

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

Barb DeLong, Brad Pivar and Jim Karpe for SWAN. swannys.org

Questions, comments or suggestions? Send to: 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

**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

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.

CCO Name	24/7 hotline
Advanced Care Alliance	1-833-692-2269
Care Design NY	1-518-235-1888 (Normal business hours – Mon-Friday 8:30a-5p) 1-877-855-3673 (after hours, weekends, and holidays - only)
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

**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

