



AT A GLANCE:

UNDERSTANDING HEALTH PRIVACY AND CONSENT IN ONTARIO: A GUIDE FOR CAREGIVERS

This resource provides an overview of health privacy rules in Ontario as they relate to caregivers, so caregivers have the information they need to work together with providers to support patients and work together as partners in care. Read [Understanding health privacy and consent in Ontario: a guide for caregivers and care providers](#) for more in depth information.

Having information about the patient's care and recovery can be an important part of the caregiving role, yet Ontario's health privacy laws and rules can make it difficult for both healthcare providers and caregivers to understand how they can communicate effectively while ensuring patient privacy. When the legal aspects of health privacy are misunderstood – or even feared – it can result in poor communication and get in the way of caregivers supporting patient needs.

As a caregiver, what do you need to know to about privacy and consent?

With some limitations, patients have the right to: choose how their information is collected, used and disclosed by their provider and choose with whom they want their health information shared.

In law, providers presume all patients are capable of making their own decisions unless that presumption is unreasonable. Most adults make their own decisions. Babies, very young children, and unconscious people never do. To be considered capable, a patient must have:

- the ability to understand the information that is relevant to the decision to collect, use or disclose their health information, and
- the ability to appreciate the reasonably foreseeable consequences of their choices about the collection, use or disclosure of their health information.

Examples of situations where providers would assess capacity include maturing children (such as ages 10-16) or patients with a condition or diagnosis where there is often mental or developmental impairment like dementia, or a brain injury.

If a patient is incapable of making their own decisions, the patient must have a substitute decision-maker for all health decisions. Substitute decision-makers are caregivers who have the same rights to information and rights to make choices as patients.

How can you, as a caregiver, help navigate privacy and consent issues?

- With patient consent, or if you are the substitute decision maker, providers can share information with you and you can provide information to providers.
- You can prompt the patient to tell the provider they want you to be involved either out loud or in a letter you can carry with you. You can ask the provider to document the patient's consent in the health record and make sure that the provider's staff is aware of the documented consent.
- It's okay for you to remind providers that they are permitted to share certain information with you based on the consent the patient has given.
- Even without consent, providers can listen to you and collect health information about the patient from you if the information that you are offering is more timely, complete, or accurate than the patient can provide, although providers are not required to do so.
- You can also offer a different perspective or share additional information with providers by saying: "I have a different perspective" or "I have more information that could explain that" or "Could you involve me because the patient forgets?"

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DISCLAIMER

This resource document is meant to provide general information to family caregivers and care providers on the privacy and health care consent requirements in Ontario. This resource is not intended to provide a comprehensive description of the privacy and consent legislation, nor to serve as a decision tool, or as legal or clinical guidance. For advice on particular situations—especially those that are complex—caregivers and providers should consult with privacy staff in local health or community care organizations or seek their own legal advice.