

Understanding substitute decision-making for treatment decisions

Information for patients, residents and families

Read this booklet to help you understand:

- What happens when someone is not able to make a treatment decision for themselves
- Who makes the decision
- What to consider when making the decision

Some of this information may seem complicated. If you have any questions, talk to members of the health care team, including a social worker or the Ethics department.

See also the resources and glossary in this booklet.

Resources

Health Care Consent Act

www.ontario.ca/laws/statute/96h02

Consent and Capacity Board

www.ccboard.on.ca

Office of the Public Guardian and Trustee

www.attorneygeneral.jus.gov.on.ca/english/family/pgt/

Speak Up Ontario

www.speakupontario.ca

Talk to your health care provider if you would like to access hospital services such as Social Work, Spiritual Care, Ethics and Patient Relations.

Throughout this document, we will be referring to the Health Care Consent Act (HCCA).

For more information on informed consent, please see our handout: Understanding Informed Consent to Treatment.

For more information about how we determine if a patient is capable to make treatment decisions, see: Understanding Capacity for Treatment Decisions.

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What is consent to treatment?

Except in some emergency situations, a health care provider cannot treat a patient without getting consent first. Giving consent to treatment means communicating an informed and voluntary decision to have that treatment. Consent to treatment is often called **informed consent**. For more information on informed consent, see our handout **Understanding consent to treatment**.

What is a substitute decision-maker (SDM)?

When a decision needs to be made about a patient's treatment, but the patient is **incapable** of making the decision, they need someone to make the decision on their behalf. That person is their **substitute decision-maker (SDM)**.

A substitute decision-maker is a person legally permitted to give consent to or refuse a treatment on behalf of an incapable patient.

What does it mean to be incapable?

To consent to or refuse a treatment, a person must be **capable** to make that decision.

According to the Health Care Consent Act, this means the person must be able to understand the information that is relevant to making a decision about the treatment and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

To be capable, the person must be able to do both of these things (understand **and** appreciate). If the person cannot do both of these things, they are considered to be **incapable**. To learn more about how we determine if a patient is capable or incapable, see our handout **Understanding capacity for treatment decisions**.

Who is the SDM if a person is incapable?

In Ontario, the law lists who can act as an SDM and who gets priority. To find out who may be a person's SDM, move down the list in order. (See the glossary for definitions.)

1. Court-appointed Guardian of the Person
2. Attorney for Personal Care
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child (at least 16 years of age), parent, or Children's Aid Society
6. Parent who has only a right of access
7. Brother or sister
8. Any other relative

If someone is a potential SDM based on this list, they must meet all the following requirements to act as the SDM. They must be:

- **Available** and **willing** to act as the SDM
- **Capable** to make the treatment decision
- **At least 16 years old** (unless the parent of the patient), and
- **Not legally prohibited** from doing the job of an SDM, such as due to a no-contact order

If a potential SDM does not meet all four of these requirements, the health care team must continue down the list to find an SDM.

Being available does not mean that the person must live in the same city, or even the same country, as the patient who is incapable. A person is **available** if the health care team can communicate with them in a reasonable amount of time and if this person can give or refuse consent. For example, the care team may be able to reach the person by phone or e-mail.

If the patient does not have anyone to act as their SDM, the decision will be made by someone who works in a part of the Ontario government called the Public Guardian and Trustee.

Can there be more than one SDM?

Yes, a patient may have more than one SDM if there are several people on the same line of the list (for example, children of the patient). If there are several SDMs involved, they must agree on any treatment decisions. If the SDMs cannot come to an agreement, the Public Guardian and Trustee has the authority to make the decision.

What is an SDM's role?

When a patient is incapable of making a decision about treatment (such as surgery or medicine), the SDM's role is to give or refuse consent.

Acting as an SDM for one decision about treatment does not give the SDM the right to make other decisions on the patient's behalf, like where they live or who visits them. It also does not give the SDM the right to make other treatment decisions. For example, a patient may need an SDM to make a decision about surgery. But they may be capable to make other treatment decisions for themselves.

If the SDM becomes unavailable or is unable to make treatment decisions, the team will approach someone else to act as the SDM when needed.

I have been asked to make a treatment decision as the SDM. What do I consider first?

Under the law, your **first step** is to consider whether the person for whom you are making a decision previously expressed any wish that could apply to the proposed treatment or care.

Does the wish meet the following criteria?

- It was expressed when the person was capable
- It was expressed when the person was at least 16 years old, and
- It applies to the person's current situation

A wish that meets these criteria is sometimes called a **prior capable wish**.

It is fine if the wish was only said out loud. There is no requirement that it be in writing, although writing is fine, too. If the person expressed multiple wishes at different times about the same treatment or situation, the most recent capable wish should be followed.

As the SDM, you are called to act for the **patient**. If there is a prior capable wish, you must make the treatment decision according to the wish, whether you are comfortable with the wish or not. Although it can be difficult, you are called to set aside your own wants and needs, such as having more time with the patient.

I don't know of any prior capable wishes that apply to this situation. How do I make a decision?

In this case, your **second step** as the SDM is to make your decision according to the **best interests** of the incapable person. In deciding what is in the person's best interests, the Health Care Consent Act says that you must consider:

- The values and beliefs that the person held when they were capable and that you believe they would still act on if they were capable now
- Other relevant wishes of the person that did not belong in the **first step**, such as any wishes expressed before the age of 16 or while incapable
- Factors relating to the proposed treatment:
 - If they have the treatment, how would it likely affect their condition or well-being (improve, prevent from getting worse, slow the process of getting worse)?
 - If they **don't** have the treatment, how would it likely affect their condition or well-being (improve, stay the same, get worse)?

- Do the benefits of the treatment likely outweigh the risks?
- Is there another treatment option that is less restrictive or intrusive?

In your role as the SDM, you should think about:

- What the person said in the past about their current medical condition
- What you know about their personality, views, and priorities

Even though the patient is incapable, their current feelings and preferences still matter. If the patient is able to communicate their preference, consider what they say along with the advice and information provided by the care team (including risks and benefits).

What if I don't know what to do?

Acting as the SDM can involve making very difficult decisions. Even though making the treatment decision is your responsibility, friends and family might be able to provide you with emotional support and help you think through your decision. It can also help to talk openly with the patient's care team.

Sometimes the SDM and the care team disagree.

There are many ways to work through disagreement, such as clarifying medical information with the care team or seeking out other supports within the hospital or from the community.

You may find it helpful to contact a social worker, an ethicist, and/or a spiritual care practitioner within the hospital for support in working through the challenges you are facing.

Often, it's possible to resolve disagreements through an open dialogue between the parties.

As a last resort, if questions or concerns cannot be resolved in other ways, you, or someone else, may make an application to the Consent and Capacity Board (CCB). The CCB resolves issues that may come up with substitute decision-making, such as:

- The doctor who is treating the patient does not think you are following the rules of substitute decision-making
- Someone else wants to act as the SDM
- You are unsure of what is in the patient's best interests

Glossary

Attorney for Personal Care: A person authorized by a document called a Power of Attorney for Personal Care to make personal care decisions for another person when they are incapable (including treatment decisions).

Capacity: A state of being able to understand the information relevant to making a treatment decision *and* being able to appreciate the reasonably foreseeable consequences of consenting to or refusing the treatment. You may hear health care providers refer to the patient as either **having capacity** or **not having capacity**.

Consent: Agreement to a specific treatment which must be informed, voluntary, and not obtained through misrepresentation or fraud.

Consent and Capacity Board (CCB): An administrative tribunal that decides issues arising under the Health Care Consent Act, as well as other legislation, if those issues cannot be resolved in another way. Such matters include determining how to proceed if an SDM does not seem to be following the rules of substitute decision-making.

Guardian of the Person: A person who has been appointed by the court to make personal decisions for someone who is not capable to make such decisions for themselves. These decisions may include treatment decisions.

Health Care Consent Act (HCCA): Legislation in Ontario that governs issues of consent, capacity, and substitute decision-making in the context of health care.

Incapable: Not having capacity.

Partners: People who have lived together for at least one year and have a close personal relationship that is of primary importance in both of their lives. (See also definition of **spouses**)

Public Guardian and Trustee/Office of the Public Guardian and Trustee (PGT): Part of the Ontario government that makes decisions on behalf of an incapable person if no one else has the authority to do so (for example, if there is no potential SDM, or if potential SDMs do not meet the requirements for acting as an SDM).

Spouses: Two persons are spouses if they are married to each other. They are also considered spouses if they are living in a conjugal relationship outside marriage and have cohabited for at least one year, are together the parents of a child, or have together entered into a cohabitation agreement. They are not spouses if they are living separately because of a breakdown of their relationship. (See also definition of **partners**)

Substitute Decision-Maker (SDM): A person legally permitted to give or refuse consent to treatment on behalf of a patient who is incapable of making the decision. An SDM must be at least 16 years old, capable of making the treatment decision, available and willing to act, and not legally prohibited from acting as the SDM.

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