is proud to collaborate with Down Syndrome Medical Interest Group-USA (DSMIG-USA), Global Down Syndrome Foundation (GLOBAL), National Down Syndrome Congress (NDSC), National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and Down syndrome medical experts to publish a new resource.



Dedicated to significantly improving the lives of people with Down syndrome through RESEARCH, MEDICAL CARE, EDUCATION AND ADVOCACY

Our Story About Down Syndrome Research & Medical Care Get Involved Programs & Events Conferences & Membership News & Community

Global Down Syndrome Foundation >> Everything You Need to Know About COVID-19 & Down Syndrome

## Everything You Need to Know About COVID-19 & Down Syndrome

**WE NEED YOUR URGENT HELP TODAY!!**

The State of Colorado will be finalizing the *Critical Care Triage Guidelines for the State of Colorado* ("Guidelines") in the next day. The Guidelines MUST ensure that there is NO MEDICAL RATIONING OF COVID-19 that would discriminate against people with disabilities and/or our most vulnerable citizens!



HOME MEMBER LOGIN ALUMNI ASSOCIATION

ABOUT STATE AGENCIES CONFERENCES PROJECTS PUBLICATIONS RESOURCE LIBRARY MEMBER SERVICES NEWS

## COVID-19: State and Federal Resources


March 20, 2020

Topics: [Announcements](#), [State News](#).

Updated 4-2-2020

**National Guidance**

- CMS COVID-19 Disaster Response Toolkit [LINK](#)
- CMS' Most Recent Announcements Can Be Found On The CMS Current Emergencies Site [CLICK HERE](#)
- Federal Coronavirus Repository and Current Information (CDC) [CLICK HERE](#)
- Coronavirus COVID-19 Stakeholder calls: [CLICK HERE](#)
- ACL: What Do Older Adults and People with Disabilities Need To Know COVID-19
- Administration for Community Living COVID-19 Information [Webpage](#)
- Additional COVID-19 FAQs for State Medicaid and Children's



National Task Group on Intellectual Disabilities and Dementia Practices

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## Covid-19 & Down Syndrome Q & A

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## COVID-19 Resources for People With Disabilities, Families, and Service Providers





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

For constant updates, check the CDC websites and the websites of the partner organizations as well any other reliable websites.

**[www.the-ntg.org](http://www.the-ntg.org)**