



Healthcare Advocacy: Inpatient Care and Family/Support Professional Participation during Covid-19

Seeking healthcare in the midst of the many changes that have recently happened can cause anxiety and concern. Every hospital has different guidelines and policies, but here are some questions and suggestions you might consider if a family member with intellectual/developmental disabilities has to receive care in an inpatient hospital setting over the next several months, and you cannot be bedside due to visitor restrictions:

- Regardless of where you are getting care, make certain that you bring with you appropriate legal documentation regarding your role and responsibilities, including Guardianship papers, Health Care Power of Attorney Documentation, or other key paperwork that assures that your role is clear. Obtain POA form here:

<https://www2.illinois.gov/sites/gac/Forms/Pages/Forms.aspx#advancedirectives>

For people insured by Illinois Medicaid, forms are available at:

<https://www.illinois.gov/hfs/info/Brochures%20and%20Forms/Pages/medicalforms.aspx>

Designating Someone to Help You:

- [Approved Representative Consent Form IL 444-2998 \(pdf\)](#)
- [Approved Representative Consent Form IL 444-2998S \(Spanish\) \(pdf\)](#)
- [Personal Representative Designation HFS 3806F \(pdf\)](#)
 - [Power of Attorney HFS 2306 \(pdf\)](#)
 - [Limited Power of Attorney HFS 2316 \(pdf\)](#)
- If you are going directly to the hospital, call ahead to your primary/family physician and the hospital emergency room to let them know that you are coming. ***If you are in distress and need help right away, call 911 – do not try to transport yourself to the hospital.***
- Obtain and save the Emergency Department direct telephone number ahead of time:
List of Illinois Trauma Centers by Region:
- <https://www.dph.illinois.gov/topics-services/emergency-preparedness-response/ems/trauma-program/centersByReg>

(Emergency Rooms are also referred to as ED= Emergency Department)

- Upon arrival at the Emergency Room, ask about who will be able to be present in the treatment room and the waiting room. If you are with an individual whose disabilities make it difficult to communicate their needs, distress level, and/or symptoms clearly, let the care team members know that.
- Prepare for the fact that all medical caregivers will likely have full protective measures in place. They will each be wearing a gown, gloves, and a mask, and possibly a face shield. Prepare for how that might hinder communication or cause increased anxiety.
- If, after talking with the care team regarding the importance of your role as a support person to an individual with a disability, you are still not allowed entrance, request to talk with the hospital Social Worker. Even if you have to wait in the car, you should be able to talk with one of the hospital social workers via phone. Ensure that you clearly communicate all of the individual's needs, communication preferences, sensory activities/objects, needed supports and accommodations and ask that they be documented in the electronic medical record.
- If the individual communicates via sign language, provide documentation (maintain this in their medical record) if an in-person interpreter is required, or if video relay service will suffice
 - Find out how the hospital staff will be communicating with key support people, whether that is parents, guardians, DSP/PSW, or siblings – whomever is involved as a supportive person in the individual's daily life who will help with support.
 - Request an email address that will allow you to communicate with the social worker if needed
- Consider placing a sign at the door or bedside directing the care team to a **private** folder that documents an individual's communication and sensory needs. In doing so, ensure that you protect the individual's privacy and ask their permission. Example is attached.
 - See Stony Brook form (*Ballan, M. & Perri, C. (2020). COVID-19 Disability Form. StonyBrook, NY: NY.*) Our appreciation to Michelle Ballan, PhD for generously sharing.
 - The form can be filled out online and printed at: https://cpb-us-e1.wpmucdn.com/you.stonybrook.edu/dist/a/4436/files/2020/04/COVID-19-Form_IL_Fill.pdf
 - Additionally, refer to these Medical Passports from the University of South Florida:
 - http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf (English)
 - http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_Spanish.pdf (Spanish version)
 - *E.A. (2011). My Health Passport for Hospital/Clinic Visits. Florida Center for Inclusive Communities, http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_*

Form_Typeable_English.pdf. Development of this material was supported by the Administration on Developmental Disabilities (#90-DD-0668, Fox and Kincaid). For more information visit www.flcic.org For further information contact Dr. Elizabeth Perkins at eperkins@usf.edu.

- Ask specifically about when and how often hospital care team members will be communicating with an individual's home care team. Make certain that accurate phone numbers are placed at the bedside and are transferred from room-to-room within the hospital.
- If a communication device will be left bedside, offer brief written instructions on its use. Ask the bedside RN if they would like more information on how to use the device, and if so, consider talking them through the use via phone or FaceTime. Emphasize the importance of utilizing communication devices in order to deliver **safe** care.

If the individual reads Braille only, inform the staff ASAP. Request, for example, a call button marked in Braille, patient instruction sheets in Braille, and other needed accommodations.

- Request that if possible, you and the hospitalized individual have the option of participating in daily care team "rounds". During rounds, tests are reviewed, medications are adjusted, overall patient needs are discussed, and a daily care plan is developed. Given the circumstances at many hospitals right now, you may not be able to participate in rounds. You can request a call from a member of the care team to update you on changes and plans, and someone from the care team will likely try to connect with you. Make certain you know when to expect the call and what number will be used, because many medical providers will not have time to try to reach you repeatedly. Verify that sign language interpreters have been scheduled and confirmed for all interactions/evaluations/procedures/rounds with as much advance notice as possible, Request that notation be made in chart if no interpreter was present for an encounter.
- Potential questions to ask during rounds or in a follow-up call:
 - How is the current treatment working? When might we see a change/improvement?
 - Are there changes being made to the care plan?
 - What is most concerning to you at this time?
 - How are pain/discomfort being managed? How is the individual communicating their pain levels to you? How often is that assessed?
 - How can use of PCA (Patient-Controlled Analgesia) be implemented?
 - Are you able to effectively communicate with the individual you are treating? If not, how can we as a family or a support team help you with this? And how to arrange for sign language interpreters?

- When do you think that discharge may happen? If it is within the next week, can we talk with the discharge coordinator in order to better understand the plan?
- If the individual resides in a residential setting (e.g. CILA), does provider agency have any written guidelines and contact information governing hospital discharge?
- Additional key support resources available at most hospitals:
 - Patient Relations/Patient Advocacy Department: Can help with unmet needs, communication with the care team, ongoing concerns or barriers
 - Chaplaincy Department: Spiritual and religious support based on your specific needs
 - Child Life Program: Specially trained staff that can assist individuals under the age of 18 with pain control, education and preparation about needed procedures, sensory support and distraction. Dependent upon the hospital your loved one is receiving care at, Child Life Specialists may be made available to adults with developmental disabilities, but you will likely have to request the service