



COVID-19 and Down Syndrome: Visitors in Hospitals

The National Down Syndrome Society has received numerous inquiries regarding family members and caregivers of individuals with Down syndrome who have been hospitalized and cannot visit due to COVID-19. This document is intended to share guidance if an individual with Down syndrome has been hospitalized and the hospital will not allow anyone to visit them.

Hospital visitation policies vary from hospital to hospital. For the safety of the general public, many hospitals have changed their visitation policy to help prevent the spread of COVID-19.

If a hospital is not allowing visitors and is not making exceptions for family and caregivers of individuals with Down syndrome, here are some steps that can be taken:

- Contact the hospital administrator who can adjust the visitation policy and request that you be with the individual who is currently receiving treatment.
- Consider filling out [a form](#), similar to this, to give to the hospital staff. This form can provide the staff with a clearer understanding on how best to work with the individual with disabilities.
- Contact your state’s intellectual/developmental disabilities (I/DD) agency. Please click [HERE](#) to find the contact information for your state’s agency.
- HHS' Office of Civil Rights issued a [Bulletin](#) on March 28 that discusses compliance with disability rights laws, including accessibility at hospitals.
 - On page three of the bulletin, there is a section titled “For information regarding how Federal civil rights laws apply in an emergency, please visit: <https://www.hhs.gov/civil-rights/for-individuals/special-topics/emergency-preparedness/index.html>”
 - On that page, there is a section titled “OCR Identifies Practices and Resources for Emergency Responders/Officials to Help Ensure Individual Have Equal Access to Emergency Services”
 - That section includes a bullet that states emergency responders and officials should consider adopting the following practices to help make sure all segments of the community are served, including:
 - “Avoiding separating people from their sources of support, such as service animals, durable medical equipment, caregivers, medication and supplies”
- The Center for Public Representation and other organizations issued this [guidance document](#), explaining in more detail the requirements in the HHS guidance. On page 5, it discusses reasonable modifications to hospital visitor policies for people who need family or support for equal access to treatment:
 - “If the individual requires an accommodation that involves the presence of a family member, personal care assistant, communicator, or similar disability service provider, knowledgeable

about the management of their care and/or able to assist them with communicating their needs, to assist them during their hospitalization, this should be allowed provided that proper precautions can reasonably be taken to contain the spread of infection.”

- The American Academy of Developmental Medicine & Dentistry recently released [this statement](#) on providing hospitalized patients with Intellectual and Developmental Disabilities (IDD) with designated support staff during the COVID19 Pandemic:
 - “In order to ensure that visitation guidelines provide for safety for the patient, medical personnel, and the designated caregivers, it is recommended that the following are in place:
 1. Agency/family should provide a short summary of the patient’s abilities and cautions with respect to behavior
 2. Agency/family should provide written information on the patient’s decision-making abilities (e.g. supported decision-making, power of attorney, guardianship, etc.) and wishes re DNR orders, feeding support, etc.
 3. Agency/family should provide information on any dietary restrictions and list of medications taken including drug allergies
 4. Accompanying persons should be advised on any special hospital/unit protocols in place and how to abide by them
 5. Accompanying persons should wear a name/agency/family tag identifying them as being cleared by the hospital to accompany the patient
 6. Accompanying persons should be cleared as to what level of medical information they are entitled to (as next of kin, medical advocate, health proxy, etc.) which is noted on the identification tag.”
- If legal intervention is required, please contact the Disability Rights Network for your state. Click [HERE](#) to find the information for your state’s Disability Rights Network.

For more information on COVID-19 and Down syndrome, please visit:

- Visit the NDSS [website](#) for more information regarding COVID-19 and Down syndrome.
- Please visit [this CDC page](#) for additional information on COVID-19.
- Visit the LuMind IDSC COVID-19 and Down Syndrome [page](#).
- NDSS Joins National Consortium to Create Important COVID-19 & Down Syndrome Resource [Press Release](#).
- HHS Coronavirus [Resources](#) for Individuals with Autism and other Disabilities.
- HHS OCR Issues [Bulletin](#) on Civil Rights Laws and HIPAA Flexibilities That Apply During the COVID-19 Emergency.
- [View](#) the guidance to States/Health Care Providers On Avoiding Disability-Based Discrimination in Accessing COVID19 Treatment.
- Disability Rights Education and Defense Fund [resource](#) Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing based on Disability.
- DREDF Know Your Healthcare Disability Rights [factsheet](#) (available in multiple languages).
- [Guidance](#) from Disability Legal Groups on non-discrimination in medical rationing related to the HHS Guidance.

If you have any questions regarding these resources, please reach out to info@ndss.org.