

COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities

Tips for family members

As a family member of someone with an intellectual or developmental disability you might worry about your loved one falling ill with COVID-19 and having to go to the hospital. You might not be able to accompany them to the hospital and visitation may be restricted. The Hospital Transfer Form lets hospital staff know how to best accommodate your loved one'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 the Hospital Transfer Form together in advance of your loved one 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 your loved one normally communicates** and understands information. Staff will not know how your loved one communicates when healthy. Be aware that COVID-19 causes breathing difficulties which may make speaking difficult. Consider printing and providing a communication tool or board for staff to use, for example for measuring pain (see supporting materials).

Provide **important contact information**. Your loved one will likely 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 your loved one cannot. If you are unsure how to determine who is legally allowed to make decisions (in Ontario) it is important to [read about this subject now](#). Explain if your loved one 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. Some hospitals may allow visitors for this purpose, and others may not allow this.

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 your loved one does or does not want when he or she gets seriously ill with coronavirus. If you want to discuss advance care planning with your loved one, there are social stories and other materials to help you (see supporting materials).

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

What else should you do to be prepared?

Laminate the Hospital Transfer 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 for the person you care for now, as you likely won't have time in an emergency. The bag could include: the laminated Hospital Transfer 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.

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

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Name:

First

Last

DOB:

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

Attachments

note/summary from my family doctor
behavior plan
advance care plan
information about communication tools or device
substitute decision maker documentation

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 when 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)

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 if I cannot speak. 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 expressions, 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"	If you cannot guess, give me my communication board
▲ Place this sign where people can see it	Get an interpreter: my first language is
Put my communication board where I can point or look at it	Always contact my support person to help with communication
Give me a way to get your attention	Help me when I use my smart phone to contact loved ones

People I'd like to talk to while I'm an inpatient 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. **The Substitute Decision Maker Hierarchy**
Speak Up Ontario, Ontario
<https://www.speakupontario.ca/resource/the-substitute-decision-maker-hierarchy/>
- ii. **Supporting Communication with Patients who have COVID-19**
The Patient Provider Communication Forum,
<https://www.patientprovidercommunication.org/supporting-communication-covid-19.htm>
- iii. **Pain Assessment of Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program, Surrey Place, Toronto
<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.8-Pain-Assessment.pdf>
- iv. **Wong Baker FACES Pain Rating Scale**
Wong-Baker FACES Foundation, Oklahoma City, USA (Choose download for personal use)
<https://wongbakerfaces.org/>
- v. **Jack Plans Ahead For Coronavirus: A Guide for Family and Carers**
Beyond Words, United Kingdom
<https://booksbeyondwords.co.uk/coping-with-coronavirus>
- vi. **Social Story: Going to Hospital With COVID-19**
Surrey Place, Toronto [insert link]

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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.

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