



# COVID-19 Advocacy Toolkit

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## **Advocating for Your Support Person, Attendant or Communication Assistant to be with You in Hospital During the COVID-19 Pandemic**

**May 5, 2020**

***Disponible en français***

***Available in plain language***

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**This Advocacy Toolkit provides legal information and advocacy tips to people with disabilities who need their support person, attendant or communication assistant to be with them in hospital during the COVID-19 pandemic.**

**This Toolkit contains information about laws and policies in Ontario. This legal information may not apply to you if you live outside of Ontario.**

*DISCLAIMER: The information provided in these materials is not intended to be legal advice. Consult a lawyer or legal worker if you need legal advice on a specific matter. This information is current as of June 18, 2020.*

Please note that the information in this Toolkit does not apply to all situations. A person's accommodation needs may vary over time and at different points in the day. Always ask the person with the disability how to most appropriately accommodate them.

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## PEOPLE WITH DISABILITIES HAVE A RIGHT TO ACCESSIBLE HEALTH CARE

As a person with a disability, you have a right to equal access to health care. In Ontario, a law called the *Human Rights Code* says that health care providers, including hospitals, must offer their services in a way that is accessible to people with disabilities.

Each person with a disability will need different accommodations to make hospital services accessible to them. Some people need to have a support person, attendant or communication assistant with them when they go to hospital. Support persons could be paid supports like personal support workers, or chosen supports like close family members or friends. Support persons, attendants and communication assistants provide essential accommodations, and without them some people with disabilities cannot communicate effectively, make informed decisions about health care treatment, or get access to hospital services.

One example is a person who communicates using a communication device or who needs someone who knows them well to interpret their unique form of communication. Without their support person or communication assistant, this person may have no access to effective communication in the hospital and will not be able to tell hospital staff when they are in pain, what their needs are, or consent or refuse treatment. Another example is a person who needs their support person to help keep them feel calm, reassured and able to undergo medical procedures.

During the COVID-19 pandemic, many hospitals have visitation bans. These bans are important safety measures to limit the spread of COVID-19. But, because of these bans, some hospitals are not allowing support persons, attendants and communication assistants to be with people with disabilities in hospital. In this way, visitation bans prevent some people with disabilities from getting equal access to health care.

Ontario law says that people with disabilities have a right to accessible health care services, unless it would cause undue hardship. If a disability

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accommodation creates a real risk to health and safety, then the hospital may not be able to provide that accommodation. In that situation, the hospital would need to offer an alternate accommodation that meets the person's disability-related needs as much as possible. Some Ontario hospitals have made exceptions to visitation bans to accommodate a disability in a safe manner that did not cause undue hardship.

If a person with a disability requires a support person, attendant or communication assistant present with them during their hospitalization, in order to support their health care and/or assist them with essential communication, this should be allowed provided that health and safety precautions can be taken to limit the spread of COVID-19.

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## ADVOCACY TIPS

If you are a person with a disability who requires a support person, attendant or communication assistant with you when you go to the hospital, here are some things you can do. You may need to ask for help or support to get some of these things done.

**If possible, get prepared. Before going to hospital or as soon as you can:**

- **Get a letter from your family doctor or specialist.** The letter should say what disabilities you have, what accommodations you need while you are in hospital, and why these accommodations are absolutely necessary.
- **Write your own letter or record your own video.** Explain that you have disabilities and you need your support person, attendant or communication assistant with you to accommodate your disabilities. Explain that your support person, attendant or communication assistant is not a visitor. Explain what they will do to help you get health care services from the hospital, or why you will not be able to get health care services without them. Explain why you absolutely need them to be with you in hospital.
- **If possible, make a few copies** of the letter from your doctor and your own letter or video. If you can, get them laminated or put them into a plastic sleeve or another covering. If you have a smart phone or tablet, you could also save the letters there. You may want to give a copy to your support person, attendant or communication assistant.
- If you need **supports to make decisions about your health care**, it is a good idea to write a letter or record a video explaining what supports you need. If you are not able to make your own health care decisions in the hospital, even with the supports you need, then Ontario law says that another person will make those decisions for

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you. This other person could be a family member, your Power of Attorney for Personal Care or a Guardian of the Person. In most cases, hospital administrators are not allowed to make these decisions.

- Many organizations have developed forms to give information about a person’s support needs to hospitals. You can fill out the form. Or you can look at the form and decide which things in it are important and relevant for you. You can use the form to help you write your own letter or make your own video. Here are some examples of forms:
  - “Communication Passport” developed by Communication Disabilities Access Canada: <https://www.cdacanada.com/wp-content/uploads/2020/03/COVID-Communication-Toolkit-1.pdf>
  - “COVID-10 Hospital Transfer Form” developed by Surrey Place and the Centre for Addiction and Mental Health for caregivers of people with intellectual and developmental disabilities: <https://ddprimarycare.surreyplace.ca/>
- **Pack a small emergency bag** with things that you might need while you are in hospital. Leave the bag near your front door. Make sure the letters and/or video are inside. You could also include a list of important contact information you might need.

### **Before you go to hospital – if you have an appointment or know you are going to hospital:**

- **Find out what the hospital’s visitor policy says.** In Ontario, each hospital has its own visitor policy. Check the hospital’s website or call the hospital. Many hospitals have visitation bans to limit the spread of COVID-19. But at most hospitals, there are exceptions which allow the hospital to let essential visitors in. On June 15, 2020 Ontario's Chief

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Medical Officer of Health recommended that hospitals allow visitors: <https://twitter.com/celliottability/status/1272888722372079619/photo/1>. If the hospital you are going to still has a visitation ban, ask if the hospital plans to follow the Chief Medical Officer's recommendations and allow visitors.

- **Have a conversation with your support person, attendant or communication assistant.** Ask if they are willing to take safety steps that the hospital may require. For example, if the hospital lets them in, they will need to be screened for COVID-19, they may need to wear a mask, gloves or other safety equipment, and they may need to stay in hospital for the whole time you are there.
- **Call ahead and let the hospital know that you are coming and you need your support person, attendant or communication assistant to be with you.** If the hospital you are going to still has a visitation ban ask for an exemption to the visitation ban. If you can, offer to email the letter from your doctor and the letter or video you created. You can call the hospital department you are going to. You could also consider calling the hospital's accessibility coordinator, patient relations coordinator, patient ombudsman, and/or patient advocate. Remind them that the hospital's visitation ban does not follow the most recent recommendations from the Chief Medical Officer of Health.

### **When you get to hospital:**

- **If the hospital you are going to still has a visitation ban ask for an exemption to the visitation ban.** Tell the hospital staff that you need your support person, attendant or communication assistant to be with you. Show them the letter from your doctor and the letter or video you created. Explain that your support person, attendant or communication assistant is not a visitor, they are an essential accommodation for your disability. Remind them that the hospital's visitation ban does not

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follow the June 15 recommendations from the Chief Medical Officer of Health.

- If the hospital staff refuse, ask to speak with the nurse or doctor who is in charge of the department or floor you are on.
- If the answer is still no, ask to speak with the hospital's accessibility coordinator, patient relations coordinator, patient ombudsman, and/or patient advocate.
- You could also contact your local MPP and ask if they would contact the hospital administration on your behalf. To find contact information for your MPP go to: <https://www.ola.org/en/members/current>
- If you are a person with a disability living in Ontario and you need legal advice, you can call ARCH for free, confidential legal advice.

Telephone: 416-482-8255

Tel. Toll-free: 1-866-482-2724

<https://archdisabilitylaw.ca/services/legal-services/>

- You could consider making a complaint to the provincial Patient Ombudsman. More information about the Patient Ombudsman is available at: <https://patientombudsman.ca/>

### **While you are in hospital:**

- **Keep the letter from your doctor and the letter or video you created close by.** If the hospital changes its visitation ban rules or if you get moved from one department or floor to another, you may need to advocate again to have your support person, attendant or communication assistant go with you.



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- If the hospital allows your support person, attendant or communication assistant to be with you, **ask the hospital to give you a letter** confirming that they have given you an exemption to their visitation ban.