



FAQS: ON PRIVACY AND CONSENT FOR CAREGIVERS SUPPORTING SOMEONE CAPABLE OF MAKING THEIR OWN DECISIONS

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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.

Please refer to [Understanding Health Privacy and Consent in Ontario: A Guide for Caregivers and Care Providers](#) for information on privacy law in Ontario, consent, capacity, and substitute decision-making, and how caregivers and providers can support patients within the framework of privacy law.

We also offer three other FAQ resources:

[FAQs on Privacy and Consent for Caregivers of Children and Youth](#)

[FAQs on Privacy and Consent for Caregivers Supporting Someone Incapable of Making Their Own Decisions](#)

[FAQs on Privacy and Consent for Caregivers Supporting Someone in the Mental Health and Addiction System](#)

These FAQs address common questions of caregivers of patients who are “capable” under the law (that is, able to make their own privacy and health care decisions).

This includes caregivers supporting: a person before and after surgery; mature children; patients with mild to moderate mental health conditions or addiction issues; or a neighbour by taking them to their health care appointments.

If a patient is capable, the patient makes their own health care and privacy decisions. A capable patient chooses with whom to share their health information – they can invite caregivers to discuss their health care options, provide copies of their health records and other information, and ask for input – but a capable patient ultimately makes their own decisions and may choose not to include caregivers.

Q: As a caregiver, how should I introduce myself to new providers?

Tell the provider your relationship to the patient and provide context on how you are involved in the patient’s care (i.e. friend, family member, language support, day-to-day care delivery, decision making support). Being specific may help the provider understand why it is important for you to be involved.

Q: My mother says that she wants me involved in her care, but her providers keep shutting me out. What can I do to ensure I am included in conversations with her care team?

You can prompt your mother to tell the providers that she wants you to be involved. She can ask that they note this in her health record so that other providers will know. While providers should ask patients with whom they want their information shared, sometimes providers forget to do so. Having your name on file makes it easier to be included in updates. Your mother can also prepare a letter that you can carry with you that confirms her consent for information to be shared with you and the role that she would like you to have.

Q: Does the patient need to provide verbal consent for every new provider or administrative staff interaction?

Practically speaking, yes. Each provider keeps their own records. That can mean the patient has to restate your role as legitimate caregiver to every new provider and their administrative staff.

Q: I’m POA, so why won’t the providers share information with me automatically?

A power of attorney for personal care only comes into play when a patient becomes incapable. As long as the patient is capable a POA document has no validity and you are not entitled to make decisions or receive information. The patient decides how they want to involve you in making decisions and sharing information.

Q: Why does the mental health sector shut me out when I know my daughter wants me to be involved, at least at times.

The providers may not know whether your daughter wants her information shared with you and they don’t want to make a privacy mistake. They may be trying to establish trust with her and are slowly involving others. Or she may have said she doesn’t want family involved. You should prompt the provider to ask your daughter if she wants you involved and if she said no the first time, to ask her again after a few days or weeks. You can tell them you have important information they may need about her behaviour, words, actions, physical health or mental health history. The provider will then decide if they have the authority to collect that information from you.

[Please also read our companion resource: FAQs on Privacy and Consent for Caregivers Supporting Someone in the Mental Health and Addictions System](#)

Q: What can I do if the patient tells the provider not to tell me things, but I am the one who has to take care of the patient?

Talk to the patient about your basic information needs – that you don’t necessarily need to know every detail of their health information, but that there are some things that you need to know in order to

support them. If the patient understands which information you need, and why it may be helpful, they may reconsider their decision not to share. If they continue to refuse, you should try to speak with the provider to explain the impact on you and ask for their support in approaching the patient to give you at least some information. There may be little that can be done to change this difficult situation.

Q: For whatever reason, the patient is not being truthful with the provider (overstating or understating reality) – can I correct the record?

Generally, providers do not collect or document health information unless it comes directly from the patient or another provider. However, providers can listen to caregivers and collect health information from them if the information that the caregiver is offering is more timely, complete, or accurate than the patient can provide. If you can offer a different perspective or share additional information, you should say so. However, if the provider collects information from you as a caregiver, the patient has the right to ask the provider not to use that information (subject to some limits).

Q: Can friends or neighbours be given health information and updates?

Yes, if the patient consents to the sharing of their information.

Q: Should caregivers act as translators?

Providers should offer professional translation services, but in practice they are not always available. Caregivers can support patients who do not share a language with the provider by translating. This must be done only with the patient's consent.

Q: Can patients get their information online? What technology is available to patients to access their own information?

Some providers have patient portals where patients can have easy online access to their own health information. An example of this is lab results. Ontario Health is developing a provincial electronic health record that will eventually give patients online access to information – but that is not yet widely available.