Resources

- **Consent to care**
  quebec.ca/en/family-and-support-for-individuals/incapacity-loss-independance/consent-care-incapacity
- **Advance medical directives**
  Advance medical directives | Gouvernement du Québec (quebec.ca)
- **Educaloi**
  educaloi.qc.ca/en/publications/caregivers-practical-legal-tools
- **L'Appui**
  lappui.org/fr/je-suis-aidant/
- **Ligne Info Notaire**
  1-800-notaire (668-2473)
- **Portail Santé Montérégie**
  Palliative and end-of-life care
- **Advance care planning**
  advancecareplanning.ca
- **Palliative care**
  Palliative care: Preparing and deciding - Canada.ca

santemonteregie.qc.ca/ouest

Centre intégré de santé et de services sociaux de la Montérégie-Ouest
Québec

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Centre intégré de santé et de services sociaux
de la Montérégie-Ouest

Your loved one's advance care wishes

Reflection and decision-making guide

TO BETTER GUIDE YOU

Québec

As a loved one's illness progresses, questions and decisions about their care and treatment will become more and more common. There may come a time when they need someone to help them—and sometimes even make decisions for them.

As an illness progresses to an advanced or terminal stage, this could trigger conversations and reflections about palliative care and end-of-life care. Making decisions for someone else when they are no longer able to give consent can be difficult and may raise concerns or uncertainties.

Caring for a loved one comes with many different challenges. Did you know there are resources available to support you in this role? Visit lappui.org/fr/je-suis-aidant/ for more information.

Whether a person is healthy or facing a serious illness, having early discussions about their values, wishes and preferences can help prepare for any situation, making decisions easier when the time comes.

This document provides various tools to help guide conversations and decisions about end-of-life care. Its purpose is to clarify certain concepts to:

- Enhance understanding of key healthcare concepts;
- Support reflection and decision-making about end-of-life care using the recommended tools;
- Ensure the person's wishes are respected.

As the care team, we are here to support you in making decisions for your loved one, including end-of-life planning. We encourage you to share any thoughts and wishes they have expressed with us, especially if they are no longer able to do so themselves.

Let's start by clarifying some key concepts

Consent

Consent to care: Expression of the person's wishes regarding an act to be performed by the care team.

Consent to care and services must be **voluntary** and **informed**.

- **Voluntary consent:** Without any form of pressure or discrimination by the professional, caseworker, person's family or loved ones. The person gives their consent with complete confidence.
- **Informed consent:** Having all the appropriate and necessary information, which they understand, and having been informed of the consequences of their consent, the user consents with full knowledge of the facts.

Capacity or ability to give consent

You are considered capable of consenting to a medical treatment if you can understand:

- the information necessary to make a decision about your treatment;
- the consequences and risks associated with your decision.

A person may be capable of making certain decisions (e.g., deciding what they want to eat or drink) while being incapable of making others (e.g., consenting to surgery). The ability to give consent can also vary from day to day.

The health professional giving the treatment is responsible for determining whether the person is capable of giving consent.

Civil Code of Québec, sect. 10, 11, 13, 15 and 16
legisquebec.gouv.qc.ca/en/document/cs/CCQ-1991

Representative

User representative: A designated person who is authorized to give consent to care in the event your loved one is incapable of doing so because of their state of health.

When do you need a representative?

When your loved one is deemed to be incapable of giving consent to care.

What is the role of the representative?

Making decisions in the best interest of your loved one.

Who can be a user representative?

1st: Your tutor or mandatary

2nd: A married, civil union or *de facto* spouse

3rd: A close relative or a person who shows a special interest in the person of full age (*Civil Code of Québec*, Article 15)

Reflection and decision-making

1. When the person is CAPABLE of giving consent

When the person is capable of giving consent, they have the right to make their own decisions and express their wishes. The capacity to give consent is not based on whether the decision is considered good or bad, but rather on the person's ability to understand.

Even when a person is capable, open discussions between the person concerned, their loved ones, and their designated representative are important to ensure future decisions align with their wishes in the event they become incapable.

Whenever possible, it is best to prepare for health-related situations that may require decisions to be made. The following questions can help initiate reflection and discussions about health-related situations. Some topics may be sensitive, so we encourage you to use your own words when asking the person:

- What is their understanding of their current and future health condition?
- What information would they like to receive about their health condition?
- What values, beliefs, and priorities would guide their decisions?
- Have they documented their wishes in a formal document?
- Have they designated a representative or a mandatary?
- If their illness were to progress to the end-of-life stage, what would be most important to them?
  - What are the medical procedures they would agree to or refuse (e.g., resuscitation, feeding tubes, dialysis)?
  - At what point would they want to receive only comfort care and end-of-life care?
  - Do they have any concerns or wishes about end-of-life care?

2. When the person is INCAPABLE of giving consent

When a person becomes incapable of giving consent, their designated representative will make decisions on their behalf, based on the wishes they previously expressed. These decisions are often easier when you have discussed them with the person in advance. However, if you have not discussed anything ahead of time, you will have to make decisions to the best of your ability, based on what you know of their wishes.

Before meeting with the doctor and care team to discuss decisions and options, you may find it helpful to reflect on the following:

- Have they documented their wishes in an official document?
- Who is their designated representative or mandatary?
- What is your understanding of their current and future health condition?
- What information would you like to receive about their health condition?
- If they could decide for themselves, what would they choose?
- Have they ever talked about their wishes with respect to medical care or end-of-life decisions? (e.g., resuscitation, feeding tubes, transfusions, dialysis)
- At what point would they want to receive only comfort care and end-of-life care?
- Have they ever expressed concerns or wishes about medical care or end-of-life care? (e.g., pain management, loss of independence)
- Would you be able to advocate for their wishes, even if they differ from your personal choices?

Recommended tools to support reflection and decision-making

Advance care planning

Goal: Thinking about and writing down wishes

Website: advancecareplanning.ca

Advance care planning is a process of reflection and discussion about a person's values, opinions, and beliefs surrounding their end-of-life care.

This website contains various tools that can help you have discussions with the person concerned or help you consider what they might say if they were capable of giving consent. These questions and reflections can help you gain a clearer understanding of the person's wishes. We encourage you to explore these resources to better guide you and your loved one through the reflection process.

Advance medical directives

Purpose: To ensure health professionals and loved ones respect your wishes in specific medical situations

Website: québec.ca and enter "advance medical directives" in the search bar

Important

Has the person receiving care written their advance medical directives? If so, please inform the doctor and the care team.

There are several ways to express your wishes about the type of medical care you want to receive, including talking to loved ones or hiring a notary to prepare a formal document (e.g., a living will or other document).

In Québec, a legally binding document forces loved ones and care providers to respect the wishes of the person who completed it. The "Advance medical directives" form allows individuals to state in advance which of five specific medical treatments they would accept or refuse in certain clinical situations.

Clinical situations	Items of care
• End-of-life situation: a serious and incurable medical condition, end-of-life patient. • Situation in which cognitive functions are severely and irreversibly compromised: an irreversible coma or a permanent vegetative state • Other situation in which cognitive functions are severely and irreversibly compromised, with no possibility of improvement (e.g., advanced-stage Alzheimer's-type dementia or other type of dementia).	• Cardiopulmonary resuscitation • Ventilator-assisted breathing or breathing assisted by another device • Dialysis • Forced or artificial feeding • Forced or artificial hydration

Important

Only a person of full age who is capable of giving consent to care can complete their advance medical directives. These directives will be used only if the person becomes incapable.

Individuals who wish to document their advance medical directives can do so:

- By filling out the Advance Medical Directives in Case of Incapacity to Consent to Care form:
  - available from the Régie d'assurance maladie du Québec (RAMQ) at 1-800-561-9749 (toll-free) | ramq.gouv.qc.ca
  - in a notarial deed whose content is the same as that of the advance medical directives (fees apply).

Levels of care and cardiopulmonary resuscitation

Purpose: To determine care and treatments with the care team

Website: santemonteregie.qc.ca and enter "levels of care" in the search bar

This document is used during healthcare discussions to outline treatment objectives, including decisions about cardiopulmonary resuscitation. It helps guide conversations when determining suitable medical treatments. The decisions made during this discussion will be recorded in a formal document and placed in your medical record. A copy may be given to you.

During this conversation, the doctor will discuss different care options with the person and their designated representative in case of incapacity:

1. Do they want to be resuscitated if they have a cardiac arrest? You must answer "yes" or "no" to these questions.

Attempt CPR	☐ Yes	☐ No
Attempt emergency intubation	☐ Yes	☐ No

2. What level of care would best align with the person's wishes? You must choose the most appropriate level of care for the person.

Level of care	Description
Goal A Prolong life with all necessary care	The care team will perform all medically appropriate interventions, and if an intervention cannot be performed onsite, they will transfer your loved one to another hospital.
Goal B Prolong life with some limitations to care	Care incorporates interventions with the aim of correcting deterioration in health status while preserving quality of life.
Goal C Prioritize comfort over prolonging life.	The care provided focuses first and foremost on making your loved one comfortable by relieving their symptoms. Interventions to correct certain reversible health problems may also be used.
Goal D Ensure comfort without prolonging life	The care provided focuses essentially on making your loved one comfortable and relieving their symptoms.

If there is a change in their health condition, the doctor will adjust the care based on the person's choices, or on the designated representative's decisions if the person in incapable.

Decisions about levels of care and cardiopulmonary resuscitation (CPR) are not final. The person or their representative can change their mind and their decisions at any time. After they have spoken to the doctor, the old form will be replaced with a new one reflecting the updated wishes. This process does not replace verbal consent to care.

Condition with a guarded prognosis

If you are facing a progressive or serious illness, the Government of Canada website contains valuable information to help you start thinking about and preparing for palliative care. This site explains the general concepts of palliative care, including important questions to ask your care team to better understand your condition and what to expect moving forward.

See:

- Palliative care: Preparing and deciding - Canada.ca
- Three sets of questions to ask your health care team - Canada.ca

To learn more about palliative and end-of-life care resources at the CISSS de la Montérégie-Ouest, we encourage you to consult the Palliative and end-of-life care brochure.

In summary

Reflections and discussions are important at every stage of life. Keep in mind that various health events may require adjustments in care plans. It is important to review these decisions periodically.

Regardless of your questions, reflections, or the decisions you need to make, your doctor and care team are here to support you.

References:

- *Civil Code of Québec*, Article 15, 1991, c. 64, a. 15; 2002, c. 6, a. 1; 2014, c. 2, a. 67; 2020, c.11, a. 254.
- Politique clinique - Consentement aux soins et aux services POL-10251 (2021-09) CISSS de la Montérégie-Ouest

Key concepts

Feeding and hydration (artificial): When a person can no longer eat or drink, fluids or food may be given through an intravenous infusion or a feeding tube placed in the stomach.

Tutor: A person appointed by the court to care for or manage the patrimony of an incapable user.

Intubation and ventilator-assisted breathing: When a person is unable to breathe on their own, a breathing tube (intubation) is inserted in their lungs through their mouth. This tube is connected to a ventilator, which breathes for the person (ventilator-assisted breathing).

Mandatary: A person designated to represent an incapable user in a protection mandate.

Protection mandate: A legal document that allows someone to make decisions on behalf of an incapable user.

End-of-life plan: A document or set of reflections outlining personal preferences and wishes to guide loved ones and health professionals in providing palliative care.

Guarded prognosis: Unfavourable prognosis related to the progression of a disease or the severity of injuries, suggesting that the person's long-term chances of survival are uncertain.

Cardiopulmonary resuscitation: A procedure aimed at restoring normal breathing after cardiac arrest, involving airway clearance and chest compressions.

Comfort care: Care provided when curative treatments are no longer effective. Medications or non-invasive treatments are used to ensure comfort. A person receiving comfort care is not necessarily at the end of their life.

End-of-life care: Care provided in the final weeks or days of life, focusing on relieving discomfort and ensuring well-being.

Palliative care: Combination of treatments provided by an interdisciplinary team for individuals with a guarded prognosis. Palliative care aims to relieve physical, psychological, and spiritual suffering without hastening or delaying death. It supports maintaining the best possible quality of life and provides necessary assistance to both patients and their loved ones [Gouvernement du Québec, 2017]. Palliative care includes its final phase: end-of-life care.