CAUTION: POSSIBLE COVID-19 CASE

Patient Summary for Person with Developmental Disability

Emergency Contacts, Abridged Medical History, Medication Regimen, Allergy Information, Assistance Needs

I have a developmental disability. My parent/guardian or support professional believes I am showing signs of COVID-19 infection. If they cannot come with me into the hospital, please refer to the information provided here and call my guardian, service provider, and the county board of DD for any clarifications.

PERSONAL INFORMATION			
First Name:	**Middle Initial:**	**Last Name:**	**DOB or Age:**
Address:		**City, State, ZIP:**	
Name of Parent/Guardian:		**Parent/Guardian Phone/Email:**	
Name of Direct Support Professional (DSP):		**DSP Phone/Email:**	
County Board of DD Contact:		**County Board Contact Phone/Email:**	

CURRENT SYMPTOMS / RISK FACTORS			
Current COVID-19 Symptoms:	**When Did it Start?**	**Patient's COVID-19 Severity Risk Factors (check all that apply):**	
☐ Temp. Over 100°F		☐ Age 60 or Older	☐ Down's Syndrome
☐ Dry Cough		☐ Bowel Disease (Chron's, Colitis, or Similar)	☐ Hypertension
☐ Malaise/Fatigue		☐ Cancer (Current or Previous)	☐ New Chest Pain
☐ Shortness of Breath		☐ Cerebral Palsy	☐ Paralysis (Due to Any Cause)
☐ Bloodshot Eyes		☐ Chemotherapy	☐ Recurrent Pneumonia
☐ Diarrhea		☐ Chronic Heart Disease	☐ Severe Scoliosis
☐ Loss of Smell/Taste		☐ Chronic Lung Disease (Asthma or Similar)	☐ Other:
☐ Other (please specify)		☐ Diabetes	☐ Other:
☐ Other (please specify)		☐ On Prednisone, Dexamethasone, or any medication ending in the letters "-ab"	

MEDICATIONS			
Medication:	**New Medication:** (added within the last 2 weeks)	**Dosage/Frequency:**	**Preferred Form:** (liquid, pill, etc.)
	☐		
	☐		
	☐		
	☐		
	☐		
	☐		

(MORE INFORMATION ON REVERSE)

MEDICAL HISTORY		
Health Issue/Diagnosis:	**When Did it Start?**	**Notes:**

PATIENT ALLERGIES	SEVERITY

PATIENT HAS DNR ORDER:

☐ YES ☐ NO ☐ UNSURE

If yes, list order's location if known:

PATIENT HAS LIVING WILL:

☐ YES ☐ NO ☐ UNSURE

If yes, list will's location if known:

PERSONAL ASSISTANCE NEEDS			
Bathroom Use:	☐ Independent	☐ Needs Assistance	☐ Needs Total Assistance
Eating:	☐ Independent	☐ Needs Assistance	☐ Needs Total Assistance
Mobility:	☐ Independent	☐ Needs Assistance	☐ Uses Assistive Device
Communication:	☐ Talkative	☐ Limited Speech	☐ Non-Verbal/Uses Device
Social Preference:	☐ Social	☐ Not Social	☐ Varies
Sleep Schedule:	☐ Typical	☐ Inverted	☐ Intermittent/Variable

ADDITIONAL NOTES:

PATIENT'S SELF EXPRESSION, LIKES, AND DISLIKES:	
I express myself by:	
I calm myself by:	
When I'm happy, I:	
When I'm sad, I:	
When I'm scared, I:	
When I'm angry, I:	
My likes:	
My dislikes:	

PATIENT HAS MASK/FACE SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):

☐ YES

☐ NO

PATIENT HAS GENERAL TOUCH SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):

☐ YES

☐ NO

To download this form, visit www.oacbdd.org/covidform

This form has been created and distributed by the Ohio Association of County Boards of DD with substantial input and guidance from Dr. Susan Abend of the Right Care Now Project.

OACB Serving People with Developmental Disabilities

Right Care Now Project

CommunicationFIRST
Because communication is a human right.

COVID-19 Communication Rights Toolkit

with Printable Patient Accommodations Request Form

(United States)

Patients with the coronavirus who need communication tools and supports due to speech-related disabilities face greater risks of discrimination and isolation during this pandemic. **Your legal and civil rights to access your communication supports do not go away during an emergency, in quarantine, or in the hospital!** But, for safety reasons, your family members and others who help you communicate may not be allowed to join you in the hospital. And you may face other barriers to communicating your needs and desires while you are being treated.

This toolkit: (1) explains your communication rights; (2) provides tips on advocating for them, and (3) has an accommodation request form you can bring to the hospital.

What are your communication rights in health care settings?

If you are a patient in a hospital or other health care setting, you still have communication and other civil rights under Titles II and III of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA)—**even during a pandemic**. Hospitals and other health care facilities must meet your communication needs at all times. They also have an ethical duty to try to obtain your informed consent before treating or withholding treatment.

- **Communication supports:** Health care facilities are required to provide supports and services to ensure effective and clear communication 24 hours a day for patients who have hearing, vision, and/or speech impairments. The communication preferences of the patient should take priority.

- **Other reasonable steps:** Hospitals must provide other reasonable modifications and aids to give a patient with a disability equal opportunity to benefit from treatment.

- **No discrimination in treatment:** Hospitals cannot discriminate, exclude, or treat patients differently because of their disability. Treatment decisions must be based on individual needs and not on generalized assumptions about a person's disability or their quality of life. Care and treatment cannot be denied

or lowered in priority based on a person's pre-existing disability or an assumption that the person has a lower prospect of survival due to the disability. A person with a disability who has COVID-19 cannot be excluded from treatment just based on their disability or inability to communicate.

How can you protect your communication rights at a hospital?

- Complete the attached **one-page form** with your individual needs and preferences as soon as possible. If you need to be treated, bring **two copies** (laminated, if possible). If you don't have access to a printer, send a copy to your health care provider and ask them to print it out.
    - While you are healthy, it is a good idea to prepare a **communication kit** with a range of tools you might need when you are sick during a long hospital stay, and may not have access to your regular communication support people. Include instructions for hospital staff.

- Tell the hospital **registration clerk and nursing staff** that you are requesting communication accommodations and hand or send them your form.
    - Also be sure to bring your communication kit, including all devices, chargers, and communication boards you might need. Keep them close.

- **If staff refuse to provide access to your communication supports:**
    - The hospital should have a webpage about disability discrimination and communication access rights that you can point to.
    - Contact the hospital's Patient Relations office or Civil Rights Coordinator.
    - Consider filing a grievance with the hospital's Civil Rights Coordinator. Request assistance from Patient Relations if needed.
    - If necessary, file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically at www.ocrportal.hhs.gov/ocr/portal/lobby.jsf.

- **For legal assistance and referral**, you can contact the Protection and Advocacy office in your state: https://www.ndrn.org/about/ndrn-member-agencies/

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Legal References and Links

- **Americans with Disabilities Act** applies to public and private hospitals
  - Statute: 42 U.S.C. §§ 12101 *et seq.*
  - Title II Regulations (publicly run health care facilities): 28 C.F.R. § 35.130 (prohibits disability discrimination); 28 C.F.R. § 35.160 (requirement to provide communication supports)
  - Title III Regulations (private health care facilities): 28 C.F.R. § 36.302 (disability-related modifications must be made); 28 C.F.R. § 36.303 (communication supports required)

- **Section 504 of the Rehabilitation Act** covers health care facilities that accept federal financial assistance, including Medicare and Medicaid
  - Statute: 29 U.S.C. § 794
  - Regulations: 45 C.F.R. § 84.4 (prohibits disability discrimination), 45 C.F.R. § 84.52 (requires health care facilities to provide communication supports); 28 C.F.R. § 41.51 (must provide aids, benefits, and services to people with disabilities at a level affords equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others)

- **Section 1557 of the Affordable Care Act** prohibits disability discrimination in certain health programs or activities; requires covered entities to ensure programs, services, activities and facilities are accessible
  - Statute: 42 U.S.C. § 18116
  - Regulations: 45 C.F.R. § 92.101(a)(1); 45 C.F.R. § 92.205

Additional Resources

- **Communication Tools** to Facilitate Communication Between Patients and Providers During COVID-19: PPC Taskforce
- **"Health Passport"** (general fillable 4-page form): My Health Passport
- **Medical Order for Life-Sustaining Treatment** (gives patients more control over end-of-life care, including extraordinary measures and CPR): National POLST Form; California POLST Form (in 13 languages)
- **Legal Resources on Medical Rationing on Basis of Disability**: DREDF Memo

My Communication Rights and Accommodation Needs

Patient Name: _____ **Date:** _____

Emergency Contact: _____ **Tel:** _____

I am capable of communicating my needs and preferences by (e.g., using my eyes/index finger to point to the picture cards/letterboard/number choices in the communication kit I brought with me; the X app on my iPad, which needs to be charged and within my reach at all times; handwriting; modified ASL; having my communication support person present at all times; having my emergency contact read my lips or revoice my speech by video call):

_____

_____

_____

I have a communication disability and request the following reasonable accommodations under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Affordable Care Act while I am under your care:

1. Please keep a copy of this document visible at the top of my chart.
2. Please keep a copy of this document posted in a prominent, visible place near me at all times while I am in the hospital.
3. Please communicate with me using clear, plain language what the options are, the risks and benefits of each, and what the proposed course of action is.
4. **I need the communication-related accommodations listed above to communicate effectively and to provide informed consent.**
5. If I am able to communicate using my requested accommodations, please ask my opinion about everything.
6. If you have any trouble providing my requested communication supports, please make a video call to my emergency contact who can help.
7. If I am unable to communicate at any time and do not have a trusted communication support person present, my emergency contact should be contacted by video before any decision about or change to my care is made.
8. Unless I communicate otherwise, I do not consent to any decision to withhold treatment just because I have an underlying disability, or based on the assumption that my life is not as valuable as a nondisabled person, or that I will suffer less if I do not receive treatment.