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Introduction

Health care decisions are some of the most important choices that we make. In Ontario, every person has the right to make their own health and personal care decisions as long as they are capable of doing so.

In Ontario, capacity is defined by the Health Care Consent Act as understanding the information that is needed to make a decision and the ability to appreciate the consequences and/or risks of that decision. A person is presumed to be capable of making health care decisions unless there are reasonable grounds to suspect incapacity, meaning they are unable to make some or all of their care decisions.

In the event that someone is determined as being incapable of making a health care decision, the person’s substitute decision maker (SDM) will be responsible for making a decision on his or her behalf. The substitute decision maker, no matter who they are, is required to make decisions based on a person’s known care wishes. Where the person’s care wishes are unknown or impossible, the substitute decision maker must make decisions with the person’s best interests in mind.

Being appointed as a substitute decision maker comes with a lot of responsibility. It can often be a stressful and confusing role. The Erie St. Clair Community Care Access Centre (CCAC) has put together this guide to assist patients, families, caregivers and substitute decision makers in understanding consent and capacity, the role of the substitute decision maker and what resources are available to them.

What is informed consent and capacity?

In Ontario, under the Health Care Consent Act, a health care provider needs a person’s informed consent or permission in order to deliver any health care. To give informed consent, a person needs to be:

• capable of making the decision;
• and given information about:
  - their health condition;
  - the recommended treatment;
  - alternative options to the treatment;
  - and likely outcomes and risks of either accepting or refusing treatment.

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Exceptions to Informed Consent

The only exception to a health care professional needing informed consent to treatment is in an emergency situation. The Health Care Consent Act states that an emergency is when a person for whom treatment is proposed is apparently experiencing severe suffering or is at risk of sustaining serious bodily harm if the treatment is not delivered. It is the health professional’s responsibility to decide if there is an emergency situation.

The only exception to needing informed consent for admission to a care facility, such as a long-term care home, is in a crisis situation. The Health Care Consent Act states that a crisis relates to the condition of the person who is to be admitted to a care facility. In the event of a crisis, a patient can be placed in a care facility without consent if the health professional responsible for authorizing admissions to care facilities decides the incapable person requires immediate admission. It is your local Community Care Access Centre (CCAC) that determines the need for a crisis admission to a long-term care home. This is determined through a comprehensive assessment.

However, health care providers are required to follow a patient’s wishes, if known, in any and all emergency situations. It is for this reason that it is important to discuss your wishes with your health care provider while you are capable of doing so.

Who Determines Capacity?

The health professional that assesses a person for capacity depends on why capacity is being assessed. When it comes to health care, this is done for two reasons: treatment and admission to a care facility – such as a long-term care home.

Treatment

Treatment is defined as anything done for a therapeutic, preventative, palliative, diagnostic, cosmetic or other health-related reason that includes a plan of action.

The health professional proposing treatment assesses whether or not you are capable of giving consent.

A person is automatically presumed to be capable of accepting or refusing treatment unless there are reasonable grounds to suspect incapacity. Incapacity may be suspected from direct observation (e.g. the person is confused, depressed, anxious, etc.) or from information given by the patient, family or other caregivers.
Admission to a Care Facility (such as a Long-Term Care Home)
Ontario law requires the consent of a patient before admission to a care facility such as a long-term care home. However, sometimes a person does not recognize his or her need for placement into a long-term care home, even when this placement is important to their health. Those who suffer from a cognitive impairment or dementia, such as that associated with Alzheimer’s disease, often experience decline in memory, reasoning, planning and judgement. Due to this decline, they often require assistance with basic activities of daily living (ADLs).

If incapacity is suspected, the patient’s capacity will be assessed. Those who assess for capacity to consent to admission to a care facility are called evaluators.

The Erie St. Clair Community Care Access Centre (CCAC) has staff members that are specially trained and qualified as evaluators. These evaluators are also known as CCAC Care Coordinators. An assessment for capacity to consent to admission to a long-term care facility is normally referred to these CCAC Care Coordinators.

How is Consent for Capacity Assessed?
The evaluator focuses specifically on the person’s capacity to make a decision about the proposed treatment or admission. The person must be able to understand the information that is important to making the decision and to appreciate the possible consequences of a decision. Understanding means the ability to remember the information that is provided to them about the treatment or admission. Appreciating means the ability to consider the information and how accepting or refusing the treatment or admission may affect the person’s life.

A complete assessment for capacity involves the evaluator collecting as much information about the person as possible. The evaluator reviews the person’s medical history, current physical and mental health, limitations, values, beliefs, interests and information from other sources – such as family and caregivers.

Some questions that a health practitioner or evaluator may ask are:
• Is the person aware of the health issues that have prompted the recommendation?
• Is the person able to explain how the proposed treatment or admission can address their needs?
• Is the person able to explain what can happen if they refuse treatment or admission?
• Are the person’s expectations realistic?
• Is the person able to make a decision and communicate a choice?
What Happens if a Person is Found Incapable of Consent?
1. The person must be told that they have been determined incapable of making the care decision.
2. The person must be advised of his or her legal rights, unless the situation is an emergency or crisis situation.
3. The person must be informed that a substitute decision maker (SDM) will make the decision on his or her behalf.
4. The person must be told that he or she has a right to review the finding of incapacity or to request an alternative or additional Substitute Decision Maker to be appointed by applying to the Consent and Capacity Board.
5. The person’s Substitute Decision Maker will be identified and provided with all the information needed to make a decision.

Can a Finding of Incapacity Be Challenged?
If a person is found to be incapable of consent to treatment or admission to a care facility, they have the right to challenge the finding, as well as to request an alternative or additional Substitute Decision Maker, by appealing to the Consent and Capacity Board.

The Consent and Capacity Board may be contacted at 151 Bloor Street West, 10th Floor, Toronto, Ontario, M5S 2T5. Phone: 1-800-461-2036, Fax: (416) 924-8873. The Board’s website is available at www.ccboard.on.ca.

A non-emergency treatment or non-crisis admission cannot begin until the Consent and Capacity Board has given their decision or 48 hours have gone by with no formal application being made to the Board.
What is a Substitute Decision Maker (SDM)?

A Substitute Decision Maker is a person who makes decisions on your behalf when you become incapable of making them yourself. Your substitute decision maker must follow your known care wishes unless it is impossible to do so, in which case the substitute decision maker is required to act in your best interests.

The full duties of a substitute decision maker can be found in the Health Care Consent Act (see Resources on page 8). In summary, the substitute decision maker must:

- Consult with the person who had been determined as incapable, within reason and considering their condition
- Consult with any friends or relatives who ask to assist where the substitute decision maker does not know the person’s wishes
- Follow the wishes expressed by the person when they were capable unless it is impossible to do so
- Make a decision based on the person’s best interests if the person’s wishes are unknown
- When making a decision based on best interests, consider the following:
  - The person’s current wishes
  - Whether the person’s condition or wellbeing is likely to improve, worsen or stay the same if the person receives the care
  - Whether the person’s conditions or wellbeing is likely to improve, worsen or stay the same if the person does not receive the care
  - Whether the benefits of the care will outweigh the risks and negative consequences
  - Whether a less restrictive or less intrusive form of care is available and if it would have greater benefits or less negative consequences
- Only attempt to collect information that is required to make the care decision and keep all personal information confidential

Because this is an important role, it is important to consider if you would like to appoint someone to be your substitute decision maker while you are capable of making the decision. You can choose anyone to be your substitute decision maker except:

- A person who is paid to provide you with personal care,
- A person who is mentally incapable and
- Someone who is under the age of 16.

You will want to choose someone who you trust and know well. It is important to ensure the person is willing to be named your substitute decision maker and is prepared to act on your behalf should you become incapable of doing so. To make someone your substitute decision maker, you have to appoint them in writing, through a document called a Power of Attorney for Personal Care.


How Do I Create a Power of Attorney for Personal Care?

A Power of Attorney for Personal Care document allows you to appoint a specific kind of substitute decision maker – Attorney for Personal Care – and give them the power to make decisions about all aspects of your personal care, unless stated otherwise. Aspects of personal care include health care, shelter, clothing, nutrition, hygiene and personal safety.

A Power of Attorney for Personal Care must be signed and dated by you and two witnesses, all in the presence of each other, in order to be valid. These witnesses can be anyone except for the substitute decision maker, his or her spouse/partner or your spouse/partner or child. In addition, the witnesses must be over 18 years of age. In order to sign a Power of Attorney for Personal Care, you need to be capable of doing so, understanding what it means. A Power of Attorney for Personal Care is only used if you become incapable of making decisions on your own.

You are able to appoint more than one substitute decision maker. You can direct these SDMs to make decisions either jointly or separately for different aspects of personal care. For example, one Attorney of Personal Care may be responsible for your shelter, clothing and nutrition while another is responsible for direct health care. You can also name an alternate or back-up (secondary) substitute decision maker in the event that your first one becomes incapable of making a decision themselves. As long as you are capable, you can create a new Power of Attorney for Personal Care and revoke or change who you have named as your Attorney for Personal Care.

While you do not need a lawyer to help prepare a Power of Attorney for Personal Care, it may be helpful to consult one to help explain your options and help prepare the documents. No special forms are necessary, but you can obtain a Power of Attorney for Personal Care form free of charge from the Office of the Public Guardian and Trustee (see Resources on page 8).

What is the Difference Between a Power of Attorney for Personal Care and a “Living Will”?

A “living will”, also known as an “advance care directive”, is a document that is used to record your care wishes so that your substitute decision maker can refer to it if they have to make care decisions for you in the future. A Power of Attorney for Personal Care may be used for the same purposes as a “living will” but it also appoints or identifies your substitute decision maker. If you create a living will and use it to name someone as your substitute decision maker, it may be a Power of Attorney for Personal Care but only if it meets legal requirements – it is in writing, signed and dated by you and witnessed by two people.

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Can an Attorney for Personal Care Also Make Decisions About a Person’s Finances and Property?

An Attorney for Personal Care only makes decisions surrounding your personal care. Sometimes these decisions may have to take your finances into account. However, a person can only have authority over your finances and property if you name them on a different legal document called a Continuing Power of Attorney for Property.

What Happens if I Do Not Assign a Substitute Decision Maker Through a Power of Attorney for Personal Care?

Ontario law does not ensure that there will be substitute decision maker to make all of your personal care decisions for you unless you appoint an Attorney for Personal Care. However, the law does ensure there will always be a substitute decision maker to make some health decisions for you. This only includes decisions about the following:

- Health care (e.g. treatments),
- Admission to a long-term care home and
- Personal assistance services to be received in a long-term care home.

If you do not appoint a substitute decision maker through a Power of Attorney for Personal Care, your health provider must look to the hierarchy of substitute decision makers named in the law to make decisions about the above. The highest-ranking individual who is available, capable and willing to make these decisions will become your Substitute Decision Maker. The hierarchy is as follows:

1. Guardian appointed by the court with authority for health care decisions
2. Attorney for personal care
3. Representative appointed by the Consent and Capacity Board
4. Your spouse, common-law spouse or partner
5. Your child (if they are over the age of 16) or parent
6. Your parent with right of access only
   - Custodial parents rank ahead of non-custodial parents
7. Your brother or sister
8. Any other relative by blood, marriage or adoption
9. The Office of the Public Guardian and Trustee
   - The provincial Public Guardian and Trustee is the Substitute Decision Maker of last resort if there is no other person to act for you.

If there are two or more persons (for example two sisters and one brother) in the same subsection of the hierarchy, they may share the decision-making responsibility or may choose to appoint one substitute decision maker. If there is a disagreement among equally ranked decision makers that cannot be resolved, the Office of the Public Guardian and Trustee may be asked to make the decision.
If you have not appointed a substitute decision maker, anyone, including your family or friends, can apply to the Consent and Capacity Board (Phone: 1-800-461-2036) to become your substitute decision maker for medical treatment, admission to a long-term care facility and personal assistance services in a long-term care facility. They do not have to pay anything to do this. This is known as your board-appointed representative. A board-appointed representative ranks above your spouse, partner and other family members in the hierarchy of substitute decision makers named in the law.

If you have not appointed a substitute decision maker, almost anyone, including family members and friends, can apply to the Superior Court of Ontario to be appointed as your Guardian of the Person with Authority for Treatment. Like an Attorney for Personal Care, a Guardian of the Person may be authorized to make the full range of personal care decisions for you, in keeping with your known wishes.

Resources

- **Health Care Consent Act, 1996**
  [http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm)
- **Substitute Decision Act, 1992**
- Ontario Seniors’ Secretariat’s A Guide to Advance Care Planning
- **Mental Health Act**
  [http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90m07_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90m07_e.htm)
- **Office of the Public Guardian and Trustee**
  **Phone:** (416) 327 -6683
- **Consent and Capacity Board**
  [www.ccboard.on.ca](http://www.ccboard.on.ca)
  **Phone:** 1-800-461-2036
- **Erie St. Clair CCAC Website**
  [www.healthcareathome.ca/eriestclair](http://www.healthcareathome.ca/eriestclair)
The Erie St. Clair Healthline helps connect caregivers, patients and community members to health and social services in the communities of Chatham-Kent, Sarnia-Lambton and Windsor-Essex. A database of all health services in the community, the Erie St. Clair Healthline is a comprehensive source for all residents in the Erie St. Clair LHIN.

Users can simply visit the site - eriestclairhealthline.ca - choose their region and search for health services in their community, from prenatal classes to walk-in clinics to retirement homes. Each service or organization has a profile that will provide users with a variety of information, including the organization’s address, phone number and website.