



# FAQS: ON PRIVACY AND CONSENT FOR CAREGIVERS SUPPORTING SOMEONE IN THE MENTAL HEALTH AND ADDICTION SYSTEM

## ACKNOWLEDGEMENTS

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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.

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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 Supporting Someone Incapable of Making Their Own Decisions](#)

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

These FAQs address common questions of caregivers who are supporting clients receiving services from mental health and addictions services.

In law, providers must identify and label patients as “capable” or “incapable” of making their own decisions. These terms are not natural to caregivers and may not reflect a caregiver’s views of a patient. A caregiver may question a patient’s ability to make good choices for themselves. But, the law has a specific test that providers must follow that acknowledges patients may make good or bad choices for themselves as long as they have enough intellectual, maturity and developmental abilities.

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.

If a patient is incapable, the provider must turn to the patient’s substitute decision-maker 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: How can health providers help a family member who is having difficulty locating a patient?**

Under PHIPA, as long as certain conditions are met, Ontario hospitals and long- term care homes can:

- Confirm whether or not the patient is at the facility
- Name the ward where the patient is receiving care
- Disclose the general health status of the patient

Healthcare providers may also be able to deliver a message to the patient from the inquiring family member or caregiver. Providers can disclose the above basic information about the patient or resident to caregivers, provided that the hospital or home has informed the patient or resident that this will occur (by posting a public notice or getting express consent) and the patient or resident has not objected. Providers will deliver messages to patients/residents from inquiring family members and provide further information only if the patient consents.

Caregivers need to know that a hospital or long-term care home is able to provide only this basic information unless the patient or resident consents to sharing further details.

Caregivers can request that healthcare staff deliver a message to the patient; however, if a patient has told the hospital or long-term care home not to share information with family or others, staff must be very careful not to confirm the patient’s presence, since that is in itself personal health information.

**Q: Is there an expiry on patient consent to collect personal health information from a caregiver?**

No. If there is patient consent for the collection of information from a caregiver, or the health provider has identified the legal authority to collect patient information from a caregiver, the information can be collected at any time by the health provider.

With patient consent or legal cause, health providers may collect patient information from a caregiver at any time (it must be reasonable to rely on the patient consent given; if there is reason to think the consent is no longer valid, it should not be relied on).

Caregivers need to know that in most cases, health providers require patient consent to collect information from the family, unless there is other legal authority to do so.

**Q: Is there an expiry on patient consent to share or disclose patient information with a caregiver?**

There is no expiry on patient consent to share or disclose patient information with a caregiver.

Health providers are entitled to rely on a given consent to share patient information; there is typically no expiry. When patient consent is withheld, health professionals can, and should, revisit the decision with the patient from time to time or when contact with a caregiver would be beneficial.

Caregivers need to know that health professionals are not required to discuss the details of patient consent (or lack of consent) with the family. A health professional may simply tell a caregiver, “I do not have consent to share this information with you, but of course you can discuss this with the patient.”

**Q: At what age can a child make their own decisions about treatment and information sharing?**

A child of any age who passes the legal test for capacity can make decisions about their own treatment and information sharing. For children under age 16, PHIPA says that the child or the parent can make decisions, whereas children aged 16 and up can make decisions independent of a parent. If a child is capable and the parents do not agree with their wish, the child’s wish prevails.

However, under PHIPA there is an exception to a parent’s ability to make information decisions for children under 16; if a child under the age of 16 has previously consented to treatment under the Health Care Consent Act (or to counseling under the Child, Youth and Family Services Act, 2017) only the child (and not the parent) can make any related information decisions.

Healthcare providers will give the patient choice preference over the family caregiver whenever possible.

Caregivers need to understand that the wishes of their child may supersede their own preference, even if the child is a ‘minor.’

For additional information please see [FAQs on Privacy and Consent for Caregivers of Children and Youth.](#)

**Q: What are some strategies to use when a capable patient instructs the healthcare provider to stop providing patient information to the caregiver?**

While health providers respect the patient’s right to determine consent, they may benefit from discussing what has changed with the patient. For example, “I understand that you want to stop sharing all information with your caregiver. Since we have already been sharing information about your medical appointments and involving your caregiver in discharge planning, let’s walk through this together. Is there any information that you would allow us to share in order to support your care?”

When patients want to stop information sharing, health professionals need to know that a nuanced conversation about patient consent may lead to a middle ground that is beneficial to the patient.

When the patient stops sharing information, caregivers may be able to engage the patient in a discussion about basic information needs. If a patient understands which information you are proposing they share, and why it may be helpful to do so, they may reconsider the decision not to share.

**Q: What is a lock box?**

A lock box is an informal term used to describe when a patient has instructed a health information custodian (such as a hospital) not to share their personal health information with specified health professionals. A lock box is an express instruction from a patient to limit or shield some or all personal health information from select health care professionals or organizations (for example, ‘Do not share my information with Dr. X’; or ‘Do not share it with my family doctor when I leave hospital’).

Healthcare providers should refer to their organization’s policies and procedures for lock box documentation.

Family caregivers need to understand that the patient has the authority to prevent their health records from being shared for health care purposes, including to those involved in their care within an organization or externally. This is true even when it would be beneficial for these health professionals to have this information.

**Q: When a patient has withheld or withdrawn consent, what information can health providers discuss with family caregivers?**

Unless the patient or resident says otherwise, under PHIPA, Ontario hospitals and long-term care homes are able to:

- Confirm to a family caregiver whether or not the patient is at the facility
- Name the ward or unit where the patient is receiving care
- Disclose the general health status of the patient

In cases where consent is denied by a capable patient or resident, health professionals can lead caregivers to appropriate reading material and community resources, such as family support groups.

If the caregiver is known to the health system and has baseline knowledge of the patient or resident’s health, the health professional can speak with the family caregiver in general terms, without discussing any specifics of the patient case. For example, “when there is a history of bipolar disorder, families often find it helpful to identify the early warning signs of major mood swings so that early intervention is an option”.

In the absence of patient consent to share information, health professionals need to know that they can speak with the family caregiver and offer general information that may be helpful.

Caregivers need to know that health professionals cannot discuss particulars about specific patients when consent is not given but may be able to provide helpful generalized information.

**Q: What is the obligation of the health professional to disclose a patient’s personal health information in a case where there is a significant risk of serious bodily harm to a person or group of persons?**

PHIPA section 40(1) states: “A health information custodian may disclose personal health information about an individual if the custodian believes on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons.”

The decision to disclose patient information in this case rests with the health professional as a discretion (not a duty). The disclosure can be to any person (e.g., to police or to an intended victim).

Health professionals should never feel restricted by privacy law when a patient poses a significant risk of serious bodily harm to self or someone else. It will be important to document the reasons that led to the disclosure.

Caregivers need to know that health professionals have the right (rather than the obligation) to disclose patient information in cases where there is a significant risk that serious bodily harm will otherwise result. A caregiver may be able to remind the health professional of this discretion, and urge that it be exercised.

**Q: When the caregiver contacts a health professional by phone, letter or email to share information about the patient, what is the health professional's responsibility to document the contact/ information?**

Within the construct of patient consent and confidentiality, health professionals do not generally collect and document patient health information unless it comes directly from the patient, their substitute decision-maker, or other health care provider.

Health professionals need to identify a legally-supported reason to collect patient information other than from a patient, such as access to accurate or timely information (which could include a risk situation).

Caregivers need to know that health professionals are generally required to collect health information from the patient (not the caregiver) but can also collect from a third party if they cannot get the information in a timely or accurate way from the patient. If the health professional collects information from someone other than the patient, the patient can later instruct the health professional not to use the information.

**Q: If a patient on a Form 1 under the Mental Health Act is acutely psychotic, difficult to control, and posing a threat to self or others, can a health professional administer medication even if they have not obtained patient consent?**

Yes, but not for the purpose of treatment. For treatment, a capable patient, or the substitute decision-maker of an incapable patient, must provide consent. Medication though can be administered as a chemical restraint to control the situation in the moment. Once the risk to the patient or others subsides, the patient can no longer be held in a chemically restrained state.

Health professionals may chemically restrain a patient when there is a danger to that person or others, within limits and for a limited time until the risk passes. This is true even if the drug used to restrain is the same medication that the patient refused as a treatment.

Health professionals are encouraged to speak with the caregiver and explain the difference between chemical restraint and active treatment.

Caregivers need to understand that patient consent is not required to administer medication to patients (including on a Form 1) for the purpose of the chemical restraint. Caregivers are reminded that this is not part of a treatment plan, and that if capable, a patient is entitled to refuse a proposed treatment.

**Q: What recourse to collect patient information does the health professional have when treating a young adult in hospital under the Mental Health Act, Form 1?**

The general rule in PHIPA is that information should be collected directly from a capable patient. However, section 36(1)(c) allows health professionals to collect information from a parent/guardian/caregiver if it is reasonably necessary for providing health care and it is not possible to collect it directly from the patient in an accurate or timely fashion. In addition, collateral information may be collected while the patient is on a Form 1.

Health professionals will want to document the alternate source(s) of patient information (e.g., ‘I collected the following information from the parent/guardian/caregiver and here’s why, [...]’). Health professionals should also be aware that the patient can later instruct them not to use the information that they collected in this manner.

The caregiver may wish to take the initiative in this case, letting the health professional know:

- “I understand patient information can be collected from an alternative source when the patient is unable to provide it in an accurate or timely manner” or
- “I can provide important information about the observed health and behaviour of the patient. A Form 1 authorizes collateral information to be collected.”

**Q: Can a person experiencing a psychotic episode be deemed capable of making treatment decisions?**

Yes. Upon arrival in the health care system, the patient is presumed capable to consent to treatment.

Neither a mental health diagnosis nor a mental health episode, nor a person’s age, can be used to determine a patient’s capacity to make treatment decisions. Since treatment decisions fall under the Health Care Consent Act, a patient may even be detained against their will under the Mental Health Act and still be deemed capable of making their own treatment decisions.

Health professionals presume patients are capable of consent on arrival in the health system.

Caregivers need to know that the health system will not prevent patients from making their own decisions because of a mental health diagnosis or psychotic episode.

**Q: What is the legal test for patient capacity to consent?**

For both consent to treatment and for information-sharing decisions, the patient must be able to meet both prongs of the legal test for capacity:

- Able to understand the information relevant to the treatment or decision; and
- Able to appreciate the reasonably foreseeable consequences of saying ‘Yes’ or ‘No’.

Health professionals will want to document patient performance on both prongs of the legal test for capacity.

Caregivers need to know that patients are presumed capable to consent to treatment, but health professionals may assess their capacity. Only if the patient is found to be incapable will a substitute decision-maker be asked to consent to care or to make information privacy decisions.

**Q: If the patient is deemed incapable of making treatment decisions, how does the health system select the substitute decision-maker?**

The method of choosing a substitute decision maker is determined by the Health Care Consent Act and PHIPA. In Ontario, the highest ranked eligible substitute decision-maker(s) is chosen as follows:

1. Guardian of a person
2. Power of Attorney for personal care
3. Representative appointed by Consent and Capacity Board
4. Spouse or partner
5. Child or parent; parent of other person with custody; or Children's Aid (CAS) in place of parent
6. Parent with right of access
7. Brother or sister
8. Any other relative
9. Public Guardian and Trustee

The provider that is treating an incapable patient will refer to the patient record in order to identify the appropriate substitute decision-maker and possible alternative substitute decision-makers. The provider may also reach out to the caregiver or another family member of the patient in order to identify the highest-ranked substitute decision-maker.

A SDM must be at least 16 years of age unless they are the parent of an incapable child (such as a 15 year old with a child). A SDM must also be both available and willing to make decisions on behalf of the patient. A SDM must also themselves be capable of making the decision at issue.

Once the substitute decision-maker is identified, that individual will make care decisions and also control who has access to patient information, which may or may not include the current caregiver.

If two or more equally ranked substitute decision-makers disagree the Public Guardian and Trustee must act as the tie-breaker.

To identify the highest-ranked substitute decision-maker for a specific treatment decision, the health professional will review the patient chart and contact a family member for assistance, if necessary.

Once an appropriate substitute decision-maker(s) has been identified for the purpose of that treatment decision, the health professional will want to document this decision in a manner that can be understood and applied by any member of the patient care team.

Health professionals should never hesitate to share patient information with the substitute decision-maker(s). Health professionals should anticipate questions about the substitute decision-maker role from family members.

Caregivers need to know that their current role in patient support may change if the patient is found incapable for a particular treatment. In a case where the current caregiver is not the highest ranked substitute decision-maker on the above list, they may not be offered the opportunity to be involved in making care decisions for the incapable patient.

Current caregivers could also find themselves equally ranked with other members of their family as substitute decision-makers for the patient, resulting in a shared decision-making role. If two or more

substitute decision-makers cannot agree on a specific treatment, the Office of the Public Guardian and Trustee Treatment Decisions Unit will step in to ‘break the tie.’

**Q: Is the family caregiver always appointed substitute decision-maker?**

No. The caregiver may or may not be the substitute decision-maker; it depends on whether they are the highest-ranked person on the list of substitute decision-makers under section 20 of the Health Care Consent Act. In addition to establishing that prospective substitute decision-makers meet the minimum age requirement of 16 years, health professionals 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 prohibited 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 substitute decision-maker under the Health Care Consent Act, the health professional will bypass that person and move on to the next highest-ranked candidate(s) on the list.

Health professionals are able to determine the appropriate candidate for substitute decision-maker for treatment under the Health Care Consent Act along with information about the age, willingness to act, availability and capacity of the identified eligible candidates.

Caregivers need to know that the health professional’s selection of the substitute decision-maker is guided by the law and a screening process to ensure the individual meets the criteria to act in that role. If a health professional bypasses a substitute decision-maker due to incapacity, there is no formal appeal process.

**Q: How does the health system respond when equally-ranked substitute decision-makers appear unable to reach consensus on a patient care decision?**

Health professionals will advise equally-ranked substitute decision makers that they must work together and come to consensus on the proposed treatment.

If that appears impossible, the substitute decision-makers are further advised that the Office of the Public Guardian and Trustee’s Treatment Decisions Unit will be asked to make the patient care decision in their stead. This sometimes breaks the deadlock, but not always.

If the family still remains deadlocked, the health professional will pursue the decision from the Office of the Public Guardian and Trustee Treatment Decisions Unit.

Health professionals should remind substitute decision-makers who cannot come to consensus on a proposed treatment for a patient that if they cannot, the law requires that the health professional turn to the Office of the Public Guardian and Trustee Treatment Decisions Unit, a public body to make this specific decision. It does not replace the substitute decision-makers for future decisions. In this case, substitute decision-makers need to consider whether they can reasonably come to consensus and provide consent or not, recognizing that if they do not, their decision-making authority for this particular treatment will be taken away and given to a government body.



**Q: What can a health professional do if the substitute decision-maker seems not to be acting in the patient’s best interests (e.g., not returning calls from the health professional and related organizations, and not being available to the health professional to provide patient care decisions)?**

If the substitute decision-maker is not “willing” or “available” (in addition to the other criteria described above) to act in the role, the health professional is entitled to move on to the next highest-ranked person in the ranking. However, it is recommended that the substitute decision-maker be reminded of their duties under the Health Care Consent Act, so that they have an opportunity to fulfill them.

If the substitute decision-maker seems not to be acting in the patient’s best interests, the health professional should try to get to the bottom of what is driving their behaviour. For example, is the substitute decision-maker capable to make the decisions, according to the legal test (that is, 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 substitute decision-maker capable but not acting in accordance with the principles for substitute decision-making under the Health Care Consent Act, including making decisions based on his/her own wishes rather than the prior capable wishes of the patient?

If the substitute decision-maker appears incapable of making decisions that are in the patient’s best interests, the health professional can apply to Ontario’s Consent and Capacity Board, an arm’s length tribunal, and ask for a ruling, which may result in the substitute decision-maker being removed for a specific treatment decision.

Health professionals work closely with substitute decision-makers for the best possible patient outcome. In certain circumstances, health professionals have the authority to pursue an alternate substitute decision-maker or apply to the Ontario Consent Capacity Board.

When determining who the next highest-ranked substitute decision-maker(s) is, the health professional will want to document this decision in a manner that can be understood and applied by any member of the patient care team.

Caregivers need to understand that health professionals are required by law to turn to the appropriate substitute decision-maker when a treatment, information or admission to long-term care decision is required. The family caregiver may be in this role, but only if they are highest-ranked on the list.

**Q: Can the patient determine who makes their health decisions if they become incapable to make their own treatment, information or admission to long-term care decisions?**

While capable, the patient may select their own substitute decision-maker by working with a lawyer to take one among several steps, such as signing a power of attorney for personal care.

Or, once incapable, the patient can apply to the Consent and Capacity Board with a request to name a “representative,” who ranks close to the top of the list of substitute decision-makers. This application will not be considered if a legal Guardian or Power of Attorney for personal care is already in place, but the application can be made by the patient even if they are deemed incapable (or it could be made by a third party, such as the family caregiver, to ask the Consent and Capacity Board to name him/her as the patient’s representative).

Health professionals may be asked to provide patients with information about their legal options to determine their own substitute decision maker(s). It is important that clear information be provided, but

that it not appear as though the health professional is providing formal legal advice. It is always possible to say, “We have provided you with some basic information and you are, of course, free to seek legal advice.”

Caregivers need to know that patients have legal options and legal recourse should they wish to determine their own substitute decision- maker(s).

**Q: While capable, can the patient request that medical treatment be administered for a future mental health episode, even if at that later time the patient refuses treatment?**

Yes. In a case where the patient recognizes a pattern of psychotic episodes during which (s)he routinely declines treatment and experiences an extended period of illness, the patient may decide to consult a lawyer to put a so-called ‘Ulysses’ contract into place (an option available under the Substitute Decisions Act).

The Ulysses contract is a special kind of Power of Attorney for personal care because the patient effectively gives their consent to be treated in the future. It is a fairly intrusive mechanism, for obvious reasons, and one that will need to be reviewed carefully with a lawyer.

While health professionals need to take care not to look as though they are providing legal advice to patients, they can support patients seeking to break out of a negative episodic pattern by raising the ‘Ulysses’ contract and suggesting that if they are interested, they will need to consult a lawyer.

Caregivers may find it helpful to learn about the Ulysses contract (as well as powers of attorney for personal care more generally), as legal options that are available to the patient.

**Q: PHIPA carries potential monetary fines and penalties for the inappropriate collection, use and disclosure of patient personal health information. What are these fines and penalties?**

According to PHIPA section 72(1), an individual health professional who “wilfully collects, uses or discloses personal health information in contravention of PHIPA or its regulations” may face a fine of up to \$200,000 if convicted of an offence. Organizations that are health information custodians, such as hospitals, may face fines of up to \$1,000,000.

There have also been a number of prosecutions by the Attorney General for privacy breaches, resulting in fines and reputational damage, mainly related to ‘snooping’ cases. Egregious breaches have been pursued in court cases. For example, a case in which patient information was provided to a third party insurance seller, which resulted in a successful prosecution in the courts for securities fraud, and a significant fine, as well as a class action lawsuit being filed. Under recent changes to PHIPA, the Information and Privacy Commissioner of Ontario can now impose monetary penalties to encourage compliance with PHIPA or regulations. Regulations setting out how the amount of these penalties would be decided have yet to be made.

Health professionals need to know that they can be personally fined or prosecuted for privacy breaches. These fines are rare and have only been levied in egregious cases.

Caregivers need to know that health professionals are bound to work within the law governing patient information.



## WHERE TO GO FOR MORE HELP

Information and Privacy Commissioner of Ontario: [www.ipc.on.ca/health-individuals/](http://www.ipc.on.ca/health-individuals/)

Advocacy Centre for the Elderly: [www.ancelaw.ca](http://www.ancelaw.ca)

Psychiatric Patient Advocate Office: <https://www.ontario.ca/page/psychiatric-patient-advocate-office>

Consent and Capacity Board: [www.ccboard.on.ca](http://www.ccboard.on.ca)

Patient Ombudsman: <https://patientombudsman.ca>

Community Mental Health and Addictions Privacy Toolkit: [https://ontario.cmha.ca/wp-content/uploads/2017/03/privacy\\_toolkit.pdf](https://ontario.cmha.ca/wp-content/uploads/2017/03/privacy_toolkit.pdf)

Depending on the situation you are facing, you may consider contacting the Privacy Officer and/or the Patient or Client Relations office of the specific health care organization

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