



FAQS: ON PRIVACY AND CONSENT FOR CAREGIVERS SUPPORTING SOMEONE INCAPABLE 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 Supporting Someone Capable of Making Their Own Decisions](#)

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

[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 “incapable” under the law (that is, who are unable to make their own privacy and health care decisions).

This includes caregivers supporting: unconscious patients; patients with advanced dementia or cognitive impairment; patients with significant developmental disabilities or intellectual limitations; patients with severe mental health conditions or addiction issues where they are no longer able to make their own decisions; and patients with severe brain injuries. Babies and young children are also incapable to make

their own decisions but their scenarios are covered in the [FAQs on Privacy and Consent for Caregivers of Children and Youth](#).

If a patient is incapable, the provider must turn to the patient's substitute decision-maker (SDM) to make decisions for them. A SDM has the legal responsibility to make decisions for the patient and receive health information relating to those decisions. If the caregiver is not the SDM, the SDM may consent to the provider sharing information with other caregivers and may choose not to include other caregivers.

Q: Is the caregiver always appointed substitute decision-maker (“SDM”)?

No. The caregiver may or may not be the SDM; it depends on whether they are the highest-ranked person on the list of SDMs under section 20 of the *Health Care Consent Act* or section 23 of the *Personal Health Information Protection Act*. In addition to establishing that prospective SDMs meet the minimum age requirement of 16 years, providers will verify the willingness, availability and legal capacity of individuals to make treatment decisions for the incapable patient; and also ensure that the person is not stopped from acting because of a court order or separation agreement. Should a candidate be found not to meet one or more criteria to be a SDM, the provider will bypass that person and move on to the next highest-ranked candidate(s) on the list.

Q: How does a caregiver get a POA?

Choosing an attorney for personal care is a decision only capable patients can make and the patient has to complete legal forms to do this. If a patient is incapable, they cannot give a POA.

Q: What if I am not the SDM – but I want to be?

If you are a caregiver and not the SDM, you can ask the Consent and Capacity Board to appoint you as the personal representative of the patient, which will mean that you outrank others as SDM (only a court-appointed guardian or attorney for personal care (POA) would outrank you).

Q: What happens if the SDM lives outside the country? Can a local caregiver make decisions?

Geographic location does not change the SDM rankings, though it may affect SDM availability and willingness to make decisions. A SDM is “available” if it is possible, within a time that is reasonable in the circumstances, to reach them and obtain a decision. A local caregiver cannot make decisions if a SDM lives far away and is unavailable, unless the caregiver is the next person qualified to be SDM.

Q: What happens if there are multiple SDMs (such as 3 children of an elderly patient), but ultimately one SDM is more involved and makes decisions for the patient? Can decisions be made by the one SDM?

It depends. Often when there are multiple, equally-ranked SDMs, one person will take the lead. Providers need to be clear who is authorized to make the decisions and must record if one or more SDM is unavailable or has deferred to another SDM.

Q: What happens if there are multiple SDMs and they disagree? Do they have the same rights?

Yes, multiple, equally-ranked SDMs have the same rights. If they disagree, providers will advise equally-ranked SDMs that they must work together and come to consensus.

If that appears impossible, the provider should tell the SDMs that the Office of the Public Guardian and Trustee will be asked to make the decision. This sometimes breaks the deadlock.

If the SDMs still remain deadlocked, the provider may go to the Office of the Public Guardian and Trustee.

Q: What happens if a SDM does not want another caregiver to receive information? Can my brother keep me from finding out what's happening to my mother?

If your brother (alone) has been granted POA for personal care for your mother then he can prevent you from finding out what is happening to your mother. But if you are both equally ranked SDMs, he cannot keep you from finding out what is happening.

Q: Can family caregivers who are not the SDM know the patient's information?

Yes, with the consent of the SDM. In an ideal world, providers should prompt SDMs to identify additional caregivers and then include those caregivers in discussions and planning meetings and invite those caregivers to share their perspectives and insights.

If that does not happen, it is appropriate for the SDM or the additional caregiver to tell the provider they want the caregiver to be involved.

Q: My father is my mother's SDM, but I'm the one who takes her to appointments. Can I get documentation from my father that I am allowed to receive information?

Yes, you can get documentation from your father as SDM confirming that you can receive information.

Q: I am a caregiver and I don't think that the SDM is making good decisions. What can I do?

First, talk to the SDM. Next, you can discuss your concerns with the provider. You may also wish to look into a process to become appointed by the Consent and Capacity Board as a representative, or to bring a complaint to that Board that the SDM is not acting in the best interests of the patient.

Q: What can a provider do if the SDM seems not to be acting in the patient's best interests (e.g., not returning calls from the provider and related organizations, and not being available to the provider to provide patient care decisions)?

If the SDM is not "willing" or "available" (in addition to the other criteria described above) to act in the role, the provider is entitled to move on to the next highest-ranked person in the ranking. However, it is recommended that the SDM be reminded of their duties so they have an opportunity to fulfill them.

If the SDM seems not to be acting in the patient's best interests, the provider should try to understand what is driving their behaviour. For example, is the SDM capable to make the decisions, according to the legal test (i.e. has the ability to both understand the information being provided and the ability to appreciate the reasonably foreseeable consequences of saying 'Yes' or 'No' to what is proposed)? Or, is the SDM capable but not acting in accordance with the principles for SDM, including making decisions based on their own wishes rather than the prior capable wishes of the patient?

If the SDM appears incapable of making decisions that are in the patient's best interests, the provider can apply to the Consent and Capacity Board, and ask for a ruling.

Q: My mother's providers keep saying that she is capable to make her own decisions but I disagree and think she is incapable. What should I do?

You should discuss your concerns with the provider. You may have new information that would change the provider's assessment. You may wish to seek a second opinion with an independent capacity assessment.

Q: My mother's provider said that she needed a SDM so I stepped in to make decisions. She is doing much better and the provider says that she is capable to make her own decisions now. Can I still access my mother's information to help support her?

Once your mother is capable, she chooses who accesses her information. You should talk to her about telling her care providers to keep you updated and that she wants you to have access to her information.

Q: What happens if the SDM does not speak English? Can another caregiver translate?

Providers should offer professional translation services, but realistically they are not always available. Another caregiver may be asked to provide translation support for the SDM who does not share a language with the provider.

Q: As SDM, it's frustrating that I don't have online access to the patient's information. I am left having to get copies of all the information and bring it with me to their appointments. Is there an online alternative where a patient's information is stored electronically?

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