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Québec 

# Legislation Regarding End of Life Care

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2015-11-16

For the purpose of this session, the masculine form is used merely to simplify the text. No discrimination is intended.

# Purpose

- Ensuring that end of life care is respectful of their dignity and autonomy by **clarifying the rights of individuals**;
- Recognize the **importance of clearly and freely expressed wishes of the person** including the implementation of medical directives.

# Legislation Regarding End of Life Care

- The purpose of the law is to improve palliative care and end of life services. In this perspective, we can also offer the possibility of continuous palliative sedation and medical assistance to die.

# Rights regarding to end of life care

- The Right of everyone to end of life care, is subject to the requirements of the law and taking into account the functioning of the institutions, the guidelines, policies and approaches to the palliative care facilities as well as human, material and financial resources available to them;
- The right of any adult person apt to give consent to care may at any time:
  - **refuse treatment** that is necessary to stay alive
  - **or withdraw his consent** to such care.

# Rights regarding to end of life care (cond't)

- **Forbidding a person to be denied end-of life care** on the grounds that he had previously refused to receive care or that he withdrew its consent to care.

# Providers of palliative care and end of life

- **Establishments** that are operating a CLSC, a hospital or a long-term care residence, must provide end of life care;
- **Palliative care Residences:** can determine the type of end of life care & services to offer within their walls;
- **Private clinics:** doctors who practise in private clinics (or nurses within the limits of their competencies) can provide end of life care at home.

# Anticipated Medical Directives (AMD)



# Forms of expression of free will in anticipation of incapacity to consent to care

- Verbally communicate his wishes of care to close ones.
- Writing a living will.
- Express his wishes following a discussion with a health professional (medical intervention level).
- Make a mandate in anticipation of incapacity.
- **Complete the AMD forms.** (Anticipated Medical Directives) (in French: Directives médicales anticipées (DMA))

# Definition of AMD

- Written document by which an adult person that is apt to receive care expresses in advance the medical care that he accepts or refuses in case that he becomes unfit to consent to receive care.

# Particulars

- Opportunity to express his wishes without prior discussion with a health care professional.
- Same value as the wishes expressed by an apt person, so the consent of a representative is not necessary.
- It is binding, health professionals must abide by them.
- Limited to specific clinical situations and specific care.
- Priority over all other forms of expression of will.

# Targeted Clinical Situations

Clinical situations that are frequently encountered in which health professionals are questioning the relevance of some care, even if they might be necessary for the maintenance of life.

## End of life situation

- Serious medical condition, incurable, at the end of life.

## Situation of severe and irreversible cognitive impairment

- Comatose state considered irreversible or;
- Persistent vegetative state.

## Other situation of severe and irreversible cognitive impairment

- Stricken with severe and irreversible cognitive dysfunctions, without the possibility for improvement (e.g. dementia such as Alzheimer's or other type of dementia at an advanced stage).

# Targeted Care

- Cardiopulmonary resuscitation
- Ventilation assisted by a respirator or any other technical support
- Dialysis
- Forced nutrition and hydration
- Artificial nutrition and hydration

Regardless of the wishes of the person at the end of his life, the necessary care to ensure his comfort will be given, among other things the relief of suffering.

The wishes expressed in the AMD do not influence the temporary measures for maintenance of the vital functions which are necessary for organ donation, where the person at the end of life would have consented thereto.

# AMD Declaration Procedure

## Form approved by the Minister

- Obtain the form by calling the Régie de l'assurance maladie du Québec (RAMQ).
- By Mail, sent by the RAMQ.

When the form is completed and signed, it is possible to :

- Return the form by mail to the RAMQ, to be filed in the registry;
- Give the form to a health care professional, which will be placed in the user's medical file.

## By notarial Act

It is possible to express the AMD to a notary and then :

- Filed in the AMD registry;
- Give the form to a health care professional to be placed in the medical file.

# Modification and revocation

## Modification of the advance medical directives

It is always possible to modify the AMD, as long as the person who expressed them is able consent to care, by completing a new **form of advance medical directives** and sending to the RAMQ to be filed in the ADM registry, or by leaving it with a health care professional to place in the medical file.

## Revocation of the anticipated medical directives

It is always possible to cancel an AMD, as long as the person who expressed them is able consent to care, by completing the **revocation of advance medical directives form** obtained by calling the RAMQ.

# Responsibilities

## Doctors who require consent to commence or continue administration of care

- Place the AMD documents in the person's medical file. (Article 55)
- Validate with the person for which there is a significant health change, if his wishes expressed in his AMD documents still corresponds. (Article 56)
- When the doctor finds the person is now incapacitated, he must first consult the AMD registry. If the document is located in the registry, it must be removed and put in the user's medical file.
- If the AMD cannot be located, ask the relatives of the person who is unable to consent to care, if he ever expressed this wish.

# Continuous Palliative Sedation



# Definition of Continuous Palliative Sedation

Continuous palliative sedation is a treatment offered in the context of palliative care, consisting of administering drugs to a person at the end of life at the request of the person in question or by a loved one, to relieve the suffering by making the person unconscious until his death. (Article 3). The drugs are administered at the hospital, at a palliative care facility or at home.

# Legal Framework

## The Physician

- The physician should inform the patient or the person apt to consent on his behalf of the prognosis of the illness, the irreversible character of this treatment and the anticipated duration of sedation. (Article 24)
- The physician should ensure that the will of the patient is not influenced by external pressures. (Article 24)

# Legal Framework

## Consent

- The consent must be given by the user or by a person apt to consent for him.
- The form prescribed by the Minister must be used and should be filed in his medical file.
- An authorized third party can sign the consent instead of the patient.

# Legal Framework

## Authorized Third Party

An authorized third party can fill the application form for the continuous palliative sedation.

- If the person at the end of life cannot date or sign the consent form:
  - because he does not know how to write;
  - because physically he is unable to.

# Legal Framework

## Authorized Third Party

The third party must not be:

- part of the medical care team;
- minor;
- unfit adult.

# Administration of Continuous Palliative Sedation

## Professionals involved

The following professionals may administer the continuous palliative sedation:

- Doctor
- Nurse
- Pharmacist

# Medical Assistance to Die



# Definition of Medical Assistance to Die

- The law regarding end of life care defines the “*medical assistance to die*” as a medical act consisting of the administration of drugs or substances by a doctor to a person at the end of life, at his request, to relieve suffering by causing death. (Article 3 (6))

# Context

## Medical Assistance to Die

- “*Medical Assistance to die*” (MAD – or in French AMM) arises from the law regarding end of life care.
- The law includes the introduction of the MAD as a possible treatment in specific and well defined circumstances.

# Context

## Medical Aid to Die (cond't)

- With regard to medical assistance to die, in particular, the law has very restrictive conditions that a person must meet. Whether they are in a hospital, hospice or at palliative care residence, as well as at home. There are also several procedures that doctors and health organizations must respect.
- The End of Life Care Commission has a mandate to monitor the implementation of these specific requirements (Article 42 para. 2).

# Special Conditions

- Collaboration of three professional Orders :
  - Quebec College of Physicians;
  - Quebec Order of Pharmacists
  - Quebec Order of Registered Nurses
- As the medical assistance to die is a new practice, the authors of this guide first referred to the guidelines and current practices in the European countries which have authorised euthanasia in the 2000s (the Netherlands, Belgium and Luxembourg). Afterwards they consulted experts and organizations of the health network and social services of Quebec in order to specifically adapt their guidelines to the provincial context.

## Definition (cond't)

- Using this definition, the law strictly defines medical help to die; it clearly fits in a context of end of life care.
- It requires that the act be performed by a physician.
- It imposes the need to respect the autonomy of the individual.
- It limits the medical help to die to a single purpose: to put an end to the suffering of a terminally ill person by intentionally administering medication that will cause his death.

# Distinction between MAD and assisted suicide

- Medical assistance to die also differs from assisted suicide (medically or not), which is defined as the act of helping someone to voluntarily die by providing the means to commit suicide or information on how to proceed, or both, (Quebec, the Special Commission Report: *Dying with Dignity*, 2012, p. 18). Assisted suicide means that the doctor would provide lethal substances that the person administers to himself.
- The medical assistance to die is clearly distinguishable from assisted suicide because the act must be performed by a physician, in the end of life care context. Following the debate within Quebec, the option of assisted suicide, medical or not, was not retained. Indeed, the medical assistance to die was considered preferable from the perspective of end of life care.

# Special Conditions

- The law provides for such conditions as to make **the *medical assistance to die*** an exceptional practice.

## ARTICLE 26

- 1° a person covered, as per the law, by the RAMQ Act (chapter A-29);
- 2° He is of age of majority and capable to consent to care;
- 3° He is at the end of life;
- 4° He is suffering from a serious and incurable disease;
- 5° His medical condition is characterized by an advanced and irreversible decline of HIS capacities;
- 6° He experiences constant and unbearable physical or mental suffering, which cannot be alleviated to tolerable levels.

# Special Conditions(cond't)

- The person of free mind and in an enlightened manner requests for *medical assistance to die* by using the form prescribed by the Minister.
- This form must be signed and dated by the patient, in the presence of a health professional or social worker who will also sign. If the health professional is not the attending physician, the document will be given to him.

# Information

For more information:

The Government will provide guidelines through MCDC and as of December 10, contact your CLSC for further information.

Website: <http://www.agencecss12.gouv.qc.ca/services-offerts/maladie-chronique-ou-cancer/>



