Select Committee

ON THE EVOLUTION OF THE ACT RESPECTING END-OF-LIFE CARE

Consultation Paper

ASSEMBLÉE NATIONALE
DU QUÉBEC

THE COLLABORATORS OF THE SELECT COMMITTEE ON THE EVOLUTION OF THE ACT RESPECTING END-OF-LIFE CARE

SECRETARIAT AND COORDINATION OF WORK

Ann-Philippe Cormier
Constance Goodrich-Maclean
Astrid Martin

RESEARCH SERVICE

Félix Bélanger
Mathieu Houle-Courcelles
Julie Paradis
Pierre Skilling

REFERENCE SERVICE

Simon Mayer
Stéphane Wimart

COPYEDITING

Danielle Simard
Martine Dignard

GRAPHIC DESIGN AND LAYOUT

Isabelle Bédard
Louise Williams

COMMUNICATIONS

Julie Champagne

For more information on the proceedings of the Select Committee on the Evolution of the Act respecting end-of-life care, please contact the Committee Clerk, Ann-Philippe Cormier.

Édifice Pamphile-Le May,
1035, rue des Parlementaires, 3e étage
Québec (Québec) G1A 1A3
Telephone 418 643-2722
Toll-free: 1 866 337-8837
Email: cssfv@assnat.qc.ca

This document is available online in the Parliamentary Proceedings section of the National Assembly website: assnat.qc.ca.

Legal deposit – June 2021
Bibliothèque et Archives nationales du Québec

ISBN (Print): 978-2-550-89647-0
ISBN (PDF): 978-2-550-89648-7

MEMBERS OF THE SELECT COMMITTEE ON THE EVOLUTION OF THE ACT RESPECTING END-OF-LIFE CARE

Ms. Nancy Guillemette (Roberval), Chair
Ms. Marie Montpetit (Maurice-Richard), Vice-Chair

Mr. David Birnbaum (D'Arcy-McGee)
Ms. Suzanne Blais (Abitibi-Ouest)
Mr. Éric Girard (Lac-Saint-Jean)
Ms. Geneviève Hébert (Saint-François)
Ms. Véronique Hivon (Joliette)
Mr. François Jacques (Mégantic)
Ms. Jennifer Maccarone (Westmount–Saint-Louis)
Mr. Gabriel Nadeau-Dubois (Gouin)
Ms. Marilyne Picard (Soulanges)

OTHER MEMBER OF NATIONAL ASSEMBLY INVOLVED IN THE WORK

Mr. Guy Ouellette (Chomedey)

TABLE OF CONTENTS

A word from the steering committee

On March 31, 2021, the National Assembly unanimously adopted a motion creating the Select Committee on the Evolution of the Act respecting end-of-life care. At the heart of its mandate is the issue of the potential expansion of medical aid in dying for persons who are incapacitated and for persons whose only medical problem is a mental disorder. By establishing this Committee, parliamentarians were sending a strong message about their willingness to continue the collective reflection on medical aid in dying in a cross-party approach.

Québec was a pioneer in the area of medical aid in dying. In fact, the National Assembly established a Select Committee on Dying with Dignity in 2009 and adopted the Act respecting end-of-life care in 2014. Since then, perceptions and opinions on the issue have greatly evolved within society. New questions have arisen about the accessibility of medical aid in dying and it is our responsibility to address them.

With this new Select Committee, Québec is continuing its role as a forerunner in end-of-life care. Despite the complexity of these issues, we are convinced that Québec society will once again be able to lead this discussion with empathy and openness.

It is in this spirit of openness that we wish to hear the people of Québec on these important issues. With this consultation document, we are inviting the population to express their views on the issues identified therein. The testimonies, briefs and comments that will be submitted to us and the responses provided within the framework of the online consultation will guide our work. In addition, the second stage of special consultations and public hearings that will take place in August will allow citizens and groups to express their views on the subject.

It is therefore with great interest that we start this new stage of the Committee's work. We invite you to participate in large numbers.

Nancy Guillemette
Ms. Nancy Guillemette (Roberval)
Chair

Marie Montpetit
Ms. Marie Montpetit (Maurice-Richard)
Vice Chair

Mr. Gabriel Nadeau-Dubois (Gouin)
Steering committee member

Véronique Hivon
Ms. Véronique Hivon (Joliette)
Steering committee member

Introduction

On March 31, 2021, the National Assembly unanimously adopted a motion creating the Select Committee on the Evolution of the Act respecting end-of-life care. Its mandate is to analyse the issues related to the potential expansion of medical aid in dying for persons who are incapable of caring for themselves and those who are suffering from mental illness. Thus, the members of the Committee will have to ask themselves whether persons who are incapable of consenting to care could obtain medical aid in dying, for example, by means of an advance request, beyond the situation described in section 29 of the Act[1]. Similarly, the eligibility for medical aid in dying for people whose only medical condition is a mental disorder will need to be assessed, as will the potential terms and conditions surrounding this practice.

During the month of May 2021, the members of the Committee participated in several days of special consultations. The parliamentarians met with more than thirty specialists and groups from various backgrounds. These exchanges allowed the parliamentarians to familiarize themselves with complex issues, addressing them with respect, humility and empathy.

At the conclusion of these days of consultation, the parliamentarians present to the Québec population the avenues for reflection that they wish to submit for public debate.

What the words mean

The potential expansion of medical aid in dying for incapacitated persons and those whose only medical problem is a mental disorder is a sensitive issue. It is all the more important to clearly define the terms used by the Committee within the framework of its proceedings.

Medical aid in dying

Care consisting in the administration of medications or substances to a person who meets all of the criteria set forth in the Act, at the person's request, in order to relieve their suffering by hastening death.

---

[1] For further details on section 29, please refer to the section on the Act respecting end-of-life care in this document.

Capable and incapable

The Act respecting end-of-life care specifies that in order to access medical aid in dying, a person must be capable of giving consent to care. According to the criteria usually recognized by the courts, a person who is capable:

- Understands the nature of their illness;
- Understands the nature and purpose of the treatment;
- Understands the risks associated with this treatment;
- Understands the risks involved if the treatment is not given;
- Does not have their capacity to consent affected by their state of health.

According to the Curateur public du Québec, a person is incapable when they are unable to care for themselves or manage their affairs. Incapacity may be declared due to a mental or degenerative illness, stroke, intellectual disability, head injury or weakened state as a result of old age that alters the mental faculties or physical ability to express one's wishes. Capacity to consent to care must be assessed in a specific context and at a specific point in time. It is likely to change over time and may be partial or total, depending on the degree of autonomy the person has.

Advance medical directives

A form of (written) expression of the wishes of a person of full age who is capable of giving consent to care in anticipation of their inability to consent thereto. Advance medical directives are binding: the health care team has an obligation to comply with them. Currently, the Act respecting end-of-life care excludes medical aid in dying from the list of treatments covered by advance medical directives.

Palliative care

The total and active care delivered by an interdisciplinary team to patients suffering from a disease with reserved prognosis, in order to relieve their suffering, without delaying or hastening death, maintain the best quality of life possible and provide them and their loved ones the support they need. Continuous palliative sedation is care that is offered as part of palliative care[2].

---

[2] Continuous palliative sedation consists in administering medications or substances to an end-of-life patient to relieve their suffering by rendering them unconscious without interruption until death ensues.

Mental disorder

According to the World Health Organization, mental disorders "are generally characterized by a combination of abnormal thoughts, perceptions, emotions, behaviour and relationships with others". The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) states that a mental disorder is "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning".

Portrait of the evolution of end-of-life care in Québec

The legislative, legal and regulatory framework (2009-2021)

On December 4, 2009, the National Assembly created the Select Committee on Dying with Dignity. Following proceedings held in 2010 and 2011, during which its members heard 32 specialists and close to 250 citizens and groups, the Committee tabled its report, entitled Dying with Dignity. As a result of a broad social consensus, its recommendations were well received by the Québec population.

On June 12, 2013, Bill 52 on end-of-life care was introduced in the National Assembly. Adopted on June 5, 2014, the Act respecting end-of-life care came into force on December 10, 2015. The adoption of the Act places Québec as a forerunner on this issue.

In the wake of the Supreme Court of Canada's decision in *Carter v. Canada (Attorney General)*, the federal government made amendments to the Criminal Code in 2016. The amendments are consistent with the provisions of the Act respecting end-of-life care, which continue to apply in Québec.

The Act respecting end-of-life care

The Québec Act establishes the rights of end-of-life patients as well as the organization of and a framework for end-of-life care. Its objective is to ensure that everyone may have access to quality care that is appropriate to their needs, including prevention and relief of suffering.

In addition, the Act recognizes the primacy of freely and clearly expressed wishes with respect to care, in particular by establishing an advance medical directives regime. However, this regime excludes medical aid in dying.

The advance medical directives regime allows persons who anticipate a loss of capacity to refuse five types of care: cardiopulmonary resuscitation, dialysis treatments, artificial ventilation, artificial hydration and feeding.

Section 26 of the Act sets out the criteria that a person must meet to obtain medical aid in dying:

1. Be an insured person within the meaning of the the Health Insurance Act;
2. Be of full age and capable of giving consent to care;
3. Be at the end of life;

   A Québec Superior Court judgment in 2019 rendered the "end of life" criterion inoperative.

4. Suffer from a serious and incurable illness;
5. Be in an advanced state of irreversible decline in capability;
6. Experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.

Section 26 specifies that this person must request medical aid in dying him or herself, in a free and informed manner, by means of a prescribed form. The form must be signed in the presence of and countersigned by a health or social services professional.

Section 29 of the Act specifies the responsibilities of the physician who will be administering medical aid in dying. In particular, the latter must:

1. Make sure that the person's request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure;
2. Make sure that the request is an informed one, in particular by informing the patient of the prognosis for the illness and of other therapeutic possibilities and their consequences;
3. Verify the persistence of the suffering that the wish to obtain medical aid in dying remains unchanged, by talking with the patient at reasonably spaced intervals given the progress of the patient's condition.

It should be noted that section 29 was amended by legislation on June 10, 2021. From now on, when a person at the end of life has become incapable of consenting to care after having made his or her request, the physician may still administer medical aid in dying. The following criteria apply:

1. The patient meets all the criteria of section 26;
2. The person must have consented, in writing and in the presence of a health professional, in the 90 days before the date of the administration of medical aid in dying, to receive the aid even if they were incapable of giving consent to care before the administration of the aid.

Furthermore, any refusal to receive medical aid in dying expressed by this person must be respected and it is prohibited to disregard it in any manner.

The Commission on end-of-life care

The Act also establishes the Commission on end-of-life care. Its mandate is to examine any matter relating to end-of-life care. For this purpose, it must, among other things, evaluate the implementation of legislation with regard to end-of-life care and submit reports to the Minister of Health and Social Services on its status in Québec. The Commission also has the mandate to oversee the application of the specific requirements relating to medical aid in dying.

The Truchon and Gladu case and its repercussions (2019)

The debate on access to medical aid in dying was relaunched on September 11, 2019, following a Québec Superior Court judgment in the Truchon and Gladu case. Jean Truchon and Nicole Gladu are two adults capable of consent, suffering from serious and incurable degenerative diseases and experiencing intolerable suffering that does not, however, compromise their life expectancy. Since they felt that the federal and provincial criteria were restrictive, in 2017 they filed a court action to have them declared unconstitutional.

The ruling handed down by Judge Christine Baudoin rendered the "end of life" criterion set out in section 26 of the Québec Act, as well as the "reasonably foreseeable natural death" criterion set out in section 241.2 of the Criminal Code, inoperative as conditions of eligibility for medical aid in dying. These criteria were found to be unconstitutional, leading to a review of the legislation. As a result of this ruling, Jean Truchon was granted medical aid in dying on April 7, 2020.

The removal of the"end of life" criterion in section 26 thus opens the door to medical aid in dying to a greater number of patients suffering from serious and incurable diseases and meeting the other criteria of the Act. The mandate of the Select Committee is to assess whether access to medical aid in dying should be granted to persons who are incapacitated and to those whose only medical problem is a mental disorder.

The consultations carried out in Québec on the potential expansion of the Act

Since the Act respecting end-of-life care came into force, discussions have already begun in Québec on the potential expansion of medical aid in dying.

In March 2017, the Minister of Health and Social Services announced the establishment of the Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir[3], whose mandate was to study the possibility of expanding medical aid in dying for persons in a situation of incapacity. The report produced by this group of experts, co-chaired by Nicole Filion and Jocelyn Maclure, is entitled "L'aide médicale à mourir pour les personnes en situation d'inaptitude : le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence[4]". It was made public on November 29, 2019.

One of the main recommendations of this report is to allow a person diagnosed with a serious and incurable disease to write an advance request for medical aid in dying. Other recommendations of the expert group focus on the administration of advance requests, the role of relatives in reporting the existence of these advance requests and the development of end-of-life care.

Advance request for medical aid in dying

As recommended by the expert group, the advance request would be made by a person with a serious and incurable illness who is capable of making such request, so that medical aid in dying can be administered to them at the time they indicate, even if they have since become incapacitated. It is at this point that the health care team should assess the person's eligibility. Considering that the request could be accepted or refused, it would not be binding on the health care team.

Another important milestone in the discussions on the potential expansion of medical aid in dying was reached with the tabling, in November 2020, of the discussion paper Access to medical aid in dying for people with mental disorders by the Association des médecins psychiatres du Québec. In the wake of the Truchon and Gladu case, the Collège des médecins du Québec and the Commission on end-of-life care mandated the Association des médecins psychiatres to prepare a document that would define the circumstances in which medical aid in dying could be granted to persons whose only medical problem is a mental disorder.

---

[3] Expert group on the issue of incapacity and medical aid in dying

[4] Medical aid in dying for persons in a situation of incapacity: the proper balance between the right to self-determination, compassion and prudence

The conclusion drawn is that medical aid in dying could be offered to persons whose only medical problem is a mental disorder, but should not be dependent on a particular diagnosis. Instead, access should be assessed in relation to several dimensions of mental disorders: incurability and irreversibility, chronicity, attempts at treatment, refusal of treatment, suffering, decision-making ability and suicidal ideation of the person.

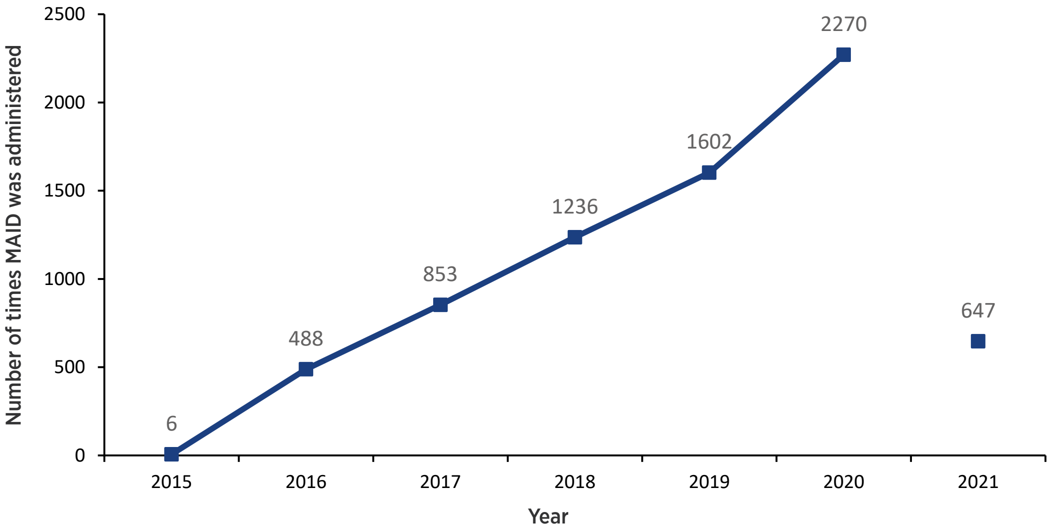
In addition to these reports, the Commission on end-of-life care has also contributed to the debate on the potential expansion of medical aid in dying. As early as 2019, in its first report on the situation of end-of-life care in Québec (Rapport sur la situation des soins de fin de vie au Québec), the Commission recommended holding public consultations on the potential expansion of medical aid in dying. This recommendation was reiterated in the Commission's 2019-2020 annual activity report (Rapport annuel d'activités 2019-2020), with specific reference to medical aid in dying for persons who are incapacitated and for persons whose only medical problem is a mental disorder.

Finally, at the initiative of the Minister of Health and Social Services, two national forums on the evolution of the Act respecting end-of-life care were organized. The first was held in January 2020. Its objective was to present the different perspectives on medical aid in dying for persons who are incapacitated. The second national forum was held in December 2020. It focused on the issues surrounding medical aid in dying for persons with mental disorders.

A statistical portrait (2015-2021)

Since the Act respecting end-of-life care came into force on December 10, 2015, the number of medical aid in dying cases has increased year after year. In 2020, 2 270 medical aid in dying procedures were administered, which accounts for 3% of all deaths that occurred in Québec. From the entry into force of the Act until March 31, 2021, 7 102 persons received medical aid in dying.

Number of times MAID was administered between December 10, 2015, and March 31, 2021



Source: *Commission sur les soins de fin de vie, brief submitted within the framework of the proceedings of the Select Committee on the Evolution of the Act respecting end-of-life care.*

Nearly two-thirds (60%) of medical aid in dying procedures were administered in hospital centres. The other locations were homes (27%), residential and long-term care facilities – CHSLDs (9%) and palliative care hospices (3%). The Commission on end-of-life care also reports that 947 physicians were involved in medical aid in dying procedures in 2019-2020. These medical acts include administration and assessment of requests. General practitioners performed 84% of these acts compared to 16% of specialist physicians.

Since December 2015, the average age of those who received medical aid in dying has been 73 years, and 89% of those who received it were aged 60 years and over. Of those to whom medical aid in dying was administered, 74% had cancer. The other persons who died in this way were mainly suffering from neurodegenerative disease (9%), lung disease (6%) and heart or vascular disease (5%).

The situation in Belgium

Euthanasia[5] has been practised since 2002 under certain essential conditions, including that of a hopeless medical situation. In Belgium, the request for euthanasia remains valid even if the patient loses the capacity to consent between the time the request is made and the time it is carried out. An advance consent agreement to obtain euthanasia is permitted. In such circumstances, euthanasia can only be carried out if the person has a serious and incurable condition, is unconscious and if his or her condition is irreversible.

Persons with mental disorders are also eligible for euthanasia. However, since such disorders do not necessarily lead to death in the short term, additional measures apply. In particular, the physician must consult a second independent physician and allow at least one month to elapse between the patient's request and the euthanasia.

In 2019:

- 2656 acts of euthanasia performed
  (2.5% of the total number of deaths)
- 27 acts of euthanasia administered via advance consent agreements (1% of euthanasia)
- 23 acts of euthanasia due to psychiatric disorders
  (0.8% of euthanasia)

Source: Neuvième rapport aux Chambres législatives de la Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie

---

[5] Euthanasia is commonly defined as the act, carried out by a third party, of intentionally ending a person's life at the person›s request.

The situation in the Netherlands

Euthanasia and assisted suicide[6] are permitted in the Netherlands when the due care criteria laid down in the law are met. It is possible to make an advance request for euthanasia through the living will. A person who is no longer able to express his or her wishes can therefore obtain euthanasia provided that a written request was made while he or she was still capable.

Persons suffering from psychiatric disorders may also apply for euthanasia or assisted suicide, but three of the six strict criteria[7] that physicians must meet must be assessed not only by the responsible physician, but also by a consultant and a psychiatrist.

In 2019 :

- 6361 reports of euthanasia and assisted suicide in 2019 (4.2% of the total number of deaths)
- 68 reports were related to psychiatric disorders (1.1% of euthanasia cases and assisted suicides)
- 162 reports were related to dementia, including two under the living will (2.5% of euthanasia cases and assisted suicides)

Source: *Rapport annuel 2019 des Commissions régionales de contrôle de l'euthanasie*

---

[6] Assisted suicide is commonly defined as helping someone to voluntarily take their own life by providing the means to commit suicide or information on how to do so, or both.

[7] These three criteria are the ability of the patient to express his or her wishes as to his or her request, the absence of any prospect of improvement in suffering and the absence of a reasonable alternative.

Presentation of the issues at the heart of the Committee's mandate

The potential expansion of medical aid in dying for persons who are incapacitated

As stated in section 11 of the Civil Code of Québec, no one may be made to undergo care of any nature, except with his or her consent. According to the Collège des médecins, consenting to care refers to the fact that a person accepts that medical care be provided to him or her, but it also implies that he or she can refuse it on the basis of his or her own will.

Capacity to consent to care is one of the fundamental guidelines of the Act respecting end-of-life care. A person requesting medical aid in dying must be able to make a free and informed choice at the time of its administration, except in the situations described in section 29 of the Act[8]. The person must also meet all the criteria set out in section 26 at the time he or she makes the request. Persons in one of the following situations are therefore excluded from it:

- Persons who have been diagnosed with a neurodegenerative disease such as Alzheimer's disease and who anticipate, in the medium or long term, the loss of their ability to consent to care;
- Persons who have suffered a sudden and unexpected accident with serious and irreversible after-effects, whether it be a cerebrovascular accident, a head injury or an accident resulting in an end-of-life coma or an irreversible vegetative state;
- Persons who have never been considered competent to consent to their care and who would not be considered competent to consent to medical aid in dying. These persons include those with severe intellectual disabilities.

Many intervenors feel that this provision of the Act undermines the right to self-determination. In other words, every person must be able to make important decisions that affect their life and body. Self-determination is the ability of a human being to lead his or her own life and to choose how to end it. Without denying this principle, other witnesses affirmed that our society has a duty to protect vulnerable persons, thus reaffirming their right to live with dignity despite their incapacity.

---

[8] For further details on section 29, please refer to the section on the Act respecting end-of-life care in this document.

Moreover, specialists report that some persons, having been diagnosed with a neurodegenerative disease, do not want to live an end of life that they consider contrary to their values and dignity. They ask to be able to give their consent in advance to medical aid in dying.

To remedy this situation, some intervenors suggest allowing the use of advance medical directives or advance requests for medical aid in dying. The distinction between these two procedures is important. Advance medical directives are provided for in the Act respecting end-of-life care. They are binding: the health care team must respect the patient's expressed wishes regarding the refusal of certain care. Advance requests, on the other hand, are non-binding. The patient's advance wishes regarding his or her end of life are implemented by the health care team in consultation with the patient's loved ones. Despite the request made when the person was capable, the health care team and the person's loved ones may refuse to comply with it. The Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir[9] supports this option in its report published in 2019.

The preparation of such a directive or request involves other issues that are important to mention. Witnesses point out, among other things, the difficulty of accurately assessing the suffering of a person who is no longer able to express it clearly. Witnesses further state that the situation leaves some doubt as to the patient's true wishes when receiving medical aid in dying. How, for example, can we assess the person's advance request if, at the time of administration, he or she shows no apparent signs of suffering or appears to be in a state of well-being? Another question arises: can we anticipate suffering without having experienced it yet and at the same time be certain that it will be intolerable? Specialists heard in Committee affirm that this is possible, citing the case of neurodegenerative diseases. Many Québec families have accompanied loved ones who suffered from Alzheimer's disease. They were able to witness the dementias associated with it and can predict them for themselves. The stages of this disease and its effects are known and documented.

Other experts believe that persons suffering from these diseases have the right to receive the best possible care, for which greater investment is necessary. Access to such care for all must therefore be prioritized in order to address the fears and suffering anticipated by persons diagnosed with these conditions.

---

[9] Expert group on the issue of incapacity and medical aid in dying.

The debate on the potential expansion of medical aid in dying for persons who are incapacitated, either through an advance request or through its inclusion in the advance medical directives regime, raises many questions that the Committee members resolve to address. These include the criteria and guidelines to be put in place, the form, content and validity of advance consent to end-of-life care. The role played by loved ones and the care team in implementing the wishes of the person who is no longer capable must also be explored. And what about the support of health professionals for possible provisions allowing the potential expansion of medical aid in dying?

Finally, in this particular context where medical aid for persons in a situation of incapacity is the subject of attention and discussion, it is necessary to address the situation of persons who have never been considered capable of consenting to their care. This includes persons living with a severe intellectual disability whose health condition meets the criteria set out in the Act.

Should these persons have access to medical aid in dying under certain circumstances? For example, when they have terminal cancer and are deemed capable of making certain decisions about their health?

The potential expansion of medical aid in dying for persons whose only medical problem is a mental disorder

The Truchon and Gladu judgment changed the landscape of medical aid in dying for persons suffering from mental disorders. This judgment rendered inoperative the "end of life" criterion set out in section 26 of the Act. This criterion prevented access to medical aid in dying for persons whose only medical problem was a mental disorder, since their health condition did not lead to the end of life. From now on, a person in this situation could have access to medical aid in dying. The mental disorder in question must, however, meet the other criteria of the Act. In particular, it must be serious and incurable as well as have caused an advanced and irreversible decline in the capacities of the person suffering from it. Furthermore, the person's suffering must be constant, unbearable and impossible to alleviate in conditions that he or she considers tolerable. In the eyes of the law, the psychological suffering experienced by the person is considered in the same way as the physical suffering.

Since the Act respecting end-of-life care did not initially provide for access to medical aid in dying for persons whose only medical problem is a mental disorder, many questions arise. Given the right to self-determination of all persons and the moral requirement to protect vulnerable persons, several divergent arguments have been put forward regarding medical aid in dying for persons whose only medical problem is a mental disorder.

Firstly, there is no consensus on the incurable nature of mental disorder. On the one hand, it is stated that the progression of mental disorders is unpredictable. Specialists believe that a case deemed irreversible or without hope of recovery at a certain point could in fact be alleviated with treatment. They also point out that no mental disorder can be deemed incurable with certainty, given the many treatments available.

Conversely, others believe that some mental disorders can be considered incurable. After having tried several treatments, the person suffering from the disorder may be left with few reasonable options to alleviate their suffering. In these circumstances, which are rather exceptional, according to several specialists, medical aid in dying could then be a way out.

Another issue raised when dealing with medical aid in dying and mental disorders is the risk of trivializing suicide. At a time when society is deploying suicide prevention programs, granting medical aid in dying for mental disorders could be seen as legitimizing euthanasia to end suffering rather than obtaining appropriate treatment. Several witnesses concluded that we should focus on improving access and quality of mental health care before expanding eligibility for medical aid in dying.

Moreover, specialists point out that suicidal ideation is an inherent symptom of some mental disorders. Therefore, it would be almost impossible for the health care team to distinguish suicidal ideation from a reasoned and genuine desire to obtain medical aid in dying, thus opening the door to misdiagnosis.

At the same time, the issue of discrimination against persons living with a mental disorder must also be taken into account. According to specialists in favour of medical aid in dying for someone whose only medical problem is a mental disorder, eligibility should be based on the individual's circumstances and conditions rather than on a diagnosis. Excluding persons with mental disorders would in some sense minimize their suffering, though it is very real and can be as intense as physical suffering.

Finally, it is relevant to assess the potential risks of abuse. Where do we draw the line? Since mental disorders do not evolve in a linear fashion, could persons receive medical aid in dying when their pain is transient or could be relieved by appropriate treatments? Specialists observe foreign experiences that make them fear, for example, that medical aid in dying might be given to persons whose suffering is caused by personal hardship or temporary conditions.

In response to these fears, several specialists argue that such situations are unlikely to occur. On the one hand, the criteria in the current Act would prevent such abuses. Indeed, the person's condition must be deemed incurable and his or her decline, advanced and irreversible. On the other hand, an assessment process that takes into account the specificities of mental disorders would prevent abuses and ensure rigorous processing of requests. Several measures are mentioned to adequately assess these specific requests for medical aid in dying. These include, for example, the assessment of compliance with criteria by at least two psychiatrists, an extended assessment period for the request for medical aid in dying, and the creation of a structure that would monitor the request assessment process at the outset.

Avenues for reflection

The members of the Select Committee on the Evolution of the Act respecting end-of-life care want to know your views on the issues presented in this document. To achieve this, here are two fictitious examples of cases for which medical aid in dying is not currently an option. Each example is followed by a series of questions. These possible scenarios and the associated avenues for reflection are not exhaustive or limiting. They are intended to open up the discussion by illustrating the complex issues facing the members of the Committee.

Inaptitude

Lucie has just been diagnosed with Alzheimer's disease. She is currently in the early stages of the disease, but fears that she will lose her cognitive abilities over the next few years. Having seen the devastating effects of the later stages of the disease on her mother, she wishes to obtain medical aid in dying when she is no longer able to recognize her loved ones and has lost all forms of autonomy, especially in terms of eating and personal hygiene.

Could Lucie give her consent to medical aid in dying in advance while she is still capable of making this decision? What form should this request take? How should it be written? Who should be responsible for implementing it?

Her physician has given her the information she needs to make a free and informed decision. Lucie wants her decision on medical aid in dying to be respected by her loved ones and by the health care team. She does not want her life to end having lost her dignity.

In your opinion, should Lucie's choice be binding on her family and the health care team or rather should it be re-evaluated as her illness progresses, especially if she does not show obvious signs of suffering?

In this case, Lucie has obtained a diagnosis. In your opinion, is obtaining a diagnosis necessary in order to make a request for medical aid in dying? Could a person make a request or give an advance directive for medical aid in dying in case he or she is the victim of an accident resulting in serious and irreversible after-effects, such as a cerebrovascular accident (CVA)?

Mental disorder

Marc is 49 years old. He has had a severe mental disorder which has affected his daily functioning for more than 20 years. He lives alone and is unable to hold a job. He is very isolated. For more than a decade, the treatments offered by his psychiatrist and his care team have been successful in alleviating his suffering. However, in recent years, the effectiveness has declined. Marc feels that his suffering is now intolerable. New treatments and therapies have been tried without success. Marc has been hospitalized a few times in recent years.

Should Marc be eligible for medical aid in dying if he requests it? In order to receive medical aid in dying, should he be obliged to undergo all the treatments offered to him, even if some of them cause side effects that he considers unreasonable?

How should a request for medical aid in dying like Marc's be assessed? Are the conditions to be met and the assessment process currently provided for in the Act sufficient?

Conclusion

The members of the Select Committee on the Evolution of the Act respecting end-of-life care are aware of the complex and sensitive nature of their mandate. The issues raised by the potential expansion of medical aid in dying for persons who are incapacitated or whose only medical problem is a mental disorder are numerous and delicate. It is for this reason that the Committee would like the people of Québec to express its views on this subject and share its experiences.

Your opinion is important and will contribute concretely to the progress of work.

How to participate in the Committee's mandate

- Complete the online questionnaire at the following adress, assnat.qc.ca/soinsfindevie.
- Submit a brief to the Select Committee Secretariat.
- Submit a request to participate in the second phase of the special consultations and public hearings. Only selected applicants will be contacted.

For further information on the proceedings of the Select Committee on the Evolution of the Act respecting end-of-life care, please contact the Committee's secretariat:

Mme Ann-Philippe Cormier
Édifice Pamphile-Le May,
1035, rue des Parlementaires, 3e étage
Québec (Québec) G1A 1A3
Telephone: 418 643-2722
Toll-free: 1 866 337-8837
Email: cssfv@assnat.qc.ca