



Rights of a person at the end of life

Act Respecting
End-Of-Life Care

Rights of a person at the end of life

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Masculine pronouns are used generically in this document.

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The Act Respecting End-of-Life Care

The Act Respecting End-of-Life Care sets out the rights of a person at the end of life and governs the organization and supervision of end-of-life care. It covers:

- / palliative care, including continuous palliative sedation;
- / medical aid in dying;
- / advance medical directives.

Palliative care

Palliative care means all the treatment and care given by health professionals to a patient suffering from a serious, incurable disease (with reserved prognosis) in order to lessen their symptoms and relieve their suffering. Without delaying or hastening death, palliative care enables a person at the end of life to maintain the best possible quality of life, providing them with physical and moral comfort, and giving them and their loved ones the support they need.

In complex situations, it may be impossible to relieve the suffering of a person at the end of life through normal palliative care. The use of **continuous palliative sedation** may then be considered as a treatment option. Continuous palliative sedation is a palliative treatment consisting of administering medication or substances to a person at the end of life to relieve their suffering by keeping them unconscious until death comes.

Medical aid in dying

Medical aid in dying is a treatment that can be requested by a person at the end of life to relieve their suffering by hastening death. The use of medical aid in dying is governed by stringent conditions set out in the Act and is administered in exceptional situations.

Advance medical directives

Advance medical directives are a written document in which a person of full age who is capable of giving consent to care indicates in advance the medical care and treatment that they agree or refuse to receive, in specific clinical situations, in the event that they should become incapable of giving consent to care. Advance medical directives are binding, meaning that health professionals that have access to them, and those close to the person, are obliged to comply with them.

Rights of end-of-life patients

Every action taken towards a person at the end of life must be imbued with respect for them and recognition of their rights and freedoms.

A person at the end of life must at all times be treated with understanding, compassion, courtesy and fairness, with respect for their dignity, autonomy, wishes, needs, and safety. In addition, members of the care team responsible for an end-of-life patient must establish and maintain open, honest communication with them.

Right to receive end-of-life care

A person at the end of life has a right to receive the care and treatment required by their state of health and to have access to quality care in accordance with their needs, particularly to prevent and relieve their suffering.

End-of-life care is provided in institutions in the health and social services network, and in palliative care hospices and at home. Every institution or palliative care hospice must have a policy on end-of-life care specifying the nature and extent of care provided under its roof. It is important that end-of-life patients and those close to them consult this policy before choosing the place where they will receive care.

Also, institutions in the health and social services network and palliative care hospices are obliged to provide any person at the end of life with a private room in the final days leading up to their death.

Medical aid in dying

Only a person of full age and capable of giving consent to care may request to receive medical aid in dying. No other person can do so for them. In addition, an end-of-life patient must meet all the criteria set out in the Act in order to obtain medical aid in dying.

Right to refuse or withdraw consent to care

Any person of full age who is capable of giving consent to care, whether at the end of life or not, has the right to refuse a treatment or to request that a treatment be stopped. This includes the choice of being fed, of being artificially hydrated, or of receiving palliative care. Regardless of the reason for their decision, a person has the right to refuse treatment, even if this risks shortening their life. A person's right to receive end-of-life care cannot be denied because they previously refused to receive certain care or withdrawn consent to certain care.

Right to be represented

In order to receive care, any person must give their free, informed consent to health professionals. When a person becomes incapable of giving consent to care, they can no longer take decisions regarding the care that their state of health requires. In this case, someone else may consent to care on their behalf. This someone can be their legal representative (mandatory, tutor or curator), a close relative (for example their spouse), or a person who can demonstrate that they have a particular interest in them. In all circumstances, this person must act in the interests and, as far as possible, comply with the wishes that the patient expressed when they were capable of doing so.

Right to express wishes for care

Any person, whether at the end of life or not, has the right to express their wishes for care in the event of incapacity to consent to care. They can do this by:

- / verbally informing those who are close to them of their wishes for care;
- / writing a living will;
- / writing down their wishes on a sheet of paper, dating it and signing it;
- / recording a video in which they express their wishes;
- / making a mandate given in anticipation of the mandator's incapacity;
- / expressing their wishes in a discussion with a doctor, who will record them in a levels of medical intervention form;
- / expressing their wishes through advance medical directives.

Commission sur les soins de fin de vie

The *Commission sur les soins de fin de vie* (commission on end-of-life care) exists to examine any matter relating to end-of-life care. Specifically, its mandate is to:

- / evaluate the implementation of legislation with regard to end-of-life care;
- / ensure that the particular requirements concerning medical aid in dying are complied with;
- / refer any matter relating to end-of-life care that requires the attention of or action by the government to the *Ministre de la Santé et des Services sociaux* and make recommendations to the Minister.

Persons at the end of life and those close to them can at any time file a complaint regarding treatment or service received in the health and social services network with a Service Quality and Complaints Commissioner, or regarding treatment or service received from a physician outside the health and social services network with the Collège des médecins du Québec. Complaints relating to end-of-life care will be dealt with as a priority.



For more information on the Act Respecting End-of-Life Care, go to the *Portail santé mieux-être* at **sante.gouv.qc.ca**.

For any other question about palliative and end-of-life care or about advance medical directives, call Services Québec:

Québec City area: 418-644-4545

Montréal area: 514-644-4545

Elsewhere in Québec: 1-877-644-4545 (toll-free)

Persons with a hearing or speech impairment (TTY):
1-800-361-9596 (toll-free)