



Report
of the Select Committee

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

December 2021



ASSEMBLÉE NATIONALE
DU QUÉBEC

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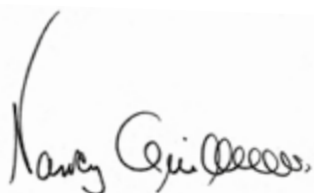
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A WORD FROM THE STEERING COMMITTEE

The Select Committee on the Evolution of the Act respecting end-of-life care began its work in the spring of 2021. Our mandate, as specified in the motion carried by the National Assembly, was to analyze the issues related to the potential extension of medical aid in dying to persons who are incapable of caring for themselves and those suffering from mental disorders.

Our contribution is in line with the trail blazed by the Select Committee on Dying with Dignity, whose report was tabled in 2012. At the time, the debate on access to medical aid in dying was the subject of numerous exchanges with experts in the medical and scientific fields and was enriched by the reflections submitted by citizens. The same was true throughout our work. Despite the constraints imposed by the COVID-19 pandemic, we noted the great interest of the Québec population in debating the issues at the heart of our mandate. This is evidenced by the thousands of responses we received through our online consultation, as well as the quality and depth of the testimonies we heard during the two special consultation phases. We would like to extend our sincere thanks to all those who took the time to share their expertise, insights and experiences with us. The Committee's work was carried out diligently and efficiently also thanks to the collaboration of the administrative staff of the National Assembly. We would also like to acknowledge the contribution of our colleagues Marie Montpetit and Gabriel Nadeau-Dubois who initiated the work of the Committee with us.

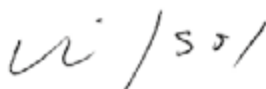
Subjects as complex and sensitive as suffering and the end of life must be addressed with the utmost respect. Throughout our deliberations, we have favoured a constructive approach that places the interests of citizens at the heart of our concerns. Guided by these values, our exchanges took place in a spirit of transpartisan collaboration in order to reach the broadest possible consensus in our recommendations and observations. At the end of our mandate, we are proud of the work accomplished and the significant progress for Québec society that our report reflects.



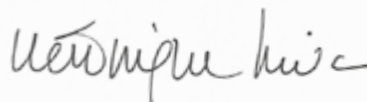
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INTRODUCTION

On March 31, 2021, the National Assembly unanimously carried a motion creating the Select Committee on the Evolution of the Act respecting end-of-life care. Its mandate is to analyze the issues related to the potential extension of medical aid in dying to persons who are incapable of caring for themselves and those suffering from mental disorder. Three major issues are at the heart of our report and are the subject of recommendations. **Can persons who are incapable of consenting to care obtain medical aid in dying, notably by means of an advance request? Similarly, should medical aid in dying be available to persons whose only medical condition is a mental disorder? And, if so, what criteria should guide the extension of medical aid in dying to these individuals?**

These are sensitive questions to address. They certainly bring us face to face with our own experience of illness, but they also force us to reflect on death and the value we all place on life. Through their testimonies, many people told us about their suffering or that of their loved ones. The seriousness of these questions demands that our responses be marked by respect and empathy. From the beginning of our work until the tabling of this report, our deliberations were guided by these principles.

Such a reflection cannot be conducted in a vacuum, in isolation from the considerations of the population. It must also take into account the provisions of the *Act respecting end-of-life care*, which governs the administration of medical aid in dying in Québec. To help us further our reflection, we carried out consultations during the spring and summer of 2021. During the month of May, the Committee held a first phase of special consultations to hear experts to conduct an exhaustive analysis of the situation. We were able to have in-depth discussions with more than thirty specialists and groups from various backgrounds on the issues at the heart of our mandate.

At the end of this first phase, the Committee published a consultation paper presenting to the Québec population the avenues of reflection that we wished to submit to public debate. In the month of June, an online consultation sought the public's opinion on the possible extension of medical aid in dying to persons who are unable to care for themselves and to those whose only medical condition is a mental disorder. The results of the survey exceeded our expectations. Over 3,400 people responded to the Committee's questionnaire, making this one of the most popular consultations held by the National Assembly.

During the month of August, a second phase of special consultations provided an opportunity to discuss these same issues with more than forty specialists, organizations and citizens. In this regard, a call for participation was launched to invite citizens to express their interest in taking part in this phase of hearings. In every respect, this consultative process was crucial and necessary, given the complexity of the questions to which we had to respond. We would like to extend our warmest thanks to all those who took part in this exercise and who had the courage, in some cases, to recall painful personal experiences. It is largely due to your testimonies, briefs, opinions and comments that we were able to successfully carry out our mandate.

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

- **2** phases of consultations
- **74** hearings
- **35** specialists and organizations heard during the first phase
- **42** individuals and organizations heard during the second phase¹
- **75** briefs submitted to the Committee secretariat
- **3,421** responses to the online questionnaire²
- More than **2,000** comments submitted to the Committee members
- **39** deliberative meetings held by the Committee members
- **46** meetings held by the steering committee

The content of the report

Our report is divided into three distinct parts. After having defined the concepts most frequently used within the framework of the Committee's discussions, the first part presents a contextualization of the evolution of the debate on medical aid in dying in Québec over the past ten years.

The second part of the report addresses the issue of the potential extension of medical aid in dying to persons who are incapable of caring for themselves. Following the format of a dialogue, it presents each of the different points of view heard during the Committee's work on this issue.

Lastly, the third part focuses on the potential extension of medical aid in dying to persons whose only medical condition is a mental disorder. It follows the same format used in the second part of the report by presenting, through questions and answers, the arguments and counter-arguments put forward by the witnesses we met. We hope that this approach will allow everyone to follow the consultations step by step and will allow for a better understanding of our observations and recommendations.

¹ Appendices II and III present the list of experts, individuals and groups heard by the Committee.

² Appendix I presents the results of the online consultation.

SETTING THE CONTEXT

Medical aid in dying is a sensitive subject where the meaning of words is very important. The concepts associated with the discussion on this act are linked to numerous disciplines, including law, medicine, ethics and philosophy. Some of these concepts may be more technical and lead to confusion or misinterpretation. For the sake of clarity, therefore, we believe it is essential to provide some preliminary definitions to ensure a common understanding of the key concepts and terms used in this report. These definitions also serve to lay the groundwork for the discussion.

Concepts and terms essential to the debate

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.

Advance request for medical aid in dying

This procedure refers to the possibility for a person to request medical aid in dying in advance by giving prior consent to receive it at a later time. In the current legal framework, there is no provision for the advance request for medical aid in dying. It is, however, called for by various groups, particularly for people who suffer from an illness leading to incapacity.

Autonomy

In its legal interpretation, the notion of autonomy refers to the capacity of an individual to act independently of any external influence. In the context of end-of-life care, it is linked to respect for the integrity of an individual's body and his or her freedom to agree on appropriate care, without the intervention of the State. Autonomy can be interpreted to mean free action, namely the expression of a will without constraint or coercion.

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 wishes³. 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.

Contemporary and anticipated suffering

The concept of suffering is central to medical aid in dying. Within the framework of this report, two facets of suffering are often used: contemporary suffering and anticipated suffering. Contemporary suffering refers to actual suffering that is experienced by a person in the present moment. It is distinct from anticipated suffering, which refers to suffering that a person expects to experience in the future and that is associated with the diagnosis received. Anticipatory suffering is based on apprehensions and may therefore differ from the actual experience that the person will have in the future. In the context of an advance request for medical aid in dying, anticipated suffering is the suffering, both physical and psychological, that a person expects to experience once incapacity has been established.

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 death⁴.

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 others⁵". 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 functioning⁶". Within the framework of this mandate, intellectual disability and autism spectrum disorder are addressed separately from mental disorders.

³ Curateur public du Québec, [Incapacity and the need for protection](#).

⁴ *Act respecting end-of-life care*, CQLR, c. S-32.0001, s. 3. The eligibility criteria for medical aid in dying are set out in section 26 of this Act.

⁵ World Health Organization, [Mental disorders](#), November 2019.

⁶ American Psychiatric Association, DSM-5, *Diagnostic and Statistical Manual of Mental Disorders*, Elsevier Masson: Issy-les-Moulineaux. 2015, p. 22.

Neurocognitive disorder

Neurocognitive disorders are characterized by the decline or loss of mental capacity that reduces a person's ability to care for themselves independently⁷. Neurocognitive disorders affect cognitive functions such as reasoning, functioning in daily activities, judgment, memory, orientation in time, place or recognition of people⁸. Subtypes of neurocognitive disorders include Alzheimer's disease, neurocognitive disorder with Lewy bodies, frontotemporal neurocognitive disorder and neurocognitive disorder due to traumatic brain injury. Neurocognitive disorders can lead to lack of capacity to consent to care. In people with neurocognitive disorders, the cognitive deficit is not present from birth or early childhood⁹. Neurocognitive disorders are thus distinct from intellectual disability and autism spectrum disorder.

Palliative care

The total and active care delivered by an interdisciplinary team to patients suffering from a disease with reserved prognosis. The aim is 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 need¹⁰. Continuous palliative sedation is care that is offered as part of palliative care¹¹.

Self-determination

Self-determination is one of the central concepts in the issue of medical aid in dying. In general, self-determination corresponds to the right of a person to make fundamental decisions about his or her life¹². More specifically, in the context of end-of-life care, the right to self-determination refers to the right to choose how and when one will die. From a legal point of view, the principle of self-determination is closely linked to the concept of consent. It imposes as a criterion of realization the capacity to exercise a free and informed choice.

7 Alzheimer Society, [What is dementia?](#)

8 CHUM, [Troubles de la mémoire et autres fonctions cognitives](#).

9 American Psychiatric Association, *op. cit.*, p. 775.

10 *Act respecting end-of-life care*, s. 3.

11 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. *Act respecting end-of-life care*, s. 3.

12 Olivier Guilloid, *Le consentement éclairé du patient : autodétermination ou paternalisme?* Thesis (Ph. D.), Université de Neuchâtel, 1986, p. 18.

History of the debate in Québec

The Select Committee on Dying with Dignity

In Québec, discussions on medical aid in dying really gained momentum in the fall of 2009. It was at this time that the Collège des médecins du Québec made its position on the issue known through a discussion paper entitled *Le médecin, les soins appropriés et le débat sur l'euthanasie*¹³. This document was echoed in the public sphere and provoked numerous reactions. On December 4, 2009, the National Assembly unanimously adopted a motion creating the Select Committee on Dying with Dignity. The parliamentarians thus acknowledged the favourable context for a broad societal debate on the issue of end-of-life care and, more specifically, medical aid in dying.

During the consultations and public hearings held in 2010 and 2011, the Committee heard 32 specialists and close to 250 citizens and groups. More than 6,500 people responded to an online questionnaire on the National Assembly website. Following these consultations, the Select Committee tabled the report *Dying With Dignity* in the National Assembly in March 2012. This unanimous report contains 24 recommendations that can be divided into two categories. The first recommendations are essentially about improving the provision of end-of-life care. Better access to palliative care is advocated, as is the recognition of advance medical directives. The other recommendations concern medical aid in dying. The Committee members recommend that it be administered to persons at the end of life who meet the eligibility criteria.

Three main principles guided the recommendations in this report. They are useful for understanding the logic of medical aid in dying in the Québec context:

- Situate medical aid in dying within a continuum of end-of-life care;
- Associate medical aid in dying with the relief of suffering;
- Ensure respect for the person's autonomy¹⁴.

The first principle expresses the central idea that medical aid in dying corresponds to care that should not be isolated from other care. Medical aid in dying is therefore seen as an additional option to existing end-of-life care, such as palliative care or palliative sedation. The second principle also allows medical aid in dying to be placed in a medical context. Indeed, this practice is associated with a specific objective, namely the relief of suffering.

As a result of a broad social consensus, the report was generally well received by the Québec population. In short, this report was a determining factor in the debate on medical aid in dying in Québec. The *Act respecting end-of-life care*, adopted a few years later, is largely based on the principles and recommendations contained in the report.

¹³ Collège des médecins du Québec, [Le médecin, les soins appropriés et le débat sur l'euthanasie](#), October 2009.

¹⁴ Select Committee on Dying with Dignity, [Dying With Dignity: Report](#), March 2012, p. 82.

“It is clear that the whole issue of medical aid in dying is based on a societal choice, which must be made following a very broad and democratic debate.”

Excerpt from the brief of the Fédération interprofessionnelle de la santé du Québec

The Act respecting end-of-life care

On June 12, 2013, Bill 52 on end-of-life care was introduced at the National Assembly. It was adopted on June 5, 2014 and the *Act respecting end-of-life care* came into force on December 10, 2015¹⁵. The adoption of this Act places Québec at the forefront of the issue of end-of-life care and more specifically of medical aid in dying. The scope of the Act is much broader than medical aid in dying. It covers, as its name indicates, all end-of-life care. Like the report, the Act calls for a continuum of end-of-life care, which is mentioned in the very first section:

The purpose of this Act is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy. The Act establishes the rights of such patients as well as the organization of and a framework for end-of-life care so that everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering¹⁶.

This first section also refers to another major principle of the Act, that of providing end-of-life care with the goal of relieving the suffering of individuals. This end-of-life care includes palliative care and medical aid in dying. As defined in the Act, both of these forms of care are specifically intended to relieve the suffering of persons at the end of life.

The Act consists of several divisions that address different aspects of end-of-life care. In particular, it specifies the rights of persons in end-of-life and details the organization of their care. Rules applicable to end-of-life care providers are set forth, as are certain requirements concerning continuous palliative sedation and medical aid in dying.

Concerning this latter care, section 26 of the Act sets out the six criteria that a person must meet to obtain medical aid in dying:

1. Be an insured person within the meaning of the *Health Insurance Act* (chapter A-29);
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 this “end of life” criterion inoperative¹⁷.

4. Suffer from a serious and incurable illness;
5. Be in an advanced state of irreversible decline in capability; and
6. Experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable¹⁸.

¹⁵ The bill was passed by a free vote. The result was 94 votes in favour of the bill and 22 against.

¹⁶ *Act respecting end-of-life care*, s. 1.

¹⁷ *Truchon v. Attorney General of Canada*, 2019 QCCS 3792.

¹⁸ *Act respecting end-of-life care*, s. 26.

The current criteria set out in this section therefore specify that the person must be capable of consenting to care at the time of obtaining medical aid in dying. Thus, persons who have lost their capacity to consent due to a neurocognitive disorder are not eligible for medical aid in dying.

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. Medical aid in dying is considered to be a form of care for which only those who meet all the criteria set out in section 26 are eligible. It is therefore not a right per se, but rather a medical practice that is part of a broader range of end-of-life care.

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.** Be of the opinion that the patient meets all the criteria of section 26, after, among other things:
 - a)** Making sure that the request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure;
 - b)** Making 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;
 - c)** Verifying the persistence of suffering and 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;
 - d)** Discussing the patient's request with any members of the care team who are in regular contact with the patient; and
 - e)** Discussing the patient's request with the patient's close relations, if the patient so wishes;
- 2.** Make sure that the patient has had the opportunity to discuss the request with the persons they wished to contact; and
- 3.** Obtain the opinion of a second physician confirming that the criteria set out in section 26 have been met¹⁹.

Furthermore, any refusal to receive medical aid in dying expressed by this person must be imperatively respected.

¹⁹ *Ibid.*, s. 29.

Moreover, the Act establishes a commission on end-of-life care under the name “Commission sur les soins de fin de vie”. It specifies its composition, its mandate and its rules of operation. The mandate of the Commission is to examine any matter relating to end-of-life care. It must, among other things, evaluate the implementation of the Act and submit a report to the Minister of Health and Social Services, every five years, on the status of end-of-life care. The Commission sur les soins de fin de vie also has the mandate to oversee the application of the specific requirements relating to medical aid in dying.

Finally, the Act recognizes the primacy of freely and clearly expressed wishes with respect to care, in particular by establishing an advance medical directives regime. This means that persons can give or withhold consent in advance to certain medical care that could be given to them if they become incapable of giving consent. Five types of care can be refused under the advance medical directives regime: cardiopulmonary resuscitation, dialysis treatments, artificial ventilation, and artificial hydration and nutrition. This regime therefore does not allow for advance requests for medical aid in dying.

On June 10, 2021, the *Act respecting end-of-life care* was amended by legislation²⁰. Section 29 of the Act was modified to allow a physician to administer medical aid in dying to a person who has become incapable of consenting to care if he or she had requested it when capable. Thus, the consent that must be given at the time of administration is no longer necessary if the person has become incapable. However, the person must have consented in writing and in the presence of a health professional within 90 days prior to the administration of medical aid in dying.

Therefore, a person may now obtain medical aid in dying even if he or she loses the capacity to consent after making such a request. This amendment came into force on June 11, 2021.

“One should not consider medical aid in dying by default, because one is not able to benefit from other care. I think that a comprehensive end-of-life care program should be promoted.”

*Dr. André Luyet, Executive Director of the Collège des médecins du Québec
Excerpt from the hearing held on May 28, 2021, special consultations*

²⁰ The *Act respecting end-of-life care* was amended by Bill 83, *An Act respecting mainly the health insurance plan and prescription drug insurance plan eligibility of certain children whose parents' migratory status is precarious and amending the Act respecting end-of-life care*.

The Truchon and Gladu case and its repercussions

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 case²¹. 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 eligibility criteria for medical aid in dying were too restrictive, they filed a court action in 2017 to have them declared unconstitutional.

In its judgment, the Superior Court determined that the “end of life” criterion set out in section 26 of the Québec statute was unconstitutional, as was the “reasonably foreseeable natural death” criterion set out in section 241.2 of the *Criminal Code*. More specifically, the judgment stated that the “end of life” criterion violates the right to equality which is guaranteed by section 15 of the *Canadian Charter of Rights and Freedoms*. It was therefore declared inoperative by the Court. Since the Québec government decided not to appeal the judgment, the “end of life” criterion in the Québec statute officially became inoperative on March 12, 2020.

The main result of this judgment will have been to broaden eligibility for medical aid in dying. Henceforth, individuals whose illness does not result in death in the short term may obtain medical aid in dying if they meet the other criteria of the Act. Among those who could obtain medical aid in dying as a result of this judgment are potentially individuals whose only medical condition is a mental disorder. Prior to this judgment, the issue of eligibility for these individuals was hardly an issue since their medical condition does not result in the end of life. These people were therefore not eligible. However, since the removal of the “end of life” criterion, these people could obtain medical aid in dying under the other eligibility conditions set out in section 26 of the Act.

Recent amendments to the *Criminal Code*²² specify that persons whose only medical condition is a mental illness cannot obtain medical aid in dying from now until March 2023²³. The Québec statute makes no such provision. It makes no distinction between mental disorders and other illnesses. They are considered in like manner as physical illnesses. Psychological suffering is also considered in like manner as physical suffering²⁴. It is therefore possible that individuals whose only medical condition is a mental disorder could obtain medical aid in dying if they meet all the criteria set out in the Act. Faced with this prospect, the Minister of Health and Social Services announced in January 2020 that she was postponing for an indefinite period the extension of medical aid in dying to these people in order to hold consultations on the subject²⁵.

21 *Truchon v. Attorney General of Canada*.

22 The amendments to the *Criminal Code* were made through Bill C-7 passed in March 2021.

23 *Criminal Code*, RSC 1985, c. C-46, s. 241.2 (2.1).

24 *Act respecting end-of-life care*, s. 26.

25 Radio-Canada. [Québec repousse l'accès à l'aide à mourir pour ceux qui souffrent de troubles mentaux](#). January 27, 2020.

The consultations on the potential extension of medical aid in dying

In October 2017, the Minister of Health and Social Services announced the establishment of the Groupe d'experts sur la question de l'incapacité et l'aide médicale à mourir, whose mandate was to study the possibility of extending medical aid in dying to persons who are incapable of caring for themselves. The report produced by this group of experts, co-chaired by Nicole Filion, attorney, and Professor Jocelyn Maclure, is entitled *L'aide médicale à mourir pour les personnes en situation d'incapacité : le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence*. It was made public on November 29, 2019. It should be noted that this report was written before the Truchon and Gladu judgment, which rendered the "end of life" criterion inoperative²⁶.

One of the main recommendations of the report is to allow a person who has been diagnosed with a serious and incurable disease to write an advance request for medical aid in dying in anticipation of his or her inability to consent to such care. The expert group's other recommendations focus primarily on the administration of advance requests, the role of loved ones in reporting the existence of such requests, and the development of end-of-life care²⁷.

Following the judgment rendered in the Truchon and Gladu case, consultations were held more specifically on the subject of medical aid in dying and mental disorders. In January 2020, the Commission sur les soins de fin de vie and the Collège des médecins mandated the Association des médecins psychiatres du Québec to make recommendations on the circumstances in which a person whose only medical condition is a mental disorder could obtain medical aid in dying. At the end of its work, the Association published in November 2020 the discussion paper *Access to medical assistance in dying for people with mental disorders*. The conclusion drawn is that medical aid in dying could be offered, under certain conditions, to persons whose only medical condition is a mental disorder, but should not be contingent on a particular diagnosis. Instead, access should be assessed in relation to several dimensions of mental disorders: the incurability and irreversibility of the disorder, its chronicity, previous attempts at treatment, refusal of treatment, suffering, decision-making ability, and suicidal thinking of the person²⁸.

For its part, the Commission sur les soins de fin de vie was instructed to hold a consultation with support and advocacy groups for persons with mental disorders. In its report, the Commission sur les soins de fin de vie identified the main concerns of the organizations it met. Among these were the difficulties in accessing mental health care and the potentially harmful message that an extension of medical aid in dying to persons with mental disorders could send²⁹.

²⁶ *Truchon v. Attorney General of Canada*.

²⁷ Groupe d'experts sur la question de l'incapacité et l'aide médicale à mourir, [L'aide médicale à mourir pour les personnes en situation d'incapacité : le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence](#), November 2019.

²⁸ Association des médecins psychiatres du Québec, [Access to medical assistance in dying for people with mental disorders: Discussion paper](#), November 2020.

²⁹ Commission sur les soins de fin de vie, [Accès à l'aide médicale à mourir pour les personnes atteintes de troubles mentaux : consultation auprès de groupes de soutien et de défense des droits des personnes atteintes de troubles mentaux et de leurs proches aidants](#), February 2020.

Another milestone in the consultations about potentially extending medical aid in dying was the organization of national forums by the ministère de la Santé et des Services sociaux. The first forum was held on January 27, 2020, on medical aid in dying in the context of incapacity. The second forum was held on December 14, 2020, and focused on medical aid in dying for persons with mental disorders. These forums brought together, notably, health and social services institutions, para-governmental organizations, user groups and professional orders. The purpose of these forums was to facilitate exchanges between the stakeholders and to further the reflection on the evolution of the *Act respecting end-of-life care*.

These consultations and reports over the past few years have therefore made it possible to initiate discussions on the potential extension of medical aid in dying in Québec. They have also advanced the reflection on these sensitive issues and created a context conducive to a broad societal debate. These are solid foundations on which the Select Committee has been able to build during its own work.

A portrait of medical aid in dying in Québec

Since the *Act respecting end-of-life care* came into force in 2015, the Commission sur les soins de fin de vie has been monitoring requests for medical aid in dying administered in Québec. The statistics collected by the Commission sur les soins de fin de vie allow us to measure the evolution of the number of deaths, to establish a portrait of the persons who obtained this care and the conditions of its administration, but also to better evaluate the nature of the suffering described by these persons.

How many times has medical aid in dying been administered?

Since the Act came into force, the number of times medical aid in dying has been administered in Québec has risen year after year. It has increased from 599 in 2016-2017 to 2,426 in 2020-2021, an increase of 405%³⁰. In total, approximately 7,000 individuals received medical aid in dying in Québec between December 10, 2015, and March 31, 2021. According to the Commission sur les soins de fin de vie, these deaths represented 3.3% of the total number of deaths in Québec in 2020-2021, compared to 2.6% in 2019-2020 and 1.9% in 2018-2019³¹. The Commission sur les soins de fin de vie projects that this percentage will continue to increase over the next three years to reach 4% or 5%.

Who obtains medical aid in dying?

According to data compiled by the Commission sur les soins de fin de vie, more men (53%) than women (47%) have received medical aid in dying since 2015. These individuals were on average 73 years old. Nearly 90% of them were over the age of 60. They were primarily suffering from cancer (74%), neurodegenerative disease (9%), lung disease (6%), and heart or vascular disease (5%)³².

³⁰ *Id.*, [Rapport annuel d'activités du 1er avril 2020 au 31 mars 2021](#), p. 11.

³¹ *Ibid.* p. 13. [The Second Annual Report on Medical Assistance in Dying in Canada 2020](#) states that this percentage places Québec in second place across Canada behind British Columbia.

³² *Id.*, [Mémoire présenté dans le cadre des travaux de la Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie](#), Brief submitted to the Select Committee on the Evolution of the Act respecting end-of-life care [hereinafter CSSFV], May 14, 2021, p. 8.

The vast majority of these individuals waited until the terminal phase of their illness to request medical aid in dying: 74% of them had an estimated prognosis of three months or less to live, 86% had a prognosis of six months or less, and 99% had a prognosis of twelve months or less³³.

Following the Court decision in the Truchon and Gladu case, 19 individuals obtained a judgment from the Superior Court of Québec in order to receive medical aid in dying without their being considered at the end of their life³⁴. The majority of them had a neurodegenerative disease and a life expectancy of one year or more.

Where is medical aid in dying administered?

Since 2015, medical aid in dying has been administered primarily in hospitals (60%), although more than a quarter of deaths (27%) occurred at home. A mere 9% of requests were administered in residential and long-term care facilities (CHSLDs)³⁵. Owing to the COVID-19 pandemic, the Commission sur les soins de fin de vie has noted significant variations in these statistics. In 2020-2021, close to 40% of deaths occurred at home³⁶. Once difficult to obtain, access to medical aid in dying is increasingly available in palliative care hospices.

Who administers medical aid in dying?

The *Act respecting end-of-life care* specifies that only physicians may administer medical aid in dying. Since the Act came into force, medical aid in dying has been provided mainly by general practitioners. In 2020-2021, they claimed 87% of the fees paid by the Régie de l'assurance maladie for procedures related to this type of care, compared with just 13% for specialist physicians³⁷. The Commission sur les soins de fin de vie estimates that more than 1,100 physicians have been involved, in one way or another, in the administration of medical aid in dying³⁸ and that their number is increasing every year.

Other health care professionals are involved in this process. For example, before administering medical aid in dying to a person who requests it, the physician must confer “with any members of the care team who are in regular contact with the patient³⁹”. To this end, the Act specifies that institutions offering end-of-life care must, among other things, “establish measures to promote a multiple-discipline approach by health and social services professionals and the collaboration of the various other resources concerned who provide services to its users⁴⁰”.

³³ *Ibid.* p. 9.

³⁴ *Ibid.*

³⁵ *Ibid.*

³⁶ *Id.*, [Rapport annuel d'activités du 1^{er} avril 2020 au 31 mars 2021](#), p. 20.

³⁷ *Ibid.*

³⁸ *Ibid.*

³⁹ *Act respecting end-of-life care*, s. 29.

⁴⁰ *Act respecting end-of-life care*, s. 7.

Why is medical aid in dying requested?

The Commission sur les soins de fin de vie collects data on the nature of the suffering of individuals who have received medical aid in dying. This suffering is described in a form filled out by physicians after the administration of this care.

In 2020-2021, more than nine out of ten people (93%) experienced both physical and psychological suffering. In 1% and 7% of cases respectively, only physical or psychological suffering was indicated by the physician⁴¹. According to the Commission sur les soins de fin de vie, the suffering described by these persons is similar to that most frequently observed in persons at the end of life:

The vast majority of these forms [...] mention suffering related to loss of ability to perform activities that gave meaning to one's life (97%) or activities of daily living (93%) and a large majority refer to a loss of dignity (78%). Just over half (58%) report inadequate pain control or concerns in this regard and the same proportion mention inadequate control of other symptoms or concerns in this regard. About 44% indicate that the person perceived themselves as a burden to family, friends or their caregivers. Just over one-third (37%) refer to loss of bodily functions and about one-quarter (24%) report suffering from isolation or loneliness⁴².

The forms submitted to the Commission sur les soins de fin de vie help us to better understand the reasons why this suffering could not be alleviated in conditions that the person considered tolerable. Some of the most common reasons given were that treatment was ineffective (65%), the person refused treatment (26%), side effects were unacceptable (25%) and there was no treatment (33%)⁴³.

Why are some requests for medical aid in dying not administered?

Each year, approximately one third of requests for medical aid in dying are not administered in Québec^{44,45}. According to the Commission sur les soins de fin de vie, there are a number of reasons for these “non-administration” cases. In 2020-2021, the main reasons are as follows: in 34% of cases, death occurred before the assessment of the request was completed or before medical aid in dying was administered. In one-third of cases (33%), the person did not meet or no longer met the eligibility criteria. Finally, withdrawal of the request for medical aid in dying accounted for 18% of cases⁴⁶.

41 Commission sur les soins de fin de vie, [Rapport annuel d'activités du 1^{er} avril 2020 au 31 mars 2021](#), p. 45.

42 *Ibid.* p. 17.

43 *Ibid.* p. 45.

44 *Id.*, Rapport sur la situation des soins de fin de vie au Québec du 10 décembre 2015 au 31 mars 2018, p. 56.

45 *Id.*, [Rapport annuel d'activités du 1^{er} avril 2020 au 31 mars 2021](#), p. 32.

46 *Ibid.* p. 33.

The reflection on the potential extension of medical aid in dying: striking a balance between the right to self-determination of individuals and the protection of vulnerable persons

In the opinion of the vast majority of the experts and organizations we have heard, the *Act respecting end-of-life care* has fulfilled its objectives. It has allowed thousands of people to alleviate their suffering and die with dignity while respecting their choices. The Québec population's perceptions of medical aid in dying have evolved positively since the Act came into force, as shown by the responses to the online consultation conducted within the framework of the Select Committee's proceedings. Medical aid in dying is an integral part of end-of-life care, on par with palliative care. We note that there is an even greater consensus on this practice today than when the Act was adopted.

The requests made by many civil society actors and the judgment rendered by the Québec Superior Court in the Truchon and Gladu case⁴⁷ have led us to consider the potential extension of medical aid in dying to persons who are incapable of caring for themselves and to persons suffering from mental disorders. These questions are complex and raise important ethical issues. As parliamentarians, they require us to seek a balance between two fundamental principles: respect for the right to self-determination of individuals and the role the State has to play in protecting vulnerable persons.

While not mutually exclusive, reconciling these two principles nevertheless remains a challenge that we have had to deal with. Mindful of this responsibility, it is with humility that we present to you the results of our work on the two issues at the heart of the mandate of the Select Committee on the Evolution of the Act respecting end-of-life care.

⁴⁷ *Truchon v. Attorney General of Canada*.

MEDICAL AID IN DYING FOR PERSONS WHO ARE INCAPABLE OF CARING FOR THEMSELVES

What do we mean by incapable in the current mandate?

The first part of our mandate concerns the potential extension of medical aid in dying to persons who are incapable of caring for themselves. Before addressing the substance of the issue, we first had to determine what is meant by a “person who is incapable of caring for him or herself”. This term can indeed encompass several categories of persons who are incapable of consenting to care. In the context of our mandate, we have identified three categories of persons who are likely to be incapable of caring for themselves:

- Situate medical aid in dying within the continuum of end-of-life care;
- Associate medical aid in dying with relief of suffering;
- Ensure personal autonomy is respected.

These categories are very different one from the other and the people they include have their own realities. It should be noted that they are not necessarily incapable of consenting to care. Without being exhaustive, these three categories allowed us to better orient and organize our discussions. In fact, we came to different conclusions regarding the extension of medical aid in dying to these categories of individuals. The specific characteristics of each of these types of incapacity guided our analysis and directed our conclusions.

Persons with a severe form of intellectual disability or autism spectrum disorder

First, it should be noted that intellectual disabilities and autism spectrum disorders can manifest themselves in different forms. Their degrees of severity also vary. As part of our mandate, we had to look specifically at people who are incapable of consenting to medical aid in dying because of their condition. Several advocacy groups for people with intellectual disabilities and autism spectrum disorders made a point of expressing their apprehensions about the work of our Committee.

At the outset, it should be noted that our mandate does not include determining whether or not access to medical aid in dying will be made available to these individuals because of their intellectual disability or autism spectrum disorder. Moreover, this aspect is not included in the current provisions of the *Act respecting end-of-life care* and we do not wish to see it amended in this sense. As Martin Caouette, a professor in the Department of Psychoeducation at UQTR, said, “Persons with an intellectual disability should have the possibility of accessing medical aid in dying, but the reason for accessing it should never be intellectual disability⁴⁸”. Instead, the reason should be a serious and incurable illness, such as cancer.

Currently, the Act does not distinguish between persons with an intellectual disability or an autism spectrum disorder. These citizens can request medical aid in dying and receive it only if they meet the eligibility requirements set out in section 26 of the Act. Among these criteria is the ability to

⁴⁸ Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 25, 2021, at 9 a.m.

consent to care. As several witnesses pointed out during the consultations, ability must be assessed by the physician, as is the case for all persons requesting medical aid in dying. A physician should not conclude that a patient is incapable simply because he or she has an intellectual disability or an autism spectrum disorder. These diagnoses do not systematically lead to an inability to consent to care. These clarifications seem essential to us, among other things, considering the prejudices and stigmatization to which these people are subjected. In its brief, the Fédération québécoise de l'autisme mentioned that “the lack of knowledge of the characteristics of autism on the part of people who accept or refuse requests for end-of-life care also represents a risk when it comes to free and informed consent⁴⁹”. Indeed, several individuals and groups reminded us that clinical judgment can still to this day be affected by the presence of a diagnosis of intellectual disability or autism spectrum disorder, based on prejudice, among other things. We believe that it is important to adapt the evaluation process for requests for medical aid in dying in all circumstances by focusing on the person’s needs.

As part of our mandate, we had to look more specifically at the possibility of giving access to medical aid in dying to persons whose level of capability would not be deemed sufficient to consent to this care. It should be noted that the level of capability required to consent to medical care varies according to the nature of the care⁵⁰. Given the definitive nature of medical aid in dying, the level of capability required is necessarily high.

Thus, there are individuals with, for example, profound intellectual disabilities who are not in a position to consent to medical aid in dying even if they meet the other eligibility criteria. For them to have access to this care, another person would have to consent on their behalf. This is called substituted consent. This practice is already provided for under certain conditions in section 11 of the *Civil Code of Québec* for care other than medical aid in dying⁵¹. However, there was a broad consensus among the individuals and groups participating in the Committee according to which substituted consent for medical aid in dying should not be permitted. Many of them explained this position to us, recalling that medical aid in dying is different from other care, given its irremediable nature. For some, substituted consent for this care goes against the principle of self-determination. As the Curateur public du Québec notably pointed out, for a person, requesting medical aid in dying “represents the ultimate expression of his or her self-determination⁵²”.

We share this position on substituted consent. We believe that the use of substituted consent for medical aid in dying should be excluded from the outset. Consent on behalf of others could lead to too great a risk of abuse. Its application would be directly contrary to the self-determination of vulnerable persons: those with intellectual disabilities or autism spectrum disorders. We recognize, of course, that such people may find themselves in difficult living conditions if they suffer from a serious illness and persistent suffering. Nevertheless, we believe that the *status quo* is preferable to extending access to medical aid in dying to those who have never been capable of consenting to such care. Great caution must be exercised in this matter.

49 Fédération québécoise de l'autisme, [Avis de la Fédération québécoise de l'autisme](#), brief submitted to the CSSFV, p. 5.

50 Collège des médecins du Québec and Barreau du Québec, [Le médecin et le consentement aux soins](#), September 2018, p. 17.

51 *Civil Code of Québec*, SQ 1991, c. 64.

52 Curateur public du Québec, [Mémoire du Curateur public du Québec à la Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie](#), brief submitted to the CSSFV, p. 7.

This conclusion on substituted consent applies to all persons who are incapable of caring for themselves. We reiterate that a person can only make a request for medical aid in dying for himself or herself.

Persons who have suffered a traumatic brain injury or stroke

Few witnesses spoke directly about the case of victims of a traumatic brain injury or stroke during the public hearings. We have nevertheless taken the time to analyze their situation. First, it should be mentioned that these health conditions do not always result in incapacity, which is one of the possible sequelae. Moreover, traumatic brain injuries and strokes have the particularity of being unforeseen. They are unexpected and sudden.

In fact, persons who have suffered a traumatic brain injury or stroke have not always been incapable, they become so. In theory, such a person could have given advance consent to certain care or expressed a refusal of care. This logic underlies advance medical directives. Any person can write such directives on consent or refusal of care in anticipation of incapacity.

In the course of our work, we examined the relevance of granting medical aid in dying on the basis of advance requests. It is however difficult to apply this practice in the case of traumatic brain injuries and strokes because of their unpredictable nature. A person would have to give advance consent to medical aid in dying for a chance event. Similarly, a person would have to anticipate his or her medical condition after the accident, though difficult to predict. The sequelae of a traumatic brain injury or stroke are likely to vary in time and according to their severity^{53,54}. Therefore, we believe that an advance request for medical aid in dying in anticipation of a traumatic brain injury or stroke is not justified. The inability to obtain a prior diagnosis leads to a great deal of uncertainty that would interfere with informed decision making.

It should also be noted that the existence of advance medical directives already largely responds to the concerns expressed by some of the witnesses heard. The drafting of such directives allows a person to refuse in advance care that would keep him or her alive artificially. Victims of traumatic brain injury and stroke often have other options, such as refusing treatment, to avoid being condemned to a vegetative or comatose state, as many anticipate or fear. Many individuals have told us, however, that advance medical directives remain a little known and little used tool. We believe that steps must be taken to remedy this situation.

Persons suffering from a neurocognitive disorder

For the most part, our discussions on the issue of medical aid in dying for persons who are incapacitated therefore turned to those suffering from neurocognitive disorders. These disorders have specific characteristics that lead us to consider the possibility of extending medical aid in dying to people who suffer from them. Like victims of traumatic brain injury or stroke, persons with neurocognitive disorders have not always been incapable of consenting to care. They, too,

⁵³ Center for Disease Control and Prevention, Moderate and Severe TBI, May 2021.

⁵⁴ Ji Y. Chong, [Overview of stroke](#), Merck Manual, April 2020.

have the capacity to give free and informed consent to certain care in advance or to refuse care in advance. However, they differ from traumatic brain injury and stroke victims in that they can obtain a diagnosis of their illness before they become incapacitated. The effects of neurocognitive disorders are generally not incidental like a stroke. These few characteristics guided our reflection on the possibility of requesting medical aid in dying in advance.

The questions that fueled our reflection

The proposal to implement an advance request for medical aid in dying for persons suffering from neurocognitive disorders generated many reactions during the special consultations and public hearings. Several questions were raised, thereby helping to shed light on the underlying issues. In fact, the various testimonies and points of view we heard were very enlightening and contributed to our discussions on the relevance of implementing an advance request for medical aid in dying. The purpose of this section is to present the main questions that inspired our exchanges as well as our positions on these issues.

Would the self-determination of persons suffering from neurocognitive disorders be better respected if they could request medical aid in dying in advance?

For many of the witnesses heard by the Committee, it is up to each individual to determine what he or she considers to be a dignified end of life that respects his or her values. No one should interfere with a person's express wish to end his or her suffering at the time deemed appropriate. When a person suffers from a neurocognitive disorder resulting in incapacity, he or she should have the right to make an advance request for medical aid in dying while still capable of doing so. An early request would ensure that his or her wishes are respected in the event of incapacity.

For others, the principle of an individual's self-determination can only be respected if the person is still able to make decisions for him or herself at the present time. The difficulty of predicting with certainty the evolution of a neurocognitive disorder complicates anticipatory decision-making. In other words, can the decision to have recourse to medical aid in dying be made in a free and informed manner if the person does not know what state he or she will be in as the illness progresses?

We are faced with an issue that refers to the principles and values of each individual, but also to those of our society and the responsibilities of the State towards its citizens. From the outset, we do not believe that it is responsible or even desirable to grant medical aid in dying on demand to every individual. As Dr. Michèle Marchand rightly points out, “the patient can accept or refuse the proposed care, but never, neither here nor elsewhere, can he or she demand it⁵⁵”. The principle of self-determination, while essential in our view, thus has obvious limits. Medical aid in dying, it should be remembered, is part of a continuum of care. Its administration is governed by strict and precise guidelines. It is also based on a person's ability to make informed decisions for him

⁵⁵ Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 28, 2021, at 9 a.m.

or herself. This implies, among other things, that the person making the request is capable of understanding the consequences of the evolution of his or her illness on his or her state of health.

In the opinion of the co-chairs of the Groupe d'experts sur la question de l'incapacité et l'aide médicale à mourir, Nicole Filion, attorney, and ethicist Jocelyn Maclure, it is imperative that a person first obtain a diagnosis of neurocognitive disorder before being able to make an advance request for medical aid in dying⁵⁶. This position echoes those of other witnesses heard throughout our consultations. According to these experts, such a diagnosis would allow a person with a neurocognitive disorder to be accompanied by his or her physician and to better understand the evolution of his or her state of health before making a decision with such far-reaching consequences as requesting medical aid in dying. We believe that this is an essential prerequisite to any extension of the Act to persons who are incapable of caring for themselves.

How can we ensure that the dignity is respected for those who have become incapacitated due to the progression of their illness?

It is an established fact that neurocognitive disorders necessarily lead to a significant loss of autonomy for people who suffer from them. Stakeholders have described to us in precise detail the deterioration of living conditions in the most advanced stages of Alzheimer's disease or other similar diseases. These testimonies echo those we received from numerous caregivers through the online consultation.

In the opinion of the vast majority of the experts heard, neurocognitive disorders can lead to a loss of dignity for people who suffer from them. As Dr. Judes Poirier points out, one does not die with dignity from Alzheimer's disease⁵⁷. The apprehension of this end of life can also cause great suffering for those who have been diagnosed with a neurocognitive disorder. These observations argue in favour of extending medical aid in dying by means of an advance request so that these individuals can have access to this care.

Furthermore, various stakeholders heard by the Committee maintain that all persons who are unable to look after themselves must have access to quality care that allows them to live with dignity. According to these participants, the extension of medical aid in dying would be in contradiction with the respect of the intrinsic dignity inherent in every human being. This fundamental dignity must be preserved throughout a person's existence. Respect for this principle is all the more necessary when a person is put in a state of vulnerability, which is the case for those who have become incapacitated due to a neurocognitive disorder. For these stakeholders, other types of care must be given priority in order to alleviate the suffering of persons who have become incapacitated.

There is no doubt that the issue of respect for dignity has been at the heart of the debate surrounding access to medical aid in dying for many years. This issue is closely linked to that of the person's self-determination regarding his or her end of life. What constitutes a dignified end of life is highly subjective and, in general, is based on one's own beliefs and values. It is not our place

⁵⁶ *Ibid.*, May 14, 2021, at 9:30 a.m.

⁵⁷ *Ibid.*, May 20, 2021, at 9 a.m.

to judge the validity of these beliefs, but rather to ask ourselves what our society's responsibilities are towards persons who suffer from the deterioration of their state of health.

In our opinion, respect for the dignity of individuals must include listening to their needs within the framework provided by the *Act respecting end-of-life care*. Can persons who have become incapacitated be spared unnecessary suffering when it has been established that their health condition will worsen and their faculties will inevitably decline? We think it is reasonable to believe so, if that is their wish and their medical condition justifies it. While reiterating our society's responsibilities towards vulnerable persons and the fundamental role that health care teams must play in accompanying them throughout their illness, we consider that the debate on the potential extension of medical aid in dying to persons who have become incapacitated is legitimate and necessary. We must collectively find ways to respect their right to die with dignity.

Should better access to care precede the extension of medical aid in dying?

The issue of access to quality health care for persons with neurocognitive disorders was raised several times during our deliberations, particularly by stakeholders who opposed advance requests. Indeed, some of them mentioned that care for the elderly has been underfunded over the years. This lack of funding has allegedly hindered access to resources, but also affected the ability of the health and social services network to provide care adapted to their needs. Yet, this type of care is very important for persons with neurocognitive disorders. It should be noted that they can no longer express their needs or discomforts clearly. It is therefore essential that the care team be able to spend time with each individual. The goal is to recognize their signs of discomfort, respond appropriately to their needs and, when necessary, try different treatments to ease their suffering. In the absence of such care, many stakeholders stated that it would be premature to offer the possibility of making an advance request for medical aid in dying. Some people might then be tempted to make such a request for lack of a better option, anticipating the lack of care.

In this regard, the groups and experts who supported advance requests did not question the need for increased investment in appropriate care for persons with neurocognitive disorders. Rather, it was noted that access to care and the implementation of a potential advance request are two different debates. Even with the best care and treatment, a person diagnosed with a neurocognitive disorder should have the possibility of choosing his or her end of life. Moreover, waiting until access to quality care is perfect before allowing an advance request would be tantamount to writing off that possibility. As Dr. Judes Poirier mentioned, there is always room for improvement when it comes to care. In light of the demographic situation and the aging of Québec's population, the prospect of implementing advance requests would thus be continually postponed.

While we believe that more can and should be done in the area of care for the elderly, we do not believe that this issue is in conflict with discussions on advance requests for medical aid in dying. Improving access to appropriate health care and extending medical aid in dying can be done in parallel.

Would the difficulty in predicting the course of neurocognitive disorders stand in the way of making an informed decision if it were possible to make an advance request for medical aid in dying?

In general, neurocognitive disorders such as Alzheimer's disease inevitably progress. The decline in capability associated with these neurocognitive disorders is progressive and irreversible. According to the experts consulted, it is not possible to accurately predict the rate of progression or the effects of the disease. During the public hearings, geriatrician David Lussier mentioned these difficulties:

Alzheimer's disease progresses with a gradual decline, but there are individuals who will remain stable for years and years and then deteriorate significantly following an event such as a hip fracture, whereas other types of dementia will be very, very stable for even longer and without gradual deterioration⁵⁸.

In addition, the symptoms of a disease such as Alzheimer's will vary from person to person depending on the areas of the brain affected. While the initial manifestations of the disease are often characterized by short-term memory loss, other symptoms appear over time and according to the individual. These symptoms vary and take many forms: impaired reasoning, lack of judgment, language disorders, visual-spatial dysfunction and behavioural disorders such as wandering or agitation⁵⁹. Two individuals who have this disease and have reached the same stage may therefore find themselves in diametrically opposed situations. One could show signs of aggression on a constant basis, while the other could be in a relatively serene and tranquil state. Under these conditions, it would be difficult to formulate an advance request for medical aid in dying in an informed manner. The person making the request would not know precisely what symptoms would occur and in what order they would appear.

The specialists we had the opportunity to ask questions to nevertheless mentioned that the evolution of neurocognitive disorders is inexorable for everyone. The condition of those affected will inevitably be marked by an irreversible decline in capability and severe deterioration. In the terminal stage, individuals end up in a bedridden state, meaning that they can no longer leave the bed⁶⁰.

Proponents of the advance request indicated that the uncertainties related to the evolution of the disease could be partially overcome by the requirement to obtain a diagnosis prior to making a request for medical aid in dying. This obligation would ensure that the person was well informed about his or her illness and had the opportunity to discuss its multiple possible effects with his or her care team, including his or her physician. Although the person could not accurately predict the symptoms of his or her illness, he or she would have enough information to understand the possible implications and effects. The person could then complete an informed and educated advance request if he or she so wished.

⁵⁸ *Ibid.*, May 14, 2021, at 11:50 a.m.

⁵⁹ Juebin Huang, [Alzheimer Disease](#), Merck Manual, March 2021.

⁶⁰ American Psychiatric Association, *op. cit.*, p. 799.

An advance request would also allow for specifying the conditions under which a person would want to receive medical aid in dying and the conditions under which he or she would not want to receive it. These details would thus provide additional information to the care team and physician about the various effects of the neurocognitive disorder that the person finds tolerable or intolerable. Having to provide these details would indicate that the person has inquired about the probable course of the illness and has been able to think about it. The terms and conditions of potential advance requests would therefore have an important role in ensuring that the person makes an informed decision and is aware of the possible trajectories of his or her illness.

The difficulty of accurately predicting the course of neurocognitive disorders is a challenge to the implementation of advance requests. The medical condition of individuals with neurocognitive disorders can vary widely. This leaves much room for interpretation regarding their eligibility for medical aid in dying. However, the more advanced stages of these diseases all seem to be characterized by serious impairment of the person's capacities. These severe impairments seem inevitable in the evolution of neurocognitive disorders. They could justify recourse to an advance request if the person so desires. We believe that advance requests should not be applied when the person is in the early stages of the disease during which the impairment of his or her functioning is minor. The application of an advance request should instead occur when the person's capacities are severely impaired. Thus, persons who become incapacitated should also meet the Act's eligibility criterion which requires that the person's medical condition be characterized by an advanced state of irreversible decline in capability⁶¹.

In the context of an advance request for medical aid in dying, should the assessment of suffering be based on the suffering anticipated by the person or on the contemporary suffering observed by the health care team, or both?

The issue of assessing suffering in the context of an advance request is certainly one that generated the most discussion within the Committee. When a person is capable of consenting to care, he or she is usually able to express fairly clearly the suffering he or she is experiencing. The person can inform the health care team on how his or her suffering is progressing and how it is presenting itself. The person can also identify the threshold of suffering that he or she considers unbearable when it is reached. However, when the person has become incapacitated, the care team is no longer able to interact with him or her and obtain essential information. And yet, it is the person who is in the best position to define and assess their suffering. The person suffering from an illness is often referred to as the expert on their own suffering. As mentioned earlier in this report, suffering is an essential eligibility criterion for medical aid in dying. It should remain so in the context of an advance request. In order to rule on the eligibility of the advance request, we first had to determine whether it is possible to accurately assess suffering when the person becomes incapacitated.

Although they differed, the testimonies of the various stakeholders shed light on this issue. From the outset, several witnesses and groups told us that an advance request for medical aid in dying should state the threshold of anticipated suffering that the person considers unbearable. The person could specify the situations that he or she considers to be physical or psychological

⁶¹ Act respecting end-of-life care, s. 26.

suffering and that he or she does not wish to undergo after becoming incapacitated. Once the care team has determined that the expected stage or threshold of suffering has been reached, the medical aid in dying protocol should be initiated.

According to other persons heard, this approach has certain weaknesses. First, the difficulty of anticipating suffering was often mentioned. Brian L. Mishara, a professor in the Department of Psychology at UQAM, explained that it is very difficult for a person to predict how he or she will feel in the future and what he or she will find unbearable⁶². It is possible that as the disease progresses, a person may adapt and look at their condition differently than they anticipated. What appeared unbearable may in fact turn out to be a situation that the person finds tolerable. This is due to a poor anticipation of suffering and an adaptation to it.

In addition, assessing the contemporary suffering of a person who is incapacitated based solely on the suffering that he or she anticipated may pose its own set of difficulties for the care team. The person's inability to express him or herself clearly prevents the physician and the care team from adequately addressing the person's wishes or even confirming his or her suffering. For example, we were told that apparent signs of suffering by a person who has become incapacitated could be a temporary discomfort or an unmet need. However, in this regard, health care professionals told us that the care team accompanying the patient is usually able to distinguish between transient pain or discomfort and persistent suffering.

The question of “happy dementia”

We now come to one of the recurring themes of the public hearings, what some specialists refer to as “happy dementia”. This concept refers to a state of general well-being in which a person suffering from a neurocognitive disorder may find themselves at certain times during their illness. In this state, the person shows no apparent signs of suffering. On the contrary, the person seems to show certain serenity. However, the very concept of “happy dementia” is not unanimously accepted by the specialists we heard. Dr. Judes Poirier pointed out that this concept must be nuanced insofar as even in this state, the degeneration of the brain is present. By relying on apparent suffering, this concept does not allow for the consideration of potential psychological or existential suffering related to distress, anxiety or fear that cannot be expressed. It is indeed important to remember at this point that suffering is a global experience that is not limited to physical pain. The *Act respecting end-of-life care* explicitly states that suffering can be both physical and psychological⁶³.

62 Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 20, 2021, at 5 p.m.

63 A document produced by the Collège des médecins and a group of researchers at the CHUM on persons at the end of life specifies that psychological suffering can be of a psychological, social and existential nature. On this subject, see: Mona Gupta et al., [Exploring the psychological suffering of person requesting medical assistance in dying](#), November 2017, p. 13.

On this subject, family physician Alain Naud makes this reminder:

[...] It is important to understand that suffering is also psychological suffering, and physical suffering goes far beyond simple physical pain. It can be, for example, no longer being able to eat, being totally bedridden, having punctures, repeated examinations, being completely dependent on others for all one's basic needs. All this is physical suffering⁶⁴.

Without deciding on the medical or scientific basis for the concept of “happy dementia”, we have taken a closer look at the phenomenon. How should a potential advance request for medical aid in dying be handled if the person shows no apparent signs of suffering? Considering that it is then no longer possible to confirm the person's wish to obtain medical aid in dying, would it be in the person's best interests to administer medical aid in dying when he or she does not appear to be suffering?

Some proponents of the advance request mentioned to us that in a “happy dementia” situation, the wishes must be respected in the name of the person's right to self-determination. Anticipated suffering, as described in the request, should take precedence over contemporary suffering. In other words, even in the absence of signs of suffering that are objectively detectable by the physician, medical aid in dying should be administered if the person's medical condition is consistent with what he or she described in the advance request.

Furthermore, professor of law and health care ethics Jocelyn Downie suggested that “happy dementia” be directly addressed in the advance request⁶⁵. She proposed that the person be allowed to indicate whether he or she wishes to receive medical aid in dying in the event that he or she falls into a state of wellness or “happy dementia”. This clarification would thus help the care team and the physician in addressing the anticipated request when the person is incapacitated. However, by following this route, medical aid in dying could be administered to a person who is no longer able to give consent and who does not show signs of suffering. This would risk placing the physician, the care team and the loved ones in a delicate situation.

Such are the complexities of the issues that we have dealt with in the assessment of suffering. Although there are obvious challenges in assessing the suffering of a person who has become incapacitated, we believe that these challenges are not insurmountable. We must refer to the principles underlying the *Act respecting end-of-life care*. In this regard, it should be recalled that medical aid in dying is a form of care whose objective is to relieve suffering. This objective remains fundamental, even in the context of an advance request. The medical condition of a person who has made an advance request should therefore be characterized by contemporary suffering in order for medical aid in dying to be administered. This suffering would also have to be objectively verifiable. That is, when the person has become incapacitated, the physician, supported by the care team,

⁶⁴ Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 18, 2021, at 10:10 a.m.

⁶⁵ *Ibid.*, May 20, 2021, at 2:40 p.m.

should be able to observe and validate the presence of contemporary suffering. Consequently, the anticipated suffering described by the person in his or her request would not in itself automatically give access to medical aid in dying.

Loss of dignity is an important factor in suffering, especially psychological suffering. What does or does not constitute a loss of dignity can hardly be validated by the physician and the care team when the person has become incapacitated. We believe that the elements mentioned in the advance request, without automatically giving access to medical aid in dying per se, should nevertheless be taken into account in the assessment of psychological suffering.

We are convinced that care teams and physicians are able to recognize the signs of suffering in the people they accompany. However, the difficulty in communicating with the person who has become incapacitated makes the assessment of suffering more difficult. For this reason, we believe that the physician should involve the care team and the person's loved ones in the assessment. Nicole Filion, attorney, co-chair of the Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir, summed up well during the consultations what such a process could look like:

[...] the evaluation of suffering will have to be carried out by the team of physicians, of course, but also by the whole multidisciplinary care team that often accompanies the patient, such as social workers, occupational therapists, etc. And obviously it can't be done in silos either. The care team and the physician were encouraged to enter into a dialogue with the designated third party. [...] Chances are that the patient has also designated him or her because that person knows his or her history, values, etc., and obviously his or her background. And so we invited the physician and the care team to dialogue with the designated third party, but also, obviously, with the patient's loved ones⁶⁶.

In short, despite the difficulties mentioned, it appears to us that it is possible to rigorously assess the suffering of a person who has become incapacitated. This assessment should be based on contemporary signs of suffering that the physician can observe and validate. The physician should also communicate with the care team and loved ones, if necessary, in order to obtain an overall picture of the suffering.

“When we have lived with illness for generations, as we have done in my family, we know exactly where our limit of tolerance is for our own future. In my mind, and in my mother's mind, it couldn't be clearer.”

*Daphnée Ayotte, on the prevalence of neurocognitive disorders in her family
Excerpt from the hearing held on August 18, 2021, special consultations*

⁶⁶ *Ibid.*, May 14, 2021, at 9:30 a.m.

Could the extension of medical aid in dying to allow for an advance request lead to abuses?

During the consultations, several experts cautioned us of the potential risks of abuse if medical aid in dying were extended. These considerations obviously accounted for a large part of our reflection. Before making a decision on a potential recommendation on advance requests, it was necessary to examine the possible negative effects that this could have. We are particularly concerned because advance requests involve individuals who may be very vulnerable. Persons who have become incapacitated can no longer express themselves clearly, have significant losses of autonomy and, in some cases, are isolated. Considering the social obligation to protect vulnerable people, we believe it is essential to address each of the risks of abuse that have been raised.

The risk of conflicts of interest

One of the main risks of abuse that were mentioned during the hearings is that of conflicts of interest affecting the entourage of a person who has made an advance request. We have in mind, for example, family members who, upon the person's death, are likely to receive benefits, such as an inheritance. Family members may be tempted to act in their own interests, rather than in the interests of the incapacitated person. A hasty notification of an advance request by a relative would constitute an obvious abuse and would go against the person's wishes.

Similar abuses had been mentioned during the work of the Select Committee on Dying with Dignity. However, they have not been observed since. We are convinced that the care teams, together with the loved ones, will be able to give careful consideration to advance requests, as they are already doing for requests since the *Act respecting end-of-life care* came into force.

External pressure

There was also concern about the risk of persons with neurocognitive disorders perceiving some pressure from their loved ones or even social pressure to make an early request. This would be a serious departure from the spirit of the *Act respecting end-of-life care*. Section 29 of the Act states that a request for medical aid in dying should “not be made as a result of external pressure”. It must be recognized, however, that such pressure could also be exerted in the context of current requests for medical aid in dying. However, according to what we have been told, this type of abuse has not been observed. Care teams have the duty and the ability to detect whether the decision is made completely freely, without external pressure. Potential advance requests should be conducted in the same spirit.

Inability to confirm consent

Stakeholders have cautioned us against advance requests. According to these witnesses, the person who made the advance request for medical aid in dying while capable is unable to confirm his or her consent once he or she becomes incapacitated. These same witnesses mentioned that the interests and wishes of the person who has become incapacitated may run counter to what he or she wrote in the advance request. Because the individual has become incapable of consenting to the processing of the advance request, he or she can no longer express a refusal. In other words, the wishes of the person who has become incapacitated would potentially not be respected. On this point, other stakeholders have told us that the best way to ensure that a person's wishes are

respected is to rely on the advance request made when the person was capable of consenting. Now that the person has lost capacity, he or she is no longer able to exercise autonomy and give informed consent.

The fear of being a burden

Other stakeholders are apprehensive about individuals with neurocognitive disorders making an advance request for fear of becoming a burden to their loved ones. The lack of appropriate care may fuel this sentiment. The problem is that a person may make an advance request not to prevent the suffering they anticipate or to express their deepest wishes, but rather because they fear becoming such a burden.

However, retired general practitioner Marcel Boisvert presented this possibility in a different way. He acknowledges that some seriously ill people want to avoid being a burden to their loved ones, but he equates this attitude with altruism. In his opinion, this is not misapplication, but rather an expression of certain values of the person⁶⁷. Without making a clear decision on this issue, we believe that the care team would again have a central role to play in understanding the person's motives for making an advance request and in discussing the subject with them.

The devaluation of the lives of persons who have become incapacitated

Does the extension of medical aid in dying mean that our society places less value on the lives of those who become incapacitated? This was certainly the cautionary note expressed by several witnesses during the consultations. Persons with neurocognitive disorders may interpret a potential extension of medical aid in dying as a message that their lives are not worth living. Full professor Gina Bravo of the Université de Sherbrooke told us that this is one of the fears that emerged from a study she conducted with various groups concerned about the extension of medical aid in dying⁶⁸.

This consequence would be the opposite of the spirit in which we have conducted our work. Respect for human life is one of the core principles that have guided all our reflections. A potential extension of medical aid in dying should therefore be clearly explained in order to avoid giving the impression that society places less value on the lives of persons with neurocognitive disorders.

We take very seriously all the risks of abuse mentioned. They have been taken into consideration throughout the entirety of our deliberations. While some abuses appear to us to be less likely to materialize, others seem likely and would require strict guidelines to be avoided.

Is it possible to regulate the extension of medical aid in dying with clear guidelines?

In light of these reflections, one question remains to be developed, namely, the oversight of a potential expansion of medical aid in dying. Beyond knowing whether this extension is desirable, we must also determine whether this practice can be regulated by setting clear guidelines in order to prevent abuses.

⁶⁷ *Ibid.*, May 21, 2021, at 4:30 p.m.

⁶⁸ *Ibid.*, May 18, 2021, at 3:50 p.m.

The Act respecting end-of-life care already provides the basis for a possible extension of medical aid in dying. The guidelines and eligibility criteria already in place would apply to the advance request. Indeed, the principles and logic underlying the administration of medical aid in dying in Québec cannot be departed from. However, modifications are to be expected, considering that the persons concerned by the advance request lose their capacity to consent. To take into account the particularities of neurocognitive disorders, a separate process appears necessary.

To this end, several proposals for a framework were made to us during the consultations. Some of these proposals were submitted to us by groups opposed to the extension of medical aid in dying. The addition of eligibility criteria, changes to the obligations of the physician administering medical aid in dying and the role of loved ones were all mentioned. Considering all the proposals that were presented to us, we conclude that it is possible to rigorously supervise advance requests for medical aid in dying. Such a framework would control the risk of abuses, but without making this practice too difficult to access. In the next section, we will discuss the various guidelines that were presented to us and provide details of a proposed framework for advance requests.

Our recommendations

Taking into account the issues raised during the public hearings, in the briefs submitted and in the online consultation, we have arrived at a comprehensive vision of the extension of medical aid in dying for persons who have become incapacitated. We have made a point of turning over every stone to cover and address all aspects of this topic. Based on our discussions, we have concluded that the advance request for medical aid in dying should be permitted with strict supervision in anticipation of loss of capacity due to neurocognitive disorder. In our opinion, the advance request is in keeping with the spirit of the *Act respecting end-of-life care* and would be a logical development. Indeed, this Act already recognizes the right of patients to refuse certain care in advance.

The advance request for medical aid in dying is also a response to a widespread desire in society, namely to be able to choose one's end of life even if one has a neurocognitive disorder. We felt through our consultations that society has evolved a great deal on the issue of medical aid in dying since the Act was passed in 2014. The online consultation tends to support the idea that there is strong advocacy for the implementation of an advance request. More than 85% of respondents said they supported the idea that a person with a neurocognitive disorder could obtain medical aid in dying if he or she requested it while capable⁶⁹.

RECOMMENDATION 1

The Committee recommends that a person of full age and capacity be permitted to make an advance request for medical aid in dying following a diagnosis of a serious and incurable illness leading to incapacity.

⁶⁹ Appendix I presents the results of the online consultation.

In recommending the implementation of an advance request, we recognize that advance consent can be offered for care such as medical aid in dying. However, we had some concerns about the informed nature of this consent. Considering the definitive nature of medical aid in dying, we feel it is crucial that the person understand all the implications of the procedure when making the request. We also believe it is essential that the person be fully informed of the nature of his or her illness, its effects, its evolution, and the treatment and care options available. Without all this information, the person cannot provide fully informed consent.

With this in mind, we support the idea put forward by several stakeholders of requiring a diagnosis of an illness leading to incapacity in order to be able to make an advance request. This is one of the recommendations of the Groupe d'experts sur la question de l'incapacité et l'aide médicale à mourir. This requirement ensures that the person will have access to a care team to be informed about his or her illness. At the time of diagnosis, the person is usually given all relevant information about the course and effects of his or her illness. As well, it is very likely that the person will undergo some form of medical follow-up that will allow him or her to obtain more information about the disease and the various treatment and care options.

The requirement for a diagnosis ensures that the person would not have to make an advance request based on hypothetical situations. He or she would not have to imagine countless scenarios based on all the illnesses that could lead to incapacity to consent to care. The person would be able to make an advance request based exclusively on the evolution of the diagnosed illness.

We also discussed the relevance of imposing a minimum period of time between the receipt of a diagnosis and the filing of an advance request. Such a period of time would allow the person to absorb the shock of being diagnosed with a neurocognitive disorder, thus avoiding making a decision under the influence of emotion. Nonetheless, we felt it best not to impose a time period. On the one hand, we believe that it will take some time for the person to adequately formulate his or her advance request. On the other hand, a time period could prevent a person with a late diagnosis from making an advance request before they lose their capacity to consent, as several stakeholders have pointed out to us.

“We have witnessed the loss of cognitive functions, of her ability to reason, we have gone through as much grief as there are aspects of her personality that have vanished in time, and we have had to accept that the memories that link our lives are being forgotten. In short, we watched helplessly as the very essence of her humanity disappeared.”

*Catherine Leclerc, about her mother suffering from a neurocognitive disorder
Excerpt from the hearing held on August 18, 2021, special consultations*

RECOMMENDATION 2

The Committee recommends that when a person makes an advance request for medical aid in dying, the physician ensure:

- a) The free nature of the request by verifying, among other things, that it is not the result of external pressure;
- b) The informed nature of the request, in particular by ensuring that the person has fully understood the nature of his or her diagnosis, by informing the person of the foreseeable course and prognosis of the disease, and of the possible therapeutic options and their consequences.

The process of making an advance request must be subject to a formal oversight. It is important that this process be carried out rigorously in order to dispel any doubt as to its validity. In this sense, it is important to ensure that the advance consent is freely expressed. As with current requests for medical aid in dying, it would be unacceptable for an advance request to be made because of outside pressure. It must always be the result of the person's wishes.

The physician who receives an advance request therefore has an essential role. He or she must ensure the free and informed consent of the person. This is a fundamental principle for all medical treatment in Québec. It is all the more important in the context of an advance request for medical aid in dying, since the person will no longer be able to consent at the time the care is provided. It is therefore the physician's responsibility to confirm that the advance request was made under the proper conditions. This step is critical to ensuring the quality and value of the advance request.

RECOMMENDATION 3

The Committee recommends that the advance request for medical aid in dying be entered on a form intended solely for that purpose; that it be completed and signed before a physician; that it be countersigned by two witnesses or made in notarial form.

RECOMMENDATION 4

The Committee recommends that the person clearly identify the manifestations of his or her health condition that should give rise to the advance request.

Considering the important implications resulting from an advance request, other measures must be put in place to ensure the thoroughness of the process. We believe that a form specific to advance requests is necessary. This form would ensure that the process is consistent and that the care teams have the information they need. The person should be able to indicate in detail the manifestations of his or her future condition that he or she considers unbearable. The person could also specify the nature of the suffering he or she anticipates and considers intolerable.

These details will help health care providers determine the moment at which the person wishes to obtain medical aid in dying.

The advance request form should also be completed and signed in front of a physician. This step would ensure that the form has been completed under proper conditions. This document, because of its importance, should be countersigned by two witnesses or made in notarial form. The purpose is not to make the advance request process more complex, but rather to ensure that the document is correct and valid. The health care team that will be required to assess it should have no doubt as to the value to be placed on it. At the time of administering medical aid in dying, there should be no lingering ambiguity about the person's true wishes.

RECOMMENDATION 5

The Committee recommends that the advance request remain valid unless the person indicates otherwise; that it may be amended as long as the person is capable of doing so.

Since advance requests involve persons who may lose capacity, we deemed it preferable that the document remain valid indefinitely. The person would not be required to confirm on a recurring basis whether the content of the request still corresponds to their wishes. However, he or she could amend or withdraw the advance request at will, as long as he or she is deemed capable of doing so. The advance request must be as faithful as possible to the person's wishes, and a simple amendment process is the best way to ensure this. Similarly, a person should also be able to easily withdraw his or her advance request if he or she so desires.

RECOMMENDATION 6

The Committee recommends that advance requests for medical aid in dying be recorded in the Advance Medical Directives Register.

RECOMMENDATION 7

The Committee recommends that a reference to an advance request for medical aid in dying be indicated on the back of the health insurance card.

RECOMMENDATION 8

- a) The Committee recommends that the person designate on the form a trusted third party responsible for making known his or her advance request for medical aid in dying and for advocating on his or her behalf for the processing of the request at the appropriate moment; that the trusted third party consent in writing to the role assigned to him or her.
- b) The Committee recommends that, in the absence of or inability to act of a designated trusted third party, the responsibility to protect the patient's wishes and to act be assumed by a member of the health care team.

Reporting advance requests soon became a key issue for their implementation. Currently, the issue does not arise because individuals must themselves express their will to receive medical aid in dying. If they became incapacitated, they would no longer be able to indicate that they had made an advance request. This is similar to the situation of advance medical directives that apply when the person has become incapable of consenting to care. We therefore thought it logical to use this regime as a model for advance requests. To this end, the *Act respecting end-of-life care* already provides for an Advance Medical Directives Register. We therefore deem it appropriate that this register also be used to record advance requests for medical aid in dying. A single register would centralize all requests for care made by capable persons in anticipation of their incapacity.

As a further means of communicating the existence of an advance request, a person should place a sticker on the back of his or her health insurance card indicating that he or she has made such a request. This option already exists to indicate a person's wish to donate organs. We believe this is a simple and easy-to-implement proposal that would indicate the existence of an advance request to health care providers. The sticker could also be a way of indicating that the person has written advance medical directives.

However, we do not feel that these two measures are sufficient to ensure that the wishes of people with neurocognitive disorders are respected. Health care professionals have told us that the Advance Medical Directives Register is not currently being used optimally. For this reason, we have carefully considered the idea of a trusted third party to communicate the advance request. This idea was submitted to us by the Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir, but also by several other stakeholders. The person requesting medical aid in dying would have to designate a loved one or a trusted third party who would be mandated to inform the care team of the advance request.

Nevertheless, we need to clearly define the responsibilities of this trusted third party. First, it should be specified that the only role that would be assigned to the trusted third party would be to report the advance request recorded in the Register by way of a written application. This is in no way a substituted consent. The third party is simply requesting that the advance request be processed at the moment agreed upon with the person making the request. It is then the physician's responsibility to assess the advance request.

The trusted third party would be required to expressly consent to the role assigned to him or her. This ensures that the person fully understands his or her responsibility and the implications of the role. The mandate given to the trusted third party can be difficult for a loved one because of the emotional charge associated with it. This is why we feel it is important that the person consent to it in writing.

What would happen if there were no trusted third party? It is indeed possible that the person making an advance request is very isolated and has not been able to designate a third party. It is also conceivable that the designated third party is deceased or absent at the time the advance request should be reported. In the absence of a trusted third party, the health care staff would be responsible for consulting the Register to determine if the person who has become incapacitated made an advance request. The sticker on the back of the health insurance card could also be useful to the care team in these situations. It would therefore be the responsibility of the care team to

ensure that the person's wishes are respected and to act accordingly. If the care team determines that an advance request exists, the physician must assess it. However, we reiterate that the best option is one in which a trusted third party has been designated. This person is in a position to inform the team about the moment that the person considers appropriate for processing his or her advance request. The third party knows the person best and will have had the opportunity to talk with the person to fully understand his or her wishes.

“Loved ones are often in the best position to relay the patient's wishes and to interpret the meaning of his or her gestures, behaviours and manifestations.”

Ms. Nicole Filion, attorney, co-chair of the Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir

Excerpt from the hearing held on May 14, 2021, special consultations

RECOMMENDATION 9

The Committee recommends that when the trusted third party files the application on the advance request, the physician review both the application and the advance request, take them into consideration, and act on them without delay.

It is important to remember that the role of the third party is not to decide when medical aid in dying will be administered. He or she simply submits an application to the care team to have the advance request processed and evaluated. The decision regarding the administration of medical aid in dying rests with the attending physician, as is the case under the current Act. Thus, when an application is received, the physician, supported by the health care team, would be under an obligation to review it in the same way as the advance request. This would have to be done within a reasonable time frame to avoid unnecessary suffering and to respect the person's wishes. The physician would therefore be required to determine whether medical aid in dying should be administered in light of the content of the advance request and the person's medical situation. Finally, the physician would have to respond promptly to the application and to the advance request by sharing his or her conclusions with the trusted third party and other loved ones, if applicable.

RECOMMENDATION 10

The Committee recommends that before administering medical aid in dying, the physician must:

1. Be of the opinion that the person meets all of the following criteria:
 - a) the person is an insured person within the meaning of the Health Insurance Act (chapter A-29);
 - b) the person suffers from a serious and incurable illness;
 - c) the person is in an advanced state of irreversible decline in capability;
 - d) the person experiences constant and unbearable physical or psychological suffering, including existential suffering, which cannot be relieved in a manner deemed tolerable. This suffering is observed and validated by the physician.
2. Confer with members of the care team who are in regular contact with the person making the request, if applicable
3. Obtain the opinion of a second physician confirming compliance with the criteria. The physician consulted must be independent of both the patient requesting medical aid in dying and the physician seeking the second medical opinion. The physician consulted must consult the patient's record, examine the patient and provide the opinion in writing.

The existence of an advance request does not mean that the person who wrote it will necessarily obtain medical aid in dying. As with current requests, the physician must assess it. The approach we propose for the assessment of the advance request is similar to the one that already exists in the *Act respecting end-of-life care*. Before administering medical aid in dying, the physician will still need to verify that the person meets the eligibility criteria. However, we are proposing certain adjustments to these criteria. These changes have been made necessary by the fact that the person is no longer capable of consenting to care. We need to take into account the different reality that physicians will face in assessing eligibility for medical aid in dying. We are convinced that these adjustments will considerably reduce the risk of abuses in the treatment of advance requests.

It should be mentioned at the outset that the person would no longer have to be capable at the time medical aid in dying is administered. However, the person will have to be insured within the meaning of the *Health Insurance Act*, as is currently the case. The physician will also have to confirm that the person has a serious and incurable illness.

Furthermore, the physician will have the duty to ensure that the medical situation of the person who has become incapacitated is characterized by an advanced and irreversible decline in capability. The assessment of this eligibility criterion will be particularly important in a context where the person has become incapacitated. Indeed, we wish to avoid having medical aid in dying administered to persons whose stage of illness does not justify it. A rigorous assessment by the physician and the care team will determine whether the decline in the person's physical and cognitive capacities is the justification for this care.

In addition, the way in which suffering is assessed must be reviewed in the context of an advance request. As mentioned earlier in this report, the issue of suffering has been one of the most difficult to resolve. Nevertheless, we have arrived at a solution that we believe is balanced and applicable. Just as for capable persons seeking medical aid in dying, the person who has become incapacitated would have to experience contemporary suffering to be eligible for medical aid in dying. His or her suffering must be confirmed by the physician and the health care team, since he or she may not be capable of expressing it. Objective signs of suffering should be observed by the physician in order for him or her to administer medical aid in dying.

We point out that psychological suffering, although more difficult to assess, must be taken into account. The various components of psychological suffering, including existential distress, must therefore be assessed, as is already the case for current requests for medical aid in dying. To do so, the physician and the care team can rely on the content of the advance request. Moreover, the person's suffering must be constant, unbearable and impossible to relieve under conditions deemed tolerable.

Finally, as already provided for in section 29 of the *Act respecting end-of-life care*, before administering medical aid in dying, the physician should obtain the opinion of a second physician regarding the person's eligibility for this care. This second physician should validate that the person who has become incapacitated meets the eligibility requirements set out in this report.

We believe that we have arrived at a balanced and prudent proposal. It recognizes the right to self-determination of individuals and ensures that it is respected, including for those who have become incapacitated. Our proposal also takes into account the principle of protection of vulnerable persons. We see the possibility of making an advance request as an extension of the right to self-determination for persons who become incapacitated due to neurocognitive disorders. Considering their potential vulnerability, we felt it was essential to maintain the current guidelines of the *Act respecting end-of-life care* and to modify them when necessary to take into account the particularities specific to neurocognitive disorders.

In summary, we believe that this approach is in keeping with the logic of prudence that has guided the discussion on medical aid in dying in Québec since the beginning. We also believe that our proposal will succeed in meeting the expectations of a large part of the population.

“We put the person at the centre of our interventions because we recognize that the person with Alzheimer’s disease remains a full person despite the disease and, as such, he or she is entitled to the dignity and respect of his or her values and choices.”

*Sylvie Grenier, general manager of the Federation of Québec Alzheimer Societies
Excerpt from the hearing held on August 10, 2021, special consultations*

Observations

The Committee suggests:

- That the existence of advance medical directives be indicated on the back of the health insurance card.
- That the application to initiate the processing of the advance request be made in writing.
- That it be possible to attach a complementary video to the application, but that the written request take precedence.
- That the physician discuss with the patient the medical advances related to his or her illness.

MEDICAL AID IN DYING FOR PERSONS WHOSE ONLY MEDICAL CONDITION IS A MENTAL DISORDER

The current situation

At present, the *Act respecting end-of-life care* does not distinguish between mental disorders and other illnesses. Section 26 of the Act states that in order to obtain medical aid in dying, the person must have a serious and incurable illness, without specifying the nature of the illness. However, a thorough reflection on medical aid in dying and mental disorders was made necessary by the Québec Superior Court judgment in the Truchon and Gladu case⁷⁰. This judgment rendered the “end-of-life” criterion inoperative, thus extending potential access to medical aid in dying to persons whose only medical condition is a mental disorder. Previously, these individuals were generally not eligible for this care since their medical condition does not lead to an imminent end of life.

The issues surrounding access to medical aid in dying because of a mental disorder are numerous. Mental disorders have specific characteristics that distinguish them from other illnesses such as cancer or lung and heart disease. However, at the time the judgment was rendered, the collective reflection on access to medical aid in dying for persons whose only medical condition is a mental disorder had not yet taken place. This is why the extension of access to medical aid in dying to these individuals was postponed by the Minister of Health and Social Services in January 2020 for an indefinite period.

It should be specified, however, that it is possible for persons with a mental disorder to obtain medical aid in dying in certain circumstances. When they have a serious and incurable illness other than their mental disorder, these people can obtain this care. For example, a person suffering from schizophrenia and incurable cancer could obtain medical aid in dying if he or she is deemed capable and meets the other eligibility criteria. This person would be eligible for this care not because of his or her mental disorder, but rather because of the cancer.

The questions that fueled our reflection

As we did for persons who are incapacitated, we examined the issues surrounding the potential extension of medical aid in dying to persons whose only medical condition is a mental disorder. We assessed the various arguments that were presented to us.

⁷⁰ *Truchon v. Attorney General of Canada*, 2019 QCCS 3792.

Considering the right of individuals to make decisions about their lives, should persons whose only medical condition is a mental disorder have access to medical aid in dying?

The right to self-determination of individuals is one of the important considerations that guide the reflection on medical aid in dying in Québec and that remain essential to the current discussion. There is no doubt that persons suffering from mental disorders have the right to make decisions about their lives and their end of life. While most stakeholders agree on the legitimacy of self-determination, not everyone agrees on the weight to be given to it in this specific context. In this regard, representatives of the Réseau communautaire en santé mentale feel that self-determination sometimes has a “broad back” in this debate. They fear that relying exclusively on this principle will lead to “medical aid in dying on demand”⁷¹.

Self-determination is not the only principle that should be taken into account in this discussion. The protection of vulnerable persons, the ability to consent and the risk of abuse are all elements that enter into the equation. Although it is a principle we hold dear, the right to self-determination is not absolute. It must necessarily be circumscribed in order to maintain a balance with the other values involved in an ethical reflection on the subject. In this regard, it is important to remember that only persons who meet the well-defined eligibility criteria set out in the Act may obtain medical aid in dying. Any possible extension of this type of care must take into account these eligibility criteria and society's responsibility to protect persons who are vulnerable.

Could the difficulty in assessing the capability of persons suffering from mental disorders be an obstacle to extending medical aid in dying?

Capacity to give consent to care is a key consideration in the issue of medical aid in dying. All persons must be capable of consenting to this care in order to request it. We therefore had to ask ourselves about potential difficulties in assessing the capacity to consent of persons suffering from mental disorders. In itself, this is a sensitive topic because it may imply that persons with mental disorders are not capable of consenting to care. This would be an abusive generalization. Inability to consent to care should never be presumed on the basis of diagnosis alone.

However, psychiatrists have told us that the ability to consent of some individuals suffering from mental disorders may sometimes be limited by their illness. In his brief, psychiatrist Louis Morissette states, for example, that “a mental disorder can interfere with a person's decision-making capacity. Both the cognitive and affective aspects can be disrupted by a mental disorder”⁷². In the same vein, psychiatrist Félix Carrier mentions that certain serious mental disorders can interfere with the judgment of persons suffering from them. Such situations would compromise their ability to make a request for medical aid in dying in a free and informed manner.

Evidently, not all persons suffering from mental disorders have their decision-making capacity affected to the point that they are no longer deemed capable of consenting to care. It is therefore

⁷¹ Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, Second phase, August 11, 2021, at 1:15 p.m.

⁷² Louis Morissette, [Aide médicale à mourir pour les personnes dont le trouble mental est le seul problème médical invoqué](#), brief submitted to the CSSFV, p. 6.

important to be able to clearly distinguish between persons who are capable and those who are incapable. The assessment of capacity is therefore essential. The care team must be able to determine whether the person's decisions are the result of informed consent or whether the person's judgment is clouded by his or her mental state.

On this subject, the representative of the Association des médecins psychiatres du Québec, Dr. Guillaume Barbès-Morin, was reassuring: "The assessment of ability to consent to care is already a process that is omnipresent and well established in current medical practice in Québec, as it is elsewhere, for both physical and mental health conditions, which are, in any case, often intertwined⁷³".

In view of the specific characteristics of mental disorders, the Association des médecins psychiatres du Québec proposes in its discussion paper that the assessment of ability be longitudinal and not based on a single meeting. In addition, the assessment should go beyond cognitive skills and take into account in particular emotional reactions, interpersonal dynamics and the effects caused by the disorder⁷⁴. Such a process would contribute to overcoming the difficulties associated with assessing the ability of individuals with mental disorders.

It also appears relevant to us to recall that physicians are accustomed to assessing the capacity of their patients. Psychiatrists would necessarily be involved in a possible process involving medical aid in dying. They would play a leading role in assessing the capacity of persons suffering from mental disorders. Their expertise would inevitably be called upon. Given this fact, the assessment of the capacity of persons suffering from mental disorders does not seem to be a major obstacle to their access to medical aid in dying. The assessment of the capacity to consent of persons with mental disorders must certainly be adjusted, but it seems possible. Moreover, it should be recalled that persons suffering from a mental health disorder and another illness that meets the criteria of the Act are already subject to an assessment when they request medical aid in dying.

Should mental disorders be distinguished and treated differently from other illnesses in the context of medical aid in dying?

According to some stakeholders, it would be discriminatory to deny medical aid in dying to individuals whose only medical condition is a mental disorder. These experts insist that in no case should mental health issues be distinguished from physical health issues. Both clinical conditions can cause severe suffering to the persons who are affected. The distress experienced by some should not be underestimated. As Dr. Laurent Boisvert cautions, the impossibility of having access to medical aid in dying may even lead people to seek an alternative, sometimes very violent, way to end their suffering.

73 Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 20, 2021, at 1:30 p.m.

74 Association des médecins psychiatres du Québec, *op. cit.*, p. 36.

However, these arguments are not shared by all. Rather, it is a matter of recognizing the particularity of mental disorders and treating them with appropriate care. For instance, psychiatrists Bertrand Major and Pierre R. Gagnon point out that suicidal thoughts are inherent to certain mental disorders, unlike physical illnesses such as cancer. In their opinion, given this particularity, medical aid in dying should not be offered to persons suffering solely from mental disorders.

Several stakeholders, particularly from the community, rightly report that discrimination against persons suffering from mental disorders is a phenomenon that is observed day after day with regard to access to housing, work and services. They reject the idea that, in the name of the self-determination of individuals, medical aid in dying can be extended to individuals whose only medical condition is a mental disorder. In reality, the daily lives of these very persons are punctuated by various forms of discrimination that, in many cases, impede their recovery. Before extending access to medical aid in dying, these stakeholders believe that we must first act on the social determinants of health, because they have a corollary effect on the living conditions of persons suffering from mental disorders.

Without minimizing the differences between mental health issues and physical illnesses, we are convinced that mental disorders can cause severe suffering in the same way as other forms of illness. But in our opinion, this criterion alone cannot be used to determine whether or not to extend access to medical aid in dying to persons whose only medical condition is a mental disorder.

“We may not be able to treat or cure the disease, but by intervening in the person's living conditions, we may succeed in alleviating his or her suffering and avoid offering death as the ultimate response to that suffering.”

*Jérôme Gaudreault, General Director of the Association québécoise de prévention du suicide
Excerpt from the hearing held on August 12, 2021, special consultations*

Can certain mental disorders be considered incurable and irreversible?

Within the current legal framework, two eligibility criteria for medical aid in dying have particularly caught our attention with respect to persons whose only medical condition is a mental disorder. These are the incurability of the illness and the irreversible decline in capability associated with it, both of which are criteria set out in section 26 of the *Act respecting end-of-life care*. There is no doubt in our minds that mental disorders can present in a severe form. The question is whether some of them are considered incurable. Are they likely to result in an irreversible decline in a person's capability?

In its discussion paper on medical aid in dying and mental disorders, the Association des médecins psychiatres du Québec reminds us that, outside of the end-of-life context, there is always uncertainty regarding the prognosis of illnesses. This observation applies to both mental disorders and physical illnesses. To reduce this uncertainty to a minimum, the Association suggests that three criteria be used to assess whether a mental disorder is incurable and results in an irreversible decline in the

person's capability⁷⁵. The first is the chronicity of the disorder. This refers to the length of psychiatric follow-up and treatment. The second criterion relates to previous attempts at relevant treatments. Thus, the psychiatrist should look at factors such as the history of treatment attempts and their nature. Finally, the third criterion pertains to the person's refusals of treatment. Should the situation arise, the psychiatrist should consider treatment discontinuations and refusals and the reasons that prompted them. Through this approach, the Association proposes to assess each person on a case-by-case basis to determine whether the mental disorder can be envisaged as incurable. It is therefore not a particular diagnosis that can be used to affirm and verify whether the decline in capability is irreversible. Psychiatrist Mona Gupta insists that the assessment of the incurability of a mental disorder should be based on the persistence of the disorder and resistance to treatment: "[...] we are not talking about the second year in which someone suffers from something, we are talking about someone who has been suffering for years, even decades, who has tried many things⁷⁶". Only in such cases can we reach the conclusion of incurability.

However, the position of the Association des médecins psychiatres du Québec on the incurability and irreversibility of certain mental disorders does not seem to enjoy consensus within the profession. Several psychiatrists and groups of psychiatrists have expressed divergent opinions on the subject. According to psychiatrist Bertrand Major, for example, there is no such thing as an incurable mental disorder under any circumstances. In psychiatry, there is "always something to offer⁷⁷". Many treatments exist and must be tried, as not all individuals respond to them in the same way. Moreover, some stakeholders recalled that psychiatry is a constantly evolving field. Some treatments are not yet in use and new therapeutic options are being developed.

The Fédération des médecins spécialistes cautions us nonetheless against this argument. It states in its brief that there may be situations where medicine fails to treat some individuals adequately:

Medical specialists as caregivers believe that it is possible to provide exceptional care to cure or alleviate many pathologies (including psychopathologies), but they are also aware of the limitations of modern medicine in relieving certain types of suffering. There are exceptional situations where even the best care – psychiatric or physical – will not succeed in allowing the patient to live a life he or she finds acceptable⁷⁸.

Other stakeholders insist on the unpredictability of mental disorders. It is common in psychiatry, they say, to see reversals in the health conditions of persons with mental disorders. The trajectories of mental disorders are unique to each individual and can be influenced by a multitude of factors (social, biological, psychological, etc.). According to Georgia Vrakas, a professor in the Department of Psychoeducation at UQTR, we cannot predict the evolution of mental disorders. When they occur, the recovery process is not linear and can be long.

⁷⁵ Association des médecins psychiatres du Québec, *op. cit.*, p. 28.

⁷⁶ Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 14, 2021, at 10:40 a.m.

⁷⁷ *Ibid.*, May 20, 2021, at 3:50 p.m.

⁷⁸ Fédération des médecins spécialistes du Québec, [Mémoire de la Fédération des médecins spécialistes du Québec – Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie](#), brief submitted to the CSSFV, p. 9.

For example, a person with a mental disorder may experience a decline in capability over the course of his or her life, but be fully functional a few years later after appropriate treatment has been initiated. The decline in capability is therefore not necessarily irreversible. For several of the experts we heard, the unpredictable nature of mental disorders means that medical aid in dying for individuals for whom this is the only medical condition should not be considered. It is too radical a solution in the eyes of these experts.

We heard the testimonies of several individuals who, after years of unsuccessful treatments, managed to achieve a better balance. These witnesses told us that if they had been eligible for medical aid in dying, they would undoubtedly have applied for it at a time when their health condition seemed hopeless. Today, these same persons are doing much better and are able to cope with their illness because they have received a correct diagnosis and appropriate treatment. Thus, the uncertainty surrounding the trajectories of mental disorders prompts us to be very cautious.

We note, at the conclusion of our work, that there is no clear medical consensus on the incurability of mental disorders and the irreversible decline in capability that would be associated with them. There are differing positions among specialists. As legislators, it is difficult for us to comment on this issue. We recognize, of course, that mental disorders can present in very severe and treatment-resistant forms. However, we are not in a position at this time to say whether they may be incurable or result in an irreversible decline in capability.

“Believe me, I was discouraged, even disillusioned, having followed the recommended treatments and all. However, the problem was that I didn't have the right diagnosis!”

*Georgia Vrakas, professor in the Department of Psychoeducation at UQTR
Excerpt from the hearing held on May 21, 2021, special consultations*

Is it possible to assess the constant and unbearable nature of suffering related to mental disorders?

According to the psychiatrists we heard, very often persons with mental disorders consider that their suffering is permanent and will never be alleviated. This perception would be caused by the condition itself. The fluctuation of associated suffering therefore requires a long period of assessment. According to psychiatrists Mona Gupta and Guillaume Barbès-Morin, it is possible to measure the psychological suffering of a person with a mental disorder, even if the patient has difficulty understanding it him or herself. Psychiatrists have the necessary tools to make this assessment. However, as with some physical illnesses, it may be difficult to find the cause of this suffering and to alleviate it in the best way possible.

While stating that “the very existence of the criterion of intolerable suffering is a real challenge⁷⁹”, the Association des médecins psychiatres du Québec nevertheless proposes a process for assessing the constant and unbearable nature of psychological suffering. In particular, the psychiatrist should evaluate “the severity of the symptoms, the degree of functional incapacity over time, the adaptive mechanisms and how these have evolved over time⁸⁰”. Before authorizing any request for medical

⁷⁹ Association des médecins psychiatres du Québec, *op. cit.*, p. 32.

⁸⁰ *Ibid.*

aid in dying, the psychiatrist would be obliged to consider strategies to ameliorate the social circumstances that contribute to the suffering of the patient being assessed.

We share the view that the suffering associated with mental disorders can be caused by many factors, including social ones. The assessment process proposed by the Association des médecins psychiatres du Québec addresses much of the complexity of this issue. Nevertheless, we note that not all specialists share the Association's view on this point. Psychiatrists have told us that it is very difficult to accurately assess the constant and unbearable suffering of some individuals with mental disorders.

Is it possible to distinguish between suicidal ideation and a reasoned desire to obtain medical aid in dying?

As the experts heard by the Committee reported, many persons with mental disorders are convinced that death is the only option to end their suffering. This “suicidal impulse” may even be an intrinsic part of some mental disorders. For individuals who suffer from these disorders, judgment is often impaired by the illness. According to some psychiatrists, this desire to die may indicate a will to stop suffering and to be helped. It is incumbent upon the psychiatrist to provide this help and to accompany the patient.

Psychiatrist Mona Gupta points out that not all mental disorders are associated with suicidal ideation. Her colleague, Dr. Guillaume Barbès-Morin, insists on the fact that it is possible to distinguish these suicidal ideas from a reasoned desire to die. In this specific case, psychiatric expertise is essential to understanding the reasons behind the patient's will to stop living.

Undoubtedly, this issue brings us back to the question of the capacity of persons whose only medical condition is a mental disorder to make a free and informed decision about their end of life. We do not question that psychiatrists already play a key role in the process of assessing capacity. We believe that this responsibility would be greatly increased if the extension of medical aid in dying to these individuals were to be adopted. As such, we believe that suicidal ideation represents an additional challenge that must be taken seriously. While we cannot definitively resolve this fundamental issue, we can only reiterate the need to offer suicide prevention services as soon as possible to anyone who needs them. As a society, we have a duty to help individuals struggling with suicidal ideation and to support the organizations that accompany them.

Should better access to mental health care precede the potential extension of medical aid in dying to persons whose only medical condition is a mental disorder?

Most of the specialists and groups heard during the special consultations agreed that access to mental health care is uneven and sometimes limited. Excessively long waiting lists for consultation and care were cited, as was the lack of funding for community organizations. In light of this state of affairs regarding the availability of services, stakeholders expressed concern about the prospect of extending access to medical aid in dying. Many said they feared that individuals would request medical aid in dying because of a lack of services, support and appropriate care.

Specialists and groups in favour of extending medical aid in dying to persons whose only medical condition is a mental disorder wished to make some clarifications. Individuals who only use primary care services for mental disorders would not be eligible for medical aid in dying. Rather, the extension of such care is intended for persons with severe forms of mental disorders and who have had secondary or tertiary psychiatric care over long periods of time⁸¹. Similarly, to be eligible for medical aid in dying, persons whose only medical condition is a mental disorder would have to have tried relevant treatments according to the proposal of the Association des médecins psychiatres du Québec⁸².

However, some psychiatrists indicated to us that even secondary and tertiary care in psychiatry is not optimal. The more resistant and persistent forms of mental disorders can sometimes be difficult to treat adequately in some remote regions, as the distribution of psychiatric resources is uneven across regions. In this regard, psychiatrist Pierre R. Gagnon mentioned that, in Québec, “there is no procedure or protocol for treating patients who are resistant to treatment by referring them to specialists who have specific expertise and who could help them⁸³”. This would constitute a distinction from other specialties such as oncology where the provision of services is more developed and where it is easier to transfer individuals in order for them to obtain the necessary care.

For other specialists, this is a false dilemma. The lack of specialized treatment in psychiatry should not prevent the debate on medical aid in dying from being held. In this regard, general practitioner Alain Naud drew a parallel with palliative care. He recalled that, at the time of the adoption of the *Act respecting end-of-life care*, it had been possible to improve the quality of and access to palliative care while implementing medical aid in dying. In his opinion, the same could be done regarding access to psychiatric resources.

We recognize that at present access to mental health care can be difficult in Québec. It is clear to us that more can be done in this area. Access to psychiatric care warrants improvement, particularly in certain remote regions where the provision of specialized treatment appears to be more limited. This lack of services fueled our discussions and was the subject of many exchanges. However, it is not a determining factor on which we based our recommendation.

81 The term “primary care” refers to the outreach services offered to the general population by various health and social service providers. They are generally the first place a person goes to seek help, often through the family physician or another professional. Secondary care services intervene with specific clientele when the level of care required, the complexity or the therapeutic impasse call for a more specialized approach. Tertiary services offer highly specialized services to patients suffering in particular from refractory psychiatric disorders. On this subject, see: <https://www.santementalecovid.ugr.ca/soins-services-premiere-ligne-sante-mentale>; <http://chumpsy.chiatrie.ca/clinique/deuxieme-ligne>; <https://www.chumontreal.qc.ca/patients/psychiatrie>

82 Association des médecins psychiatres du Québec, *op. cit.*, p. 29.

83 Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 20, 2021, at 3:50 p.m.

“When we think of mental illness, we think of our neighbour who suffered from depression after his divorce. We don't think of the person with OCD so severe that he or she spends 20 hours out of 24 washing, to the point where his or her hands are covered in blood. We don't think about those individuals because we don't know them.”

*Dr. Mona Gupta, psychiatrist and professor of psychiatry
Excerpt from the hearing held on May 14, 2021, special consultations*

Could the possibility of requesting medical aid in dying for a person whose only medical condition is a mental disorder complicate his or her therapeutic relationship with his or her care team?

In psychiatry, the relationship between a person suffering from a mental disorder and his or her care team is of primary importance. Several groups we heard expressed concern that the possibility of obtaining medical aid in dying for persons whose only medical condition is a mental disorder would make therapeutic relationships more complicated. It is possible that individuals could be unwilling to try treatments if the option of obtaining medical aid in dying is open to them. As well, some stakeholders believe that the extension of medical aid in dying could extinguish hope for remission among persons with mental disorders. Hope, that “very precious therapeutic ingredient⁸⁴” in the relationship with psychiatrists, must be preserved.

Dr. Félix Carrier believes that psychiatrists should never have to tell persons suffering from mental disorders that death may be an appropriate or medically justified option for them. For this reason, he recommends that potential requests for medical aid in dying be handled by a third party. An external institution or committee should be responsible for assessing these requests for medical aid in dying. In this way, treating physicians would retain exclusively their therapeutic, accompanying and supportive role. The situation would by no means preclude the psychiatrist from openly discussing this option with his or her patients, but he or she would not have to endorse it.

However, the negative effects of a potential extension on the patient-therapist relationship are not unanimously agreed upon. For some stakeholders, the possibility of obtaining medical aid in dying could be a source of appeasement. It would even lead to relevant discussions with psychiatrists. Simon Courtemanche, who collaborated on the Association des médecins psychiatres du Québec's discussion paper on medical aid in dying as a patient-partner, agrees. The possibility of requesting medical aid in dying would have helped him to verbalize more quickly the problems he was experiencing. The request for medical aid in dying could have been a kind of “passageway⁸⁵” allowing him to express himself more freely.

While we cannot state with any certainty what the potential adverse effects on the therapeutic relationship between the care team and persons with mental disorders may be, this concern remains on our minds. We cannot ignore the appeal that medical aid in dying represents for

⁸⁴ Pierre R. Gagnon and other co-signing psychiatrists, [Mémoire préparé par un groupe de psychiatres québécois sur l'aide médicale à mourir \(AMM\) lorsqu'un trouble mental est le seul problème médical invoqué \(TM-SPMI\) soumis à La Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie de l'Assemblée nationale du Québec](#), brief submitted to the CSSFV, p. 3.

⁸⁵ Special consultations and public hearings on the evolution of the *Act respecting end-of-life care*, First phase, May 20, 2021, at 1:30 p.m.

persons in situations of psychological distress. The consequences of extending access to this care on therapeutic follow-up would need to be better documented.

Could the possibility of extending access to medical aid in dying lead to abuses?

Beyond the issues that have been addressed so far, we must also revisit the risks of abuse that were raised during our proceedings. Several psychiatrists, members of the health care sector and community organizations cautioned us about the harmful effects that could result from an extension of access to medical aid in dying. The risks of abuse that were presented to us concern not only persons who would request medical aid in dying, but also all persons suffering from mental disorders.

The effects on suicide prevention

The testimony of the Association québécoise de prévention du suicide left a deep impression on us. According to the organization, extending medical aid in dying would not be without effects on persons with suicidal tendencies. The Association fears “a modification of the Québec social norm relating to suicide, causing it to become more acceptable, even trivialized⁸⁶”. In other words, it could send the signal that death is a legitimate or even appropriate option for persons suffering from mental disorders. This would undermine decades of suicide prevention efforts.

Such effects are difficult to assess, but they warrant further consideration. The possibility that an extension of medical aid in dying could negatively affect efforts in this area is definitely a major source of concern.

Prognostic errors

Is it desirable for medical aid in dying to be administered to persons whose medical condition is likely to improve following the natural course of the disease or with the help of new treatments? Several stakeholders pointed out that the incurability of mental disorders is difficult to establish. This is an obstacle that can lead to prognostic errors.

Medical aid in dying is care of last resort for persons whose illness cannot be cured and whose decline in capability is irreversible. Given the lack of consensus in the medical community on the incurability and irreversibility of mental disorders, a strong doubt remains as to whether medical aid in dying is appropriate care. In this context, the risk that this gesture be premature appears very real to us. We are faced here with the grim prospect of individuals obtaining medical aid in dying rather than appropriate medical follow-up that would favour a fully satisfying life.

Concerns regarding the “slippery slope”

Some specialists and groups have expressed concern about the possibility that the application of the criteria for access to medical aid in dying will become more flexible over time. Some witnesses fear what they term “the slippery slope”, which they interpret to mean that the extension envisaged in the present mandate would go beyond the framework initially intended. Stakeholders anticipate the eligibility of individuals whose reasons for requesting medical aid in dying would include precarious economic conditions, life fatigue, or personal or professional setbacks.

⁸⁶ Association québécoise de prévention du suicide, [Aide médicale à mourir et prévention du suicide](#), brief submitted to the CSSFV, p. 14.

In response to this contention, specialists in favour of extending medical aid in dying argue that a rigorous evaluation process adapted to the specificities of mental disorders, as proposed by the Association des médecins psychiatres du Québec, would help prevent such abuses.

External pressure

As in the case of persons who are incapacitated, there is a concern that those with mental disorders may feel pressure to request medical aid in dying. Several witnesses pointed out that persons suffering from mental disorders are subject to a certain social stigma. Too many of them experience discrimination on a daily basis. In the opinion of several witnesses heard, this stigma isolates them and fosters a feeling of devaluation that could lead them to request medical aid in dying out of desperation.

All the risks of abuse were discussed and taken into consideration. Any possible extension of medical aid in dying must be circumscribed in order to eliminate the risks of abuse.

Is it possible to regulate the extension of medical aid in dying with clear guidelines?

The issue of a legal framework was the subject of few proposals during our consultations. Aside from positions of principle and arguments on the relevance of extending access to medical aid in dying, relatively few groups submitted detailed proposals for the guidelines to be put in place. Most of the groups and specialists in favour of an extension referred instead to the framework proposed by the Association des médecins psychiatres du Québec. It must be recognized that this proposal is the most complete and most rigorous to have been presented to us. This major contribution fuelled a large part of our work.

The process for assessing requests for medical aid in dying from persons whose only medical condition is a mental disorder proposed by the Association addresses some of our concerns. Thus, it appears essential to take into account the chronicity of symptoms, suicidal thinking, and treatment attempts and refusals in the process of assessing requests. The administration of medical aid in dying to a person without medical justification must be avoided. We nevertheless continue to have doubts about the incurability and irreversible decline in the capabilities of a person with a mental disorder.

We would also like to point out that the framework proposals do not take into account all of the risks of abuse submitted to the Committee. In this regard, we are concerned about the effects of extending access to medical aid in dying on all persons suffering from mental disorders. We are also concerned about the efforts made in the area of suicide prevention.

Our recommendation

It was after analyzing all of these issues that we were able to arrive at an informed position on the extension of medical aid in dying to persons whose only medical condition is a mental disorder. We scrutinized the extensive arguments that were presented to us. They gave us food for thought and led to numerous exchanges. From the outset, we would like to emphasize the difficulties in reaching a decision on the issue given the divergent viewpoints heard. From our work, however, a conclusion emerges that is unfavourable to the extension of medical aid in dying to persons whose only medical condition is a mental disorder.

RECOMMENDATION 11

The Committee recommends that access to medical aid in dying not be extended to persons whose only medical condition is a mental disorder; that, to this end, section 26 of the *Act respecting end-of-life care* be amended.

This recommendation is in line with the precautionary principle that Québec has upheld since the beginning of work on medical aid in dying. We believe that the risks associated with extending access to medical aid in dying to persons whose only medical condition is a mental disorder would entail too many variations and could therefore not be closely monitored. In order to implement this recommendation, we believe that section 26 of the *Act respecting end-of-life care* should be amended to avoid the possibility that a mental disorder as the only medical condition give access to medical aid in dying.

We are aware that our proposal could disappoint persons suffering from mental disorders for whom medical aid in dying might be a viable option. We do recognize the difficult conditions in which these individuals may find themselves and the great suffering they must tolerate, sometimes for long periods of time. Psychiatrists have shared with us compelling cases of persons living with mental disorders whose suffering and impairment of daily functioning is significant. Nevertheless, we believe that, for the following reasons, it is not desirable to extend access to medical aid in dying to persons whose only medical condition is a mental disorder.

Incurability

One of the main reasons we arrived at the recommendation to not extend access to medical aid in dying is the lack of consensus among psychiatrists and other specialists on the incurability of mental disorders and the irreversibility of the decline in capabilities associated with them. As legislators, we have no choice but to defer to the specialists on this very specific issue. The disagreement within the medical community on this matter is clear and of concern to us. Given the irremediable nature of medical aid in dying, the persistent doubts about the incurability of mental disorders lead us to exercise the greatest caution. For this reason, we believe that it is not appropriate to extend access to medical aid in dying to persons whose only medical condition is a mental disorder.

It is true that major medical organizations such as the Collège des médecins and the Association des médecins psychiatres du Québec have expressed support for such an extension. However, we found that this position is by no means a consensus within the medical profession. Many psychiatrists and groups of psychiatrists assert that no mental disorder can be considered incurable. The discussion paper of the Association des médecins psychiatres du Québec also includes a survey that illustrates the disagreement within this profession regarding medical aid in dying. The survey was conducted among Québec psychiatrists in early 2020. It shows that 54% of psychiatrists are open, under certain circumstances, to extending medical aid in dying to persons whose only medical condition is a mental disorder. Conversely, 36% of respondents are opposed to it in all situations⁸⁷.

Social acceptability

The extension of access to medical aid in dying to persons whose only medical condition is a mental disorder does not seem to enjoy a social consensus. We have not seen any particular mobilization within society in this regard. This silence contrasts with the echo heard on the advance request for medical aid in dying demanded by a large part of the population and by several organizations. In terms of extending medical aid in dying to persons whose only medical condition is a mental disorder, we noted instead the apprehension of several community groups working in the field of mental health. These concerns had already been highlighted by support and advocacy groups for persons with mental disorders and their caregivers during the consultations held by the Commission sur les soins de fin de vie⁸⁸. They urge us to be cautious. Finally, the results of our online consultation tend to support the idea that the public is divided on the subject. Nearly 50% of respondents said that medical aid in dying should be available to persons whose only medical condition is a mental disorder, while one quarter said that it should not be available. Lastly, nearly 25% of respondents appeared to be undecided on this issue. Although this is not a factor in determining our decision, we feel that this result is noteworthy.

The diagnosis

One aspect of mental disorders that we have noted is the difficulty of making the right diagnosis. According to several specialists, it can take several years to make the right diagnosis of a mental disorder. This information strikes us as crucial since the treatments that the person will receive to alleviate his or her suffering depend on the diagnosis. In this regard, the testimony of Georgia Vrakas, a professor in the Department of Psychoeducation at UQTR, who drew on her personal experience, was particularly compelling.

⁸⁷ Association des médecins psychiatres du Québec, *op. cit.*, p. 15.

⁸⁸ Commission sur les soins de fin de vie, [Accès à l'aide médicale à mourir pour les personnes atteintes de troubles mentaux : consultation auprès de groupes de soutien et de défense des droits des personnes atteintes de troubles mentaux et de leurs proches aidants](#), February 2020.

The therapeutic relationship

Several psychiatrists and other members of the health care workforce told us that the extension of medical aid in dying could make the therapeutic relationship with their patients more complex. The Association québécoise de prévention du suicide had a similar concern about the work done with persons with mental disorders. Its representatives are worried that they will consider a request for medical aid in dying rather than the support and therapy options available. The role of suicide prevention workers would be more difficult in such circumstances. These concerns have remained with us throughout our discussions. Again, they call on us to be cautious.

The choices we had to make about the extension of medical aid in dying to persons whose only medical condition is a mental disorder were difficult. Nonetheless, we believe that we have arrived at the appropriate recommendation. Given the significant disagreements that persist in society and in the medical community on the issue, this is a prudent position that echoes the concerns heard by the members of the Committee.

GENERAL OBSERVATIONS

The role of specialized nurse practitioners

In addition to the two main components of our mandate, a number of related topics were discussed during the special consultations. Some of them caught our attention, notably the role that specialized nurse practitioners could play in medical aid in dying. The Collège des médecins du Québec, the Ordre des infirmières et infirmiers du Québec and the Fédération interprofessionnelle de la santé du Québec all asked us to allow specialized nurse practitioners to administer medical aid in dying. There appears to be strong support for this idea among those who participated in the Committee's proceedings. This proposal could improve access to this care in all regions of Québec. It would help to share the task with physicians who, for the time being, are the only ones who can administer medical aid in dying. **Consequently, the Committee suggests that specialized nurse practitioners be allowed to administer medical aid in dying.**

The use of advance medical directives

The topic of advance medical directives also came up repeatedly during our discussions. Several groups and individuals informed us of problems with this regime that was put in place through the *Act respecting end-of-life care*. From the outset, many stakeholders pointed out that advance medical directives are not well known and that their use by citizens is limited. The most recent data presented by the Commission sur les soins de fin de vie tends to confirm that very few individuals have entered their advance medical directives in the Régie de l'assurance maladie du Québec's Register⁸⁹. Advance medical directives are an integral part of the end-of-life care continuum in Québec. For this reason, we believe it is necessary to adequately inform the public through an awareness campaign, as recommended by several stakeholders, including the Commission sur les soins de fin de vie⁹⁰. **Consequently, the Committee suggests that the government conduct an awareness campaign on the possible use of advance medical directives.**

Consulting the Advance Medical Directives Register

We also feel it is important to point out that it is imperative that care teams refer to the Advance Medical Directives Register. On a few occasions during special consultations, we were informed that the Register is not always examined. Yet, the *Act respecting end-of-life care* provides that when a physician notes that a person is incapable of giving consent to care, he or she must consult the Register⁹¹. This is an essential step in ensuring that patients' wishes are respected. We consider it useful to recall that the accessibility and use of the Register by physicians and care teams are of great importance. In fact, according to our recommendations, it will also be used to record advance requests for medical aid in dying. **Consequently, the Committee suggests that a reminder be given of the importance of systematically consulting the Advance Medical Directives Register.**

89 The Commission sur les soins de fin de vie reports that, as of March 31, 2018, 29,774 persons had entered their advance medical directives in the Régie de l'assurance maladie du Québec's Register. This corresponds to 0.5% of the adult population of Québec. On this subject, see: Commission sur les soins de fin de vie, *Rapport sur la situation des soins de fin de vie au Québec* du 10 décembre 2015 au 31 mars 2018, p. 67.

90 *Id.*, [Mémoire présenté dans le cadre des travaux de la Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie](#), brief submitted to the CSSFV, p. 20.

91 *Act respecting end-of-life care*, s. 57.

CONCLUSION

Since the adoption of the *Act respecting end-of-life care*, the perception of the Québec population regarding medical aid in dying has been constantly evolving. The way in which this care is viewed depends in large part on the experiences of each individual. Although the principle of dying with dignity is widely accepted in our society, the possible extension of access to medical aid in dying is still being debated. This observation should not surprise us. Whatever our values, the conditions in which we die are of concern to all of us. It is therefore in a spirit of openness and humility, imbued with humanistic values, that we carried out the mandate entrusted to us. Our conclusions were not drawn in advance. On the contrary, they took shape owing to the essential contribution of specialists, health professionals and citizens who shared their personal experiences and expertise with us.

During our discussions, the possibility for persons who are incapacitated to make an advance request for medical aid in dying became evident. The support of a large number of experts and groups as well as the serious nature of the proposals submitted were decisive elements. Our recommendations on the implementation of an advance request for medical aid in dying were indeed drawn from the contributions of the many stakeholders who contributed to our reflection. They present the principal trends that have emerged in Québec society in recent years on this issue. In summary, the advance request will make it possible to better respect the wishes of persons suffering from neurocognitive disorders by offering them an additional option for end-of-life care.

The second part of our mandate, that of opening medical aid in dying to persons whose only medical condition is a mental disorder, has led to the opposite conclusion. The consultations revealed the differences of opinion that persist within the medical profession about the incurability of mental disorders and the irreversible decline in capability that may be associated with them. We have also taken note of the reluctance of several community organizations and mental health workers, as well as of part of the population. In keeping with the precautionary principle, we have therefore recommended that access to medical aid in dying not be made available to persons whose only medical condition is a mental disorder.

We are convinced that we have arrived at recommendations that, while prudent, propose amendments to the *Act respecting end-of-life care* that are consistent with the evolution of the public debate on medical aid in dying. As we have observed throughout our mandate, despite the difficulty of addressing these issues, there is still a great deal of interest in these matters in Québec. We have opted for a balanced approach, which we hope will meet the expectations of the population of Québec.

Finally, we would like to extend our warmest thanks to all of the people who participated in the Committee's work. The briefs, responses and comments received within the framework of the online consultation allowed us to deepen our knowledge and our analyses on this topic. Addressing topics such as medical aid in dying in the context of public hearings can be challenging. We applaud the courage and generosity of the citizens who shared with us their personal experiences or those of their loved ones. These testimonies constitute an essential contribution to the collective reflection on medical aid in dying.

LIST OF RECOMMENDATIONS AND OBSERVATIONS

Recommendations

RECOMMENDATION 1

The Committee recommends that a person of full age and capacity be permitted to make an advance request for medical aid in dying following a diagnosis of a serious and incurable illness leading to incapacity.

RECOMMENDATION 2

The Committee recommends that when a person makes an advance request for medical aid in dying, the physician ensure:

- a) The free nature of the request by verifying, among other things, that it is not the result of external pressure;
- b) The informed nature of the request, in particular by ensuring that the person has fully understood the nature of his or her diagnosis, by informing the person of the foreseeable course and prognosis of the disease, and of the possible therapeutic options and their consequences.

RECOMMENDATION 3

The Committee recommends that the advance request for medical aid in dying be entered on a form intended solely for that purpose; that it be completed and signed before a physician; that it be countersigned by two witnesses or made in notarial form.

RECOMMENDATION 4

The Committee recommends that the person clearly identify the manifestations of his or her health condition that should give rise to the advance request.

RECOMMENDATION 5

The Committee recommends that the advance request remain valid unless the person indicates otherwise; that it may be amended as long as the person is capable of doing so.

RECOMMENDATION 6

The Committee recommends that advance requests for medical aid in dying be recorded in the Advance Medical Directives Register.

RECOMMENDATION 7

The Committee recommends that a reference to an advance request for medical aid in dying be indicated on the back of the health insurance card.

RECOMMENDATION 8

- a) The Committee recommends that the person designate on the form a trusted third party responsible for making known his or her advance request for medical aid in dying and for advocating on his or her behalf for the processing of the request at the appropriate moment; that the trusted third party consent in writing to the role assigned to him or her.
- b) The Committee recommends that, in the absence of or inability to act of a designated trusted third party, the responsibility to protect the patient's wishes and to act be assumed by a member of the health care team.

RECOMMENDATION 9

The Committee recommends that when the trusted third party files the application on the advance request, the physician review both the application and the advance request, take them into consideration, and act on them without delay.

RECOMMENDATION 10

The Committee recommends that before administering medical aid in dying, the physician must

- 1. Be of the opinion that the person meets all of the following criteria:
 - a) the person is an insured person within the meaning of the Health Insurance Act (chapter A-29);
 - b) the person suffers from a serious and incurable illness;
 - c) the person is in an advanced state of irreversible decline in capability;
 - d) the person experiences constant and unbearable physical or psychological suffering, including existential suffering, which cannot be relieved in a manner deemed tolerable. This suffering is observed and validated by the physician.
- 2. Confer with members of the care team who are in regular contact with the person making the request, if applicable
- 3. Obtain the opinion of a second physician confirming compliance with the criteria. The physician consulted must be independent of both the patient requesting medical aid in dying and the physician seeking the second medical opinion. The physician consulted must consult the patient's record, examine the patient and provide the opinion in writing.

RECOMMENDATION 11

The Committee recommends that access to medical aid in dying not be extended to persons whose only medical condition is a mental disorder; that, to this end, section 26 of the *Act respecting end-of-life care* be amended.

Observations

The Committee suggests:

- That the existence of advance medical directives be indicated on the back of the health insurance card.
- That the application to initiate the processing of the advance request be made in writing.
- That it be possible to attach a complementary video to the application, but that the written request take precedence.
- That the physician discuss with the patient the medical advances related to his or her illness.
- That specialized nurse practitioners be allowed to administer medical aid in dying.
- That the government conduct an awareness campaign on the possible use of advance medical directives.
- That a reminder be given of the importance of systematically consulting the Advance Medical Directives Register.

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APPENDIX I

Results of the online consultation

As part of its proceedings, the Select Committee on the Evolution of the Act respecting end-of-life care conducted an online consultation from June 25 to August 24, 2021. The purpose of the consultation was to obtain the public's views on the issues at the heart of the Committee's mandate. A total of 3,421 questionnaires were completed.

Comments submitted by the respondents

The questionnaire included three optional open-ended questions in which citizens could share their comments:

- Do you have any further comments on access to medical aid in dying for persons who are incapacitated?
- Do you have any further comments on access to medical aid in dying for persons whose only medical problem is a mental disorder?
- Do you have any further comments on medical aid in dying or on the work of the Select Committee on the Evolution of the Act respecting end-of-life care?

Approximately one third of respondents submitted at least one comment. In total, 2,076 comments were submitted by respondents. Half of these (50%) were in the section on access to medical aid in dying for persons who are incapacitated. More than a quarter of the comments (27%) were in the section on mental disorders. The remaining comments concerned medical aid in dying in general or the work of the Committee (23%).

The content of the comments submitted by respondents is quite reflective of the diversity of views expressed by the experts and organizations heard by the Committee members during the special consultations and public hearings. All of the comments were forwarded to the Committee members, along with a summary analysis of the comments.

Presentation of the results

Number of respondents: 4,755

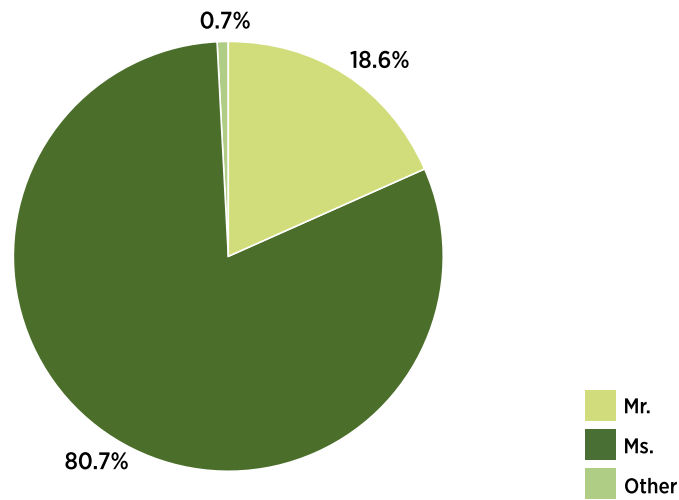
Number of respondents having completed the questionnaire: 3,421

Completion rate: 72%

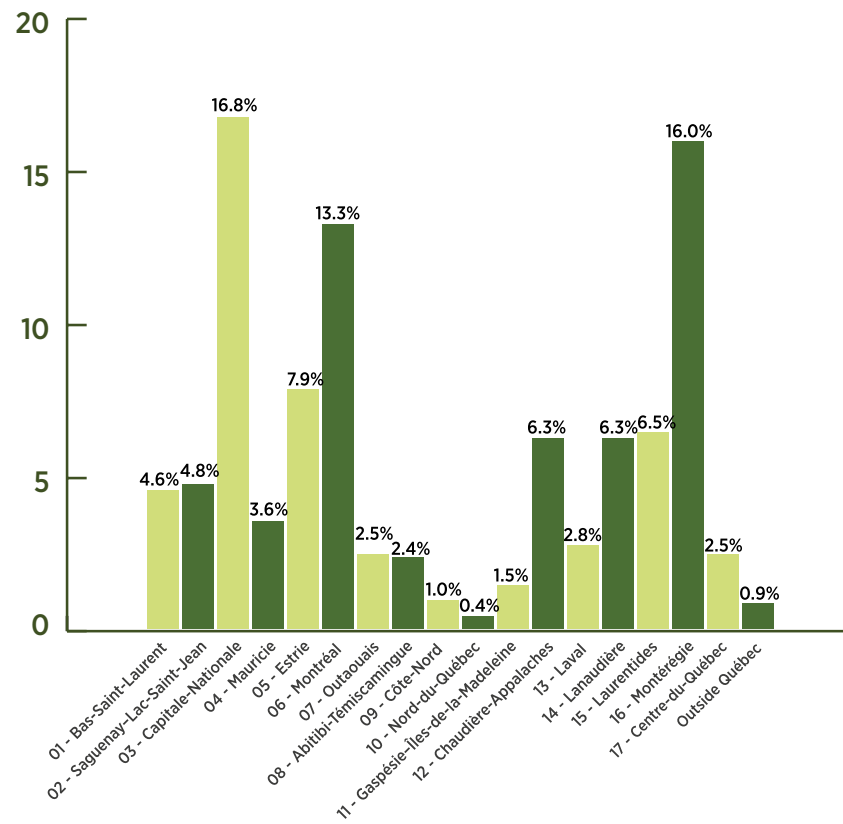
Only answers from people who completed the questionnaire in full are included in the results.

Identification questions

1) Title



2) Administrative region

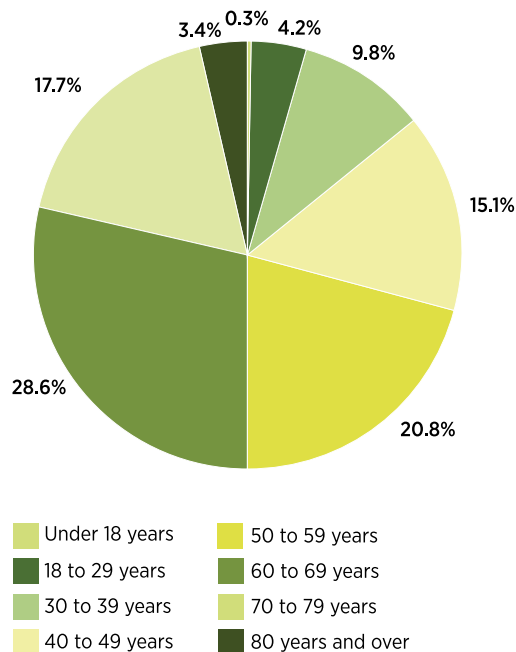


3) Situation of the respondents

The respondents could select all of the options that corresponded to their situation.

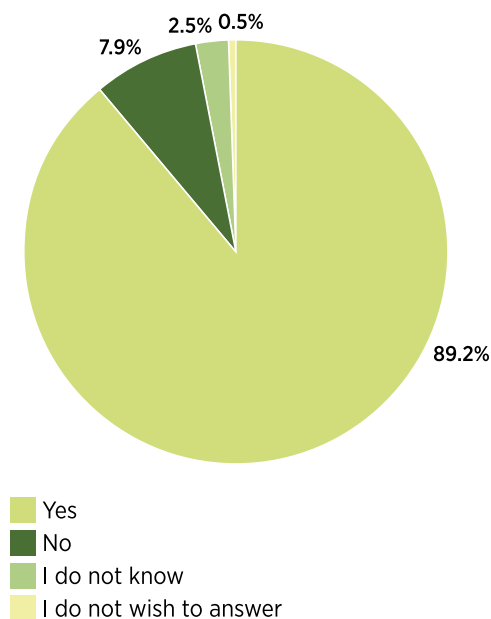
| | |
|---|-------|
| Citizen interested in the evolution of the <i>Act respecting end-of-life care</i> | 76.4% |
| Person who has accompanied a loved one (relative, friend) at the end of life | 37.8% |
| Person whose loved one (relative, friend) obtained medical aid in dying | 11.4% |
| Person who has applied for medical aid in dying | 1.1% |
| Health care personnel (physician, nurse, orderly, etc.) | 18.6% |
| Researcher interested in medical aid in dying or end-of-life care | 1.1% |
| Person in the legal field | 0.7% |
| Palliative care volunteer | 1.5% |
| Other, please specify: | 6.8% |

4) Age group



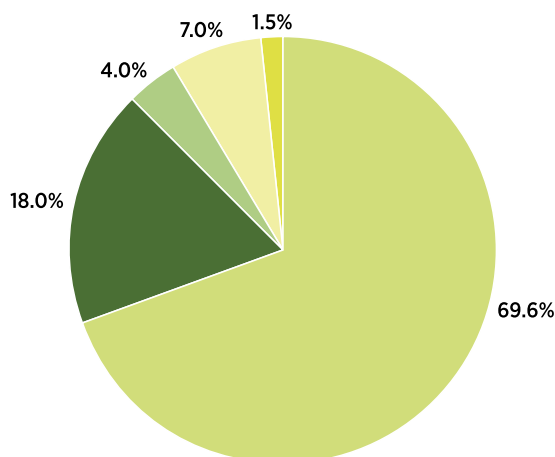
Medical aid in dying and incapacity

5) In your opinion, are there any situations in which a person who is not capable of consenting to care should be eligible for medical aid in dying?



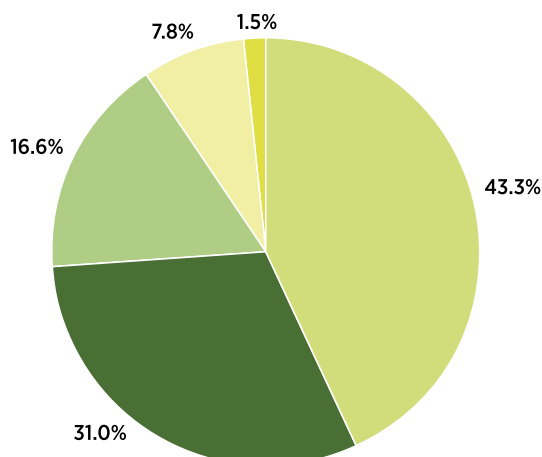
6) The following arguments are sometimes made about access to medical aid in dying for persons who are incapacitated. Indicate your level of agreement with the following statements.

The right of every person to make decisions about his or her life and end of life is undermined by the requirement that he or she be capable of consenting to care at the time medical aid in dying is administered.



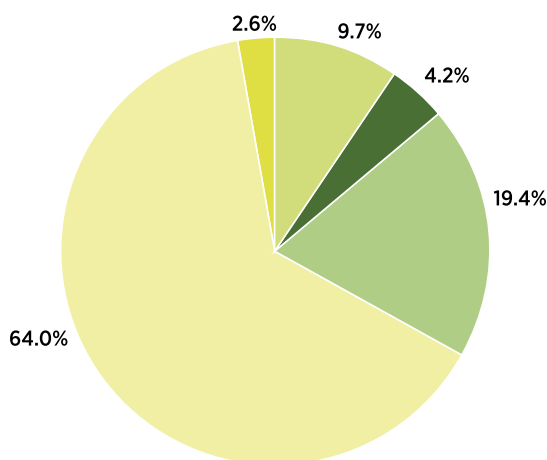
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

It is difficult for the care team or loved ones to accurately assess the suffering of a person who is no longer able to express it clearly.



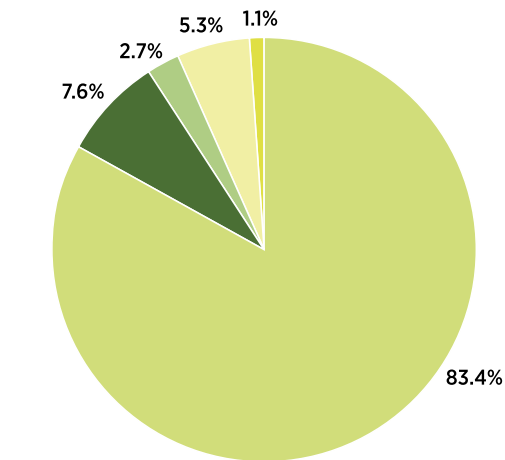
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

Allowing advance application for medical aid in dying could send a negative signal about the value society places on the lives of persons with a neurodegenerative disease.



Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

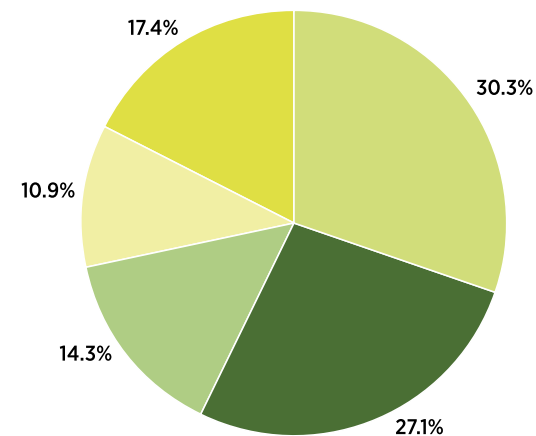
Granting an advance request for medical aid in dying to a person with a neurodegenerative disease would spare him or her an end of life that he or she considers contrary to his or her values and dignity.



Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

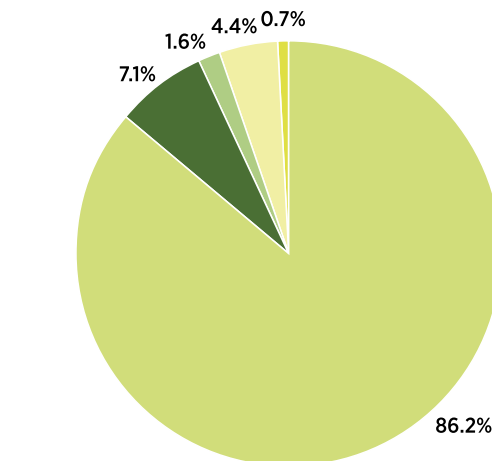
7) Several categories of persons who are incapacitated could, on reasonable grounds, have access to medical aid in dying. Indicate your level of agreement with the following statements, which present these different categories.

A person who has never been capable of consenting to health care, such as a person suffering from a severe intellectual disability.



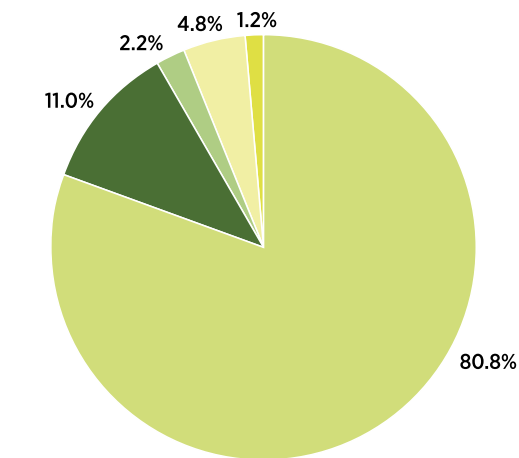
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

A person who has been diagnosed with a neurodegenerative disease such as Alzheimer's-type dementia or another related disease and who requested it while capable.



Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

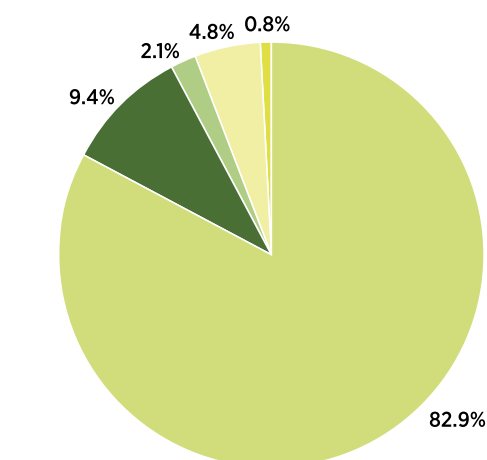
A person who has been the victim of a sudden and unexpected accident with serious and irreversible after-effects, such as a stroke, and who requested it while capable.



Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

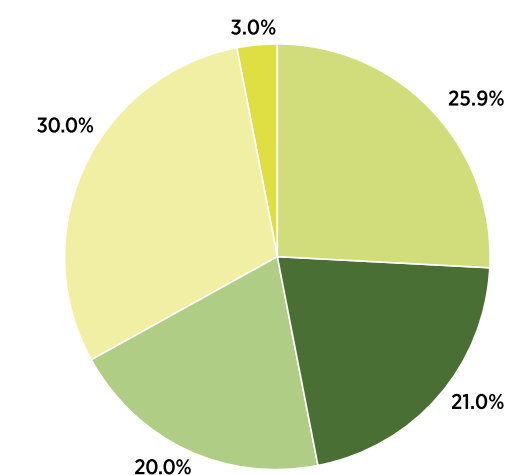
8) In order for a person to be able to receive medical aid in dying once he or she has become incapacitated, it has been proposed that he or she should be able to make his or her wishes known in advance while still able to consent to care. Indicate your level of agreement with the following statements.

A person should be able to request medical aid in dying in advance if he or she meets all the criteria.



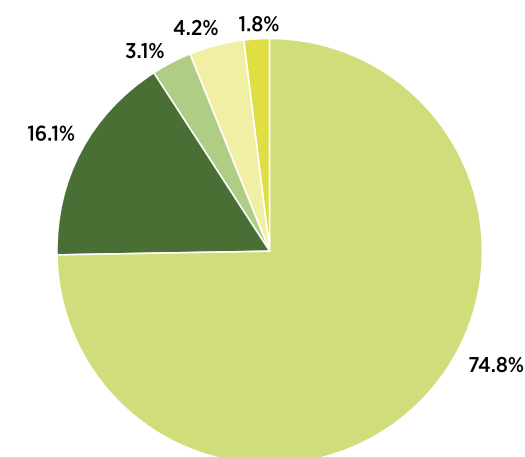
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 Totally disagree
 I do not know

In order to request medical aid in dying in advance, a person would absolutely need to have been diagnosed with a serious and incurable disease.



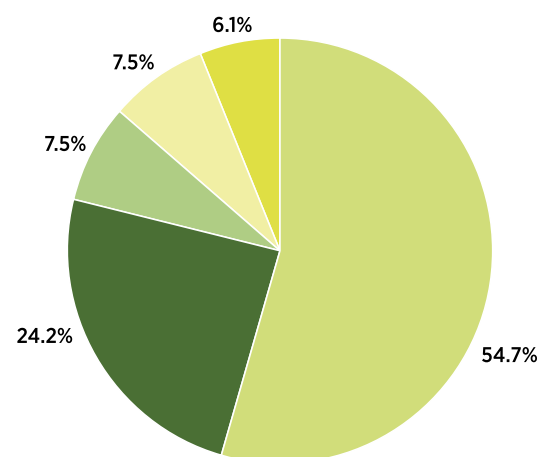
Totally agree
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 Somewhat disagree
 Totally disagree
 I do not know

Any advance request for medical aid in dying that meets the person's criteria should obligatorily be complied with.



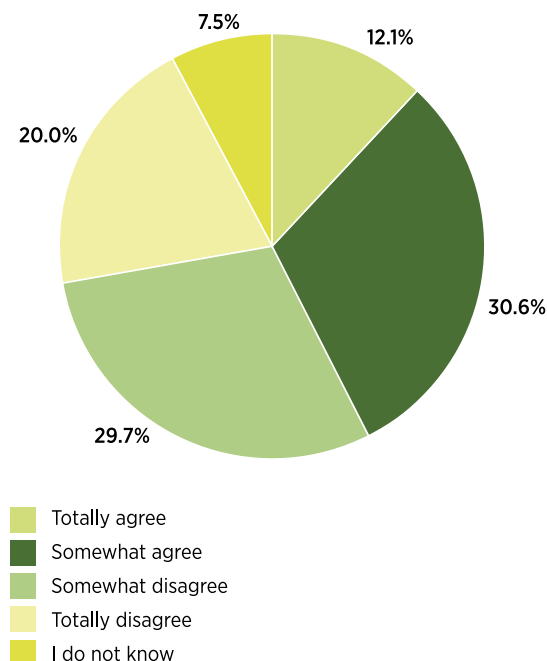
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

Medical aid in dying requested in advance should be administered even if the person does not appear to be suffering.

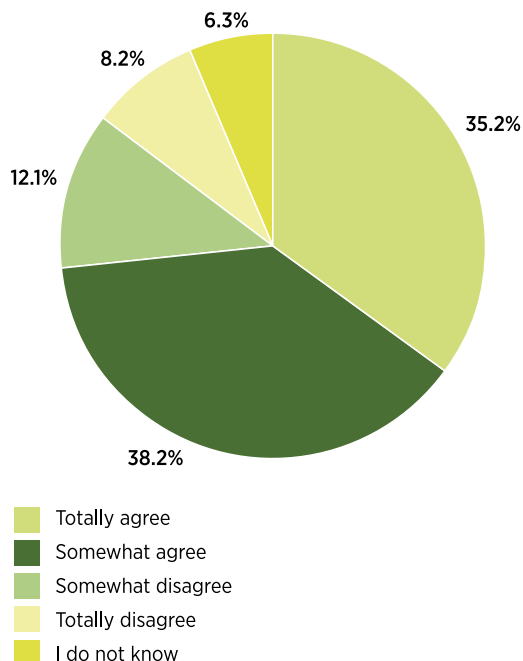


Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

The responsibility for determining whether the time has come to apply the advance request should rest with the physician or medical team.

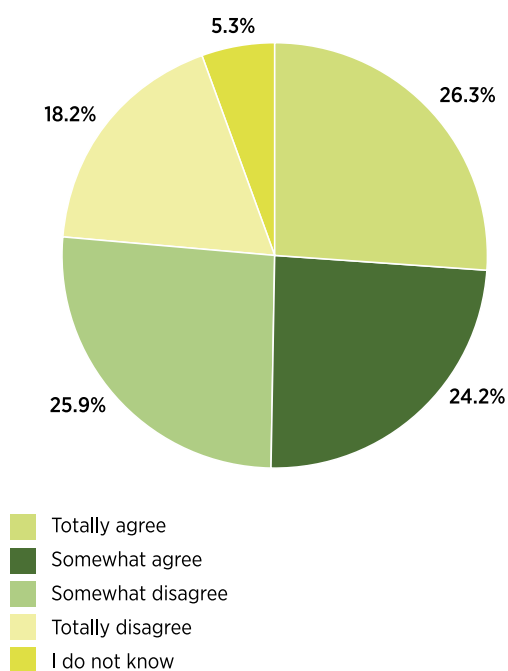


The responsibility for determining whether the time has come to apply the advance request should rest with a designated loved one.

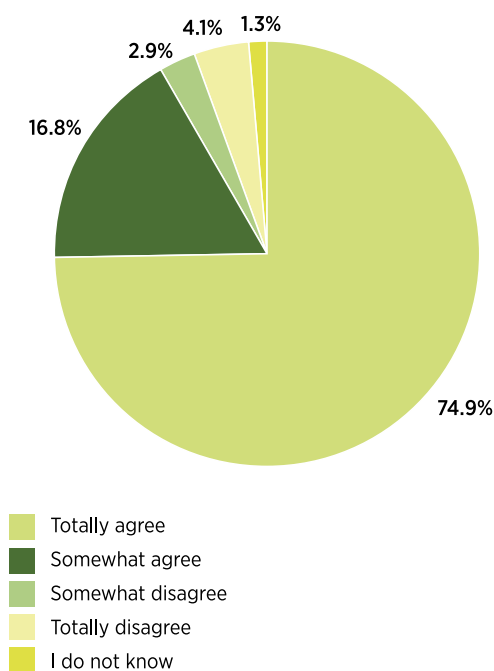


9) If it were to become possible to make an advance request for medical aid in dying, it would be necessary to provide for the terms and conditions. Indicate your level of agreement with the following statements.

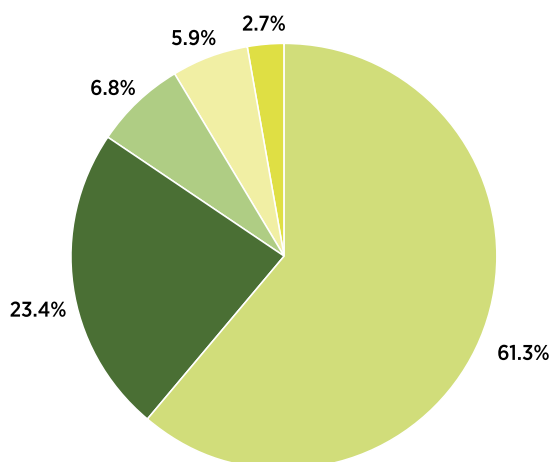
The oral request should be admissible.



The request made in writing before a witness should be admissible.

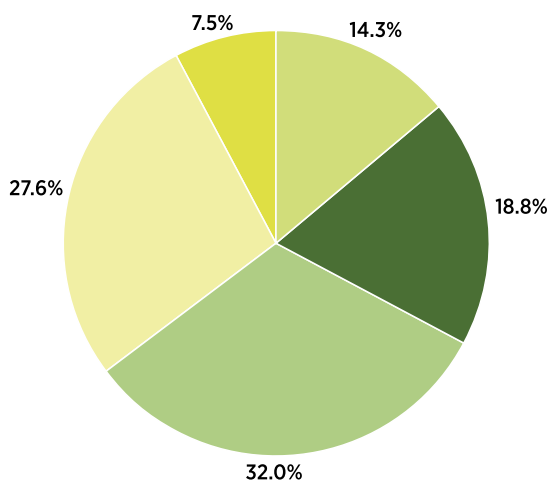


The request made by audio-visual recording should be admissible.



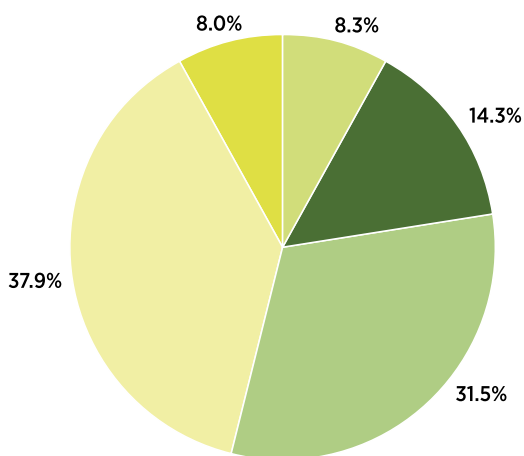
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

The request should be notarized.



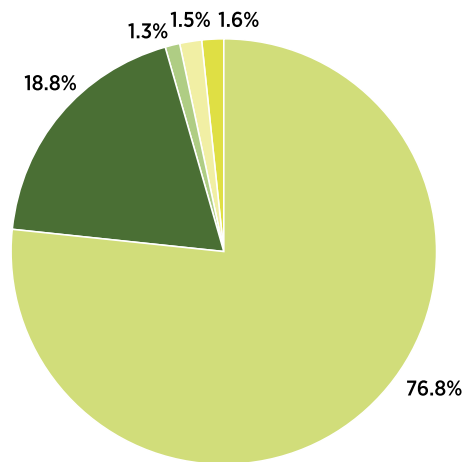
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

An admissible request should have a defined period of validity.



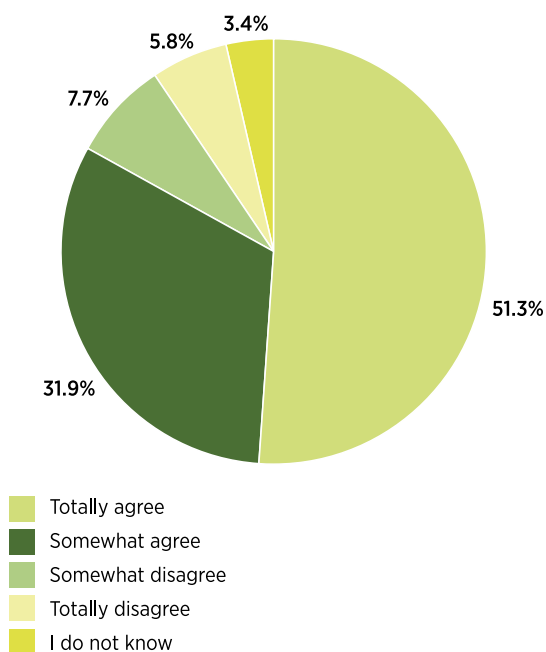
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

A request should be easily amendable or revocable by the person who made it.



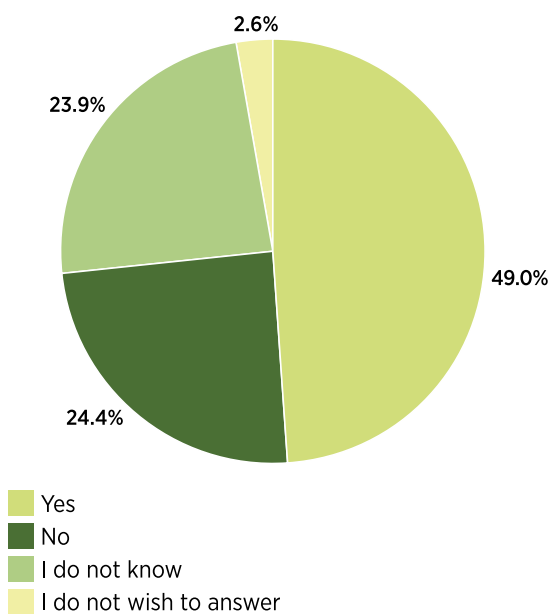
Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

The request should contain detailed information about the suffering and living conditions that the person anticipates and finds unbearable.



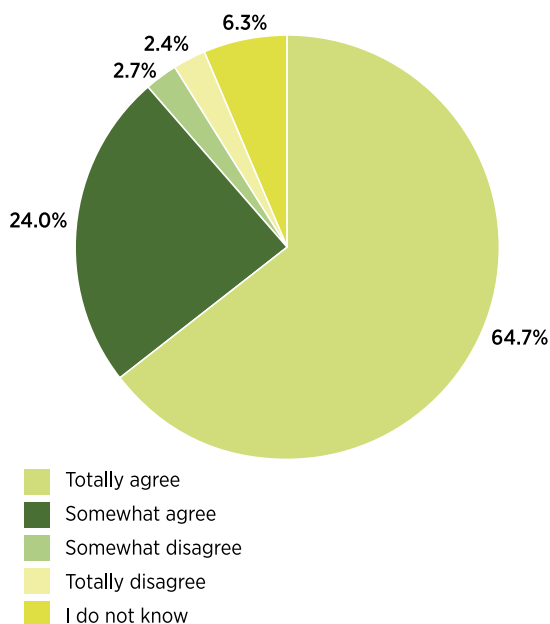
Medical aid in dying and mental disorders

10) In your opinion, should medical aid in dying be available to persons whose only medical problem is a mental disorder?

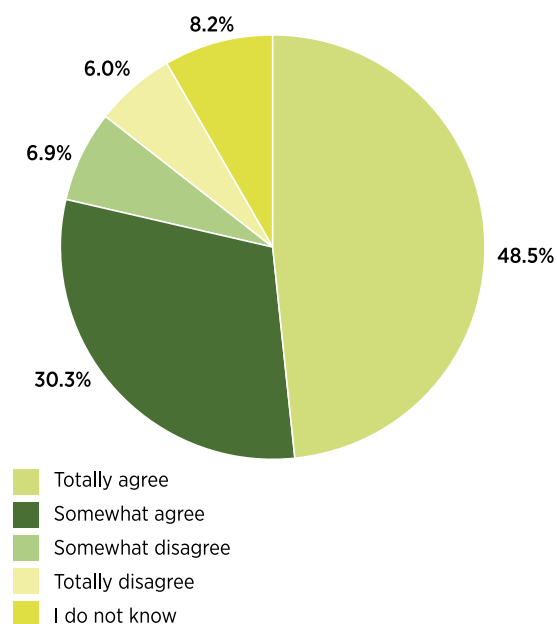


11) The following arguments are sometimes made about access to medical aid in dying for persons whose only medical problem is a mental disorder. Indicate your level of agreement with the following statements.

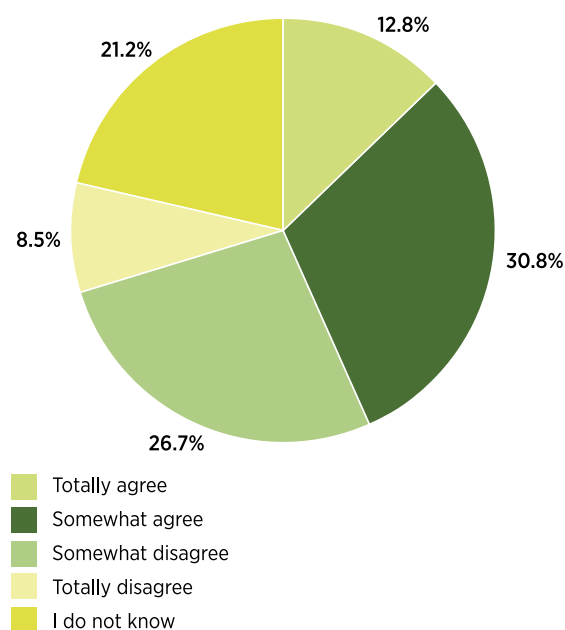
Some mental disorders may be incurable and cause intolerable suffering.



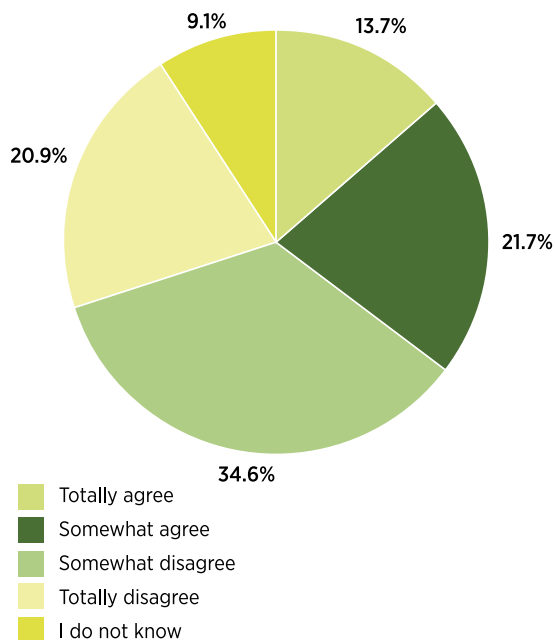
Denying medical aid in dying to persons with a mental disorder would be discriminatory, as this decision would be based on a diagnosis and not on the individual's circumstances and living conditions.



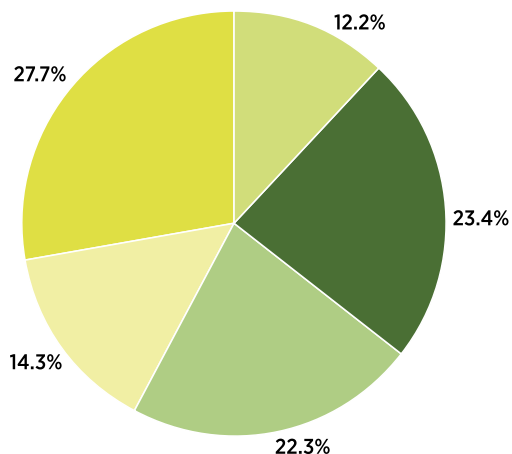
A mental disorder cannot be declared with certainty to be incurable. A case that is deemed irreversible may at some point be alleviated with treatment.



Granting medical aid in dying on the grounds of mental disorder could give the impression that death is an option for ending suffering rather than obtaining treatment.

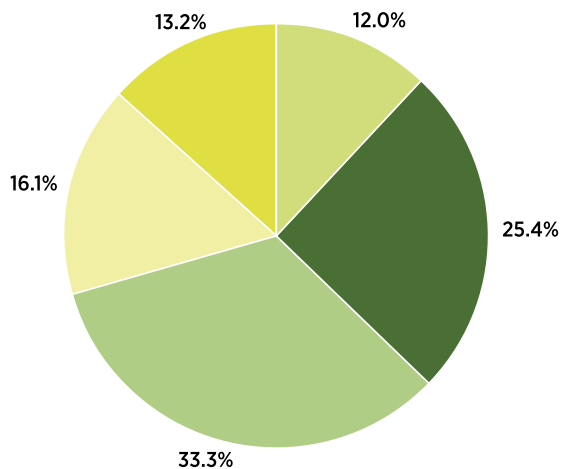


The criteria already provided for in the *Act respecting end-of-life care* would be sufficient to regulate access to medical aid in dying for persons whose only medical problem is a mental disorder, thus avoiding any abuse.



Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

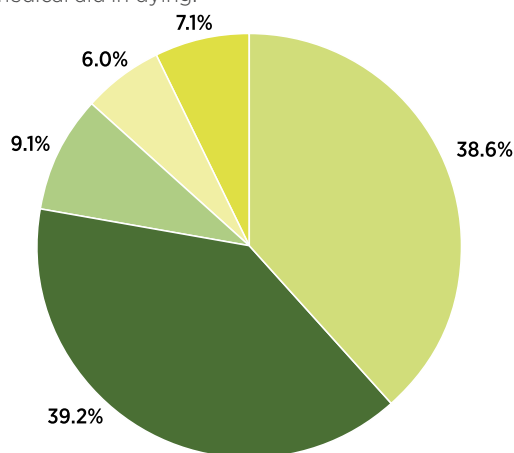
There are risks of abuse if access to medical aid in dying is granted to persons with mental disorders.



Totally agree
 Somewhat agree
 Somewhat disagree
 Totally disagree
 I do not know

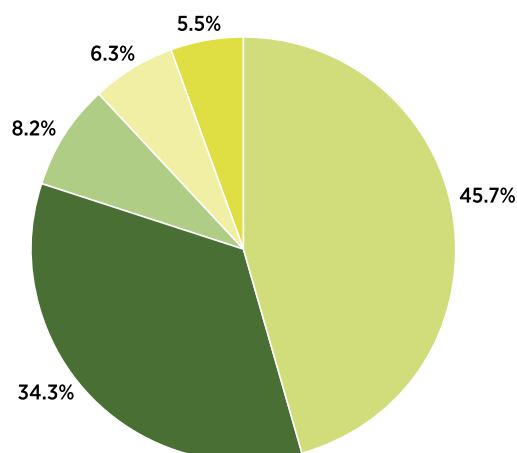
12) Certain conditions could be put in place to regulate access to medical aid in dying for persons whose only medical problem is a mental disorder. Indicate your level of agreement with the following statements.

There must be a minimum period of time between the moment the diagnosis is received and the request for medical aid in dying.



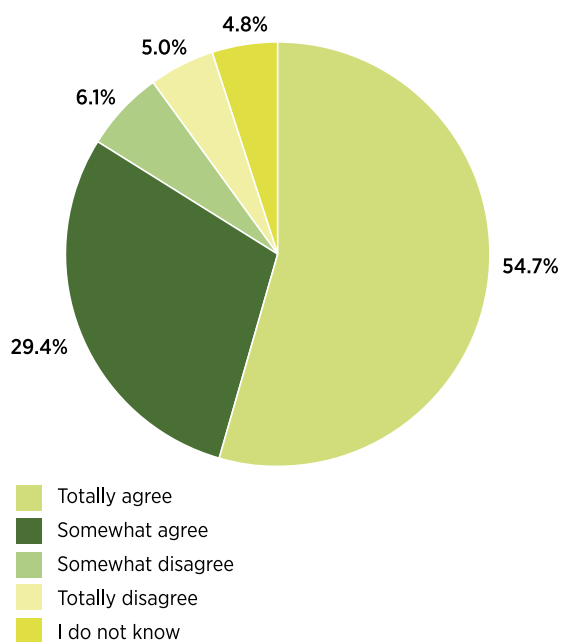
Totally agree
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 Totally disagree
 I do not know

The person must have tried at least one treatment that could reasonably improve his or her situation.

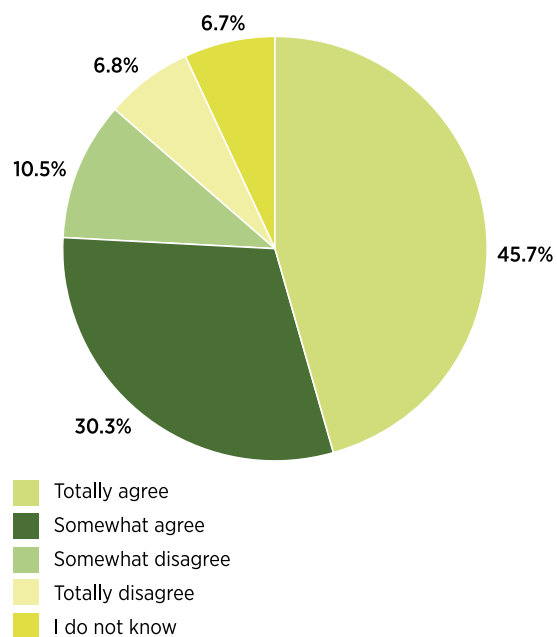


Totally agree
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 Somewhat disagree
 Totally disagree
 I do not know

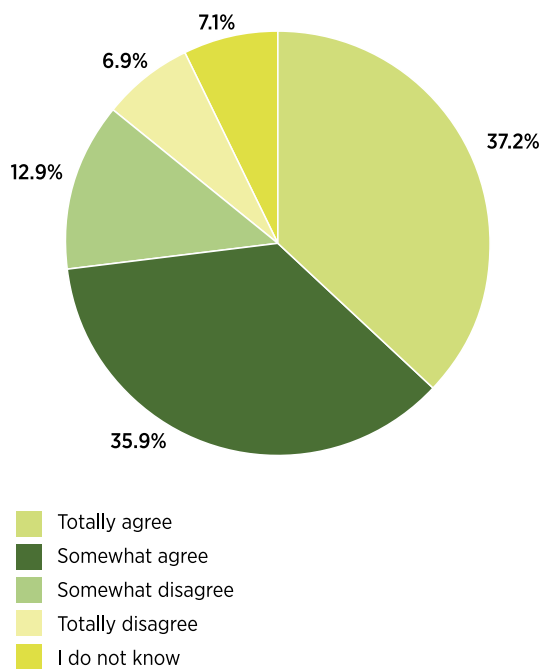
The person must have been assessed by at least one psychiatrist.



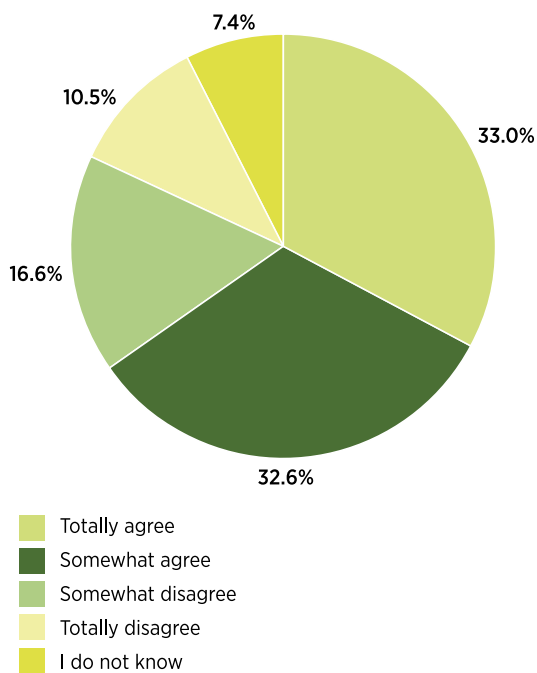
The person must have a mental disorder that is deemed incurable.



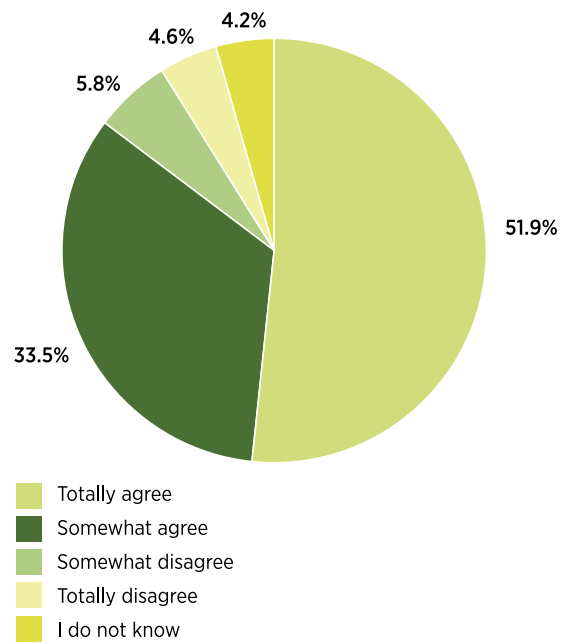
The person's loved ones must be involved in the process.



The person must not have refused treatment that offers a reasonable possibility of alleviating his or her suffering.

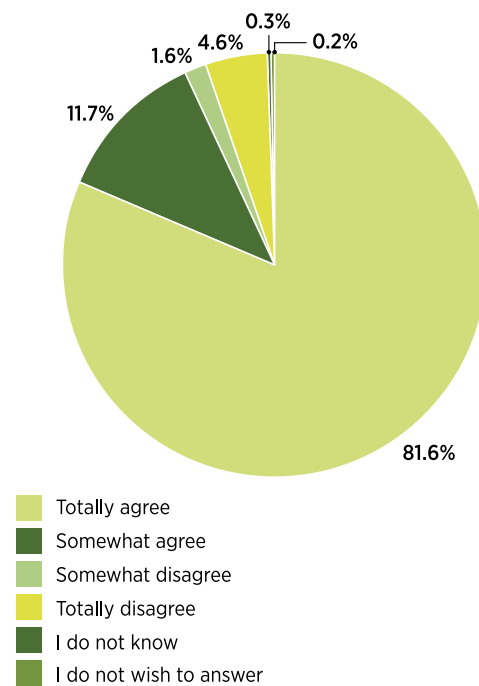


The person must have had prior access to care and services aimed at improving his or her condition.

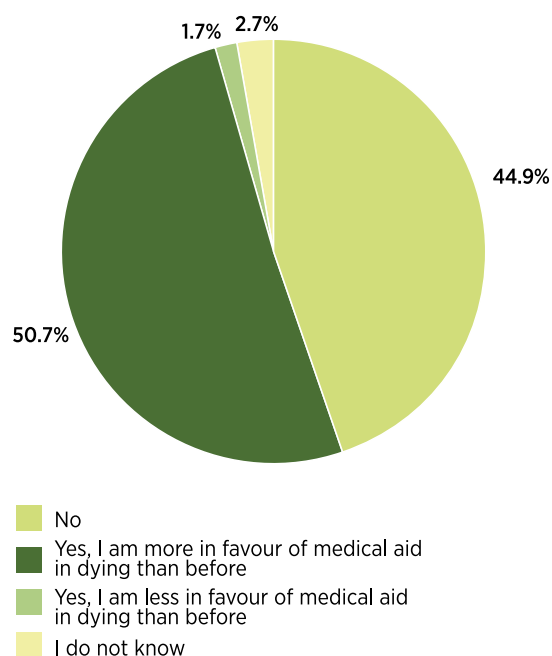


General questions

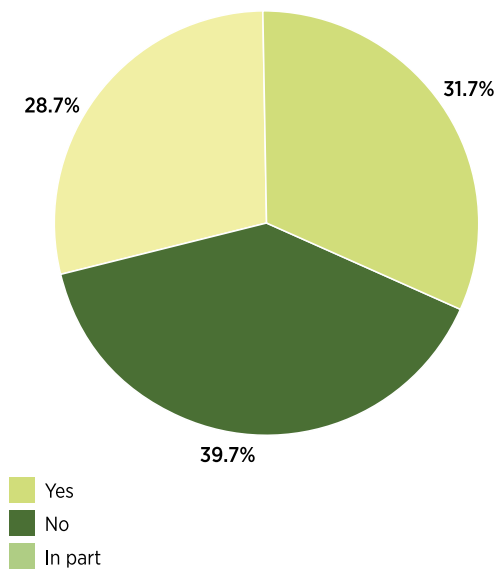
13) In general, do you agree or disagree with medical aid in dying?



14) Have your views on medical aid in dying changed since the *Act respecting end-of-life care* was passed in 2014?



15) Have you read the discussion paper (available on the National Assembly website) that the Committee prepared on the evolution of end-of-life care?



APPENDIX II

List of experts heard during the first phase of special consultations and public hearings

In alphabetical order

Dr. Marcel Arcand, family physician and professor of family medicine
Prof. Louise Bernier, professor of law
Dr. Marcel Boisvert, retired palliative care physician
Prof. Gina Bravo, professor of community health sciences
Prof. Martin Caouette, professor of psychoeducation
Dr. Félix Carrier, psychiatrist and professor of psychiatry (008M)
Ms. Danielle Chalifoux, attorney, president of the Institut de planification des soins du Québec
Chambre des notaires du Québec (017M)
Collège des médecins du Québec (020M-2)
Commission sur les soins de fin de vie (002M-2)
Mr. Simon Courtemanche, patient-partner, Association des médecins psychiatres du Québec
Dr. Guillaume Barbès-Morin, psychiatrist
Curateur public du Québec (019M)
Ms. Sandra Demontigny, author
Prof. Jocelyn Downie, professor of law and health care ethics (015M)
Dr. Pierre J. Durand, professor of social and preventive medicine
Ms. Nicole Filion, attorney, co-chair of the Groupe d'experts sur la question de l'incapacité et l'aide médicale à mourir
Dr. Pierre R. Gagnon, psychiatrist (004M-2)
Dr. Bertrand Major, psychiatrist
Groupe interdisciplinaire freudien de recherche et intervention clinique (016M)
Dr. Mona Gupta, psychiatrist and professor of psychiatry (003M)
Ms. Jacqueline Herremans, attorney, chair of the Association pour le Droit de Mourir dans la Dignité Belgique
Prof. Serge Larivée, professor of psychoeducation
Prof. Jocelyn Maclure, co-chair, Groupe d'experts sur la question de l'incapacité et l'aide médicale à mourir
Dr. Michèle Marchand, family physician
Mr. Jean-Pierre Ménard, attorney, Ménard, Martin Avocats
Prof. Brian L. Mishara, professor of psychology (010M)
Dr. Alain Naud, family physician and professor of family medicine (006M)
Dr. Félix Pageau, internist-geriatrician (012M)
Prof. Suzanne Philips-Nootens, retired professor of law
Dr. Judes Poirier, professor of medicine and psychiatry
Dr. Louis Roy, palliative care physician (018M-2)
Prof. Jocelyne Saint-Arnaud, professor of social and preventive medicine (007M-2)
Prof. Carole Sénéchal, professor of education
Prof. Timothy Stainton, professor of social work (014M-2)
Prof. Irene Tuffrey-Wijne, professor of intellectual disability and palliative care (013M)
Prof. Georgia Vrakas, professor of psychoeducation (021M)

The figures in brackets correspond to the document numbers of the briefs on the website of the National Assembly.

APPENDIX III

List of individuals and organizations heard during the second phase of special consultations and public hearings

In alphabetical order

Association des groupes d'intervention en défense des droits en santé mentale du Québec (052M)
Association des retraitées et retraités de l'éducation et des autres services publics du Québec (046M)
Association québécoise de prévention du suicide (039M-2)
Association québécoise des neuropsychologues (001M)
Association québécoise pour le droit de mourir dans la dignité (011M-2)
Ms. Daphnée Ayotte
Mr. Yoland Bergeron (026M)
Dr. Laurent Boisvert, family physician
Carpe Diem - Centre de ressources Alzheimer
Collectif des médecins contre l'euthanasie (041M)
Commission des droits de la personne et des droits de la jeunesse
Confédération des organismes de personnes handicapées du Québec (047M)
Conseil pour la protection des malades (042M)
Mr. Christian Debray
Prof. Thomas De Koninck, professor of philosophy (045M)
Prof. Isabelle Dumont, professor of social work
Ms. Donna Farmer (051M)
Fédération des médecins omnipraticiens du Québec (060M)
Fédération des médecins spécialistes du Québec (055M)
Fédération des Mouvements Personne d'Abord du Québec (073M)
Fédération interprofessionnelle de la santé du Québec (056M)
Fédération québécoise de l'autisme (025M)
Federation of Québec Alzheimer Societies
Mr. Gordon Friesen (049M)
Ms. Kim L. Giard
Ms. Catherine Joly
Ms. Catherine Leclerc (075M)
Les usagers de la santé du Québec (035M)
Mr. Jonathan Marchand (064M)
Dr. Louis Morissette, forensic psychiatrist (031M)
Office des personnes handicapées du Québec (029M)
Ordre des infirmières et infirmiers du Québec (038M)
Ordre des orthophonistes et audiologistes du Québec (054M)
Ordre des psychologues du Québec (037M)
Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec (043M)

The figures in brackets correspond to the document numbers of the briefs on the website of the National Assembly.

Regroupement des organismes de base en santé mentale des régions de la Mauricie et du Centre-du-Québec (028M-2)

Réseau citoyen Vivre dans la Dignité (036M)

Réseau communautaire en santé mentale (040M)

Ms. Guylaine Ricard

Dr. Paul Saba, family physician (057M)

Ms. Natalia Manole, attorney

Société québécoise de la déficience intellectuelle (030M)

Dr. Pierre Viens, family physician (033M-2)

The figures in brackets correspond to the document numbers of the briefs on the website of the National Assembly

APPENDIX IV

Individuals and organizations not heard who submitted a brief

In alphabetical order

Assembly of First Nations Québec-Labrador and First Nations of Québec and Labrador Health and Social Services Commission (074M)

Association des médecins psychiatres du Québec (009M)

Association Uni-T : Voix pour les valeurs chrétiennes (070M)

Barreau du Québec (022M)

Ms. Lisette Benoit (063M)

Ms. Claudette Brien and Mr. Claude Major (032M)

Ms. Sophie Brouillet (067M)

Collectif-Québec / Association québécoise pour le droit de mourir dans la dignité (034M)

Conférence des Tables régionales de concertation des aînés du Québec (024M)

Ms. Lisa D'Amico (065M)

Ms. Sylvie Dussault (062M)

Mr. Jean-Pierre Filion (027M)

Dr. Raphael Goyette (058M)

Institut de planification des soins du Québec (005M)

Ms. Sophie Lachapelle (023M)

Ms. Lori Anne Lanigan (068M)

Ms. Marika Lhoumeau (053M)

Mr. Paul Mackey (066M)

Maison Vivre (059M)

Ms. Andréanne Masson (048M)

Ms. Sylvie Moreau (069M)

Observatoire Vieillissement et Société (050M)

Regroupement provincial des comités des usagers (044M)

Prof. Louis-André Richard (072M)

Mr. Gerry Roy (061M)

Toujours Vivant-Not Dead Yet (071M)

The figures in brackets correspond to the document numbers of the briefs on the website of the National Assembly

APPENDIX V

Motion establishing the Select Committee on the Evolution of the Act respecting end-of-life care

This motion was carried unanimously by the National Assembly on March 31, 2021.

“THAT, pursuant to Standing Order 178, a select committee be established to examine the issues related to extending medical aid in dying to persons who are incapable of caring for themselves or who are suffering from a mental illness;

THAT the name of this committee be “Select Committee on the Evolution of the Act respecting end-of-life care”;

THAT the Committee be composed of eleven members distributed as follows:

six (6) Members from the parliamentary group forming the Government, including the Committee Chair;

three (3) Members from the Official Opposition, including the Committee Vice-Chair;

one (1) Member from the Second Opposition Group;

one (1) Member from the Third Opposition Group;

THAT each parliamentary group forward to the Director of the Committees Service the list of its Committee members, including the name of the Chair and of the Vice-Chair, not later than seven (7) days after this motion has been carried;

THAT the Committee allow any independent Member to take part in its proceedings according to the terms set out in Standing Order 132;

THAT the Committee’s steering committee be composed of the Chair, the Vice-Chair, the member from the Second Opposition Group, the member from the Third Opposition Group and the clerk;

THAT the Committee may hold deliberative meetings as soon as this motion is carried;

THAT the Committee may hold online consultations pursuant to Standing Order 173.1;

THAT the Committee may hold special consultations and public hearings for a period not exceeding 15 days, including special consultations with expert witnesses;

THAT the Committee hold an initial phase of special consultations and public hearings to hear the expert witnesses to obtain an overview of the issues related to extending medical aid in dying to persons who are incapable of caring for themselves or who are suffering from a mental illness;

THAT, following the initial phase of consultations, the Committee publish a consultation document that is to be made available to the public before the beginning of the second phase of special consultations;

THAT, following the publication of this document, the Committee hold a second phase of special consultations and public hearings and that it hear all individuals whose testimony the steering committee deems relevant;

THAT the Committee may hold special consultations during deliberative meetings or in-camera meetings at the request of a witness;

THAT the Committee may use video conferencing within the framework of hearings;

THAT the Committee may hold virtual hearings and deliberative meetings, provided the decisions are made unanimously;

THAT the Committee may travel or meet in a place other than the precincts of the National Assembly;

THAT the steering committee determine the individuals and organizations that the Committee will hear;

THAT the steering committee may determine the total length of each hearing as well as the length of each witness's presentation and exchanges with members of the Committee;

THAT the organization of proceedings be entrusted to the Committee's steering committee, including the preparation of the schedule according to any request for changes made by individuals and organizations;

THAT the Committee be convened by its Chair, pursuant to Standing Order 148 even if it is to consider an order of reference from the Assembly;

THAT during ordinary hours of meeting, the majority of the Committee's sittings be on Mondays and Fridays and that during extended hours of meeting, the majority of the Committee's sittings be on Mondays;

THAT the Committee not be limited to three (3) clear days, following special consultations, in which to hold deliberative meetings for the purpose of agreeing upon any observations, conclusions or recommendations that it wishes to include in its report;

THAT the Committee table its report not later than 19 November 2021⁹²;

⁹² Following the prorogation of the 1st Session of the 42nd Legislature, the National Assembly passed a motion to continue the work of the Select Committee during the 2nd Session. The motion provides for the tabling of its report no later than December 10, 2021.

THAT the rules pertaining to standing committees be observed in the Committee insofar as they are consistent with the provisions of this motion;

THAT the Committees Service ensure the necessary support for the smooth functioning of the Committee;

THAT the Committee have the resources needed to fulfill its mandate, particularly in terms of support for research and publicity;

THAT the National Assembly be responsible for providing research support to the Committee;

THAT the ministère de la Santé et des Services sociaux support the Committee's research officers at the Committee's request."

Parliamentary Committees Directorate

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