

<b>SUBJECT:</b>	END OF LIFE CARE POLICY
<b>TO:</b>	Physicians Healthcare professionals involved in end of life care Clinical Direction Managers CIUSSS West-Central Montreal users
<b>FROM:</b>	Professional Services Directorate Nursing Care administration
<b>APPROVED BY:</b>	
References:	-Law concerning end of life care -Palliative care and end of life, Development plans and end of life 2015-2020, MSSS - Assisted death, Guide, CMQ, 2015 - Palliative sedation at end of life, Guide, CMQ, 2015 - Support document for healthcare professionals – Anticipated medical directives, MSSS, 2015

## 1- GENERAL PROVISIONS

### 1.1 Subject

The *Loi concernant les soins de fin de vie (Law concerning end of life care)* requires that every facility adopt a policy concerning end of life care. This policy must consider the ministerial approaches and be distributed to the staff of the facility, to the healthcare or social services professionals working in the facility, to individuals at end of life and to their next of kin (art. 8).

### 1.2. Ministerial Orientations

The Minister determines the approaches the CIUSSS must consider in providing end of life care, including those that the facility must consider during the development of the End of life care policy (art. 19).

### 1. 3. Values and guidelines

The following values and guidelines derive from the Law concerning end of life care and the End of life care policy. They were also taken into consideration in the 2015-2020 MSSS Palliative and end of life care development plan.

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### 1.3.1 Values

The following three fundamental values must guide all services provided in palliative and end of life care in Quebec:

- The respect of the intrinsic value of each person as a unique individual, the respect the individual's dignity as well as the recognition of the value of life and the inevitable character of death.
- The involvement of the individual in any decision concerning him or her; to this end, there must be a free and informed consent given to any decision, respecting the individual's autonomy. Depending of their request, each person is informed of everything concerns him or her, including their true condition, and the respect that will be given to their choices.
- The right to truly compassionate services from healthcare professionals, respecting the values that give a sense to the existence of the individual and that take into account the culture, religious beliefs and practices, including those of the next of kin.

### 1.3.2 Guidelines

Four guidelines arise from these shared values to direct the actions of the CIUSSS Managers and professionals:

- The individual presenting a disease with guarded prognosis must be able to count on the support of the healthcare and social services network to provide proximity services within its community.
- The palliative and end of life care are part of a continuum of care where the needs and the choices of individuals are at the heart of the planning, organisation and service delivery, to provide a quality accompaniment, adapted to the condition of the individual at end of life, in a collaborative approach.
- Maintain and support individuals until the end of their life in their community, if this is what they wish and if their condition allows it, must be a priority.
- It is essential to provide the next of kin with the support, both physical and mental, they need as this is a fundamental element of the approach recommended.

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## 2- DÉFINITIONS

### 2.1 Users

Any individual receiving healthcare or social services in one of the facility of the institution or at home.

### 2.2 Next of kin

Any person of the entourage who provides significant continuous or occasional support as a non-professional, to an individual with decreasing independence is considered a natural caregiver. It can be a member of the family or a friend.

### 2.3 Capacity to consent to care

Capacity of an individual to understand the nature of the disease for which an intervention is offered, the nature and the objective of the treatment, the risks and the advantages of said treatment, whether they receive it or not.

### 2.4 Rescinds of treatment

The cessation of care or treatment susceptible to maintain life.

### 2.5 Refusal of care

The refusal to receive care, a treatment, an intervention or to live in a health centre.

### 2.6 Guarded prognosis

Unfavorable provisions linked to the evolution of a disease or to the severity of injuries, according to which the chances of medium to long term survival of the patient are compromised.

### 2.7 Palliative care

Active and global care received from an interdisciplinary team by individuals suffering from a guarded prognosis disease, with the objective of alleviating the suffering without hastening or delaying death, of helping them have the best quality of life possible and providing them and their next of kin with the support they need.

### 2.8 End of life care

Palliative care provided to individuals at end of life and medical help to die.

### 2.9 Continuous palliative sedation

A possibility offered within palliative care, consisting of administering medication or substances to an individual at the end of life with the objective of alleviating the suffering by maintaining a continuous state of unconsciousness until death.

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### **2.10 Medical help to die**

A treatment consisting in the administration of medication or substances by a physician to an individual at end of life, at that individual's request, with the objective of alleviating the suffering by causing death.

### **2.11 Advanced medical directives (AMD)**

Instructions given by an individual with the capacity to consent about decisions concerning his or her care in the eventuality that he or she is no longer capable of making them. Through such instructions, an individual can also request medical help to die.

## **3- ROLES AND RESPONSIBILITIES OF THE CIUSSS**

### **3.1 Information to users**

The Internet site of the CIUSSS will contain the following information:

- The Code of ethics
- The End of life care Policy
- The Clinical palliative and end of life care program

The citizen guide to medical help to die will be given to individuals requesting medical help to die.

### **3.2 Offer of service**

Palliative and end of life care must be provided to users, regardless of the pathology, and across every healthcare environment, in accordance to legislative provisions.

The transfer to various CIUSSS facility of individuals who cannot receive end of life care at home will be done according to the transfer procedure developed.

When an individual at end of life requests end of life homecare from one of our facilities, but that the condition or the environment of that individual does not allow for such care to be provided, the CIUSSS must offer an accommodation in one of its facility or direct him or her to another facility (art. 11).

The CIUSSS has implemented measures to promote interdisciplinarity between various healthcare or social services professionals and the collaboration of various concerned parties providing services to its users (art. 7). To meet this objective, an intra CIUSSS work group has started to work on this mandate. (ISG : interdisciplinary support group)

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### 3.3 End of life care clinical program

The form of end of life care provided in all CIUSSS facilities are:

- Palliative care provided to individuals at end of life.
- Medical help to die.
- Access to continuous palliative sedation.
- Distribution of the information to beneficiaries and to their next of kin regarding the advanced medical directives and the implementation of mechanisms giving access to these directives to the CIUSS team of caregivers.

### 3.4 Structure of governance:

- CIUSSS end of life care stakeholder: Direction of professional services.
- End of life care program Comanager: Associate Director, direction of nursing care and Head of the palliative care division.
- The ISG reports to the Direction of professional services.

### 3.5 Code of ethics

The CIUSSS Code of ethics includes end of life care procedures, and it will be available to all users requesting it.

### 3.6 General direction

#### 3.6.1 Role of the President and CEO

Each year, the President and CEO of the CIUSSS must present a report to the board of directors on the application of this policy. In particular, the report must include the following:

- The number of individual at end of life having received palliative care.
- The number of continuous palliative sedation administered.
- The number of medical help to die requests received.

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- The number of medical help to die administered.
- The number of medical help to die refused and the reasons for which they were refused.

The report must also indicate, if needed, the number of continuous palliative sedation and medical help to die administered at home by a physician, as a physician practicing his or her profession within the CIUSSS.

The report is published on the Internet site of the CIUSSS and sent to the Commission<sup>1</sup> on end of life care instituted according to article 38, each year before June 30, at the latest. The facility must include a summary of this report in a special section of the management annual report (art. 8).

For two years following the implementation of the Law, the President and CEO of the CIUSSS must present his report to the board of directors every six month. The CIUSSS will send it to the Commission on end of life care and make it available to the public on its Internet site as early as possible (art. 73).

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<sup>1</sup> President of the Commission on end of life.  
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### 3.6.2 Role of the Council of physicians, dentists and pharmacists (CPDP)

Adopt clinical protocols applicable to continuous palliative sedation and to medical help to die. Such protocols must meet the clinical standards developed by the professional orders concerned.

Implement evaluation and follow-up mechanisms regarding the quality of care provided.

Must be notified by the physician providing the continuous palliative sedation.

Must also be notified by the physician about the administration of medical help to die through the form prescribed by the ministry within 10 days of the administration.  
(*Formulaire de déclaration de l'administration d'aide médicale à mourir Parties 1, 2 et 3 - DT9233 / Declaration of medical help to die administration form Parts 1, 2 and 3 - DT9233*)

### 3.6.3 Role of the Council of nurses

The council of nurses of the facility must work in collaboration with the CPDP for the adoption of clinical protocols applicable to the continuous palliative sedation and medical help to die (art. 33).

## 4- CONTINUOUS PALLIATIVE SEDATION

### 4.1 Conditions

Before consenting to continuous palliative sedation, the individual at end of life or, when appropriate, the person who can consent to care, must be informed of the prognosis regarding the disease, of the irreversible nature of this act and of the likely duration of the sedation. The physician must also ensure that the consent is given freely by verifying that it is not the result of external pressures (art. 24).

### 4.2 Consent

The consent to continuous palliative sedation must be given in writing on the form prescribed by the Minister (*Formulaire de consentement à la sédation palliative continue – DT9231 / Consent to continuous palliative sedation form – DT9231*) and kept in the medical file of the individual (art. 24).

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If the individual consenting to the continuous palliative sedation cannot sign the form, because he or she does not know how to write or is physically incapable of doing it, a third party can do it in the presence of this individual. The third party cannot be a member of the team caring for the individual, a minor or an incompetent person having reached the age of majority (art. 25).

#### 4.3 Declaration notice of the physician

The physician providing the continuous palliative sedation in a CIUSSS facility or at home must notify the CPDP within 10 days of the administration (art. 34).

### 5- MEDICAL HELP TO DIE

#### 5.1 Medical help to die request

The individual must formulate a free and informed medical help to die request through the form prescribed by the Minister. Said form must be dated and signed by the individual (Formulaire : *Demande d'aide médicale à mourir* – DT9232 / Form: *Medical help to die request* – DT9232).

The form must be signed in front of two witnesses (art. 241.2(5) of the Criminal Code) who understand the nature of the medical help to die request and in front of a healthcare or social services professional, who must countersign it, and if they are not the attending physician of the individual, will give it to said attending physician. (art. 26 of the Law concerning end of life care). A witness cannot be considered as being independent if he or she:

- Knows or believes that he or she would benefit from the testamentary estate of the individual making the request or receive a material benefit, including monetary, following the death of the individual.
- Is the owner or the operator of the healthcare facility where care is provided to the individual making the request or of the facility where this person is residing.
- Participates directly to providing healthcare services to the individual making the request.
- Provides direct personal care to the person making the request.

When the individual requesting the medical help to die cannot date and sign the form because he or she does not know how to write or is physically incapable of doing it, a third party can do it in the presence of this individual. The third party cannot be a

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member of the team caring for the individual, a minor or an incompetent person having reached the age of majority.

Furthermore, the authorized third party cannot know or believe that he or she would benefit from the testamentary estate of the individual making the request or receive a material benefit, including monetary, following the death of the individual. They must also understand the nature of the medical help to die request (art. 27 of the Law concerning end of life care and article 241.2(4) of the Criminal Code).

An individual can at any time and by any mean rescind its medical help to die request.

He or she can also, at any time and by any mean, request the postponement of the administration of the medical help to die (art. 28).

Any information or document linked to the medical help to die request must be indicated or added to the individual's file whether the physician performs the act or not, including the medical help to die request, the reasons supporting the physician's decision and, when appropriate, the opinion of the physician consulted.

The request to rescinded or postpone the administration of medical help to die must also be registered or added to the individual's file (art. 32).

## 5.2 Eligibility criteria

To obtain medical help to die, the individual must meet all the following criteria:

- Be insured within the meaning of the Health Insurance Act.
- Have reached the age of majority and be capable to consent to care.
- Be at the end of life.
- Suffer from a severe and incurable disease.  
Be in a medical situation characterised by an advanced and irreversible decline of capacities.
- Experience constant unbearable physical or psychological pain that cannot be alleviated in conditions deemed to be tolerable (art. 26).

## 5.3 Cases of conscientious objection

### 5.3.1 Physician

Any physician, practicing his or her profession within the CIUSSS, who refuses a medical help to die request on grounds not based on article 29 must, as soon as possible, notify the Director of professional services (DPS) and, when appropriate, forward him the medical help to die request form. The DPS must then take the necessary steps to find, as

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soon as possible, a physician that will accept to process the request in compliance to article 29.

If the request for medical help to die is refused by a physician practicing his or her profession in a private office, said physician must, as soon as possible, notify the Director of professional services (DPS) of the CIUSSS providing service in the territory where the individual formulating the request is residing, or notify the person he designated (art.31).

### 5.3.2 Other healthcare professional

A healthcare professional can refuse to participate in the administration of medical help to die for personal convictions. This person must notify his or her immediate superior.

However, the healthcare professional must ensure the continuity of care offered to the individual, in compliance to his or her Code of Professional Conduct and the wishes of the individual (art. 50).

### 5.4 Criteria evaluated by physicians

Prior to administering medical help to die, the physician must:

- Confirm the free nature of the request, by verifying among other things, that the request is not the result of external pressures.
- Confirm the informed nature of the request, including by explaining to the individual making the request the prognosis of the disease, the possible therapeutic options and their consequences.
- Confirm the persistence of the pain and the reiterated desire to obtain medical help to die, by conducting interviews at various moments and spaced over time, within a reasonable delay in light of the evolution of the disease of the individual.
- Discuss with the members of the team providing care who are in regular contact with the individual, if appropriate.
- Discuss the request with the next of kin, with the individual's permission.
- Ensure that the individual had the opportunity to talk about the request with the persons he or she wishes to contact.
- Obtain the opinion of a second physician to confirm that the conditions provided for in article 26 are met (Formulaire : *Avis d'un second médecin sur*

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*les respects des conditions pour obtenir l'aide médicale à mourir – DT9234 / Form: Opinion of a second physician regarding meeting the conditions required to receive medical help to die – DT9234).* (art.29). There must be a minimum delay of 48 hours between the first evaluation of the physician accepting to perform the act and the opinion issued by the second physician consulted.

- There must be a delay of 10 clear days (10 complete days, excluding the day the request is presented) between the moment when the medical request to die is presented and the administration of such treatment. However, this delay can be shortened if the physician administering the medical help to die and the physician giving the second opinion deem that the individual's death or loss of ability to give an informed consent is imminent. In such circumstances, the delay can be determined by the physician administering the medical help to die.
- There cannot be any link between the physician administering the medical help to die and the physician giving a second opinion. Both physicians must also be independent with respect to the individual requesting the medical help to die. To be considered independent one from the other, neither physicians can:
  - Be advising the other as part of an ongoing mentoring relationship or be in charge of supervising his or her work.
  - Know or believe that he or she would benefit from the testamentary estate of the individual making the request or receive a material benefit, including monetary following the death of the individual, except a normal compensation for performing the service linked to the request.
  - Know or believe that he or she is linked to the individual making the request in any way that would influence his or her objectivity.

### 5.5 Medical help to die interdisciplinary support group

Within the organization of the facility there should be a medical help to die interdisciplinary support. Two objectives regulate the functions performed by this group:

- When requested, provide support to the healthcare teams in the clinical administrative path of the medical help to die request.
- When requested provide support to the decision makers of the facility regarding the assurance of the quality and the availability of resources.

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## 6- ADVANCED MEDICAL DIRECTIVES (AMD)

There are two ways to express a wish in terms of advanced medical directives.

- The individual himself completes the form *Directives médicales anticipées en cas d'incapacité à consentir à des soins* (Anticipated medical directives in case of incapacity to consent to care) prescribed by the Minister, that can be requested from the Régie de l'assurance maladie du Québec (RAMQ), and has it signed by two witnesses.
- The individual asks a notary to register his or her wishes in a notarised act which content reiterates that of the *Directives médicales anticipées en cas d'incapacité à consentir à des soins* form (Anticipated medical directives in case of incapacity to consent to care).

### 6.1 Conditions

- The anticipated medical directives only applies in case of incapacity to consent to care.
- The form limits the anticipated medical directives to specific clinical situations.
- The anticipated medical directives can be registered or added to a medical file by a healthcare professional.

### 6.2 Consent

The anticipated medical directives have the same value as the wish expressed by the individual. The anticipated medical directives carry an enforceable value, meaning that healthcare professionals who have access to said directions have the obligation to respect them in precise clinical situations.

### 6.3 Responsibilities of the physician

To respect the wishes expressed in the AMD, a physician must:

- Confirm, with the individual in which he notices a significant change of health, that the wishes expressed in the AMD recorded in his or her medical file still reflect his or her wishes. (article 56)
- Consult the AMD Register when he determines that an individual became incapable of consenting to care; if the AMD concerning this individual is registered, he transfers them to the medical file, and refers to them if the specific care stated on the form are indicated.

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- Inquire to the next of kin of an individual incapable of consenting to care if there are AMD (that would not have been added to the medical file or to the AMD Register), or if the individual has rescinded the AMD in the medical file or in the Register.

#### 6.4 Role of healthcare professionals

Healthcare professionals must be able to:

- Inform the individual and provide explanations regarding the benefits, risks and consequences of a treatment in targeted clinical situations and ensure that such explanations are well understood.
- Direct an individual to a healthcare professional with a more specialised expertise when necessary; a chronic medical illness can require the opinion of a specialist concerning a treatment.
- Add the individual's AMD in the medical file when they receive them.

#### 6.5 Modalities concerning adding AMD in a medical file

To ensure that healthcare professionals will have access to his or her AMD, an individual can:

- Add them to the advanced medical directives Register by returning the completed, signed and dated form to the RAMQ; if said directives were expressed on a notarised act, the notary will transmit the act to RAMQ to be added to the Register.

or

- Give the AMD to a healthcare professional who will add them to the medical file.

or

- Give the AMD to a next of kin, who will give them to a healthcare professional when the individual is incapable of making a decisions.

#### 6.6 Applicability and validity conditions

##### 6.6.1 Conditions of applicability

ADM concern only the following clinical situations:

End of life situation

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- Serious and incurable end of life medical condition.

Severe and irreversable impact on cognitive functions situation

- Comatose state considered irreversible, or
- Permanent vegetative state

Other situation having a severe and irreversible impact on the cognitive functions

- Severe and irreversible impact on cognitive functions, without any possibility of improvement (for example, an advanced state of Alzheimer-type dementia or other kind of dementia).

The care targeted for each clinical situation are:

- Cardiorespiratory reanimation.
- Ventilator or any other technical support dependency.
- Renal dialysis.
- Forced or artificial feeding.
- Forced or artificial hydration.

If another care context is targeted, the substituted consent is required for any treatment required, except in case of emergency.

#### 6.6.2 Conditions of validity

To be valid, AMD must:

- Be made on the form prescribed by the Minister, in front of two witnesses or in a notarised act, by an individual having reached the age of majority and competent to consent to care at the time the document is signed.
- ADM are valid as long as they are not modified or rescinded.
- The law concerning end of life care specifies that it is assumed that an individual has received the necessary information enabling him or her to make an informed decision about signing the AMD.

#### 6.7 Terms of access

Healthcare professionals can access AMD either through the Advanced medical directives Register or through the medical file of the individual.

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- Before giving a treatment targeted in the *Directives médicales anticipées en cas d'incapacité à consentir à des soins* form (*Anticipated medical directives in case of incapacity to consent to care*) to an individual incapable to consent to a treatment indicated in one of the clinical situations listed in the AMD and for which the treatment indicated in said form could be necessary, the physician must consult the Advanced medical directives Register to verify that there are AMD and follow them if so. Consulting the Register is required by the Law concerning end of life care when a person is incapable of consenting to care. However, in an emergency situation, healthcare professionals might not be able to consult the Register before providing first aid in a timely manner.
- Only AMD of which healthcare professionals are aware of are applicable.
- Furthermore, an individual could have prepared AMD without having them added to the Register or to his or her medical file. As such, when admitted to the facility, the individual could be carrying a document indicating how to obtain his or her AMD or to whom said AMD have been given. The healthcare professionals can inquire if there are AMD, and should he or she receives such AMD, they must be added to the medical file of the individual.

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