

My Hospital Form for Patients with Intellectual and Developmental Disabilities

Tips for caregivers

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 hospital.

When should you fill in this form?

In an emergency you will not have time to gather information. Fill in My Hospital Form together in advance of the person with an intellectual or developmental disability 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 apple sauce).

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. If you are unsure how to determine who is legally allowed to make decisions it is important to [read about this subject now](#). 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 care partners 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).

Use your judgement and relationship with the person with an intellectual or developmental disability to determine what conversations will be helpful in coping emotionally with being ill and preparing for potential hospitalization.

What else should you do to be prepared?

Laminate My Hospital Form or put it in a clear plastic sleeve or zip lock bag together with any other important documentation. If the hospital will not accept paper forms, ask if you can email the form to a staff member.

Pack a hospital bag now, as you likely won't have time in an emergency. The bag could include: the laminated Hospital Form and other important paper work, health card, personal care items (e.g., toothbrush, comfortable clothes), comfort items (e.g., pictures, stuffed animals, a favourite book, Ipad/device loaded with music, shows, movies), phone and phone charger or other communication devices. 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 or electronic device.

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 electronic device. Consider if passwords will need to be removed or labelled onto the phone if you want staff to be able to access the device.

My Hospital Form

For Patients with Intellectual and Developmental Disabilities

Name:		DOB:
First	Last	

ALERTS (write detailed notes in the box below):

Medical I have allergies (may include food, latex, medications including general anesthetic) I have swallowing difficulties I have a family history of complications with anesthetic	Important information about my care I need someone who knows me well to be with me. I need this to be able to communicate with staff and/or to remain calm and keep everyone safe I have communication support needs (e.g., device, board, speech impairment, ESL, deaf/hard of hearing, blind) I need sedation for painful procedures (e.g., swabbing, IV, bloodwork) I may hurt myself if scared or confused I may hurt others if scared or confused I might try to run away if I am scared or confused I have a hard time staying still I have physical care needs (e.g., eating, mobility, bathing)
Attachments note/summary from my family doctor behavior plan advance care plan information about communication tools or device substitute decision-maker documentation	
Notes:	

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		
Primary Care Provider (family doctor & NP)		

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	Speaking, but I only have a few words that I use	Facial expression, I have no other way to communicate, and I may not be able to tell you about pain
Speaking, but I don't like speaking to strangers	Using a picture, letter board or device	

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 signals" ▲ 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	Write it down	Let my caregiver or staff explain	Put my hearing aid in
Speak slowly	Repeat things	Use simple language	Speak louder so I can hear you because I am hard of hearing
Use pictures	Use gestures	Ask me to repeat it back	

To help me with medical procedures (e.g., needles, x-rays, or bloodwork):

Show and tell me what you are doing	Tell me how well I am doing	Get me to look away and proceed as quickly as you can
Let me ask questions	Hold my hand	Play music or sing
Use numbing cream for needles	Remind and help me count to ten	Other:
Be quiet so I can concentrate	Suggest a little something to look forward to after	
Remind me to take deep breaths		

If I am...	I show it by:	You can help me by:
Scared/nervous		
Uncomfortable/overstimulated		
In pain/hurting		
Sad		
Angry		

Other things I would like you to know to help me while I am in the hospital:

Supporting materials

- i. **Substitute Decision-Making**
Advance Care Planning Ontario, Ontario
<https://www.advancecareplanningontario.ca/substitutue-decision-makers>
- ii. **Pain Assessment of Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019
<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.8-Pain-Assessment.pdf>
- iii. **Wong Baker FACES Pain Rating Scale**
Wong-Baker FACES Foundation, Oklahoma City, USA (Choose download for personal use)
<https://wongbakerfaces.org/>
- iv. **Jack Plans Ahead For Coronavirus: A Guide for Family and Carers**
Beyond Words, United Kingdom
<https://booksbeyondwords.co.uk/coping-with-coronavirus>
- v. **Social Story: Going to Hospital With COVID-19**
Surrey Place, Toronto
<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2020/05/Social-Story-Going-to-the-hospital-with-COVID19.pdf>
- vi. **Advance Care Plan: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023 <https://ddprimarycare.surreyplace.ca/tools-2/general-health/advance-care-planning/>

Copyright and Disclaimer

This document is developed by the Developmental Disabilities Primary Care Program (DDPCP) at Surrey Place, Toronto. The DDPCP supports family physicians and other caregivers of to optimize the health and healthcare of adults with intellectual and developmental disabilities. This publication was made possible through support from the Ontario Ministry of Health and the Ontario Ministry of Children, Community and Social Services.

The content of this tool was subject to review by primary care providers and other relevant stakeholders. Special acknowledgement to Dr. Yona Lunskey, Director of the Azrieli Adult Neurodevelopmental Centre, and Senior Scientist at

the Centre for Addiction and Mental Health, Toronto, and Dr. Ullanda Niel, family physician with special training in the care of adults with developmental disabilities from Queen's University.

All rights reserved. The content of this tool may not be reproduced or stored in a retrieval system in any form or by any means without the prior written permission of the copyright owner, Surrey Place. Permission to use, copy, and distribute the tool is granted with proper citation as outlined below. Contact ddpcp@surreyplace.ca for permission to adapt this tool to your local practice setting.

This tool is developed as a guide only. While great effort has been taken to assure the accuracy of the information provided, Surrey Place, the Developmental Disabilities Primary Care Program, the reviewers, printer and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

Cite this tool as

PLEASE USE THE BELOW CITATION WHEN REFERENCING

THIS TOOL: *My Hospital Form for Patients with Intellectual and Developmental Disabilities*. Lunskey Y. & Niel U., with the Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023