



THE ONTARIO

caregiver

ORGANIZATION

UNDERSTANDING HEALTH PRIVACY AND CONSENT IN ONTARIO

A GUIDE FOR CAREGIVERS
AND CARE PROVIDERS



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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.

INTRODUCTION

Many people who receive healthcare have friends or family members involved in protecting their health or promoting their recovery. These caregivers are a vital part of our healthcare system and play an important role in patient wellbeing and successful patient outcomes. When caregivers are recognized, valued and engaged by providers as partners on the care team, it can lead to better health outcomes and a better experience for patients, caregivers and providers.

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.

This resource explains the health privacy laws in Ontario to both caregivers and healthcare providers so they have the information they need to work together to support patients and work together as partners in care. The goal is to help both caregivers and care providers feel more informed and empowered to make health privacy laws work to support the best possible patient care.

This resource does not answer legal questions or give legal advice. It provides general information to give caregivers and providers a better understanding of the rules. Unfortunately, there is not always an easy “yes” or “no” answer to health privacy questions. Some answers will be dependent on the context. You may find you need legal advice to better understand your rights and options.

In our four companion resources, we have developed answers to frequently asked questions by caregivers:

[FAQs on Privacy and Consent for Caregivers Supporting Someone Capable of Making Their Own 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.

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

[**FAQs on Privacy and Consent for Caregivers of Children and Youth**](#) is for caregivers of children of any age (but specifically under the age of 16). This includes addressing decision-making authority after divorce or with split families.

[**FAQs on Privacy and Consent for Caregivers Supporting Someone in the Mental Health and Addiction System**](#) is for caregivers of individuals who receive mental health or addiction services to better understand the additional rules and considerations of that unique context.

We have also developed two at a glance resources that summarize what both caregivers and care providers need to know:

[**At a Glance: Understanding health privacy and consent in Ontario - For Caregivers**](#)

[**At a Glance: Understanding health privacy and consent in Ontario - for Care Providers**](#)



KEY TERMS

In this document ...

Caregivers: are people who provide physical and emotional support to a family member, partner, friend or neighbour.

Providers: are health practitioners, organizations, residences and programs who provide health care and services to patients.

Patients: are the recipients of the health care or service. For ease of reading we have only used the word “patients”, but by patients we also include clients, residents, and care or service recipients.

Consent: is giving permission for

A health care decision such as: treatment, counseling, admission to a care home (such as long-term care) or personal assistance service (such as oral care, bathing, dressing, or assistance with medications and mobility)

A privacy decision such as: the collection, use or disclosure of a patient’s personal health information or having a copy of a patient’s health records

Capacity: is the legal name for the mental ability to make decisions for oneself.

If a patient is capable, the patient makes their own privacy and health care decisions.

If a patient is not capable (“incapable”), the patient needs a substitute decision-maker to make privacy and health care decisions for them.

Substitute decision-makers (SDMs): have the right and responsibility to make health care and privacy decisions on behalf of incapable patients.

POA: means “Power of Attorney”. A POA is a legal document that gives someone the right to make health care or financial decisions for someone else. The person who is named in the document as the decision maker is known as the “attorney for personal care”. An attorney for personal care is one type of SDM.

PHIPA: THE HEALTH PRIVACY LAW

There are laws that create patient privacy rights and put responsibilities on providers. The most important law is called the [Personal Health Information Protection Act \(PHIPA\)](#). It applies to almost all health providers in Ontario.

A patient's rights are to:

- Choose how their information is collected, used and disclosed by their provider
- Have a copy of or view their own health records held by a provider
- Choose with whom their health information is shared
- Ask for their record to be corrected if it is inaccurate or incomplete
- Restrict their providers from collecting, using or disclosing their health information with other health care providers (in whole or in part)

If a patient is incapable, a SDM exercises these privacy rights on behalf of the patient.

There are serious penalties for providers if they do not respect patient privacy rights and follow the law.

- Privacy breaches by providers can lead to prosecutions with fines of up to \$200,000 for individual providers and up to \$1 million for provider organizations and jail time
- Providers can be sued for snooping, negligence and breach of contract
- Privacy complaints can go to the [Information and Privacy Commissioner of Ontario](#) who oversees compliance with PHIPA and has the power to order providers to do things or stop doing things
- Regulatory Colleges (like the College of Psychologists of Ontario) can discipline their members for privacy breaches including suspending licenses to practice

Sharing too much information with caregivers can also undermine a patient's trust and compromise the provider-patient relationship.

These penalties and consequences can cause providers to be extra cautious about sharing information with caregivers.



The privacy law you have to know about is PHIPA. But there are additional laws that impact on privacy in certain settings like:

- Indigenous, First Nations, Métis and Inuit laws
- [Mental Health Act](#) for psychiatric facilities
- [Freedom of Information and Protection of Privacy Act](#) for hospitals, the Ministry of Health, and public health
- [Municipal Freedom of Information and Protection of Privacy Act](#) for school boards and municipal services
- [Long-Term Care Homes Act](#) for long-term care homes

CAPACITY, CONSENT AND SUBSTITUTE DECISION-MAKING

Decision-Making

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.



Situations where providers would need to assess capacity include:

- Maturing children (such as ages 10-16)
- Patients with a condition or diagnosis where there is often mental or developmental impairment, but that impairment is not fixed and can fluctuate or can deteriorate (such as dementia or a brain injury)
- Patients with a moderate to severe intellectual or developmental disability
- After a patient has regained consciousness
- After a patient has resumed taking medications or after a course of treatment that was designed to return mental functioning (such as hydration or some psychiatric medications)
- After a psychotic episode passes
- When a patient:
 - is confused, incoherent, showing irrational thinking or does not appear to understand their situation, choices or surroundings
 - has fluctuating wishes or alertness
 - seems unable to retain information
 - lacks maturity
 - is engaged in reckless behaviour

Assessing Capacity

Providers must presume all patients are capable of making their own health care and privacy decisions unless it is unreasonable to do so. Sometimes providers skip a formal capacity assessment when it is obvious to everyone that a patient is or is not capable. Most adults are capable and make their own decisions. Babies, very young children, and unconscious people never do.

In health care, capacity assessments are the responsibility of the provider who proposes the treatment. Capacity is assessed by the provider asking the patient questions related to the health care or privacy decision. The provider may also run standardized tests or procedures that measure cognitive ability and brain function.

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.

If the patient does not have the ability defined by either part of this two-part test, the patient is incapable of making their own decisions.

Some patients are capable of making some but not all of their decisions. A patient may be capable of consenting to have a bone set after breaking a leg, but at the same time, incapable of consenting to proposed psychiatric medications based on their denial of having a mental illness.

Some patients are permanently incapable: such as a person with a severe brain injury, severe developmental disability or intellectual limitation or someone with an advanced case of dementia or cognitive impairment.

Capacity can fluctuate. Patients may be capable at one time and not another. For example, if a patient has just had surgery and is on heavy pain medication, they may be incapable to consent to further treatment at that time. As the pain medication is decreased, the patient may regain capacity.

Formal Capacity Assessments

Some patients will receive formal capacity assessments such as:

- when admitted to a psychiatric facility
- when someone has reasonable grounds to believe the patient is not able to make their own property or financial decisions
- by an evaluator, for capacity to make decisions about personal assistance services or admission to a long-term care facility
- when there is a permanent condition, disability, limitation or injury and a person requires a legal decision-maker for all activities of daily living, finances and health care

This is the ranked list for SDMs:¹

1	Court-Appointed Guardian , if the guardian has authority to give or refuse consent to information decisions (<i>note, very few people have a “guardian of the person” as someone has to go to court in order to obtain this status</i>)	<p>These are the legally-appointed SDMs, meaning there is a legal process to become one of these.</p> 
2	Attorney for Personal Care or Attorney for Property , if the consent relates to the attorney’s authority to make a decision on behalf of the individual (A power of attorney for personal care and a power of attorney for property are documents where the patient when capable chose who should make decisions for them if they became incapable)	
3	Representative Appointed by <u>Consent and Capacity Board</u> (note, very few people have this. Someone has to go to the CCB to become this.)	
4	Spouse or Partner	<p>Automatic Family Member SDMs</p> <p>If there was no legal process above, a family member will make decisions.</p>
5	Parents or Children	
6	Parent with right of access only	
7	Siblings	
8	Any other relative	
9	<u>Public Guardian and Trustee</u>	<p>SDM of last resort</p> <p>If there is no family, the Public Guardian and Trustee steps in to make decisions.</p>

¹Table adapted from infographic available here: <https://www.speakupontario.ca/resource/the-substitute-decision-maker-hierarchy/>



I am sometimes shocked when I hear my spouse downplay his symptoms to his provider. He says his pain is a 2 out of 10. Meanwhile, I have just spent 4 days trying to convince the provider to do a home visit for a pain assessment because he couldn’t move and has been in excruciating pain. Now it looks like I’ve exaggerated the situation and I’m worried his doctor isn’t going to address the pain and we’re going to end up back in the hospital. I feel totally helpless because the doctor said my spouse makes his own decisions and I need to back off. Except once the doctor leaves without adjusting the pain meds, I’m going to be the one left here managing my spouse at home.

The rules for these kinds of assessments are found in the Substitute Decisions Act. Some of these capacity assessments can cost money and can only be performed by assessors or evaluators with specific credentials.

Choosing the SDM

The law gives a list of possible automatic SDMs that tells providers who can make decisions for an incapable patient. The provider must go down the list starting at the top to find the first person (or group) who can act as SDM.

Requirements for a Substitute Decision Maker (SDM)

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.

SDM Rights

SDMs can:

- Rightfully demand to be included as the decision-maker in any treatment, counseling, admission to care home and personal assistance services where the patient is incapable
- Ask to bring additional caregivers to meetings or appointments to support them as they support the patient
- Share the patient's health information and records with whomever they choose
- Ask for copies of health records or if there is a patient portal for electronic access online to health records
- Ask providers to keep other caregivers updated or approve information sharing with other caregivers (although providers may ask that there be one person for them to update)
- Ask for a second opinion



Before she died, I was the caregiver for my husband's grandmother and was her primary visitor in her long-term care home. She had advanced dementia. Her daughter (my mother-in-law) was her decision maker but she lives abroad and was not easy to reach. I never knew what to expect when I asked the care home staff for an update. Would I be told how she was? Or told I had to speak with my mother-in-law – when I knew she didn't know? It didn't make sense to me that I was excluded from getting information because I was the only one in the family who had time and could be there to support her. It made everything more complicated and I worried information was not being communicated properly.

CAREGIVERS AND PROVIDERS

Patients Benefit from the Involvement of Their Caregivers

Caregivers play an important role in helping patients activate their rights. It is acceptable and important for caregivers to help patients and their SDMs to:

- Take notes
- Understand their health care and information choices
- Ask questions
- Advocate for more, better, different, less or no care
- Ask to have a caregiver with them in meetings and appointments for support
- Ask for copies of health records or if there is a patient portal for electronic access online to health records
- Remember their appointment dates, times and locations
- Remember what to do and understand what to expect in their care, recovery or management
- Take precautions to protect patients from harm
- Provide background context to providers to better understand the patient's unique circumstances

Providers Benefit When Patients Have Caregivers

Caregivers can play an important role in giving providers a more complete and accurate picture of a patient's history, context and experiences.

This helps providers when:




- A patient is scared, confused and alone
- There is not enough time to get to know a patient
- They do not receive a patient's full health history from other providers
- A patient is a poor historian and forgets to share key health details
- A patient is not able to or does not want to share their health history or explain what is happening to them
- They wonder if a patient is understating (or overstating) the situation and no one can provide context or confirmation
- They are unsure if they have adequately explained what is happening and the options available to the patient
- Access to translation services is not readily available

Caregivers often ask questions that help providers customize health care to the patient. Caregivers also support providers by helping patients remember appointments and recovery instructions and by explaining complex health information in a manner more easily understood by the patient.



Sharing Information Between Caregivers and Providers

The law allows sharing of information between caregivers and providers (with some limits). There are steps caregivers and providers can take to improve information sharing with caregivers and clarify a patient's choices about caregiver involvement.

Caregivers

- Caregivers can ask the patient they care for to tell the provider to keep them informed.
 *Can you tell the nursing home staff that you would like them to keep me updated?*
- It's okay for caregivers to remind providers that they are permitted to share certain information based on the patient's consent.
 *If you check the chart you will see that my neighbour has given permission for me to talk to you and for you to tell me how they are doing.*
- SDMs of incapable patients are entitled to information and copies of health records in order to make health care decisions.
 *I'm my grandmother's substitute decision-maker. Could I have a copy of her chart so I can understand the options for her hospice care?*

Providers

- Providers should proactively ask patients with whom they would like their information shared so they get the supports they need for their health journey – such as:
 *Who can we call to let them know you are here and that you are safe?*
Who is taking care of you? I assume you'd like us to share information with them. Is that right?
- Even if a patient says “no” the first time, providers can ask a patient about caregiver support once there has been improvement in the patient's clinical status. It may be appropriate to explore why the patient does not want information shared.
 *Family support can have a very positive effect on your recovery. Have you thought of someone you'd like us to call?*



My mother doesn't speak English. She's able to make her own decisions about her health but she doesn't understand what is being asked of her when we go to appointments so she asks me to come with her. Once we get in to see the provider, I am often told I have to leave. But sometimes, they want me to stay to translate. Am I allowed to stay with her? Should I be insisting that I get to stay? I worry that families like ours do not have access to good health services due to language barriers including mishandling of privacy and consent conversations.

- Sometimes patients misunderstand and think that sharing information is an all or nothing option. Providers can clarify that information sharing can be minimal.



To better help me help you, I will need to talk with the people who care about you – like your daughter-in-law. This doesn't include information about your personal life. Only things to help you get better. Is that okay with you?

Your parents are worried about you. I'd like to tell them you are okay and give them tips on how to support you. I'm not going to tell them what you just told me about your sexuality. What's not okay to share with your family?

- In the presence of the patient who is accompanied by a caregiver, a provider can ask a caregiver questions like:



Often family have more information that can help me understand the full picture, what changes have you seen?

What's your view?

Do you have any questions about how to care for the patient?

- 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. Caregivers can offer a different perspective or share additional information with providers by saying:



I have a different perspective.

I have additional information to help with this assessment.

I have more information that could explain that.



Barriers to Sharing Information Between Caregivers and Providers

Providers still have to respect the rights of patients, patient safety, professional standards of practice and their responsibilities for privacy compliance. If a capable patient or a SDM says they do not want information shared with a caregiver, a provider must follow that instruction.

It can be difficult for providers to respond to caregiver requests for information when:

- Patient care is delivered quickly without time for giving updates (such as in an emergency)
- They do not know whether the patient wants their information shared with that caregiver
- The patient has asked that the caregiver not receive information
- They are trying to build trust with the patient and need to create a safe place for the patient to share
- The patient says one thing and caregiver says another thing
- There are multiple SDMs/caregivers who disagree with each other (or disagree with the patient)
- Caregivers are not sharing information between themselves
- The patient seems uncomfortable in the presence of the caregiver or there may be signs of abuse

When in doubt, a provider must lean towards protecting privacy and a patient's rights. If a patient does not want their information shared with a caregiver, the provider should reassure the patient their information will not be shared.

If a provider collects information from a caregiver, a patient has the right to ask the provider not to use that information. If that happens repeatedly, a provider may choose to stop collecting information from the caregiver.

When there is no consent to share information, providers should still be polite, supportive and sensitive to a caregiver's concerns. A patient's illness can have a major impact on family and friends. Providers can provide reassurance to caregivers such as:

How are you doing? What are you doing to take care of yourself?

I know this is difficult for you that your son has not given us permission to share information with you. But we can ask again when he is feeling better.



My 17-year old transgender child has a general anxiety disorder. When we go for health care appointments, I know they want me to stay with them. But I'm often made to feel embarrassed or overly controlling when I tell their providers they want me to stay. My child hates having to ask for me to be with them- so they just passively go without me. It makes me feel anxious every time we have to see a new provider. Once we know the provider, I am usually included in conversations with my child, but until they get to know us, those initial interactions are painful.

COMPLAINT MECHANISMS

If you are not satisfied with how you are being treated as a caregiver by a provider, you should say something. You can raise your concerns with:

- The provider and let them know you are unhappy
- The provider's patient relations office or a manager or leadership member
- The provider's Privacy Officer
- [Information and Privacy Commissioner of Ontario](#) if you have a privacy complaint
- [Patient Ombudsman](#) if you have already made a complaint to a public hospital, long-term care home or home and community care support service and you are not satisfied with the outcome
- [Consent and Capacity Board](#) if you want a review of a provider's decision of capacity or incapacity or a SDM's compliance with the rules for substitute decision-making
- Regulated health professional Colleges - all regulated health professionals belong to regulatory bodies called "Colleges". If your complaint is only about a regulated health professional, such as a physician, nurse, physiotherapist, etc., you should contact the appropriate College.

We also recommend the following resources:

- Ontario Caregiver Organization training tool for care providers, "Consent...It's all in the ask!"
- Speak Up Ontario, "[The Substitute Decision Maker Hierarchy](#)"
- [Advocacy Centre for the Elderly](#) resources [on consent, capacity](#) and [long-term care](#)
- [Psychiatric Patient Advocate Office](#) resources on privacy, patient rights and responsibility, and consent and capacity



My 29 year old son has a significant developmental disability and continues to live with me as an adult and relies on me for all his physical care needs. I'm his decision-maker. When he was a baby and a child, we had wonderful support. I was considered a key partner in his care team and I worked really well with his providers. They listened to me and I felt included in his health planning. Since he became an adult, all the coordination is gone. I'm not included in updates. I have to fight to get the information we need from his specialists. It takes me so much more time and effort to gather information and I don't feel like all his providers have up-to-date information. The transition from the the children's system to the adult system has been extremely disappointing. I have to be a strong advocate for him - but that strains my relationships with his providers. I just want to be treated with respect.



Ontario Caregiver Helpline: 1-833-416-2273

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www.ontariocaregiver.ca



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