# My Hospital Form for Patients with Intellectual and Developmental Disabilities

Tips for families/support persons

Sometimes an individual with an intellectual or developmental disability may need to enter the hospital, and a family/support person may be unable to accompany the individual or visitation may be restricted. The Hospital Form lets hospital staff know how to best accommodate someone's medical and communication needs and try to help the person cope with being in the hospital.

#### When should you fill in this form?

Fill in the Hospital Form together in advance of the person becoming sick enough to require hospitalization.

#### What information goes into this form?

- Include *medical information* about diagnoses, medications and life-threatening issues like swallowing problems, allergies, especially allergies to latex or to medications used to put people to sleep. Be sure to include instructions that are unique to the person (e.g., only takes pills crushed in applesauce).
- Explain how the person normally communicates and understands information. Staff will not know how this person communicates when healthy. Consider printing and providing a communication tool or board for staff to use, for example for measuring pain (see supporting materials).
- Provide the person's *important contact information*. Someone may be too ill to make decisions on his or her own. Doctors will need to know who the *substitute decision-maker* is. This is a person who can legally make decisions about medical care if someone can't make such decisions themselves. Explain if someone will need *a support person* that knows them well to stay calm or communicate while at the hospital, especially during procedures or conversations about care. Most hospitals should allow support persons for this purpose, but there can be situations where this may not happen easily or immediately.

Attach any additional *important documents* to the form, like a medication list, a doctor's note summarizing health history, photocopies of any legal documents about substitute decision-makers (if this exists) or an *advance care plan*. An advance care plan explains what kind of medical care someone does or does not want when he or she gets seriously ill. If you want to discuss advance care planning with a person with intellectual and developmental disabilities, there are social stories and other materials to help you (see examples in the supporting materials).

#### What else should you do to be prepared?

- Laminate the Hospital Form or put it in a clear plastic sleeve or zip-top bag together with any other important documentation. Bring the form to the hospital or send it through a secure patient portal.
- Pack a hospital bag now, as you likely won't have time in an emergency. The bag could include: the Hospital Form and other important paper work, personal care items (e.g., toothbrush, comfortable clothes), and some comfort items (e.g., pictures, stuffed animals, a favorite book.) Print out and laminate pictures of the person happy and healthy with loved ones as a comfort item and for staff to understand more about the person. Alternatively, make sure these pictures are loaded onto his or her phone.
- Prepare communication devices. Label all devices with a name and phone number to call if found. Label which chargers go with each device. Indicate on the form if your loved one needs help to use their phone or tablet. Ensure that if passwords are needed, the hospital staff has a way of getting that information.

# Hospital Form for Patients with Intellectual and Developmental Disabilities

| Last |
|------|

Date of Birth:

| Medical  | Important information about my care  |
|--|--|
| I have no known allergies<br>I have allergies (may include food, latex, medications<br>including general anesthetic). List allergies in notes below.<br>I have swallowing difficulties<br>I have a family history of complications with anesthetic | I need someone who knows me well to be with me. I<br>need this to be able to communicate with staff and/or to<br>remain calm and keep everyone safe<br>I have communication support needs (e.g., device, board<br>speech impairment, ESL, deaf/hard of hearing, blind)<br>I need sedation for painful procedures (e.g., swabbing, IN<br>bloodwork) |
| Attachments  |  |
| note/summary from my family doctor   | I may hurt myself if I'm scared or confused or in pain   |
| behavior plan  | I may hurt others if I'm scared or confused or in pain   |
| advance care plan  | I might try to run away if I'm scared or confused or in pa   |
| information about communication tools or device  | I have a hard time staying still   |
| substitute decision-maker documentation  | I have physical care needs (e.g., eating, mobility, bathing  |

Notes:

Name: First

#### HEALTH DECISIONS ARE USUALLY MADE

On my own

With support

By my substitute decision-maker

#### PEOPLE WHO ARE IMPORTANT TO ME AND HOW TO REACH THEM

| Relationship:                        | Name: | Contact details: |
|--------------------------------------|-------|------------------|
| Substitute Decision-Maker 1          |       |                  |
| Substitute Decision-Maker 2          |       |                  |
| Primary Care Provider                |       |                  |
| Close family member/support person 1 |       |                  |
| Close family member/support person 2 |       |                  |

#### **INFORMATION ABOUT MY HEALTH**

| Diagnoses: | Medications: List names, dosages, special considerations (e.g. liquid instead of pills, take medication mixed in food) |  |
|------------|--|--|
|            | Medication list attached   |  |
|            | Pharmacy Name:   |  |
|            | Pharmacy Number:   |  |
|            | Notes:   |  |
|            |  |  |
|            |  |  |
|            |  |  |

#### **MY COMMUNICATION AND SUPPORT NEEDS** I have a device, communication tools or a board that I can use to help us communicate. It should be with me at all times, and if it is not with me, call my substitute decision-maker to ask for it. Normally I communicate by: Speaking Using a picture, letter board or device Speaking, but I don't like speaking to strangers Facial expressions or gestures, I have no other way to Speaking, but I only have a few words that I use communicate, and I may not be able to tell you about pain I need you to: Create a sign to describe my body language for "Yes, No, I don't know" and "I want my communication board" A Place this sign where people can see it Put my communication board where I can point or look at it Give me a way to get your attention If you cannot guess, give me my communication board Get an interpreter: my first language is Always contact my support person to help with communication Help me when I use my smart phone to contact loved ones People I'd like to talk to while I'm hospitalized and what help I need to reach them by video call or phone Name: Phone number: Application (e.g., Facetime, WhatsApp, Skype): Things that you can do to help me understand: Look at me when you speak Let my family/support person explain Speak slowly Use simple language Use pictures Ask me to repeat it back Write it down Put my hearing aid in **Repeat things** Speak louder so I can hear you because I am hard of hearing Use gestures To help me with medical procedures (e.g., needles, x-rays, or bloodwork): Show and tell me what you are doing Hold my hand Let me ask questions Remind and help me count to 10 Use numbing cream for needles Suggest a little something to look forward to after Be quiet so I can concentrate Get me to look away and proceed as quickly as you can Remind me to take deep breaths Play music or sing Tell me how well I am doing Other: If I am... I show it by: You can help me by: Scared/nervous Uncomfortable/overstimulated In pain/hurting

| MY COMMUNICATION AND SUPPORT NEEDS   |  |  |  |  |  |
|--|--|--|--|--|--|
| Sad  |  |  |  |  |  |
| Angry  |  |  |  |  |  |
| Other things I would like you to know to help me while I am in the hospital: |  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |

### **Supporting materials**

- i. The Substitute Decision Maker Hierarchy Speak Up Ontario, Ontario advancecareplanningontario.ca/substitue-decision-makers
- ii. Pain Assessment of Adults with Intellectual and Developmental Disabilities Health Care for Adults with Intellectual and Developmental Disabilities vkc.vumc.org/assets/files/idd/3-8\_Pain\_Assessment.pdf
- iii. Wong Baker FACES Pain Rating Scale Wong-Baker FACES Foundation, Oklahoma City, USA (Choose download for personal use) wongbakerfaces.org/

## Copyright

This document complements "Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines", published in Canadian Family Physician, Volume 64(4): April 2018, p254-279.

Originally published as: My Hospital Form for Patients with Intellectual and Developmental Disabilities. Lunsky Y. & Niel U., with the Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023

Modified with permission of the copyright owner, Surrey Place, Toronto, Canada. This tool was reviewed and adapted for U.S. use by Vanderbilt Kennedy Center, Toolkit Advisory Committee, including primary care providers, self-advocates, and family caregivers.

All rights reserved. The content of this tool may not be reproduced or stored in a retrieval system, or transmitted in any form or by any means without the prior written permission of the copyright owner. All content © Surrey Place, 2023. Contact the IDD Toolkit at <u>iddtoolkit@vumc.org</u> for permission to adapt information and tools to your local practice setting.