

# Help with Covid-19 Hospitalization for People with Developmental Disabilities

We created this on April 10th. We will update it as things change.

## Purpose

This nine page document has info that will be useful to you if you are a person with developmental disability who must go to the hospital during the Covid-19 pandemic. This page is addressed to 'you', the person with disability, and should also be read by the caregiver for such a person.

We want every person with disabilities to be treated fairly and get the care you need. Care might include having someone stay with you in the emergency room and the hospital. Not everyone with a developmental disability needs someone with them-- but if you want to have a support person, then the hospital must allow it.

## Contents

The next page has words about the right of the self-advocate to fair treatment, and the requirement to allow a patient support person. The document includes words from official government documents, both Federal and New York State. We left space at the top so you can write "My name is \_\_\_\_\_"

After that comes a script which a caregiver or advocate can use to tell hospital staff they must allow such a 'support person'. A page about rights follows, this time in voice of the caregiver.

Next, we provide a 2-page health form, from Stony Brook, which can be printed out and filled out in advance. Last, 3-page guidance issued April 10th by NYS on "Visitation" (patient support).

## How to use

We recommend that you print out this entire document, fill out the Stony Brook form, and have it ready to go. We hope that you do not need to go to the hospital.

But if you do go to the hospital, you have the tools to ensure that you are treated fairly, and that your support person is allowed to be at your bedside in the ER and during the hospital stay.

## Hopes for the future

We hope to get even stronger words from the New York State government in the future, with regard to fair treatment. If that happens we will send out an update.

Yours in hope, BJ Stasio and Arnold Ackerly for SANYS. [sanys.org](http://sanys.org)  
Barb DeLong, Brad Pivar and Jim Karpe for SWAN. [swannys.org](http://swannys.org)

Questions, comments or suggestions? Send to: [jim.karpe@gmail.com](mailto:jim.karpe@gmail.com)

**I have a developmental disability.**

**This is NOT a health condition.**

**You must NOT use it to make  
health care decisions about me.**

**By law, you are required to treat me  
the same as other people  
of my age and my health history.**

**Thank you.**

Discrimination on the basis of developmental disability is illegal:

‘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.’

[www.tinyurl.com/us-c19-mar28](http://www.tinyurl.com/us-c19-mar28)

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**I may need someone to support me  
during my ER visit and hospital stay.**

**My support person will make it easier for  
the doctors and nurses to do their jobs.**

**Per NYS Department of Health, you are required to  
allow me to have a patient support person.  
And you must give them a gown, gloves and a mask.**

**Thank you.**

NYS Department of Health policy issued April 10th states that during this pandemic crisis:

“Hospitals are required to permit a patient support person at the patient bedside for ... patients with intellectual and/or developmental disabilities....” [tinyurl.com/nys-c19-apr10](http://tinyurl.com/nys-c19-apr10)

## Script for person accompanying an individual with I/DD

*Use this tool as needed. The page before this has person-first language, for use by self-advocates. You can also post that near the bed of any patient with I/DD. The same ideas are on the next page in the voice of the person who is accompanying someone who cannot easily speak for themselves.*

*Below is guidance on how to let people know that they are required to let you into ER or hospital room, and can be used regardless of whether the person can speak for themselves. You might be dealing with an EMT or a triage nurse or a hospital executive. Adapt words below as needed.*

*Suggestion: be insistent and immovable-- but never hostile.*

*The person across from you is well-meaning, but overwhelmed and exhausted.*

**Your task is to help them act as required by the NYS Department of Health.**

I am the support person for an individual with a developmental disability. You are required to let me be here in the emergency room and during hospitalization. And, you want me here---I can help your staff. I can help them understand the patient, and I can communicate with the patient. My presence will prevent problems before they happen.

[Next stage] Everything is moving so fast right now-- perhaps you are not aware of the updated Covid-19 guidance issued by the NYS Department of Health on April 10th. You are now required to allow us to designate two support people, and have one of us present in the emergency room and during hospitalization. [tinyurl.com/nys-c19-apr10](https://www.tinyurl.com/nys-c19-apr10)

[Next stage] Let's get on the phone with the Care Coordination Organization.

### Care Coordination Organization: Emergency Call Numbers (Apr 10)

When an extension is listed, such as x1, press that number as soon as you hear the recording.

	<b>CCO Name</b>	<b>24/7 hotline</b>
	Advanced Care Alliance	1-833-692-2269
	Care Design NY	1-877-855-3673 x0
	LIFEPlan CCO	1-800-232-7145
	Person Centered Services	1-833-200-0678 x1
	Prime Care Coordination	1-607-222-9156
	Southern Tier Connect	1-607-376-7526 x101
	Tri-County Care	1-844-504-8400 x1

**I am here with a person who has a  
developmental disability.**

**This is NOT a health condition.  
You must NOT use it to make  
health care decisions about this person.**

**By law, you are required to treat this person  
the same as other people  
of their age and health history.**

**Thank you.**

Discrimination on the basis of developmental disability is illegal:

‘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.’

[www.tinyurl.com/us-c19-mar28](http://www.tinyurl.com/us-c19-mar28)

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**I am here to support  
a person with a developmental disability  
during their ER visit and hospital stay.**

**My involvement will make it easier for  
the doctors and nurses to do their jobs.**

**Per NYS Department of Health, you are required to  
allow me to act as a patient support person.**

**And you must give me a gown, gloves and a mask.**

**Thank you.**

NYS Department of Health policy issued April 10th states that during this pandemic crisis:

“Hospitals are required to permit a patient support person at the patient bedside for ... patients with intellectual and/or developmental disabilities...” [tinyurl.com/nys-c19-apr10](http://tinyurl.com/nys-c19-apr10)

# COVID-19 DISABILITY FORM

Please answer the questions on this form to help physicians provide you with proper medical treatment, in case you need to go to the hospital for COVID-19 related symptoms. Complete as many of the questions as possible.

What is your name? \_\_\_\_\_

Is this form being completed by someone else other than you?  yes  no

legal guardian  aide or staff member  family member  other

If you checked yes, what is the person's name \_\_\_\_\_ Relationship to you \_\_\_\_\_

Do you receive or have you received services from the New York State Office for People with Developmental Disabilities (OPWDD) or Office for Mental Health (OMH)?  yes  no  I don't know

\*\*\*Note to doctors: This means there may be special laws in place to protect me and a special process needs to be followed if my usual decision maker/guardian requests to withhold or withdraw life sustaining treatment. Please check in with your institution's social worker or risk management department to be sure the appropriate process is being followed.

How do you communicate best? (check all that apply)

- Talking  Writing or typing things down  
 Pictures  Using sign language  
 Pointing to words  Using a voice app  
 I cannot communicate in a way you will understand, please ask my family, staff or guardian (circle the person)  
 Other (please describe) \_\_\_\_\_

Do you need anything to help you communicate?

(E.g. assistive devices)  no

yes (please describe) \_\_\_\_\_

Does anyone help you communicate?  no

yes, person's name \_\_\_\_\_

Do you use any assistive devices for mobility?  no

yes list the device(s) \_\_\_\_\_

Do you have any triggers (e.g., being touched, trauma, doctors of a particular gender, noises, lighting, smells, textures):  
\_\_\_\_\_

What is your response to triggers?  
\_\_\_\_\_

How can you best be helped when triggered?  
\_\_\_\_\_

What is your typical response to a medical exam?

- Fully/partially cooperates  Fearful  
 Aggressive  Resistant

I like it when health professionals (please describe)  
\_\_\_\_\_

I do not like it when health professionals (please describe)  
\_\_\_\_\_

Do you have any medical problems that you go to the doctor for?

yes  no

What are they?  
\_\_\_\_\_

Please list the name of the doctor you would like contacted if you are at the hospital.

Name \_\_\_\_\_

Phone Number \_\_\_\_\_

Are there any diagnoses, medical problems or behaviors that we should consider as cautions? (e.g., aggression, biting, pica, aspiration risk):  
\_\_\_\_\_

Are there any specific modifications that could help with these cautions?  
\_\_\_\_\_

Do you have seizures?  no

yes, list the type and frequency \_\_\_\_\_

Do you take any medication at home every day?  yes  no

By prescription?  no

yes, list the names and dosage \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Over the counter?  no

yes, list the names and dosage \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Do you have any allergies?  no

yes, please list \_\_\_\_\_

**Do you use tobacco** (e.g., cigarettes, cigars, or chewing tobacco)?

yes, please list \_\_\_\_\_ how often \_\_\_\_\_

no

**Do you use alcohol?**  no

yes How much do you use in a week? \_\_\_\_\_

**Do you use any other drugs** (eg., marijuana, cocaine, or opiates)?

yes, please list \_\_\_\_\_

no

**Who can we talk to about medical problems if you can't answer questions?** Name \_\_\_\_\_

Phone number \_\_\_\_\_

Who do you trust to make medical decisions if you aren't able to?

Name \_\_\_\_\_

Phone number \_\_\_\_\_

**Do you have a health care agent?**  no

yes, Name \_\_\_\_\_

Phone number \_\_\_\_\_

**I live** (check one box):

By myself

With my family

With roommates

In a group home

Supported living

Nursing home

Other (please describe) \_\_\_\_\_

Does anyone you know have COVID-19?  yes  no

I don't know

When were you told the person has COVID-19? \_\_\_\_\_

What was the last date you saw this person? \_\_\_\_\_

**Capacity to consent**

Capable/Own Guardian

Substitute Decision Maker

Supported Decision Making Team

Guardian/Conservator

Other, Please describe \_\_\_\_\_

How was this decided? \_\_\_\_\_

**For patients who are their own guardian / have capacity:**

**Do you have** (check all)  1) an advance directive  2) a health care agent  3) a living will  4) a MOLST form?

*If so please bring a copy of each document to the hospital*

**If while you are in the hospital you can't breathe on your own, do you want a machine to help breathe for you?** (Mechanical ventilation)

Do you not want it at all?

Do you want a trial to see if it is helping?

Do you want it for as long as it is needed?

**If while you are in the hospital your heart stops, do you want your doctor to try to restart it with pushing on your chest, medications, and electric shocks?** (Resuscitation)  yes  no

**If you can't eat or drink like you normally do, do you want liquid food and water to be given to you through a tube to your stomach or in a vein?** (Artificial nutrition/hydration)  yes  no



April 10, 2020

**Health Advisory: COVID-19 Updated Guidance for  
Hospital Operators Regarding Visitation**

On March 18, 2020, the New York State Department of Health issued a health advisory, available on the Department's COVID-19 website, regarding hospital visitation restrictions. On March 27, 2020, the Department issued updated guidance specific to obstetrical and pediatric settings. **This advisory replaces all previously issued guidance regarding hospital visitation.**

**Effective immediately, hospitals must suspend all visitation except for patient support persons, or family members and/or legal representatives of patients in imminent end-of-life situations.**

**Hospitals are required to permit a patient support person at the patient bedside for:**

- Patients in labor and delivery;
- Pediatric patients;
- Patients for whom a support person has been determined to be essential to the care of the patient (medically necessary) including patients with intellectual and/or developmental disabilities and patients with cognitive impairments including dementia.

During this unprecedented time, a support person for the patients described above may be critical to avoid negative health outcomes unrelated to the COVID-19 public health emergency. Given the risk of COVID-19 in healthcare settings, healthcare providers should thoroughly discuss the potential risks and benefits of a support person's presence at the bedside with both the patient (if 18 years of age or older) and the support person. For those patients and support persons who through informed decision making determine a support person at the bedside is essential for the patient's care, hospitals should develop protocols for ensuring a support person at bedside minimizes risk of potential COVID-19 transmission, including when the patient is confirmed or suspected to have COVID-19.

- For **labor and delivery**, the Department considers **one support person** essential to patient care throughout labor, delivery, and the immediate postpartum period, including recovery. This person can be the patient's spouse, partner, sibling, doula, or another person they choose. This person can stay in all Article 28 settings with the patient and will be the only support person allowed to be present during the patient's care. This restriction must be explained to the patient in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patients fully understand this restriction, allowing them to decide who they wish to identify as their support person.

- For **pediatric patients**, the Department considers **one support person at a time** as essential to patient care in the emergency room or during hospitalization. For hospitalized pediatric patients, especially with prolonged hospitalizations, the patient or family/caregiver **may designate two support people**; but only one support person may be present at a time. This restriction must be explained to the patient's family/caregivers in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that the family/caregiver fully understand this restriction. Individuals age 70 years or older, are not encouraged to be support persons at this time due to increased risk of COVID-19 infection.
- For **patients for whom a support person has been determined to be essential to the care of the patient (medically necessary) including patients with intellectual and/or developmental disabilities (I/DD), and patients with cognitive impairments including dementia**, the Department considers **one support person at a time** as essential to patient care in the emergency room or during hospitalization. For these hospitalized patients, especially with prolonged hospitalizations, the patient or family/caregiver **may designate two support people**; but only one support person may be present at a time. This support person can be the patient's family, caregiver, or another person they chose. In these settings, the person will be the only support person allowed to be present during the patient's care. This restriction must be explained to the patient and support person in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patients fully understand this restriction, allowing them to decide who they wish to identify as their support person. Individuals age 70 years or older, are not encouraged to be support persons at this time due to increased risk of COVID-19 infection.
- For **patients in imminent end-of-life situations**, the Department considers **one family member and/or legal representative at a time** as a support person who should be permitted at the patient bedside. The Department defines imminent end-of-life situations as a patient who is actively dying, where death is anticipated within less than 24 hours. The patient and/or family/caregiver **may designate up to two support people**; but only one support person may be present at a time. In the event the patient is a parent of a minor child, one adult family member and one child may be permitted at the patient bedside. This restriction must be explained to the patient and/or support person in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patients and/or support person fully understand this restriction. Individuals age 70 years or older, are not encouraged to be support persons at this time due to increased risk of COVID-19 infection.

**The support person of a patient with confirmed or suspected COVID-19 who has been a close contact of the patient** has potentially already been exposed to COVID-19. These support persons should:

- Wear a surgical or procedure mask throughout their time in the hospital,
- Practice scrupulous hand hygiene,



- Remain in the patient's room except for entrance and exit from the hospital; and
- While in the room, a gown and gloves should be worn to prevent the person's hands or clothes from becoming contaminated. Eye protection should be worn while in the room if available.

**If the support person of a patient with confirmed or suspected COVID-19 has not been a close contact of the patient** and does not have a history of confirmed COVID-19, the support person should:

- Wear a surgical or procedure mask throughout their time in the hospital,
- Practice scrupulous hand hygiene,
- Remain in the patient's room except for entrance and exit from the hospital, and
- While in the patient's room, a gown and gloves should be worn to prevent the person's hands or clothes from becoming contaminated. Eye protection should be worn while in the room if available.
- Again, in these circumstances the risks of acquiring COVID-19 should be fully explained, so that the patient and support person can make an informed decision of whether or not the support person's presence at the patient bedside is essential to the patient's health .

**If the patient does not have confirmed or suspected COVID-19**, the support person should:

- Wear a surgical or procedure mask throughout their time in the hospital,
- Practice scrupulous hand hygiene, and
- Remain in the patient's room except for entrance and exit from the hospital.

**Hospital staff must screen the support person** for symptoms of COVID-19 (e.g., fever, sore throat, runny nose, cough, shortness of breath, muscle aches, or diarrhea) and conduct a temperature check prior to entering the clinical area and every twelve hours thereafter for the remainder of their presence at the bedside. When providing personal protective equipment to a support person, instructions on PPE conservation strategies should be provided to minimize unnecessary waste (i.e. prolonged wearing).

If a support person has confirmed or suspected COVID-19 or presents with or develops symptoms of COVID-19, they should be excluded from the facility. In this situation, through informed decision making the patient and family may choose to select a different support person.

Hospitals should develop clear protocols for communicating with family members or caregivers of any patient who do not have a support person at the bedside. This should include considerations for assisting patient and family member communication through remote methods when possible , for example, via phone or video call.

Hospitals must post signage notifying the public of the suspension of visitation in all hospital entrances and in parking lots. In addition, these policies should be posted to the hospital's website and social media pages.