Centre universitaire
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McGill University
Health Centre

Title of policy: MUHC End-of-Life Care Policy	
Manual: MUHC – Policies and Procedures	**Requesting Department/ Sector:** Directorate of Professional Services
Policy: New ☑ Revised ☐ Updated	**Effective date :** July 2016
Key words: End-of-life care; palliative care; advance medical directives; continuous palliative sedation.	
Approved by: ☐ Supervisor/Department Head ☐ Risks/Ethics ☐ Operations Committee ☐ Council/Committees	
Scope: ☑Throughout the Hospital ☐ Specific Department __☐ Other _________________________	
Specific site: ☐ Yes ☑No Site __________	**Distributed to**: ☑Staff ☑Management ☑Patients

PREAMBLE

The following policy establishes the responsibilities of the McGill University Health Centre (MUHC) regarding end-of-life care and presents the issues arising from it. This document is intended to delineate the legal and ethical norms to guide this type of care within the institution.

Healthcare professionals must also use their clinical judgement within the scope of the therapeutic relationship to determine the best clinical care to be provided in each situation. Each patient and/or family unit is unique. Being sensitive to the particularities of each therapeutic relationship will contribute to the excellence of care. In addition to the proposed legal and ethical norms, an engaged, humane and compassionate approach is necessary in a context that can be quite emotionally charged.

Clinicians and managers must recognize that the human condition is a complex reality with pressures, limits and ambiguities. Moreover, within our highly diverse society, ethical dilemmas may arise between norms that may appear to be in conflict while being legitimate in their own right. Thus, the simplistic application of one norm to the detriment of another may compromise the ability to respond adequately to the specific needs of each individual, particularly in relation to end-of-life care.

Given these inherent challenges, the following points should serve to guide our actions:

- The norms clearly delineated in this document;
- The reflection that each facility must undertake when articulating and adapting these norms to its respective environment;
- The fundamental compliance with the spirit of the Act;
- A common decision-making approach where the values and perspectives of everyone involved, both patients and healthcare professionals, are carefully taken into consideration;
- A compassionate clinical approach;
- An appreciation of the limits of what can be accomplished in order to meet the community’s needs.

Using this policy, the various facilities of the MUHC should develop end-of-life care procedures that contribute to serving the interests of patients and their families, as well as the community.

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1 GENERAL PROVISIONS

1.1 Purpose of the Policy

Purpose

The *Act respecting end-of-life care* expects that all institutions adopt a policy regarding end-of-life care. This policy applies to patients, employees, physicians and volunteers of the MUHC and is intended to guide them in the decision-making process regarding end-of-life care, as well as to clarify the roles, responsibilities and obligations of all concerned. Its main components are: the MUHC clinical program for end-of-life care, continuous palliative sedation, medical aid in dying, and advance medical directives.

For information purposes, the definition of palliative care that is commonly accepted and has been adopted by several bodies is that of the World Health Organization (WHO), namely:

> *"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention, relief of suffering and by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*

1.2 Guiding Values and Principles

The following guiding values and principles originate from the *Act respecting end-of-life care* (2014) and the *End-of-life Palliative Care Policy* of the *Ministère de la santé et des services sociaux* (MSSS) (2004). They were also adopted in the MSSS' 2015-2020 *Development Plan* for palliative and end-of-life care.

1.2.1 Values

Three fundamental values must guide all palliative and end-of-life care services offered by the MUHC, namely:

- The respect of the intrinsic value of each person as a unique individual, the respect of the person's dignity, as well as the recognition of the value of life and inevitability of death;

- The participation of each person in all decisions that concern the person; to this end, all decisions require the person's free and informed consent and must respect the person's autonomy. In accordance with the person's wishes, the person shall be informed of everything that concerns him/her, including the person's true state of health and the respect afforded to the individual's choices;

- The right to compassionate services from caregivers, which shall respect the values that give meaning to the person's existence and take into account the individual's culture as well as religious beliefs and practices, while not forgetting those of their loved ones or of the healthcare professionals providing care.

1.2.2 Guiding Principles

Emerging from these shared values are four guiding principles that should steer the institution's healthcare providers and managers' actions:

- The individual presenting with an illness to which a guarded prognosis is attributed must be able to count on the support of the health and social services network to ensure access to nearby services within the community;

- Palliative and end-of-life care are part of a continuum of care in which the needs and choices of people are at the heart of the planning, organization and delivery of services in order to ensure quality support adapted to the health condition of the person at the end of life through a collaborative approach;

- Keeping and supporting individuals in their community until the end of their life, if that is what they wish and if their condition doesn't present any obstacles, must be favoured;

- The physical and moral support provided to loved ones during the disease progression is essential, as it constitutes a fundamental component of the recommended approach.

2. DEFINITIONS

1. Patients

Any person who receives health or social services in any MUHC facility.

2. Loved Ones

Any person in the patient's circle of family and friends who provides significant, ongoing or occasional support as a non-professional to the patient – particularly in the context of loss of autonomy. It can be a family member or a friend.

3. Palliative Care Hospice

Palliative care hospices are private, not-for-profit organizations, managed by independent, administrative boards who give a large role to the contribution of volunteers.

They are holders of an accreditation issued by the Minister, which allows them to offer palliative and end-of-life care to patients, as well as provide support to loved ones up to the bereavement phase. Their status under the LSSSS was clarified through the *Terms of administrative supervision of palliative care hospices*, which were established in 2008.

4. Capacity to Consent to Care

The individual's ability to understand the nature of the illness for which an intervention is proposed, the nature and purpose of the intervention, and its risks and benefits, whether or not the patient receives the intervention.

5. Discontinuation of Treatment

The act of stopping care or treatments that can be life-sustaining.

6. Refusal of Care

The act of a person who refuses to receive care, treatment or an intervention, or to be hospitalized.

7. Guarded Prognosis

Unfavourable prognosis associated with the progression of a disease or the seriousness of lesions whereby the chances of the patient's survival in the long term are more or less threatened.

8. Palliative Care

Active and comprehensive care provided by an interdisciplinary team to persons suffering from a disease with a guarded prognosis, with the aim of alleviating their suffering, without hastening or postponing death, helping them maintain the best quality of life possible and offering them and their loved ones the support that they need.

9. End-of-life Care

Care offered to patients at the end of their life (including continuous palliative sedation and medical aid in dying.)

10. Continuous Palliative Sedation

Care offered as part of palliative care that consists of the administration of medication or substances to a person at the end of life in an effort to alleviate suffering by rendering the person unconscious in a continuous and permanent manner.

11. Medical Aid in Dying

Care comprising the administration of medication or substances by a physician to a person at the end of the person's life, at the person's request, with the purpose of relieving the person's suffering by causing death.

12. Advance Medical Directives

Instructions that a person, who has the capacity to consent to care, gives about decisions to be made regarding care in the event that the individual is no longer able to make these decisions for him/herself. The person cannot, however, request medical aid in dying through these directives. Advance medical directives are based on the presumption that standard consent conditions have been respected, namely that a legally competent person has made free, informed and enlightened choices.

3 ROLES AND RESPONSIBILITIES OF THE INSTITUTION

3.1 Information for Patients

The MUHC's End-of-life Care Policy and Code of Ethics are available publicly on the MUHC's Web site (http://muhc.ca), in the sections [The Act respecting end-of-life care] and [Code of Ethics].

3.2 Service Offering

The MUHC offers end-of-life care and ensures that it is provided in an interdisciplinary manner, as well as in in continuity and complementarity with other care that is being provided, or has been provided, to persons in need.

More specifically, palliative care and medical aid in dying must be offered to patients, regardless of their pathology, in all of the institution's healthcare settings, as per legislative provisions.

The MUHC must offer every patient, who is receiving end-of-life care, a private room for the final few days preceding the patient's death.

3.2.1. Procedures to Transfer Patients Admitted to the MUHC for Medical Aid in Dying

All requests to transfer patients from the community so that they may receive medical aid in dying must be sent to the chair of the MUHC's Interdisciplinary Support Group for Medical Aid in Dying / associate director of professional services.

3.3 End-of-life Care Program

3.3.1 Clinical Program for Palliative and End-of-life Care

The forms of end-of-life care to be offered at the MUHC are:

- Palliative care offered to patients at the end of their life;
- Access to continuous palliative sedation;
- Medical aid in dying;
- Distribution of information to patients and their loved ones regarding advance medical directives and the putting in place of mechanisms authorizing MUHC healthcare teams to access these directives.

The detailed Clinical Program for Palliative and End-of-life Care will be soon available publicly on the MUHC's Web site.

3.3.2. Governance Structure

The End-of-life Care Program falls under the auspices of the Directorate of Professional Services.

3.4 Code of Ethics

The MUHC Code of Ethics, which takes into account the rights of patients at the end of their life, is available publicly on the MUHC's Web site (http://cusm.ca), in the section [Code of Ethics]. In addition, the MUHC is obliged to give this document to every patient who requests it.

3.5 Executive Office

3.5.1 Role of the President and Executive Director

In accordance with the Act, the president and executive director of the MUHC must report annually to the Board of Directors on the implementation of this policy. The report must indicate, in particular, the:

- Number of patients at the end of their life who received palliative care;
- Number of continuous palliative sedations administered;
- Number of requests for medical aid in dying administered; and the
- Number of requests for medical aid in dying not administered, including the reasons why they were not administered.

This report will be submitted to the *Commission sur les soins de fin de vie* and made public on the MUHC's Web site. These responsibilities are delegated to the MUHC's director of professional services.

3.5.2 Role of the Council of Physicians, Dentists and Pharmacists

The Council of Physicians, Dentists and Pharmacists (CPDP) must adopt, in collaboration with the institution's Council of Nurses, the clinical protocols applicable to continuous palliative sedation and medical aid in dying. The protocols must comply with the clinical standards developed by the professional orders concerned. In addition, the CPDP or one of its committees assesses the quality of care provided, particularly with regard to the applicable clinical protocols.

The CPDP must be informed by the physician providing continuous palliative sedation within 10 days of its administration.

The CPDP must also be informed by the physician about the administration of medical aid in dying by using the forms stipulated by the Ministry within 10 days of its administration.

3.5.3 Role of the Council of Nurses

The institution's Council of Nurses must work in collaboration with the CPDP to adopt the clinical protocols applicable to continuous palliative sedation and medical aid in dying.

4 CONTINUOUS PALLIATIVE SEDATION

4.1 Conditions

In accordance with the Act, before giving consent to continuous palliative sedation, a patient at the end of life or the person who may give consent to care on behalf of the patient (when applicable) must be informed of the prognosis of the illness, of the irreversible nature of the sedation and of the anticipated duration of the sedation, among other things.

The physician must also ensure that the consent is being given freely and in an informed manner by verifying, amongst other things, that it is not the result of external pressure.

4.2 Consent

Consent to continuous palliative sedation must be given in writing using the form stipulated by the Minister (*Continuous Palliative Sedation Consent Form* – DT9231*)* and be entered in the patient's medical record. If the patient giving consent to continuous palliative sedation cannot date and sign the form because the patient cannot write or is physically incapable of doing so, a third party may do so in the patient's presence. The third party cannot be a member of the team responsible for caring for the patient, a minor or a person who has reached the age of majority but lacks the capacity to give consent.

4.3 Physician's Declaration Notice

A physician with privileges at the MUHC who provides continuous palliative sedation must inform the CPDP within 10 days of its administration by using the *Declaration of Continuous Sedation* form, available on the MUHC Intranet site, in the section Act Respecting End-of-Life Care.

5 MEDICAL AID IN DYING

5.1 Request for Medical Aid in Dying

Patients must themselves request medical aid in dying, in a free and informed manner, by means of the form stipulated by the Minister. This form must be signed and dated by the patient (Form: *Request for Medical Aid in Dying* – DT9232).

The form must be signed in the presence of a health or social services professional who countersigns it; if the professional is not the patient's attending physician, the professional gives the signed form to the attending physician.

If the patient requesting medical aid in dying cannot date and sign the form because the patient cannot write or is physically incapable of doing so, a third party may do so in the patient's presence. The third party cannot be a member of the team responsible for caring for the patient, a minor or a person who has reached the age of majority but lacks the capacity to give consent.

A person may, at any time and by any means, withdraw a request for medical aid in dying.

The individual may also, at any time and by any means, request that administration of medical aid in dying be postponed.

All information or documents pertaining to a request for medical aid in dying must be entered or filed in the patient's medical record, whether or not the physician administers the aid, including the form used to request medical aid in dying, the reasons for the physician's decision and, where applicable, the opinion of the physician consulted.

A patient's decision to revoke the request for medical aid in dying or to postpone the administration of such aid must also be entered in the patient's medical record.

The MUHC must ensure to provide the patient with all the resources available to make an informed decision.

5.2 Eligibility Conditions

In order to obtain medical aid in dying, the patient must meet all of the following conditions:

- Be insured in the sense of the Health Insurance Act;
- Have reached the age of majority and have the capacity to give consent to care;
- Be at the end of one's life;
- Have a serious and incurable disease;
- Be in a medical situation marked by an advanced and irreversible decline of one's capacities;
- Experience constant and unbearable physical or psychological suffering, which cannot be relieved in a manner the patient deems tolerable.

5.3 Cases of Conscientious Objection

The MUHC recognizes the rights of healthcare professionals to “conscientious objection” WITH RESPECT TO MEDICAL AID IN DYING. Although the MUHC is committed to respecting the rights of patients and those of healthcare professionals, the institution will ensure that its patients have access to all options within a reasonable period of time.

5.3.1 Physicians

Physicians who are providing care to a patient must recognize all requests for medical aid in dying submitted by a patient to any healthcare professional.

Physicians must inform their patients if their personal convictions prevent them from providing medical aid in dying. They must also inform their patients that they will advise the director of professional services.

All physicians practicing their profession in a facility operated by the MUHC who refuse a request for medical aid in dying due to conscientious objection must, as soon as possible, notify the director of professional services and forward the request form for medical aid in dying that they were given, if that is the case, to the director. The director of professional services must then take the necessary steps to find, as soon as possible, a physician willing to carry out the request.

In such a case, the physician must nevertheless ensure that continuity of care is provided to the patient, in compliance with the Code of Ethics and the patient’s wishes. Exercising “conscientious objection” is not and cannot be interpreted as abandonment of the patient. Preserving the therapeutic and humane relationship between physicians and their patients, as well as the values and principles outlined in the Code of Ethics of the *Collège des médecins du Québec*, must transcend personal values and convictions.

5.3.2 Other Healthcare Professionals

Healthcare professionals must recognize all requests for information regarding medical aid in dying or requests for medical aid in dying from a patient.

Healthcare professionals may refuse to participate in the administration of medical aid in dying due to their personal convictions. They must, as soon as possible, notify their immediate superior, who will be responsible for finding an appropriate replacement.

Healthcare professionals must nevertheless ensure that continuity of care is provided to patients, in accordance with the Code of Ethics and the patient’s wishes.

5.4 Criteria Assessed by Physicians

Before administering medical aid in dying, physicians must ensure:

- That the person meets the eligibility criteria in accordance with the Act;
- That the request is being made freely, in particular by ascertaining with the patient that it is not being made as a result of external pressure;

- That the request is an informed one, notably by informing the patient of the prognosis for the illness, as well as other treatment or palliative possibilities and their consequences;
- That there is persistent suffering and that the patient's wish in obtaining medical aid in dying remains unchanged by talking with the patient at different, reasonably spaced intervals, given the progress of the patient's condition;
- To discuss the patient's request with any members of the care team who are in regular contact with the patient, when appropriate;
- To discuss the patient's request with the patient's loved ones, if the patient so wishes;
- That the patient has had the opportunity to discuss the request with the persons the patient wished to contact;
- To obtain the opinion of a second physician confirming that the criteria set out in section 26 have been met (Form: *Opinion of a second physician confirming compliance with the conditions to obtain medical aid in dying* – DT9234).

5.4.1 Interdisciplinary Support Group for Medical Aid in Dying

The MUHC has established within the institution the Interdisciplinary Support Group for Medical Aid in Dying. Three objectives guide this group: (1) support the healthcare teams that seek assistance with regard to the clinical-administrative process for requests for medical aid in dying; (2) provide psychological, moral and spiritual support to professionals participating in the medical aid in dying process; and (3) provide support to the institution's decision-makers that request assistance with regard to quality assurance and the availability of resources.

6 ADVANCE MEDICAL DIRECTIVES

All persons having reached the age of majority, who have the capacity to give consent to care, may indicate their wishes in advance through advance medical directives in case they lose the capacity to give their consent to care. This can be done through a notarial act *en minute* or in the presence of witnesses on the form stipulated by the Minister.

6.1 Conditions

- Advance medical directives apply only in cases where the person lacks the capacity to give consent to care.
- The form limits advance medical directives to specific clinical situations and interventions.
- Advance medical directives may be filed in the advance medical directives registry or entered in the patient's medical record by a healthcare professional.

6.2 Consent

Advance medical directives carry the same weight as wishes expressed by the patient. Advance medical directives have enforceable value, meaning that healthcare professionals who have access to them are obliged to respect them in specific clinical situations insofar as nothing indicates that they do not comply with ethical and legal norms concerning free and enlightened consent.

6.3 Role and Responsibilities of Healthcare Professionals

6.3.1. Responsibilities of Physicians

In order to respect a person's wishes, as expressed in the person's advance medical directives, a physician must:

- In the event that a patient's state of health changes significantly, verify with the patient, whether the advance medical directives entered in the medical record still reflect the patient's wishes;

- Consult the advance medical directives registry when a person does not have the capacity to give consent to care. If the registry contains advance medical directives regarding that person, the physician enters them in the patient's medical record and refers back to the directives if specific care is indicated on the form;

- When a person does not have the capacity to give consent to care, ask the patient's loved ones whether the patient has expressed advance medical directives (which may not have been entered in the patient's medical record or filed in the advance medical directives registry), or whether the person has revoked advance medical directives that are still in the medical record or registry.

6.3.2. Responsibilities of All Healthcare Professionals

All healthcare professionals must be in a position to:

- Inform the patient and provide explanations regarding the benefits, risks and consequences of care in specific clinical situations and ensure that the explanations are well understood;

- Refer, when necessary, the patient to a healthcare professional who has more specialized expertise;

- Ensure, when a person provides advance medical directives, that the person has the capacity to give consent to care and that the directives still reflect the person's wishes. Healthcare professionals cannot make any changes to the advance medical directives form. Only patients with the capacity to give consent can change their advance medical directives by completing a new form;

- Enter advance medical directives in the patient's medical record when provided.

6.4 Procedures Regarding the Entry in the Medical Record

To ensure that healthcare providers can access their advance medical directives, persons may:

- Record advance medical directives in the advance medical directives registry by returning the completed form, duly dated and signed, to the RAMQ; if the directives were filed through a notarial act *in minute*, the notary sends the act to the RAMQ to be filed in the registry;

Or

- Give the advance medical directives to a healthcare professional, who will enter them in the patient's medical record;

Or

- Give the advance medical directives to a family member or friend, who will give them to a healthcare professional when the person lacks the capacity to give consent.

6.5 Conditions for Enforceability and Validity of Advance Medical Directives

6.5.1. Conditions for Enforceability

Advance medical directives are intended solely for the following clinical situations:

- End-of-life cases
    - Serious and incurable end-of-life medical conditions

- Cases of severe and irreversible impairment of cognitive functions
    - Comatose state deemed irreversible, or
    - Permanent vegetative state

- Other cases of severe and irreversible impairment of cognitive functions
    - Severe and irreversible impairment of cognitive functions without possibility of improvement, for example Alzheimer-type dementia or any other type of advanced dementia

The care involved for each clinical situation is:

- Cardiopulmonary resuscitation
- Assisted ventilation with a respirator or other type of technical support. Kidney dialysis.
- Forced or artificial feeding. Forced or artificial hydration.

If another context of care is contemplated, consent is needed for any other care/intervention required, except in emergency cases.

6.5.2 Conditions of Validity

- Advance medical directives must be made by a person who has reached the age of majority and has the capacity to give consent to care at the time of signing, in the presence of two witnesses, the form stipulated by the Minister or the notarial act *in minute*.

- Advance medical directives are valid as long as they are not modified or revoked.

- The *Act respecting end-of-life care* specifies that there is a presumption that the person has received the information needed to make an informed decision at the time of signing the advance medical directives.

6.6 Access Procedures

Healthcare professionals may access advance medical directives either by means of the advance medical directives registry or by consulting the patient's medical record.

- Before providing care, referred to in the *Advance Medical Directives in Case of Incapacity to Consent to Care* form, to a patient who lacks the capacity to give consent to care and who finds him/herself in one of the clinical situations referred to in the advance medical directives and for whom specific care stipulated on the form is indicated, the physician must consult the advance medical directives registry to verify if directives exist and, should this be the case, follow them. The *Act respecting end-of-life care* requires that the advance medical directives registry be verified when a patient lacks the capacity to give consent. However, in emergency cases, it may be impossible for healthcare professionals to consult the registry before providing initial care in a timely manner.

- Only advance medical directives made known to healthcare professionals are applicable.

- Furthermore, a person may have prepared advance medical directives without having filed them in the registry and without their being entered in the patient's medical record. As such, individuals could have them on their person at the time of admission to the institution, have a document stipulating how to obtain their advance medical directives or may have even given them to a person they trust. Healthcare professionals must inquire whether or not advance medical directives exist. If they are given such directives by the patient personally or by a family member or friend, the professionals must enter them in the patient's medical record.

- If the advance medical directives have been revoked, the advance medical directives form is no longer valid and the physician must obtain consent for all care required subsequently. If the advance medical directives have been recorded in the advance medical directives registry and the patient regains the capacity to give consent, the physician must advise the patient to contact the RAMQ to update the patient's advance medical directives in the registry.

6.7 Specific Consideration(s)

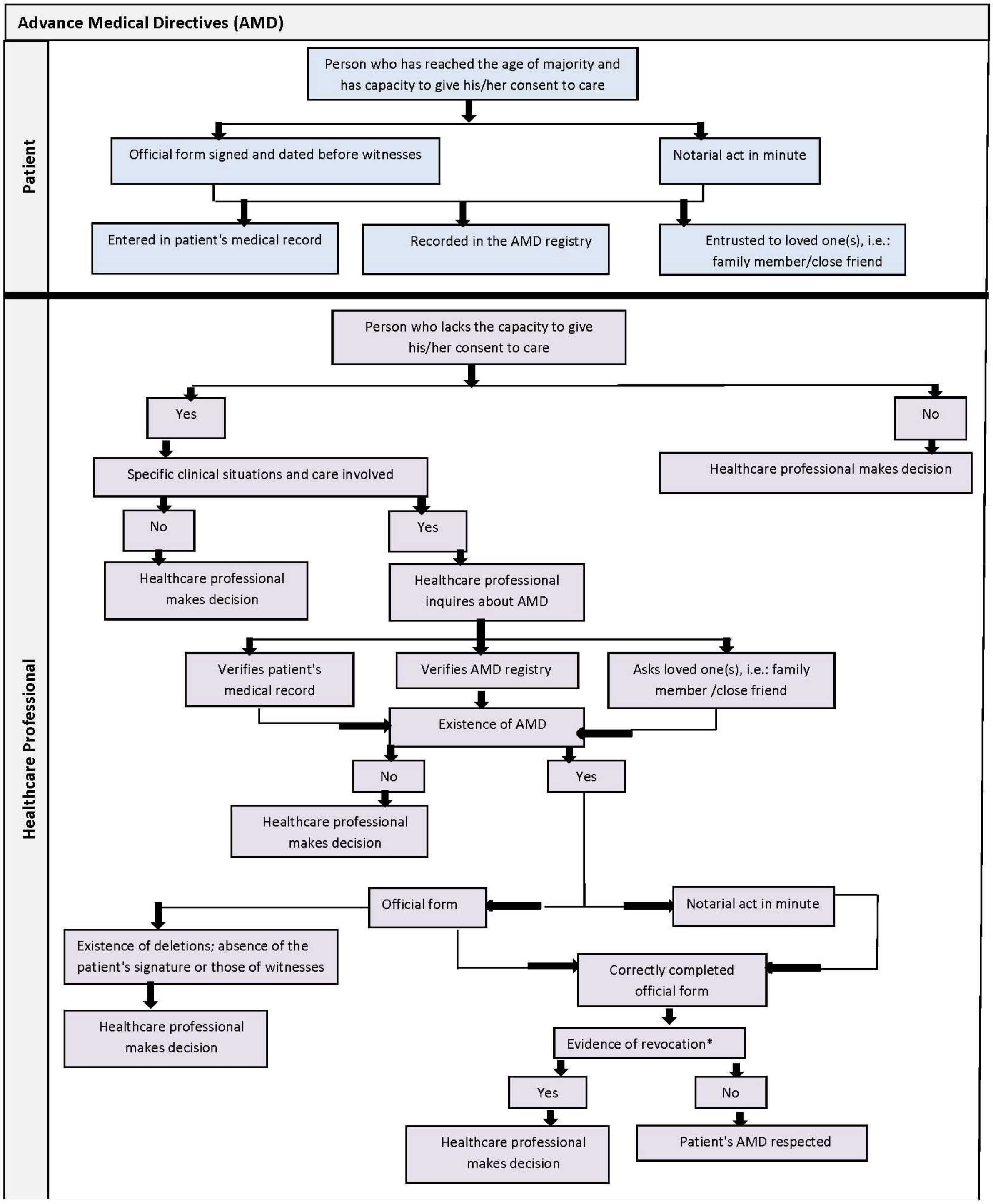
Pre-eminence of Advance Medical Directives

- Instructions relating to care expressed in a mandate given in anticipation of a person's incapacity do not constitute advance medical directives.

- In the event of an inconsistency between those wishes and the instructions expressed in advance medical directives, the latter shall prevail.

6.8 Validation of Advance Medical Directives

Decision-making Algorithm



*Revocation revokes all previous AMD. In the event of a conflict with the instructions relating to care expressed in a mandate given in anticipation of incapacity and a person's AMD, the AMD shall prevail (art. 62 of the *Act respecting end-of-life care*).

7 FINAL PROVISIONS

7.1 Entry into effect

This policy enters into effect on December 10, 2015.

7.2 Responsible for enforcement

The MUHC Directorate of Professional Services is responsible for enforcing this policy.

7.3 Dissemination

This policy is available publicly on the MUHC's Web site (http://muhc.ca), in the section [The Act respecting end-of-life care].

7.4 Revision

The MUHC Directorate of Professional Services is responsible for the revision of this policy.

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