

SELECT COMMITTEE

Dying With Dignity

REPORT

MARCH 2012



A place for every citizen

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A WORD FROM THE COMMITTEE CHAIR AND VICE-CHAIR

Being a part of the Select Committee on Dying with Dignity was a profoundly life-changing experience. During this mandate, we discussed serious and universally important matters with Quebecers, who proved to be remarkably candid and analytical. Their participation in this consultation gave practical meaning to our work, and we are extremely grateful to them, especially since we understand how intimidating the parliamentary process can be and how difficult it must have been for some of them to open up about personal experiences.

Given the large turnout at the hearings, it is clear that Quebecers were ready for this debate and felt it was important. In fact, the debate spread well beyond Parliament, and the public hearings gave rise to countless conferences, retreats and programs devoted to the subject. Moreover, the Committee's consultation paper has been used in numerous educational projects in high schools, colleges and universities alike. By making the public aware of the topics debated, we feel we have paved the way to a more open discussion of end-of-life matters, and that, in and of itself, is a legacy the Committee will leave behind.

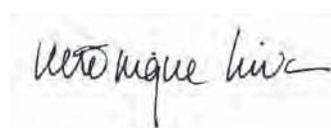
We would like to thank all the National Assembly collaborators who directly and indirectly contributed to our work and whose exemplary engagement was instrumental to our success. At the top of the list is the research team—Hélène Bergeron, Danielle Simard, Robert Jolicoeur and David Boucher—who were there for the Committee from start to finish and whose skills, professionalism and dedication were invaluable. We would also like to highlight the exceptional work of the Committee's clerk, Anik Laplante, who turned out to be indispensable to the smooth operation of this unprecedented undertaking. Anik played several important roles: acting as liaison between the public and the Committee, organizing the work, setting up our work sessions and coordinating the preparation of the report.

As MNAs, it was extremely enriching to work in a spirit of non-partisanship and to be able to set party lines aside. We thank our colleagues and members of the Committee for giving so generously of their time, for the professionalism they brought to the task and for always keeping our citizens at the forefront of their reflections. Keenly aware of our tremendous responsibility, we left no stone unturned, methodically studying the issues from every possible angle, and held serious, in-depth discussions. We spent many long days in what at times were intense debates, but the work was carried out in a spirit of collaboration and with the utmost respect, which is why we are able to produce this unanimous report. Also in our thoughts are colleagues* who for different reasons had to resign from the Committee, particularly Geoffrey Kelley, who got us off to a great start and skilfully steered our work in the first year before his appointment to the Cabinet.

In closing, we hope our experience inspires the Québec National Assembly to launch more important social debates in the near future. For our part, we feel privileged to have had the opportunity to serve on the Select Committee on Dying with Dignity, allowing us to fully play our role as elected representatives of the people.



Maryse Gaudreault
MNA for Hull and Chair



Véronique Hivon
MNA for Joliette and Vice-Chair

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THE SIGNATORIES OF THE REPORT OF THE SELECT COMMITTEE ON DYING WITH DIGNITY



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INTRODUCTION

To die peacefully, surrounded by family and friends, or to simply slip away in one's sleep—such is the way many people would like their life to end. Unfortunately, the dying process can be agonizingly slow or involve a lengthy decline. In fact, over the past few decades, remarkable medical and pharmaceutical advances have increased life expectancy, sometimes at the expense of quality of life. What is our society's answer to the suffering experienced by some people at the end of life? How should we respond to requests for help to die? How do we ensure that people die with dignity?

BACKGROUND OF THE COMMITTEE'S MANDATE

In the past 30 years or so, when end-of-life issues have been debated in Québec, euthanasia and assisted suicide have periodically come to the fore. Who can forget the cases involving terminally ill people who publicly claimed the right to receive help to die or involving people who helped a loved one die? As well, opinion polls conducted in recent years have consistently shown that 70% to 80% of Quebecers are in favour of euthanasia.

However, fall 2009 marked a turning point in this debate in Québec. The Collège des médecins du Québec published a major discussion paper¹ on the topic, concluding that under exceptional circumstances, euthanasia could be a final step in the continuum of appropriate end-of-life care. As well, polls conducted by the federations of general practitioners² and specialist physicians³ revealed strong support for euthanasia under exceptional circumstances. Moreover, a large opinion poll⁴ confirmed a trend that has been in the making for years, namely that a majority of Quebecers are in favour of euthanasia. Lastly, also in fall 2009, various associations called for a vast public debate on the topic.

¹ Collège des médecins du Québec. *Physicians, Appropriate Care and the Debate on Euthanasia – A Reflection*, October 16, 2009, 9 pages.

² Fédération des médecins omnipraticiens du Québec. Press release “The FMOQ Reveals the Results of its Consultation on Euthanasia”, October 29, 2009.

³ Fédération des médecins spécialistes du Québec. Press release “Euthanasie: La FMSQ dévoile les faits saillants de son sondage”, October 13, 2009.

⁴ HANDFIELD, Catherine. “Les Québécois favorables à l’euthanasie,” [online], updated August 11, 2009. [<http://www.cyberpresse.ca/actualites/quebec-canada/sante/200908/10/01-891423-les-quebecois-favorables-a-leuthanasie.php>] (Consulted on August 12, 2009).

All these developments convinced the members of the National Assembly that Quebecers were ready to give this matter serious thought. The members also felt it was their responsibility to take up this public debate and offer all citizens the opportunity to express themselves. As such, at the initiative of the Member for Joliette, the National Assembly unanimously adopted a motion⁵ on December 4, 2009 creating a select committee to study the issue of dying with dignity.

The members deliberately chose not to limit the process to euthanasia, although it would be the main issue. They firmly believed the mandate of the Select Committee should be broader in scope so that other end-of-life issues, such as palliative care and respect of an individual's end of life wishes, could be debated.

EXPERT CONSULTATION AND GENERAL CONSULTATION

Because of the complexity and sensitivity of the topic, the members decided to proceed in two steps. First, they would hear experts to learn more about the topic and acquire a better understanding of the issues. Thus, in February and March 2010, they heard experts⁶ from various disciplines, including medicine, law, philosophy, ethics, sociology and psychology.

Following these hearings, the Select Committee released a consultation paper in May 2010 to inform the public about the topic and invite them to participate in the second phase of its work, the general consultation⁷. Quebecers were asked to submit their point of view by way of a brief or comments, by taking part in a public hearing in one of the cities visited by the Committee, or by completing an online questionnaire on the National Assembly website.

⁵ Appendix I contains excerpts from the motion.

⁶ Appendix II lists the experts who participated in the special consultations of the Committee on Health and Social Services, the parliamentary standing committee charged with this first step.

⁷ Appendix III lists the organizations and individuals who participated in the general consultation of the Select Committee on Dying with Dignity.

We are pleased with the remarkable success of this public consultation, confirming the tremendous relevance of this Select Committee. It is interesting to note that 75% of the briefs received were from citizens as opposed to organizations, and that close to 30% of the online respondents were under the age of 30.

The Select Committee on Dying with Dignity – Statistics

- 32 experts heard over a 6 day period
- Over 3,200 copies of the consultation paper
- 273 briefs
- 239 individuals and organizations heard over 29 days of public hearings in 8 cities (Gatineau, Montréal, Québec City, Rimouski, Saguenay, Sherbrooke, Saint-Jérôme, Trois-Rivières)
- 114 individuals heard during the open mic periods⁸
- 6,558 answers to the online questionnaire⁹
- Over 16,000 comments received by email, mail and fax, and by way of the online questionnaire
- 21 meetings during the mission to France, Belgium and the Netherlands
- 51 deliberative meetings held by the Committee members

Important issues were addressed during the public hearings. Aside from euthanasia and, to a lesser extent, assisted suicide, complex questions were raised, including the refusal and cessation of treatment, palliative care, palliative sedation and advance medical directives. The Quebecers conducted themselves in a dignified and respectful manner throughout the consultations. We were very impressed by the calm and frank discussions, which were extremely enriching, with citizens graciously accepting our devil's advocate role.

The testimonies—some of which were moving, others, troubling—helped deepen our initial understanding. We were profoundly affected by this extraordinary experience, this unique encounter with citizens on a topic that goes to the heart of the human condition and of people's most fundamental

⁸ Period during which citizens at the hearing were invited to briefly express their points of view.

⁹ Appendix IV presents the results of the online consultation.

values. It has been a privilege to participate in this democratic exercise and to listen to what Quebecers have to say on this topic: no study will ever match the value of this experience. We cannot adequately express our gratitude to all those who took the time to share their opinions and experiences, whether in person or in writing. We would also like to acknowledge the dedication of palliative care workers, who are there to support patients until their last breath. We met many during the hearings and were extremely impressed with their work and dedication.

Of course, the debate on euthanasia and assisted suicide is not limited to Québec. Elsewhere in the world, governments have reflected on the question, and many have legislated to allow these practices. In June 2011, a delegation of the Committee travelled to Europe to learn more about the debate currently going on in France and to study the experiences of Belgium and the Netherlands¹⁰. This mission was most enlightening, and we would like to thank everyone we met during our travels.

THE COMMITTEE'S REPORT

After a great number of deliberative meetings and almost an entire year during which we carefully studied all the arguments and issues, the Select Committee on Dying with Dignity is pleased and proud to present its unanimous report to the National Assembly and to the Québec public. Aside from some indispensable definitions and legal concepts, the report contains two main parts. The first concerns end-of-life care and delves into such issues as the refusal and cessation of treatment, palliative care, palliative sedation, and planning end-of-life care in the event of incapacity. The second presents the results of our reflection on euthanasia. More specifically, it describes the context, states the arguments for and against this practice, and sets out our position. Lastly, it explains the issues surrounding complex questions on which we have not expressed an opinion, because, in our view, they require deeper reflection as part of a separate initiative.

¹⁰ Appendix V presents the program, the report on the mission in Europe and a summary of foreign experiences.

We worked tirelessly in a spirit of exceptional collegiality, putting partisanship and party lines aside. We firmly believe that our recommendations reflect the wishes of a large majority of Quebecers. Our sole guide was at all times the wellbeing of and respect for others in all their complexity in life, at the end of life, and in death.

THE BASIS FOR THE DISCUSSION

To ensure everyone had a shared understanding of the terms used, the Select Committee provided a few definitions on dying with dignity in its consultation paper, published in May 2010. It also explained what the law says about this matter.

We believe it relevant to repeat this information to provide the basis for the discussion. However, in light of the comments heard during the hearings and further to our research, some of the definitions have been refined.

WHAT THE WORDS MEAN

Advance medical directives¹¹

Instructions a capable person gives in writing or otherwise concerning decisions to make on his care in the event he is no longer able to make such decisions.

Assisted suicide¹²

The act of helping a person commit suicide by providing him with the means to do so or information on how to proceed, or both.

Capacity to consent to care

A person's ability to understand the nature of the illness for which treatment is proposed, the nature and purpose of the treatment, and the risks and benefits of receiving or not receiving such treatment.

Cessation of treatment

Stopping treatments that have the potential to prolong life.

¹¹ In the consultation paper, the term "living will" was used. The Committee is now using the term "advance medical directives". However, other terms are also used, including "end-of-life will", "biological will", "end-of-life directives" and "advance directives".

¹² The term "suicide assistance" is also used.

Continuous palliative sedation¹³

Continuous administration of medication to relieve pain by rendering a person unconscious until his death.

Euthanasia

An act that involves deliberately causing the death of another person to put an end to that person's suffering.

Intermittent palliative sedation

Administration of medication to a person, with alternating periods of alertness and sleep, to relieve pain by rendering the person unconscious.

Palliative care

According to the World Health Organization, palliative care is "the active, total care of patients whose disease is no longer responding to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Palliative care is organized and delivered thanks to the collaborative efforts of an interdisciplinary team that includes patients and their families [...]"¹⁴.

Refusal of treatment

Refusal to receive treatment that has the potential to sustain a person's life.

Therapeutic obstinacy

Use of aggressive treatment to prolong the life of a patient in the terminal stage of an illness, with no real hope of improving his condition.

¹³ The consultation paper used the terms "palliative sedation" and "terminal sedation." Although these are the more commonly used terms, the Committee has decided, going forward, to use "intermittent palliative sedation" and "continuous palliative sedation," which it feels more clearly distinguish between the two types of sedation.

¹⁴ World Health Organization, cited in Ministère de la Santé et des Services sociaux, End-of-life Palliative Care Policy, [Québec], 2010, p. 7.

WHAT THE LAW SAYS

Healthcare provisions

The health sector is under Québec's jurisdiction. The *Act respecting health services and social services*¹⁵ and especially the *Code of Ethics of Physicians*¹⁶ and the *Code of Ethics of Nurses*¹⁷ guide the administration of healthcare. Moreover, the *Civil Code of Québec* provides a framework for, among other things, the issue of consent to care. It deals with adults who are capable of giving consent for themselves, those who are not, and minors.

The basic principle is that no person can undergo care without his consent, except in emergency situations. This consent must be free and informed, which means the person must not feel any pressure in making his decision. In addition, the person must obtain all necessary information relating to the care he will be given, including the nature and objectives of the care, the associated risks and their effects, and the consequences of refusing or ceasing treatment.

Accordingly, the will of an adult with the capacity to consent must be respected, principally by his right to autonomy. Indeed, the *Civil Code* recognizes that people have the right to make all the medical decisions that affect them. This rule applies even if refusal or cessation of treatment leads to death.

The Criminal Code of Canada¹⁸

Under the Canadian Constitution, the federal parliament has jurisdiction in the area of criminal law. According to the *Criminal Code of Canada*, euthanasia and assisted suicide are crimes. However, it is up to the provinces to enforce criminal law. The Attorney General in each province is therefore responsible for deciding whether to lay charges and undertake criminal and penal prosecution.

The Canadian and Québec charters

The *Charter of Human Rights and Freedoms of Québec*¹⁹ and the *Canadian Charter of Rights and Freedoms*²⁰ affirm many values, including respect for the right to human dignity and integrity. Dignity refers to one's value as a person and the respect one is due, while integrity applies to one's physical and psychological protection.

¹⁵ R.S.Q., c. S-4.2.

¹⁶ R.R.Q., c.M-9, r. 17; R.S.Q., c. C-26, s. 87.

¹⁷ R.R.Q., c. I-8, a. 3; R.S.Q., c. C-26, s. 87.

¹⁸ R.S.C. 1985., c. C.-46.

¹⁹ R.S.Q., c. C-12.

²⁰ R.S.C. (1985), app. II, no 44.

PART 1

End-of-life care: an area that needs improvement

End-of-life care was at the heart of the general consultation held by the Committee. Many of the witnesses brought up related topics such as the refusal and cessation of treatment, palliative care and palliative sedation. Another recurring theme was the need to plan one's end-of-life care. Although receiving the best possible care at the end of their lives was certainly a concern for those who testified, so was the need for assurance that medical staff would respect their decisions.

That said, education and changing mentalities have profoundly altered the doctor-patient relationship in the last 40 years. Paternalism ("doctor knows best") has given way to autonomy ("patient knows best"). Whereas before, doctors had the last word in treatment-related matters, today, the patient's wishes come first.

REFUSAL AND CESSATION OF TREATMENT: PRACTICES THAT REQUIRE A BETTER UNDERSTANDING

In the last century, medical advances have made it possible to treat people with increasingly serious illnesses. Forestalling death, these advances influence medical practice. In some cases, physicians' desire to cure their patients, to keep them alive or to prolong their lives at all costs has led to therapeutic obstinacy.

The early seventies were characterized by important legislative developments in the area of personal autonomy. The Canadian and Québec charters and the *Civil Code of Québec* confirm a person's right to inviolability and autonomy. Under these principles, no person may be subjected to any type of care, be it medical examinations, testing, treatments or any other intervention, without his free and informed consent. The right to consent to care implies the right to refuse or interrupt care, even if this decision could lead to death. For example, a person may decide to stop hemodialysis or ask to be removed from the respirator keeping him alive. The representative of an incompetent person (tutor, curator, person appointed in a mandate in anticipation of incapacity or relative) may make this decision on his behalf.

By placing more importance on a person's autonomy, the *Civil Code of Québec* has helped, among other things, curtail unnecessary treatments and therapeutic obstinacy. That said, based on what we heard from both





“ I spent my entire life fighting for him to get care, and then I had to fight to let him die. ”

Christian Caillé, whose son suffered from an orphan disease and died at age 10
– Excerpt from the hearing of February 10, 2010 in Québec City, general consultation

“ We sometimes get the impression that people feel they are victims of the medical system. Patients and their families are often poorly informed about their right to refuse or accept the treatment options available to them. ”

Maison Mathieu-Froment-Savoie
– Excerpt from brief, general consultation

health professionals and families, these practices still occur now and again in Québec health establishments. As one nurse said, “It’s often easier for the healthcare team to try and keep a person alive with treatments that are either pointless or disproportionate than to take the time to sit down with the family and the patient to discuss the possibility of stopping treatment and providing comfort care instead”²¹.

The testimony of Christian Caillé was especially moving in this regard. His son died of an orphan disease at age 10, after spending half his life in hospital. He suffered enormously in the last months of his life: respiratory distress, non-stop heartburn, liver pain, repeated drops in blood pressure. He was also force-fed through a tube. Even if his death was no longer avoidable, Mr. Caillé and his wife had to fight tooth and nail to stop treatment.

Also, based on the testimonies, there is still confusion among the public and in the healthcare sector regarding the refusal and cessation of treatment, even though these practices are widely recognized. Some even associate them with a form of euthanasia. We believe that greater public awareness and better education for health professionals are essential to eliminate these ambiguities, reduce ethical dilemmas and better clarify the decisions of patients and their families.

PALLIATIVE CARE: AN APPROACH TO CARE TO BE DEVELOPED

Science has made such dramatic advances in the last century that death has become, for some, a failure to avoid, an enemy to control. It can even be said that we live in a death-denying society. In the 1970s, the advent of palliative care helped change this way of thinking, since this approach views death as a natural process of life.

We no longer try to cure the dying at all costs or resign ourselves to watching them suffer as they wait for death but rather try to ease their physical and psychological suffering and help improve their quality of life until the end. Moreover, support is not only given to the patient, but also to his loved ones. To quote the famous Dr. Thérèse Vanier of Saint Christopher’s Hospice in London, England, the palliative care approach is “all that remains to be done when there is nothing more to do”.

²¹ Excerpt from the hearing of intensive care nurses from Hôpital Maisonneuve-Rosemont, general consultation, Montréal, September 10, 2010.

A broad consensus was achieved among the participants in the consultation on the importance of palliative care. Everyone agreed that its development should be a priority and that lack of up to date data on the subject could dampen efforts in this regard.

Palliative Care at a Glance

- Palliative care began in 1967 in Great Britain, where Cecily Saunders opened Saint Christopher's Hospice to help cancer patients.
- In Québec, in the 1970s, Royal Victoria Hospital, at the initiative of Dr. Balfour Mount, and Hôpital Notre-Dame were the first to set up palliative care units for cancer patients.
- In 1985, Maison Michel-Sarrazin became the first palliative care hospice in Canada.
- In 1998, palliative care became one of the priorities of the Programme québécois de lutte contre le cancer.
- In 2000, a report was released on the palliative care situation in Québec²².
- In 2004, the Ministère de la Santé et des Services sociaux launched its *End-of-Life Palliative Care Policy*²³.

Palliative care in Québec

Many witnesses lamented the lack of a comprehensive, up-to-date assessment of palliative care in Québec. The last time the situation was assessed was in 2000. And without a clear picture of existing resources and regional needs, there can be no effective action. Consequently, the Ministère de la Santé et des Services sociaux must obtain an assessment of the palliative care situation in Québec which includes regional comparisons and ensure it is updated on a regular basis.

²² LAMBERT, Pierrette and Micheline LECOMTE, *État de situation des soins palliatifs au Québec - Le citoyen : une personne du début à la fin de sa vie*, Québec, March 2000, 467 p.

²³ Ministère de la Santé et des Services sociaux, *End-of-Life Palliative Care Policy*, Québec, 2004, 98 p.

“ Palliative medicine, with the help of other health professions, seeks to control physical [...], psychological [...] and spiritual symptoms; tries to improve the quality of life of patients and their loved ones by making patients comfortable and helping them be at peace with themselves and in harmony with their families; and allows patients to die naturally. ”

Réseau de soins palliatifs du Québec
– Excerpt from brief, general consultation

End-of-Life Palliative Care Policy

In 2004, the Ministère de la Santé et des Services sociaux published an important document titled *End-of-Life Palliative Care Policy*. The result of a vast consultation and joint effort with the healthcare sector, the Policy sought to improve the accessibility, continuity and quality of palliative care.

Implementation of the Policy

During the hearings, all the witnesses agreed the Policy is a valuable document that is still relevant today. They also unanimously agreed that implementation of the Policy is far from complete. Like these witnesses, we therefore note the delay in the implementation of this Policy, even though it is universally supported and its objectives of fair access to care, service continuity, quality of services and increased awareness among stakeholders of the inescapable nature of death are still relevant. Moreover, we subscribe to the underlying principles of the Policy, especially keeping patients in their “natural living environment”, i.e. their homes.

Although Québec pioneered palliative care in Canada, by 2000 it had fallen far behind. However, according to statements made during the hearings, the situation has since improved. “In 10 to 15 years, Québec went from meeting 10% of its needs to 20% to 60% depending on the region and type of illness”²⁴. Nevertheless, despite recent progress, far too many end-of-life persons who need palliative care do not have access to it. Needless to say, this results in unnecessary suffering. A central element of the continuum of end-of-life care, palliative services must form an integral part of the health and social services network’s service offer.

Furthermore, the aging of the population will invariably lead to an increase in the number of people with cancer and other diseases. Consequently, the Policy must be implemented right away.

Moreover, we were surprised to learn that palliative care falls under the purview of the Québec cancer directorate of the Ministère de la Santé et des Services sociaux, as one of the Policy objectives is to extend palliative care to diseases other than cancer. Therefore, to give new impetus to this type of care, we recommend that an administrative unit be created specifically for this purpose.

“ In the early 2000s, Québec adopted an excellent end-of-life palliative care policy. [...] However, we have to face facts and recognize it has proven difficult to find the time and financial and human resources needed to turn it into reality. Today, much like 10 years ago, access to palliative care [...] remains very limited everywhere in the province. ”

Dr. Bernard Lapointe,
Chief of the Palliative Care Division,
Jewish General Hospital
– Excerpt from brief, expert consultation

²⁴ Brief submitted by Maison Michel-Sarrazin as part of the general consultation, p. 29. These statistics “are based on data from various sources, including government documents and the recent work of the Palliative Care Committee of the Capitale-Nationale region, on needs for palliative care beds”.

To ensure prompt implementation of the Policy, we ask that the Ministère de la Santé et des Services sociaux submit a report thereon to the appropriate National Assembly committee for consideration no later than one year after publication of the Select Committee's report. This plan should also include an assessment of palliative care in Québec.

RECOMMENDATION N^o 1

The Committee recommends that the Ministère de la Santé et des Services sociaux obtain an assessment of the palliative care situation in Québec. This assessment should:

- Report on the existing resources across Québec;
- Report on needs and the resources required to meet them;
- Report on the state of palliative care in each region;
- Be regularly updated.

Lastly, we invite the Health and Welfare Commissioner, responsible for assessing the performance of our health system, to look into the palliative care situation. His insight will guide the actions of policymakers and help improve the welfare of people at the end of their lives.

Key improvements needed in the delivery of palliative care

As stated earlier, the main goals of the *End-of-Life Palliative Care Policy* are accessibility, continuity and quality of care, as well as raising awareness among stakeholders of the inescapable nature of death. Various measures are proposed to this end. Based on what we heard from experts and citizens, more effort is required in some of these areas.

Access to palliative care

Palliative care must be offered regardless of the patient's prognosis for survival and type of disease. Moreover, it must be available in various settings, including in the person's home and in residential and long-term care centres (centres d'hébergement et de soins de longue durée – CHSLDs). Based on what the Committee heard, this not the case.

Shifting to palliative care in the continuum of care

End-of-life patients have to wait too long for access to palliative care. Their transition to this type of care is usually based on a very poor prognosis for survival rather than on their overall medical condition and actual needs. This prognosis is usually less than two months for palliative care hospices and often even less for palliative care units in hospitals. This means patients are kept in curative care units where health professionals lack adequate training on the palliative approach. The issue, for the physician, is therefore to decide with the patient when the time has come to stop therapeutic treatment and transition to palliative care.

As well, some physicians have trouble resigning themselves to the fact that therapeutic treatment has become futile, so instead of offering palliative care, they sometimes suggest treatments that can unduly prolong life at the expense of quality of life, with potentially disastrous consequences for the patient.

Lastly, the palliative approach can also be beneficial for patients undergoing potentially curative treatments, yet it is rarely offered to this group.

Anyone suffering from a terminal illness should have access to palliative care as soon as warranted by their medical condition and even at the same time as curative treatment when the situation so requires. Indeed, the Policy states that patients should be offered the palliative option whenever “life-changing news is announced”. It goes without saying that the utmost care should be exercised in the way the diagnosis is delivered.

Palliative care for patients suffering from diseases other than cancer

Palliative care was essentially developed to meet the needs of people with cancer, a disease whose course is fairly predictable. Still today, little, if any, palliative care is available to patients suffering from other illnesses, such as degenerative diseases. However, these patients, as well as their families, need support to deal with the often unbearable suffering resulting from such conditions.



“ The subject of palliative care is only raised when treatment can no longer prolong life and causes toxic side effects. Because this is done too late in the game, patients see palliative care as giving up the fight, pure and simple; this feeling of abandonment leads to intense suffering, which is sometimes impossible to alleviate. ”

Dr. Serge Daneault, physician in the palliative care unit of Hôpital Notre-Dame – Excerpt from brief, general consultation

In-home palliative care

Most end-of-life persons want to stay at home as long as possible, and ideally until their death. However, for various reasons, very few get their wish²⁵.

We were surprised to learn that those who receive palliative care at home or in a palliative care hospice²⁶ must bear the cost of the medication, supplies or technical equipment required for their condition, whereas these costs are covered in a hospital setting. This is an unacceptable impediment to keeping end-of-life persons at home.

In-home palliative care takes an emotional and financial toll on the patient's family members, who must also juggle their caregiving responsibilities with work life. Since natural caregivers are the cornerstone of home care, we must look out for their welfare as well as for the patient's. Measures such as respite programs must be implemented to support them.

Whether it is for these reasons or simply because the care needed is too complex, when the end is near, patients and their families usually have to resign themselves to going to the hospital. Unfortunately, because of the shortage of palliative care beds, there is no guarantee that patients will all be treated by professionals trained in palliative care. What's more, the prospect of having to turn to the hospital is almost always upsetting and a source of extreme anxiety for the patient, especially since the emergency room is more often than not their only way in. Such situations can be avoided, and we invite everyone in the health network to find solutions.

Although a certain balance must be maintained between the different places that offer palliative care, we firmly believe, for the reasons mentioned earlier, that the focus should be on developing home care. We therefore ask the Ministère de la Santé et des Services sociaux to make this a priority.

²⁵ In Québec, 9.7% of cancer patients who could have benefited from palliative care died at home. However, given the choice, up to 80% of patients with cancer would prefer to die at home. BURGE, Frederick, LAWSON, Beverly and Grace JOHNSTON. "Trends in the place of death of cancer patients, 1992-1997," *Canadian Medical Association Journal*, 168 (3), 2003, p. 265-269.

²⁶ With the exception of Maison Michel-Sarazin, which is recognized as a health institution.

“ ... a serious illness is hard on the family's finances, and the drain during the palliative phase is even harder. [...] not only is the patient losing income, but the natural caregivers are as well [...] in palliative care, you have a person who needs treatment, but that person is part of a family, and that family is going through something too, and if we don't take that into account, we could end up with big problems down the road. ”

Danielle Minguy, president of the Alliance des maisons de soins palliatifs du Québec – Excerpt from the hearing of February 18, 2010 in Québec City, expert consultation

RECOMMENDATION N^o 2

The Committee recommends that the Ministère de la Santé et des Services sociaux give priority to the development of in-home palliative care.

Moreover, in our opinion, palliative care hospices are an ideal place to meet the needs of patients in the terminal phase of a disease who would like to stay at home but cannot. However, hospice funding, provided in large part by the community, remains a major challenge. It is important to see to their sustainability while ensuring they remain a community-based initiative.

In closing, we commend the work of community organizations such as the NOVA nurses of Montréal, Société des soins palliatifs du Grand Montréal and Envolée, who help patients die at home. We would also like to salute the work of all the home care teams. These initiatives must be maintained and increased.

Palliative care in CHSLDs

For the elderly, CHSLDs are often the last place they will live and, for many, the place where they will die. Unfortunately, few of these establishments offer true palliative care, and specialized teams are rare. The palliative approach itself seems unfamiliar to many. We feel strongly that an effort must be made to remedy this serious shortcoming.

Healthcare facilities should provide end-of-life patients with private rooms

Although many aspects of the Policy may seem relatively familiar, the issue of single-patient rooms could come as a surprise to those who have not had the experience of seeing a loved one die in a hospital setting. Yet what could be more natural than wanting quiet and privacy during those final days? Unfortunately, setting aside single rooms for dying patients is not a common practice in our healthcare facilities. Often, two families, sometimes even more, have to share a room.

How must the dying and their loved ones feel in such conditions? The lack of privacy can make it difficult for them to say their last words and share their final moments of tenderness. Furthermore, sharing a room may also make it impossible for the patient to be with his loved ones at all times. And let us not forget the fear and suffering inflicted on the roommate, who, by

being subjected to the crying visitors and ultimate death of the patient, is constantly reminded of his own impending death. Each family should be able to share their last moments with the person they love in peace and quiet. Specifically, palliative care units should have only single-patient rooms.

Continuity of palliative care

Continuity of palliative care means, among other things, that patient information is shared by the various healthcare practitioners involved in the person's treatment. In this way, the patient, or his family, does not have to repeat the information every time someone else becomes involved in the case. According to many witnesses, continuity is especially important during the transition from curative to palliative care. The concept of continuity of care is also predicated on the presence of stable multidisciplinary teams, which is conducive to building a relationship of trust between the patient and each health professional, something that is particularly important at the end of life. However, continuity is compromised in palliative care by constant staff rotation and an insufficient number of stable multidisciplinary teams.

Palliative care quality

The quality of palliative care depends on a number of factors, including access to and continuity of care. However, it also hinges on adequate training of health professionals and research in this field. Much work remains to be done on these fronts.

Training health professionals in palliative care

Training in palliative care is essential to ensure that patients receive quality care. However, initial training and professional development in this area are lacking for healthcare providers²⁷. As well, most of those who do have the required training belong to specialized multidisciplinary teams, which not all establishments have. Lastly, we were quite surprised to learn that veterinary students receive more hours of training on pain management than future family physicians, despite this being a central issue in end-of-life care.

We have to agree with the many witnesses who said that all health professionals should receive adequate training in palliative care. Consequently, we believe the Ministère de la Santé et des Services sociaux must see to this.

²⁷ Some educational institutions have taken initiative in the area of palliative care training. For example, the McGill University Faculty of Medicine requires all its family medicine residents to do a rotation in palliative care.

“ Having the person next to you die, listening to his agony and his family's pain, and knowing you're next, I call that torture. ”

Edmond Ferenczi, talking about his wife, Johanne Rodrigue, who, in the terminal stage of cancer, had to share a room for several days – Excerpt from brief, general consultation

“ ... stable teams in the departments, something we don't always get with agency nursing: medically trained, compassionate teams, whereas all too often our teams are hampered by a work structure that breaks down patient care into a multitude of acts delivered by different individuals without creating a real therapeutic link. ”

Dr Yvon Beauchamp, chief of palliative care at Hôpital du Sacré-Coeur de Montréal – Excerpt from brief, expert consultation

As stated by Dr. Michel L'Heureux, director of Maison Michel-Sarrazin, the transition from curative to palliative care implies "a change in focus from curing to caring [...]. This is not taught enough in all the fields [...] all clinicians, regardless of their specialty [...] may be called upon to participate in palliative care"²⁸.

For his part, Dr. Michel Morissette said he was not afraid about pain or losing his faculties at the end of his life but "of falling into incompetent hands; in this regard, we must focus our efforts on implementing palliative care training programs"²⁹.

“ It's unbelievable that veterinarians get better training on how to control pain than our future doctors. Veterinary students spend an average of 130 course hours just on pain management, while medical students get only about fifteen. ”

Dr. Golda Tradounsky of the Palliative Care Medicine Program of the Department of Oncology, McGill University – *Excerpt from the hearing of October 12, 2010 in Montréal, general consultation*

²⁸ Excerpt from the hearing of Dr. Michel L'Heureux, expert consultation, Québec City, February 17, 2010.

²⁹ Excerpt from the hearing of The Assembly of Catholic Bishops of Québec, general consultation, Québec City, September 30, 2010.

“ This doctor called a nurse and told her, in front of my husband and me, to give medication whenever he or I asked for it. [...] and then the shift changed, and the doctor didn't have the time to write “as needed” in his chart [...] So another nurse refused to give my husband more medication, because the chart didn't say “as needed.” We had to wait for another doctor to start his shift and come see my husband [...] Between Friday and Monday, we saw, or rather I saw, five different doctors...”

Danielle L'Écuyer, talking about her husband, André Dutrizac, who died of cancer – Excerpt from brief, general consultation



“ We trivialize what it means for a patient to go see a doctor and leave with a diagnosis of cancer or multiple sclerosis. [...] People are diagnosed with MS every day; they're often young mothers. They go in to see the neurologist and walk out with a little card that says “Next appointment” or “MRI in three months.”

Dr. Hubert Marcoux, physician in the palliative care unit of Hôpital Jeffery Hale – Excerpt from the hearing of March 9, 2010 in Québec City, expert consultation



“ Nothing has changed from the way medical students were trained 10 years ago; at this rate, the next generation of health professionals, the ones you and I will need, will not have the expertise and people skills they need to deliver quality end-of-life palliative care. ”

Dr. Bernard Lapointe, Chief of the Palliative Care Division, Jewish General Hospital – *Excerpt from brief, expert consultation*

“ The holistic character undoubtedly explains why the central philosophy of palliative care is often misunderstood in a culture where modern medicine wages a desperate battle against death; hence the tendency of many, including health professionals, families and patients, to reduce palliative services to just a specialty of contemporary scientific medicine. ”

Hubert Doucet, Chief of the Clinical Ethics Unit, Hôpital Sainte-Justine – *Excerpt from brief, expert consultation*

RECOMMENDATION N° 3

The Committee recommends that the Ministère de la Santé et des Services sociaux ensure that all healthcare professionals receive adequate training in palliative care.

Palliative care research

Research in palliative care is obviously vital to furthering and improving its quality. However, here too much remains to be done, especially regarding palliative care for people with diseases other than cancer.

On this topic, some participants suggested creating centres of excellence in palliative care for other illnesses. We think this is a good suggestion, because these centres would help update and disseminate knowledge and practices adapted to the needs of people nearing the end of their lives.

Despite the critical importance of pain management, little research has been conducted in this area in the last 20 years. This must change, particularly since the methods currently available to relieve pain have shortcomings.

Lastly, palliative care must become a priority for funding programs such as the Fonds de recherche du Québec–Santé. It is essential that research cover all aspects of palliative care, i.e. the clinical, ethical and social dimensions, as well as focus on the needs of natural caregivers and on ways to support them.

Raising awareness among stakeholders and the general public of the inescapable nature of death and of the palliative care approach

Getting society to accept that death, like birth, is a natural phase of life is no small task. However, only when we succeed in this regard will palliative care become a genuine part of the continuum of care.

The fact is that many physicians and other health professionals have trouble accepting the boundaries of medicine and their own limits. For them, death means failure. Many also don't really understand the philosophy behind palliative care. Although steps are being taken to remedy this situation, there is still much to do, because some doctors are reluctant or slow to refer patients to palliative care, thereby depriving them of proper care.

“ The legislator must encourage palliative care research. [...] However, the research must not be limited to the medical side. [...] There are many questions, for example, concerning the psychological process, the process of dying, the implications both for the patient and the family, support, and appropriate nursing care, etc. ”

Me Danielle Chalifoux, former chair of the Elder Law section of the Canadian Bar Association (Québec Division)
– Excerpt from brief, expert consultation

“ Physicians are there to save people, and death is not an option. For them, it's an admission of failure. ”

Claude Proulx, Intensive Care Unit nurse
at Hôpital Maisonneuve-Rosemont –
Excerpt from the hearing
of September 10, 2010
in Montréal, general consultation

Similarly, the public still does not understand and has misconceptions about palliative medicine. Palliative care units are often perceived as places of death, despite the fact that the type of care they provide seeks to improve the well-being of end-of-life patients and give their families support. Consequently, when a person enters the stage requiring palliative care, “It takes time and patience to explain the palliative philosophy, that contrary to what they believe, it will help them make the most of the time they have left by providing them with comfort, a listening ear and compassionate care”³⁰.

We believe that society is starting to acknowledge death as a natural part of life, but it will take some time before everyone comes around to this way of thinking. We must all come to terms with death in order to be able to discuss everything it entails with our families. What's more, we must put an end to the taboo that talking about death will tempt fate. The communication strategy set out in the Policy to stimulate debate on the meaning and values of life, if applied, is likely to produce positive results in this regard.

RECOMMENDATION N^o 4

The Committee recommends that the Ministère de la Santé et des Services sociaux create an administrative unit devoted to palliative care that would, among other things, ensure swift and full implementation of the *End-of-Life Palliative Care Policy*, more specifically:

- Providing earlier access to palliative care, as soon as required given the patient's clinical course;
- Providing access to palliative care to patients suffering from incurable diseases other than cancer;
- Keeping people suffering from incurable diseases in their home environment;
- Providing access to a private room;
- Sharing clinical information essential to a patient's medical treatment and setting up stable multidisciplinary teams.

³⁰ Excerpt from the brief of Corporation Albatros Inc., general consultation, p. 4.

RECOMMENDATION N° 5

The Committee recommends that the Ministère de la Santé et des Services sociaux send to the appropriate National Assembly committee, for its consideration, a report on the implementation of the *End-of-Life Palliative Care Policy* one year after publication of the report of the Select Committee on Dying with Dignity. The Ministère's report should contain an assessment of palliative care in Québec.

The right to palliative care and the obligation of establishments in the health and social services system to make it accessible

We consider it urgent to develop palliative care across the province and to promote its underlying culture. To do so, everyone must work together: government, establishments in the health and social services network, health professionals, medical schools, nursing schools and even, in some respects, the population at large.

Consequently, although we can deduce that palliative care is included under the general right to care set out in section 5 of the *Act respecting health services and social services*, it should be expressly mentioned in the legislation. Furthermore, the Act must also be amended to require health establishments to organize and provide palliative care, which is currently not the case. These recommendations reflect the position of the Québec Bar on the matter.

RECOMMENDATION N° 6

The Committee recommends that the *Act respecting health services and social services* be amended:

- To recognize the right of any individual to receive palliative care when warranted by his medical condition;
- To ensure that all healthcare establishments providing in-home or in-hospital end-of-life care include palliative care in their service offer.

“ If some Quebecers today are able to die under more humane conditions, it's because citizens from all walks of life, either volunteers or people from different professions and trades, have been working for 30 years to improve palliative care.” ”

Dr. Hubert Marcoux, physician in the Palliative Care Unit of Hôpital Jeffery Hale – Excerpt from the hearing of March 9, 2010 in Québec City, expert consultation

In conclusion, to borrow the words of the Collège des médecins du Québec, “Palliative medicine, where support is just as essential a part of the care as technical interventions, has [...] become the quintessential example of proper care, i.e. both personalized and proportionate”³¹.

PALLIATIVE SEDATION: NECESSARY CARE THAT NEEDS STRUCTURE

Through pain management and proper support, palliative care can usually provide end-of-life patients with some form of physical and psychological relief without altering their state of consciousness. However, the use of some pain medications, such as morphine, can have the side effect of altering the patient's consciousness. This is a common practice encountered by most families of end-of-life persons.

Although rare, there are complex situations where suffering cannot be relieved by traditional medical means. Thus, in the presence of refractory symptoms³² associated with, for example, pain, breathing problems, agitation, or psychological or existential suffering, the patient is sometimes rendered unconscious, in the same manner as a burn victim. Powerful sedatives are used to induce artificial sleep either intermittently or continuously to relieve awareness of suffering. This is known as palliative sedation.

Thanks to the testimonies of experts in the field, we were able to gain insight into this little known practice, which raised many questions among the Committee members, particularly since it seems to be a growing part of end-of-life care.

Continuous palliative sedation: no consensus on this complex practice

We, along with the medical community, believe that certain aspects of continuous palliative sedation raise very important ethical issues. In fact, the practice of palliative sedation raises serious concerns within the medical profession, above all continuous sedation, where the person is sedated until he dies. Given its possible association with euthanasia, we studied this matter at length.

³¹ See note 1, p. 4.

³² A refractory symptom is “one the patient finds unbearable and which cannot be controlled in a manner that is satisfactory to the patient, despite proper palliative care that thus far has not compromised the patient's ability to communicate with others.” Definition cited by Dr. Yvon Beauchamp in his brief presented during the expert consultation, p.10.

“ It is not the temporary forms of sedation that are raising ethical questions and creating confusion with euthanasia, but rather the prolonged forms of sedation used over several days.” ”

Maison Michel-Sarrazin – Excerpt from brief, general consultation

Patient consent

Just as for any other care, palliative sedation cannot be administered without the informed consent of the patient, or of his representative or a family member if the patient is incapacitated. Palliative care physicians try, inasmuch as they can, to anticipate critical situations that may require tough decisions, such as the administration of palliative sedation. They will therefore usually initiate a conversation early on with the patient and his family on such matters as whether to stop or continue artificial administration of food and water.

However, some witnesses told us that some doctors prefer to talk to the family, even when the patient has decision-making capacity, rather than obtain consent directly from the patient. This is unacceptable, especially when something as important as palliative sedation is involved. While we understand that it may be difficult to converse with a person whose alertness or wakefulness is compromised by his disease or heavy medication, the final decision of whether to resort to palliative sedation must be his to make. This is consistent with the precept of respect for patient autonomy.

Altered consciousness

As we have seen, palliative sedation suppresses the patient's consciousness. In the case of continuous sedation, it means that death will occur while the patient is unconscious. Deprived of his interpersonal skills and autonomy, it also means the patient will be totally dependent on others. Some witnesses told us they would never accept to die this way. Others wondered what people experience during sedation. Although they appear to be calm, no one knows for sure what they are feeling inside. We can only assume they are not suffering.

The duration of continuous palliative sedation

The duration of continuous palliative sedation is unpredictable, although research shows that average survival varies from one to six days, with a median of four days. However, it can be as long as two or even three weeks. It is easy to understand how such a situation would be unbearable for the family and stressful for the healthcare teams. In fact, some patients refuse such sedation to avoid inflicting this burden on their loved ones.

“ So, what happens when you administer terminal sedation? Basically, the patient is emptied, erased; he is unconscious, and the family continues to suffer, but the patient's no longer there. ”

Dr. Marcel Boisvert, former palliative care physician at Royal Victoria Hospital –
Excerpt from the hearing of November 25, 2010 in Sherbrooke, general consultation



“ While ethically and legally acceptable, terminal sedation becomes unbearable for families and healthcare teams when the agony [...] extends unduly, sometimes more than 15 days. ”

Dr. Yvon Beauchamp, Chief of Palliative Care, Hôpital du Sacré-Coeur
– Excerpt from brief, expert consultation

Relieving refractory psychological suffering

Physical pain typically goes hand in hand with psychological distress. However, some patients whose physical pain is controlled experience refractory psychological suffering. The medical profession is divided on the use of palliative sedation, particularly continuous sedation, in such situations.

Some doctors and palliative care settings will offer a patient intermittent but not continuous palliative sedation. Other doctors believe that any refractory symptom must be relieved, regardless of the type, and therefore continuous palliative sedation is justified when it is the only way to ease psychological suffering that cannot be alleviated.

We have to agree with this position. In fact, refusing continuous palliative sedation under such circumstances runs counter to the palliative care approach, which recognizes the importance of providing patients with whatever support they need to ease their suffering, be it physical or psychological.

Withdrawal of food and water

The practice of palliative sedation becomes especially controversial when it involves stopping artificial nutrition and hydration. For some, the combination of these two acts poses a major ethical dilemma.

According to some physicians, this is a non-issue, because for the most part, patients whose death is imminent stop eating and drink very little. Furthermore, sedated patients derive no benefit from artificial hydration, which could even result in uncomfortable fluid buildup. This camp therefore finds continuous sedation without food and water acceptable.

The other camp sees continuous sedation coupled with removal of food and water as a way of hastening death. In their view, it is difficult to argue that death is not intentional when the patient is sedated to the point of unconsciousness and fluids and nutrition are withdrawn, thus making death a certainty.

Is this practice similar to that of euthanasia?

For some physicians, continuous palliative sedation is very different from euthanasia. For others, it is simply euthanasia in disguise.

As such, some witnesses told us that palliative sedation does not shorten the life of patients in the terminal phase if the dosage is just enough to render them to a level of unconsciousness to make them comfortable. Death is then caused by the illness, which continues its natural course. As for the potential

complications of continuous sedation and the effect on life expectancy, especially in cases where a large dose is necessary, these same witnesses invoked the principle of double effect³³: the intent is to alleviate suffering and not hasten death; even though this is a potential bad effect, the goal is to achieve a good effect. In their view, what distinguishes sedation from euthanasia is the intent.

We also heard from participants who were more vocal about the lethal risk of palliative sedation, especially when continuous sedation becomes necessary. The Collège des médecins du Québec maintains that it is not the only one that sees “a very thin line between the intention to irreversibly sedate and to shorten life”³⁴. Some witnesses find it hypocritical to claim that the sole intention is to ease suffering when you already know the only possible outcome is death.

Palliative sedation: a practice that needs structure

Relieving pain and extreme suffering, particularly through continuous palliative sedation, raises highly complex questions. In fact, we are surprised that such a practice has no formal structure.

That said, some settings do have strict protocols governing palliative sedation. For example, Maison Michel-Sarrazin and some palliative care units in hospitals such as Hôpital du Sacré Coeur de Montréal and the Jewish General Hospital have adopted guidelines in this regard³⁵. However, since this is not the case across the board, there is a risk that the wrong drugs will be used or that the treatment will not be offered when indicated and desired by the patient. Like many of the witnesses, we find this situation worrisome.



“ Physicians [...] are still confused about the line between sedation and euthanasia, and even about intent [...]. The fact is that when terminal sedation is used, no doctor wants to see it go on for too long; in other words, we want it to be short, which is tantamount to hoping for death. Hoping for death without wanting to cause it but taking action that could hasten it blurs these ethical boundaries beyond recognition. ”

Dr. Marcel Boisvert, former palliative care physician at Royal Victoria Hospital
– Excerpt from brief, general consultation

³³ According to the Société française d'accompagnement et de soins palliatifs, this principle is as follows: “an act that has both a good effect and a bad effect can be performed only if the good effect outweighs the bad effect and if all of the following conditions are met: the act to be done must be good in itself or morally neutral, or at the very least it must not be prohibited; the bad effect must not be a means of achieving the good effect but must be simultaneous or a result thereof; the expected bad effect must not be intentional or approved, but simply permitted; the positive effect sought must be proportional to the undesirable effect and must not be achievable by any other means”. [<http://www.sfap.org/pdf/III-O6a-pdf.pdf>]

³⁴ Excerpt from the hearing of the Collège des médecins du Québec, expert consultation, Québec City, February 15, 2010.

³⁵ The guidelines used by palliative care settings in Québec are inspired by frameworks published by associations in the field. For instance, Maison Michel-Sarrazin applies the framework of the European Association for Palliative Care, which addresses choice of medication, dosage and method of administration.

We therefore subscribe to the idea of setting strict protocols for the practice of palliative sedation, as some palliative care settings have done. We believe the Collège des médecins du Québec should develop a practice guide and ethical standards on palliative sedation so that it is rigorously structured wherever it is used.

RECOMMENDATION N° 7

The Committee recommends that the Collège des médecins du Québec develop a practice and ethical standards guide for palliative sedation.

PLANNING END-OF-LIFE CARE IN CASE OF INCAPACITY: THE CHALLENGES

As we have seen, a person may agree or refuse to receive care or decide to stop treatment to which he had previously consented if he is capable of doing so. In case of incapacity, other than tutorship and curatorship, the law decides who will be called to make such decisions, i.e. the person named in a “mandate of incapacity”³⁶ or one of the incapacitated person’s close relations³⁷. In both cases, the incapacitated person may have expressed his wishes for care prior to becoming incapacitated. For example, he may have expressed the wish to receive all possible treatment, even if the odds of recovery are slim, or have stated that he does not want to be connected to an artificial respirator or resuscitated in the event of complications during a surgical procedure. These are known as “advance medical directives”.

The issue of respecting wishes expressed prior to incapacity was discussed several times during the hearings and is apparently a source of concern for many. Two facts emerged from the testimonies: first, the current legal framework is inadequate to ensure a person’s wishes will be respected, and second, not enough people plan for their end-of-life care.

“ When it is administered until death, continuous sedation poses ethical problems, mainly because it could be confused with euthanasia without bearing the name. This practice, without structure, worries many palliative care practitioners, many of whom are calling for standards to be developed to ensure this option is used appropriately. ”

³⁶ Article 2166 and following of the *Civil Code of Québec*.

³⁷ This may be the spouse or a close relative or an individual who demonstrates a special interest in the person (article 15 of the *Civil Code of Québec*).

Recognize advance medical directives and make sure they are known

Advance medical directives are an essential tool; they could reassure people that their wishes will be respected in case of incapacity and that their families will not be saddled with the burden of making decisions on their behalf. Some witnesses said directives also prevent agonizing dilemmas and conflicts within the incapacitated person's family. Knowing a person's wishes makes it easier for his family and healthcare team to accept treatment decisions, i.e. what to give, what not to give, and when to stop. Lastly, directives could also prevent therapeutic obstinacy. Unfortunately, according to many witnesses, families and health practitioners do not always respect advance medical directives. Indeed, a number of physicians made it clear to us that they do not feel bound by the advance wishes expressed by their patients and only view them as a guideline.

While the *Civil Code of Québec* does not expressly provide for advance medical directives, article 12 stipulates that "A person who gives his consent to or refuses care for another person is bound to act in the sole interest of that person, taking into account, as far as possible, any wishes the latter may have expressed". Therefore, no provision recognizes these directives as legally binding, and the patient's family or medical team are not required to comply. This is a big problem. Like many of the participants, we believe legislative changes are needed to ensure people's wishes are respected.

Because no clear legal framework exists, there is no provision to circumscribe the form these directives can take or their content. Directives can be either verbal or in writing. Although some people include advance directives when drawing up a mandate of incapacity, they are still not legally binding. Some CHSLDs ask new admissions whether they would like to sign a Do Not Resuscitate form and a level of medical intervention form³⁸. A number of organizations offer the public generic advance directive forms that can be general in nature, detailed or based on a set of values where the person describes, for instance, what in his opinion constitutes no quality of life and a dignified death³⁹.

³⁸ Some institutions, such as the Centre de santé et de services sociaux de Saint-Jérôme, even have a follow-up protocol.

³⁹ See, for example, the simple form proposed by the Association québécoise pour le droit de mourir dans la dignité [http://www.aqdm.qc.ca/attachments/File/Formulaires_Directives_de_fin_de_vie_et_mandat.pdf], the detailed 12-page form offered by the Jewish General Hospital [http://www.jgh.ca/uploads/PatientVisitor/directives_anticipees.pdf] and the values-based form proposed by Norman L. Cantor, *Advance Directives and the Pursuit of Death with Dignity*, Bloomington and Indianapolis, Indiana University Press, 1993.

“ We very much doubt wishes are being respected. It seems the family and the doctor have a greater say, even if the wishes are in writing. As seniors, we would like the assurance that our biological wills will be placed in our medical charts, ensuring easy access and reference for medical staff and families. ”

Association québécoise de défense des droits des personnes retraitées et préretraitées-Laval – Excerpt from brief, general consultation

“ If, as a result of your work, end-of-life wishes end up having legal weight, it would give end of life patients tremendous peace of mind. ”

Association pour le droit de mourir dans la dignité-Mauricie – Excerpt from the hearing on September 24, 2010 in Trois-Rivières, general consultation



This lack of framework, as we learned during the hearings, is problematic. First, it is harder to prove the existence of directives that were only given verbally. Moreover, even if they are in writing, the family or medical team are not always aware of their existence or where the document is kept. The validity of the document may also be questioned, because it does not attest that the directives are free and informed. Lastly, the directives are often vague, incomplete, and may contain too many or too few details. This lack of clarity can make them difficult to interpret, creating disagreement between the physician and family as to their true meaning. If the directives are too broad, the wishes of the person may not be respected, and if they are too explicit, they may not cover the situation at hand.

Some participants brought up the issue of updating advance medical directives. Since directives are typically drafted when a person is still healthy, it can be difficult to ensure they are interpreted in a manner that truly reflects the wishes of the incapacitated person in his current situation. Apparently, it is easier for patients to draft their directives when they have a disease with a predictable course.

Accordingly, to facilitate accessibility, we propose that a mandatory but simple form be developed and used, although a notarized instrument is ideal, since its value cannot be questioned. One section of the form could be reserved for clarifications that the person would like to add. This form should be signed in the presence of a witness attesting that the directives are free and informed. The person would also have the option of naming one or more trusted individuals who would be responsible for making sure the attending physician is aware of the directives. A notice should be sent out periodically to remind the public to update or revoke their directives, for instance, along with the health insurance card renewals. Advance medical directives given verbally or in writing in a document other than the prescribed form would retain their guideline value, as is the case right now.

RECOMMENDATION N^o 8

The Committee recommends that relevant legislation be amended to recognize advance medical directives and that they:

- Be legally binding;
- Take the form of a notarized act or mandatory form signed before a witness;
- Be permitted to mention the name of one or more trusted persons who would ensure the advance medical directives are known and applied.

Lastly, we recommend various measures, some of which are similar to those used for organ donation, to ensure that advance medical directives are known by health professionals. First, the directives should be recorded in a national register, such as the Québec Health Record, once it is implemented. A sticker mentioning the existence of advance medical directives should be affixed on the back of the health insurance card. When a person is admitted to a health facility, the health professionals should ask him or his family whether such directives exist. If so, they should be recorded in the patient's medical file.

RECOMMENDATION N^o 9

The Committee recommends that the Ministère de la Santé et des Services sociaux :

- Take the necessary measures to ensure advance medical directives appear in patients' medical files and are recorded in a register;
- Ensure that physicians check for the existence of such directives.

RECOMMENDATION N^o 10

The Committee recommends that the Ministère de la Santé et des Services sociaux put in place a mechanism encouraging citizens to periodically update their advance medical directives.

We strongly encourage anyone who wishes to draw up advance medical directives to discuss the matter with their family to facilitate application. We firmly believe that drafting such directives, especially with the help of one's family and physician, can ease the passage to death. This process helps people think about the end of their lives and encourages dialogue between the patient and his doctor, as well as with his family.

Educate the public on end-of-life planning

Not enough people know about end-of-life care planning tools such as the mandate of incapacity and advance medical directives. The public should be made aware of the importance of letting their doctors and families know about their wishes in case of incapacity. This of course means contemplating one's death—something not everyone is prepared to do. However, we invite society to lift the taboo on death, which has made the final days of some people even more difficult. In this regard, we believe the government should put in place methods of communication to educate the public on end-of-life planning and to make health professionals aware of the importance of complying with the tools provided by law.

RECOMMENDATION N^o 11

The Committee recommends that methods of communication on end-of-life care planning be developed to educate the public and those working in health and social services on end-of-life issues.

We were impressed with the suggestion made by the Regroupement provincial des comités des usagers to create an information guide for people diagnosed with an incurable disease. Handed out by healthcare staff, this guide would inform people of their healthcare rights (e.g. the option to refuse or stop treatment, to draw up a mandate of incapacity or advance medical directives) along with the services (e.g. palliative care) and support

systems (e.g. social workers, psychologists) available. Besides the intrinsic value of this guide, we think it would provide the healthcare staff handing it out with an opening to discuss sensitive end-of-life issues with their patients.

RECOMMENDATION N° 12

The Committee recommends that persons diagnosed with an incurable disease be given an information guide on their rights and the available services and resources.

PART 2

One more option for end of life

Although end-of-life care was discussed at length during the consultation, the issue of euthanasia and assisted suicide clearly took centre stage. Many citizens and organizations shared their points of view on the topic, and our exchanges with them were especially rewarding. The positions were often polarized between those who are open to these practices and those who oppose them. The fact is that euthanasia and assisted suicide go to the very core of our values, which naturally can vary from one person to the next, because these issues are rooted in human nature. We were impressed with the respectful and dignified manner with which the witnesses conducted themselves, a clear indication that Québec society was ready for this debate

We found it interesting that although we had asked the public, by way of the consultation document, to reflect on both euthanasia and assisted suicide, the testimonies and discussions dealt almost exclusively with euthanasia. Of course, the arguments advanced to promote either position can apply equally to euthanasia and assisted suicide. However, those who came out in favour of openness in this regard asked that euthanasia be permitted⁴⁰. Consequently, although we also reflected on assisted suicide, we focused more on euthanasia.

After many months of discussions and reflection, culminating a process that lasted more than two years, we are ready to present to Québec society a proposal that takes into account all the arguments heard as well as changes in social values, medicine and the law.

⁴⁰ People who turn to the courts on this matter do so for assisted suicide, because its legal basis is easier to invoke.

“ Personal autonomy, legally enshrined by the principle of self-determination and its corollary rule in biomedical ethics, free and informed consent, is never questioned at any time in our lives, not even in the most vulnerable or emergency situations, so why would it be different at the end of life? Why would a terminal patient at the end of his life not be entitled to self-determination? ”

Luc Thériault, former MNA – Excerpt from the hearing of February 15, 2011 in Saint-Jérôme, general consultation

THREE MAJOR CHANGES: SOCIAL VALUES, MEDICINE AND THE LAW

Changes in social values

Societies and their values are constantly evolving. Many practices that are widely accepted today were not a given that long ago. Some examples: birth control dates back to the 1960s; suicide was decriminalized in 1972; the abortion clauses in the *Criminal Code* were declared unconstitutional in 1988; the refusal and withdrawal of treatment were sanctioned with the reform of the *Civil Code* in 1994, and same-sex marriage was recognized in 2005.

First, the decline of religious practice in recent decades and the changing morals of society, increasingly centred on the development of individual freedoms and respect for personal autonomy, have changed the way we view end of life and death. In the past, society was more homogeneous and subject to various authorities. Death had a different meaning then, mainly because of religious references. But the expiatory suffering of yesteryear has lost its meaning, resulting in the unwillingness to tolerate prolonged suffering. Personal autonomy, inviolability and integrity, along with pluralistic values, have become the cornerstones of society. In view of this, we believe a person can choose to conduct his life according to his own personal values and beliefs.

Second, the value of the sanctity of life has changed considerably. No longer entrenched in religion, respect for life now means acknowledging that it is precious and that we can realize our full potential and find meaning throughout our lives, including in our last moments. We have a profound respect for human life, but that does not prevent other values from putting life's importance in perspective under certain circumstances. For example, it would be unacceptable to want to prolong life at all costs, because therapeutic obstinacy can become untenable for the end of life person. In fact, during the hearings, we found strong consensus, including among those opposed to an openness to euthanasia, for offering people the option to refuse or stop treatment, even if doing so means death.

As well, for a number of years now, polls have shown that 70% to 80% of Quebecers support euthanasia and assisted suicide. As members of the National Assembly, we travel through our ridings and across Québec, and in so doing have found that many people are especially interested in

the Committee's work, and that the opinion of most of those we meet is consistent with the results of the polls. We have also found that many organizations⁴¹ active in our society agree with the position of the Collège des médecins du Québec.

The support of these organizations and the poll results demonstrate that our values are changing and reflect what society considers legitimate. Still, the value of the polls has been questioned more than once, with some arguing that the results could be biased due to a poor understanding of the terms and the important differences in their meanings ("euthanasia" and "cessation of treatment", for example). Be that as it may, the results are consistent, regardless of the polling firm and questions asked.

The conclusions of our online consultation are also consistent with the polls, showing clear support for euthanasia and assisted suicide under exceptional circumstances. While this consultation was not scientifically conducted, the questionnaire contained very specific questions and included scenarios. We can therefore assume that the public understands the key issues and the questions asked by the pollsters.

However, we would like to stress that policymakers must also keep in mind the need to protect society's most vulnerable as well as the common good when reflecting on this matter. Major issues are at stake, and they must be examined with the utmost care before drawing a conclusion, particularly the issues of absolute respect for life, the risk of misuse and abuse, the trivialization of the fight against suicide, and the insufficient attention paid to palliative care.

Medical progress

During the twentieth century, medical and pharmacological discoveries led to remarkable advances that have resulted in better health outcomes and greater life expectancy. Thanks to these advances, we can now control end-of-life suffering fairly well, especially when people have access to quality palliative care. However, modern medicine sometimes turns the dying into chronically ill patients. People are sometimes kept alive beyond what most would consider reasonable. Indeed, for some, the medicalization of death means a quality of life that leaves much to be desired. The agony and

⁴¹ The main organizations are the Fédération des médecins omnipraticiens du Québec, the Fédération des médecins spécialistes du Québec, the Conseil pour la protection des malades, the Regroupement provincial des comités des usagers, the Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec, the nurses of NOVA Montréal, the Québec Bar, the Chambre des notaires du Québec, the Association féminine d'éducation et d'action sociale, the Association québécoise des directeurs et directrices d'établissements d'enseignement retraités and the Ordre des médecins vétérinaires du Québec.

“ A new sensitivity is clearly perceivable within the population and the medical profession acknowledging that there are exceptional situations where patients or their families, physicians and healthcare staff could consider euthanasia as a final step, required to ensure quality palliative care right to the end. In our view, this sensitivity is not necessarily inconsistent with the spirit of the *Code of Ethics of Québec Physicians*, particularly with section 58, as well as with the provisions of the *Civil Code* concerning care; in fact, quite the opposite.” ”

Collège des médecins du Québec
– Excerpt from brief,
expert consultation

unbearable suffering sometimes drag on inhumanely, because doctors are unable to completely relieve the pain, even in the best palliative care units. Under such circumstances, some patients feel they have lost their dignity and ask their doctor for help to die.

As the Collège des médecins du Québec aptly pointed out, the days of a natural death are in the past. Today, that final moment is increasingly subject to human decisions. As well, for the medical community, end-of-life care falls into the realm of ethics and professional conduct.

In fact, concurrently with scientific advances, medical ethics and rules of professional conduct have also made great strides. A new way of thinking is gradually emerging: physicians are acknowledging that in some cases, they will have to decide when to shift from curative to palliative care. Continuing treatment deemed futile, in other words, therapeutic obstinacy, is less and less accepted. Put another way, medical paternalism has gradually given way to recognition of a person’s autonomy and right to decide, once well informed, on the type and extent of treatment he will receive. This of course does not mean the physician’s role is reduced to simply carrying out the patient’s wishes. On the contrary, there is no one better placed to inform patients on their health status and to suggest curative or palliative options. Consequently, new practices have emerged on the continuum of appropriate end-of-life care, for example, palliative care, refusal and cessation of treatment, withholding food and water, and intermittent or continuous palliative sedation until death.

The palliative approach plays a key role in this continuum of care and is increasingly gaining recognition. By supporting patients until death and taking into account, to the extent possible, their wishes and needs as well as those of their loved ones, the palliative approach gives medicine a new face, one that respects personal autonomy and the limits of curative medicine.

Furthermore, we find that a growing number of physicians believe it is their responsibility to comply with a request for help to die. For them, when the end of life becomes intolerable, medicine must intervene out of compassion, in a spirit of human solidarity and respect for the patient’s freedom of choice. Many believe that if medicine can act when a person is born, it should also do its part to help with death when justified by the circumstances. A large majority of physicians seems to share this opinion, as evidenced by the results of member polls conducted by the Fédération des médecins omnipraticiens du Québec (FMOQ) and the Fédération des médecins spécialistes du Québec (FMSQ) towards the end of 2009. According to

the FMOQ⁴² poll, 75% of physicians would like to see “new regulatory and legislative guidelines allowing recourse to euthanasia”, while the FMSQ⁴³ poll concluded that 75% of physicians are in favour of “legalizing euthanasia within a clearly defined legislative framework”.

We are therefore seeing a change in the mentality of the medical profession in Québec. The Collège des médecins itself has suggested that euthanasia could today be viewed as consistent with the spirit of the *Code of Ethics of Physicians* and constitute, under exceptional circumstances, the final step in the appropriate end-of-life continuum of care.

The evolution of the law

In recent decades, the law has adapted to changing social values and in response to the public’s reaction to landmark legal cases, such as the Nancy B case, which drew huge media attention in 1992. Suffering from a degenerative disease with no hope for a cure, this young woman asked to be removed from the respirator that was keeping her alive. A Québec Superior Court judge granted her request. In 1994, the reform of the *Civil Code of Québec* clearly enshrined the need to obtain free and informed consent from a patient before initiating any treatment and the right to refuse or stop treatment, even if it is keeping the patient alive. It also enshrined the principles of autonomy, inviolability and integrity of the individual. The primacy given to maintaining life at all costs became a thing of the past.

In the early 1990s as well, an important decision was handed down by the Supreme Court of Canada. A woman by the name of Sue Rodriguez had developed an incurable, degenerative disease that prevented her from ending her life herself. Rodriguez made a public request for assisted suicide, but it was rejected in 1993 by the Supreme Court in a close five-to-four decision. Maintaining that the sanctity of life takes precedence over individual autonomy, this decision nonetheless showed the willingness of the four dissenting judges to recognize new values within Canadian society. It also reduced the traditional place occupied by criminal law in the matter. Incidentally, two cases similar to the Rodriguez case are currently before the courts, one in Québec⁴⁴ and another in British Columbia⁴⁵. Some observers believe that both could end up before the Supreme Court of Canada.

⁴² See note 2, p. 11.

⁴³ See note 3, p. 11.

⁴⁴ The case of Ginette Leblanc, a resident of Trois-Rivières, suffering from Lou Gehrig’s disease.

⁴⁵ A class action suit brought by Gloria Taylor, a resident of West Kelowna, suffering from Lou Gehrig’s disease, two people who helped their aging mother get to Switzerland for assisted suicide, a physician from Victoria claiming the right to help his seriously and incurably ill patients to end their lives, and the British Columbia Civil Liberties Association.

“ The current rules of criminal law, developed in another time, are ill-suited to the complex end of life problems, to the point that they are either inapplicable or difficult to apply sufficiently to fulfill their protective function. ”

Québec Bar – Excerpt from brief, general consultation

Moreover, we note that charges are rarely laid in these cases, and if they are, the court finds in favour of the accused or hands down a light or symbolic sentence compared with the maximum prescribed for criminal offences. Juries appear especially receptive to the motive of compassion invoked by some of those accused of helping their loved ones end their lives. As Professor Jocelyn Downie pointed out in her testimony, there is a wide divergence between the “law in the books” and the “law on the street”⁴⁶.

Specifically regarding physicians, the Québec Bar stated in its brief that nowhere in Québec or elsewhere in Canada has a jury ever convicted a physician for having administered medication that caused death in an end-of-life situation, and that charges are rarely ever brought in such cases. In fact, the Bar knows of none in Québec⁴⁷. In its view, criminal law is out of sync with today’s reality.

In our reflection on end-of-life care, we considered the changes in social values, medicine and the law. But that is not all we looked at. During these last two years of dialogue with the public and stakeholders, we heard many relevant arguments both for and against openness to aid in dying, and these were carefully weighed as well.

THE ARGUMENTS THAT FUELLED OUR REFLECTION

The expert hearings gave us insight into the main issues surrounding euthanasia, as well as the arguments put forth by those who advocate an openness to this practice and those who are against it. This insight was deepened by the general consultation. During the public hearings, we tried to play “devil’s advocate” by advancing opposing arguments to the position taken by the witnesses. We also consulted the main works or studies on the issue. By proceeding in this manner, we were able to gather all the information we needed to fuel the reflection that would lead to this report.

⁴⁶ Professor Downie: Hearing of March 8, 2010, videoconference.

⁴⁷ For a comprehensive review of the matter, we recommend reading the brief of the Québec Bar, general consultation.

We took our work sessions very seriously, knowing that it was our responsibility to accurately report on what Quebecers told us in their briefs and letters, during the hearings and in the online consultation. Besides the cold mathematical reality of the polls and computation of the number of people for or against euthanasia who expressed their views during the consultation, we tried, as elected representatives of the people, to weigh the value of the arguments in light of changing social values, medicine and the law, as well as our perception of the common good. However, we could not find literature to validate certain powerful but contradictory arguments on the experiences of European countries where euthanasia is legal. For this reason, we decided to go to Europe to see for ourselves. This mission was a very important step in the reflection process. We spared no effort to make sure that each argument raised during the consultation, for or against euthanasia, was considered.

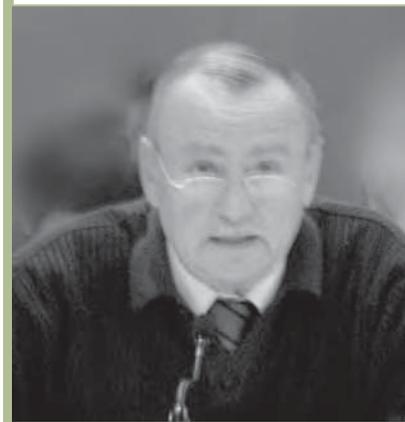
Is palliative care the answer to all difficult end-of-life cases?

We firmly believe that palliative care is the best answer to the suffering of most end-of-life patients. However, we also recognize it has its limitations.

Some participants believe palliative care can ease the physical or psychological suffering of all end-of-life patients. Therefore, the only reason someone would ask for help to die is because the health system cannot meet his needs. According to them, these requests are in fact calls for help, and no one, when properly cared for and supported, wants help to die. Proper palliative care would make these types of requests vanish. Consequently, the only solution is to improve access to and the quality of end-of-life care.

We agree with this statement to a point: universal access to palliative care would certainly reduce the number of requests for help to die, but we are convinced it would not eliminate them all. Like some participants, including the Collège des médecins, we believe that palliative care, no matter how good it may be, cannot alleviate all the suffering of end-of-life persons.

First, some pain is extremely difficult to alleviate and, in rare cases, impossible to completely control, at least not by keeping the person conscious. While palliative sedation is an option, it does not suit everyone. Some people prefer to remain alert until the end, even if it means terrible pain, so they can be with their loved ones. Others have trouble with the idea that the only option available to ease their pain is to induce an indefinite coma. Still others cannot fathom subjecting their families to the pain of sitting by their bedside while they lie unconscious, waiting for death for days or weeks.



“ ...when they ask for it, it’s because their symptoms are not well controlled. Make the pain go away, relieve the pain..., the suffering, address their sense of loss of dignity, because they will respond to the loving care of their family and loved ones, and requests for euthanasia will go away. ”

Dr. Patrick Vinay, Vice-Chair of the Board of Directors of *Vivre dans la dignité* – Excerpt from the hearing of September 7, 2010 in Montréal, general consultation

“ However, despite all the arguments in favour of palliative care, there are still exceptional cases where patients, even if they are not suffering physically and are getting good support from a palliative care team, will knowingly ask for euthanasia. ”

Dr. Gaétan Bégin, palliative care physician for 20 years – Excerpt from the hearing of September 24, 2010 in Trois-Rivières, general consultation

Then there are the physical symptoms of some diseases that are hard to control and even to describe: uncontrollable vomiting, terminal agitation, delirium and hallucinations, death rattle caused by the inability to cough and fecal vomiting due to intestinal obstruction.

The medication required to ease the pain can sometimes have undesirable side effects that can only be controlled with other medication. This pharmacological spiral can therefore keep patients from the death they would have wanted. Lastly, palliative care offers little relief to patients with degenerative diseases, who can be prone to all kinds of suffering such as a choking sensation and the fear of choking to death.

Physical pain at the end of life is often accompanied by psychological suffering that can be even more intense. Worse yet, the psychological pain can outlast the physical pain because, “Once the pain is controlled, that’s when you see the immense, senseless suffering emerge”⁴⁸. The stories we heard from families about the agony of a loved one shook us to the core, as did the accounts of people suffering from a degenerative disease, who shared with us the anxiety they were feeling about their inevitable decline.

Because of its intensity and complexity, this suffering is difficult, if not impossible, to fully relieve. It can be brought about by the decline that comes with disease, for example, incontinence and physical deformity. Some gradually lose their autonomy and ability to control their body, making them dependent on others for assistance with their most basic bodily functions. They can develop a sense of social uselessness and of being a burden on their families. Lastly, there is existential suffering, the kind that taints the reality of one’s final days, when a person no longer finds any meaning in the time he has left, or simply cannot accept that he is going to die, or when death can’t come soon enough, and those last hours spent waiting are unbearable. Psychologists, psychiatrists, social workers and volunteers can help ease this suffering; antidepressants and tranquilizers can occasionally provide some relief. However, this becomes much more of a challenge when physical and psychological suffering become intertwined in a tangle that is difficult to unravel. As a last resort, physicians will suggest palliative sedation, but as we have already explained, this is not always the right answer.

⁴⁸ Excerpt from brief of Hubert Doucet, expert consultation, p. 18.

“ Pain. Suffering feels very much like shivering. Your body curls up, your entire body contracts, from the top of your head to the tips of your toes. And it hurts! It hurts all the time. This shivering uses up all your strength, takes all your attention, and it’s exhausting [...]. Morphine eases your pain; it’s like a wave of heat that takes away the shivering and makes you incredibly relaxed [...] but if you open your eyes, you’re dizzy, everything moves, you become nauseous and sometimes throw up. Another nasty side effect you don’t often hear about at conferences and symposiums: constipation, which makes you bloated, tears your rectum [...]. Then there’s habituation, meaning they have to keep increasing the dose, and you start to hallucinate, get confused, incoherent. ”

Julie Bélanger, reading a letter written by her aunt, Claire Morissette, who died from cancer in 2007 - Excerpt from the hearing of September 8, 2010 in Montréal, general consultation

“ During this time, your body starts to shut down. You don’t eat, can’t move, you start to fade away. When you look in the mirror, all you see is a bag of bones; you look like a Holocaust survivor [...] Your skin starts to shrivel and lies in folds. It’s an absolute disgrace. What’s worse, because of the medication, your urine, bowel movements, flatulence, breath and vomit smell like death, which your caregivers have to deal with. Talk about humiliation! When you use a bedpan, the stench defies description, and someone else has to wipe your bottom. Can anything be more humiliating? ”

Julie Bélanger, continuing to read her aunt’s letter, Excerpt from the hearing of September 8, 2010 in Montréal, general consultation



“ Throughout her illness, my mother kept repeating how afraid she was of a slow death, of dragging it out, as she put it. I think her biggest fear wasn't the pain or death. She was a very proud woman, and she was afraid to die thin and ugly. She wanted to be beautiful when she died. Watching helplessly as you lose your independence, waste away and in the end lose your dignity can be more unbearable than physical pain. ”

Marie-Josée Gobeil, about the death of her mother from pancreatic cancer – Excerpt from the hearing of October 22, 2010 in Saguenay, general consultation

“ Yes, just like my colleagues, I've seen and heard of people who were full of hope; my brother Claude fought death for years and never gave up. He didn't want to die, and good for him, he was a tremendous inspiration. But sometimes people decide they've had enough. And who are we to decide for them? ”

Me Paul Brunet, Chair of the Conseil pour la protection des malades – Excerpt from the hearing of September 28, 2010 in Québec City, general consultation

Some participants emphasized that death without agony is the exception and that suffering is part of life. In their view, trying to eliminate it is unrealistic. Also, dealing with suffering and the ordeal of death is a lesson in courage that will benefit all those close to the dying person. That said, it is human nature to want to limit suffering as much as possible. After all, isn't that the purpose of medicine? We heard stories about people whose courage in the face of illness and death was admirable. However, there are many different reasons why people do not want to put up with what they consider needless suffering imposed by their illness, given that death is inescapable.

Lastly, as we have seen, palliative care is not for everyone. Some people clearly told us as much during the hearings. Of course, it is a choice, and no one has to buy into its underlying philosophy, even if we believe that the vast majority of sick end of life persons want such care.

To recap, for various reasons, palliative care is not the right answer for everyone. Unrelieved suffering is the main reason patients want help to speed up their deaths. And although opinions vary considerably as to the frequency of such requests, a few physicians and nurses⁴⁹ told us they do get them, even though the patients know their wishes cannot be honoured in the current context.

The experiences of the Netherlands and Belgium confirm our findings. These two countries offer their citizens some of the best palliative care in the world, yet a small number still asks for euthanasia. This practice accounts for just 0.7% to 2% of deaths in these countries. What we have learned is that even people with excellent family and medical support will still want to die if they are in constant, unbearable pain.

Why legislate for a small number of people?

Many witnesses questioned the desirability of legislating for such a small number of people. In their view, the government should avoid adopting laws for exceptional cases. However, as others rightly pointed out, history is filled with examples of legislation designed to protect the rights of a minority, for instance, recognition of same-sex marriage, the rights of people with disabilities and, more generally, charters of rights and freedoms.

⁴⁹ It seems, moreover, that most of the requests for aid in dying are made to nurses, attendants and volunteers, who because of the nature of their work spend the most time with patients.

“ ... not everyone experiences death in the same way. Medication doesn't work for everyone, and for these people the only choice left is when and how to die. ”

NOVA Montréal, formerly VON, the Victorian Order of Nurses, who provide in-home palliative care – *Excerpt from the hearing of October 12, 2010 in Montréal, general consultation*

“ Some opponents advance that aid in dying only concerns a small minority of end-of-life persons. That's true. [...] But what legal or moral principle justifies overlooking the rights of this minority in a free and democratic society? ”

Dr. Jana Havrankova – *Excerpt from brief, expert consultation*

“ Humbly speaking, many of my colleagues and I don’t think we can relieve the physical and psychological suffering of every single patient we see. [...] We have all experienced extreme situations where we would have liked to practice euthanasia, and maybe even did. Do we need to legislate for this? ”

Dr. Yvon Beauchamp, Chief of the Palliative Care Department of Hôpital du Sacré-Coeur – Excerpt from *brief, expert consultation*

Some physicians urged us not to intervene in this matter. They consider it unnecessary to legislate for so few people and feel they can find an acceptable solution for end-of-life patients with the means currently at their disposal. In their opinion, even if the outcome sometimes verges on the illegal, it is a matter between doctor and patient. Other participants recommended we keep the *status quo* and let case law gradually affirm the right to euthanasia.

However, we cannot leave the fate of end-of-life patients to chance, where one doctor may be willing to provide medical aid in dying while another is not. We also cannot have physicians fearing prosecution for having helped a patient to die. Lastly, it is the responsibility of elected officials and not the courts to find answers to these questions.

Are end-of-life patients able to make an informed request for help to die?

The ability of end-of-life patients to make an informed request for help to die was questioned during the consultation. The depression that sometimes accompanies an illness, isolation and lack of family support play a big role in requests for help to die. Because a request for help to die may actually be a call for help, it is important for medical practitioners to know how to identify signs of distress. That said, we must be careful not to confuse depression, in itself a disease, with the sadness and discouragement that usually goes hand in hand with a prognosis of imminent death. The fact is that no one raises the possibility of inability when a patient refuses or wants to stop treatment, or for cases of palliative sedation. If the end-of-life patient can give informed consent to receive or refuse care, even if it leads to death, then it follows that this patient is also able to ask for help to die. The physicians we met in Europe confirmed the surprising lucidity of people who request euthanasia.

Should universal palliative care precede the debate on euthanasia?

As we have seen, palliative care is not sufficiently developed in Québec, which is why it is the subject of many of our recommendations. Improving palliative care is a priority we cannot stress enough. Some people and organizations consider the debate on euthanasia premature as long as palliative care is not available to all. In their view, sick people who don't have access to end of life care may very well ask for help to die simply because adequate care is not available to ease their suffering. They therefore cannot choose judiciously. This is a very compelling argument. Another argument put forth during the hearings was that by hastening their death, some sick people might miss out on the discovery of a new treatment or drug that could have cured them or at the very least improved their life expectancy or condition.

This last assertion is not, however, made for cases where patients refuse or stop treatment, thus hastening their death and eliminating the possibility of seeing a new treatment or drug. End of life decisions, like life decisions in general, are made based on the information available to us at the time.

As has been amply pointed out, despite the best of intentions, it is unrealistic to believe that palliative care will be available to everyone in Québec in the immediate future. In the meantime, patients will inevitably suffer, and we have to find a solution for them now. Sick people are already being asked to make choices based on the services available in their regions and based on when the diagnosis was made. For example, a given treatment may not be available in a certain region, or a new drug may not yet be part of the list of authorized medications. We repeat, any action taken to authorize help to die must be accompanied by major efforts to provide quality palliative care to all those who need it.

Furthermore, we are convinced that palliative care, even if it were accessible to everyone who needed it across Québec, would not be able to ease all the suffering of end-of-life persons, and that some would want help to die. Although these people are few in number, we as a society must address their needs.

⁵⁰ Testimony given in English.

“ When you come to the fork in the road, which road do you take? You may make a mistake, you may make the right choice. You do it, we do it almost every day in our lives, where we have to choose between two things, and if you choose one, you don't get the other. That's basic to living, I think. [...] And I think that is why it is so important for the individual to make his own decision [...] at that crossroads.”⁵⁰

Sara Susan Raphals, 90 years old - Excerpt from the hearing of September 8, 2010 held in Montréal, general consultation

“ As physicians and as an order, we cannot shy away from this issue, because patients are waiting for an answer from their doctors, and when it comes to the end of life, some of them desperately need that answer. ”

Collège des médecins du Québec –
Excerpt from brief, expert consultation

Can euthanasia be considered end-of-life care?

In 2009, the Collège des médecins du Québec published its discussion paper titled *Physicians, Appropriate Care and the Debate on Euthanasia*⁵¹. This publication helped launch the current debate. The Collège des médecins concluded that “there are certain exceptional situations—uncontrollable pain or interminable suffering, for example—in which euthanasia could be considered to be a final step required to ensure provision of quality care”⁵². This forward-thinking approach, which emerged after more than three years of reflection, is a departure from the usual debate on the legalization of euthanasia and places it instead in the context of appropriate end of life care⁵³. In fact, according to the Collège, this is how the problem is viewed between physician and patient.

Viewed from this perspective, euthanasia and palliative care are not contradictory but rather complement each other in the continuum of care, because they are both motivated by the human desire to have a “good death”. The Collège is right when it says that the challenge is to make sure the care provided is as appropriate as possible, and that care is appropriate when the decision making process is sound.

As we have said, the Collège des médecins position has been favourably greeted by many organizations that have already expressed their support for this idea. Still, we are well aware that not everyone who participated in the consultation is on board.

According to some, allowing euthanasia would lead to a radical rethinking of medical ethics by abolishing the age-old prohibition of killing. The Collège nevertheless feels that its position is consistent with the spirit of the *Code of Ethics of Physicians*⁵⁴, specifically section 58, which states, “A physician must, when the death of a patient appears to him to be inevitable, act so that this death occurs with dignity. He must also ensure that the patient obtains the appropriate support and relief”. The Collège also points out that patient autonomy has become a basic principle of medical ethics.

⁵¹ See note 1, p. 11.

⁵² See note 1, p. 11. Position that was reiterated in the brief that the Collège des médecins du Québec presented during the expert consultation.

⁵³ In Belgium, euthanasia is considered a form of care.

⁵⁴ R.R.Q., chapter M-9, r.17.

According to some witnesses, the *raison d'être* of medicine is incompatible with euthanasia, and viewing it as a form of care is a travesty, because shortening life is not the same as alleviating suffering or providing care. Although we understand this point of view, we believe that euthanasia is practiced out of compassion and ultimately as a way to ease, at the patient's request, constant, unbearable suffering when all other acceptable means have fallen short. As such, euthanasia could very well fit into the continuum of end-of-life care. It bears mentioning that certain practices that may shorten life, such as the use of certain drugs, the refusal or cessation of treatment and continuous palliative sedation, are already part of the continuum of end-of-life care.

Is there a significant difference between euthanasia, continuous palliative sedation and the refusal or cessation of treatment?

As we have seen, under the law today, a person may refuse or stop treatment, even if doing so could hasten his death. None of the participants questioned this evolution in the law and medicine. However, during the debate that led to the legalization of these practices, the opposing arguments were very similar to those raised today on euthanasia.

We understand the argument where if treatment is refused or stopped, the disease will claim the person. By taking no action, healthcare staff is simply letting nature take its course. This is what is referred to as a "natural death".

Some people may find this statement surprising. As a number of witnesses rightly pointed out, medical advances have turned death into an increasingly less natural process that often involves many end-of-life decisions by the patient or his family. Should chemotherapy be continued? Should a bed-ridden patient be treated for pneumonia? Should we turn off a respirator that is keeping someone alive?

We are inclined to agree with the participants who consider it a very fine line between unplugging a respirator, which will result in death within a few minutes, and administering a medication, which will hasten death. In truth, both acts produce the same result. Because we considered it so important, this nuance was discussed at length during the public hearings. We then looked at what can be referred to as "the inequalities of fate". In other words, what do you say to a person who wants to die because of unbearable pain but who isn't "lucky enough" to have an artificial respirator to unplug or dialysis treatments to stop? More than one doctor told us that "pneumonia is a dying person's best friend," a statement that speaks volumes.



“ ... she was made unconscious, and then the artificial respirator was simply stopped. [...] Was this assisted suicide, euthanasia, cessation of treatment? Technically speaking, it's cessation of treatment, which is very easy to define. But it still takes place in steps, it's a decision-making process, and when you get to that point, whether it's the physician who induces unconsciousness, the respiratory therapist who turns off the artificial respirator, or whether I do it all myself, I can tell you very sincerely, there is really no difference anymore... ”

Laurier Thériault, about the death of his wife, France Gervais, suffering from Lou Gehrig's disease – Excerpt from the hearing of September 7, 2010 in Montréal, general consultation

“ Causing a person’s death (our own or that of another), be it through a third party (euthanasia) or by our own hand with the help of a third party (assisted suicide), is an act that undermines the sanctity of human life, the legacy of our religious traditions. ”

Comité national d’éthique sur le vieillissement et les changements démographiques – Excerpt from brief, expert consultation

We learned all about the complexities of palliative sedation at the beginning of the expert hearings. We found it very hard to wrap our heads around this practice, especially continuous sedation, and we questioned numerous witnesses about it. This type of sedation involves administering medication to provide relief by making the patient unconscious until the end. According to some, it can hasten death. This is a case where the principle of double effect, explained earlier, applies. Here again, not a single participant, not even the opponents of euthanasia, took issue with the right to resort to palliative sedation, even continuous, in exceptional cases.

In our opinion, the line between euthanasia and continuous palliative sedation is very murky indeed, particularly when food and water are also withheld. Something else we learned during the hearings is that even the medical profession is not totally clear on this matter and sometimes struggles with the criterion of intent (ease suffering at the risk of hastening death or hasten death to ease suffering). The fact is that some physicians tend to think continuous palliative sedation is a form of euthanasia, which may help explain why some doctors believe euthanasia is practiced in Québec health institutions⁵⁵.

However, despite what may seem like superficial differences between the two practices, some participants felt euthanasia unacceptably violates respect for life, since it is an act that causes instant death.

Is respect for life absolute?

There is no question that respect for life is a basic societal value that is even enshrined in the charters and laws. Naturally, the government must do everything in its power to promote this value, notably by helping improve the quality of life of the sick and actively fighting against suicide.

Some witnesses maintain that respect for life must be absolute, i.e. it must take precedence over all other values, including personal autonomy. As such, we should never allow a person to help another put an end to his life, even out of compassion. This value may also be rooted in religion. A number of participants made religious references by using the expression “the sanctity of life”. According to this view, human life is a gift from God, and God alone has sovereignty over life and death. We have profound respect for the religious beliefs of Quebecers. Nevertheless, we feel that in a secular society such as ours, the beliefs of some cannot form the basis for broad-based legislation.

“ ... placing an absolute value even on the sanctity of life can lead to cruelties. ”

Jacques Grand’Maison, sociologist and theologian – Excerpt from February 14, 2011 in Saint Jérôme, general consultation

⁵⁵ See the results of the FMOQ and FMSQ polls, where, respectively, 53% and 81% of physicians stated they thought euthanasia was already being practiced.

For others, it is the person rather than life that is sacred. The right to choose one's destiny until the end, in keeping with one's values and beliefs, is a question of freedom and autonomy.

As we have seen, further to changes in social values, medicine and the law, respect for life is now relative. There are in fact circumstances where the value of personal autonomy prevails over respect for life. In the medical world, this means offering patients the opportunity to refuse or stop treatment that could keep them alive or prolong their lives. Therefore, respect for life cannot be an obstacle to euthanasia when the patient himself makes the request. However, the value of autonomy is not itself absolute. Indeed, many laws limit the freedom of individuals. Aside from respect for life and autonomy, the value of dignity has also been enshrined in our laws.

Is dignity intrinsic or subjective?

What is dignity? To say there is no consensus on its definition would be an underestimation, for human dignity is invoked by both proponents and opponents of an openness to euthanasia. As such, the name of the Select Committee could not be more appropriate, since this concept is paradoxically unifying, and we were guided by two visions of dignity throughout our work. The testimonies of ethics experts were especially invaluable in this regard.

According to the first meaning, human dignity is a fundamental principle that endures despite loss of freedom, self-awareness or the ability to interact with others. Dignity is therefore inherent by virtue of one's humanity, regardless of age, sex, religion, social status, ethnic origin, etc. In this regard, dignity is intrinsic, absolute, objective and universal. Human dignity is inalienable and as such cannot be undermined by the conditions in which a person dies. In other words, there is no such thing as an undignified death, making it impossible to invoke loss of dignity to justify a request for help to die.

The other meaning of human dignity is closely tied to respect for personal autonomy. Autonomy here is understood as that which allows people to conduct their lives according to their convictions within the limits imposed by the rights and freedoms of others. This is referred to as subjective dignity, which is relative and personal. It logically follows that there is no one better placed to decide whether life is still worth living than the person who is dying. This assessment may be based on the suffering an individual feels, for example, as a result of his declining health. Understood in this manner, human dignity largely depends on how the person views himself. He may therefore consider it an affront to his dignity to continue living.



“ So speaking to you from the perspective of a culture of life, the end-of-life patient must take precedence over everyone else. He's the one who must be and remain at the centre of the information and decision-making process in matters that concern him... ”

Yvon Bureau, Co-president of Collectif Mourir digne et libre – Excerpt from the hearing of September 28, 2010 in Québec City, general consultation

“ We affirm that suffering in no way diminishes the dignity of a human being. ”

Québec Association of Baptist Churches – Excerpt from the hearing of September 10, 2010 in Montréal, general consultation

“ Dignity is personal. Everyone sees it differently. Countless pages have been written on dignity, and no one has managed to define it [...] It depends on the person, his values and his situation. ”

Ghislain Leblond, Co-president of Collectif Mourir digne et libre – Excerpt from the hearing of September 28, 2010 in Québec City, general consultation

“ In Oregon, one third of patients who are given drugs to help them commit suicide do not use them. So far, it seems just having the pills at their bedside gives them enough comfort to wait for a natural death. ”

Dr. Marcel Boisvert, former palliative care physician at Royal Victoria Hospital – Excerpt from brief, expert consultation

“ And, I remember, in the end—and when I say the end, I mean the last three years—I would often wake up, and he would be lying next to me, crying, saying this was so hard, because he had to find a way to die before he became a prisoner of his own body. ”

Sylvie Coulombe, wife of Roland Rouleau, who suffered from MS and used a gun to commit suicide on June 9, 2010 – Excerpt from the testimony of the Rouleau family on September 7, 2010 in Montréal, general consultation

We think the two definitions co-exist. While we understand some of the witnesses' ardent defence of intrinsic dignity, we believe that our laws subscribe to the notion of subjective dignity. Otherwise, how do you explain the right to the protection of dignity provided for in the charters if it cannot be infringed? Moreover, dignity, as it is understood in everyday life, is subjective, as demonstrated by the number of testimonies that made reference to dignified or undignified deaths.

We therefore believe only a sick person can decide what constitutes an inhumane existence with irreversible loss of dignity. Such an estimation can explain why someone might ask for help to die. In this regard, would it be a source of comfort for a person to know that when the time comes, he can die with dignity?

Would having the option of euthanasia give end-of-life patients a sense of comfort?

One of the fundamental goals of palliative care is to provide comfort and a peaceful death to end of life persons. However, as we have seen, this goal is not always achieved. We were very moved by the testimonies of terminally ill people agonizing over the prospect of their final moments. Their arguments in favour of euthanasia as a major source of comfort were taken very seriously.

The fact is that much of the fear of death stems from the fear of dying badly. The prospect of suffering can at times be worse than the suffering itself. Some patients would take comfort in knowing that they will not die in pain. It seems that simply knowing euthanasia is an option would give many the courage to wait for a “natural” death.

According to some participants, having the option to ask for help to die could reduce the number of suicides among sick people. People sometimes use very violent methods to end their suffering, often in utter loneliness. At times they act too quickly, ending their lives when they are still able-bodied and their situation is still manageable, out of fear that it will become intolerable if they wait too long. Others stop eating and drinking to speed up their death, which is equally violent.

The argument that having the option of euthanasia gives terminal patients comfort was confirmed during our mission to Europe. The doctors there explained to us that very few terminal patients who contemplate this option ultimately make the request. Moreover, among them, only a small number die in this manner. The idea that euthanasia is allowed and the mere fact of being able to talk about it openly seems enough to reassure end-of-life persons. In Belgium and the Netherlands, euthanasia often takes place at home, allowing people to die where they wish.



“ I don't know how long I'll be independent, where I'll be able to live, how incapacitated I'll be, whether I'll have pain, whether I will develop other illnesses. So for me, it's especially hard to think about the future, but when I think of assisted suicide and euthanasia, it makes me feel better, calmer, because I know that ultimately, I can have the last word, I can have control over my life, [...] I see assisted suicide and euthanasia as an emergency exit, an emergency door I can use. ”

Laurence Brunelle-Côté, suffering from Friedreich ataxia – Excerpt from the hearing of September 28, 2011 in Québec City, general consultation

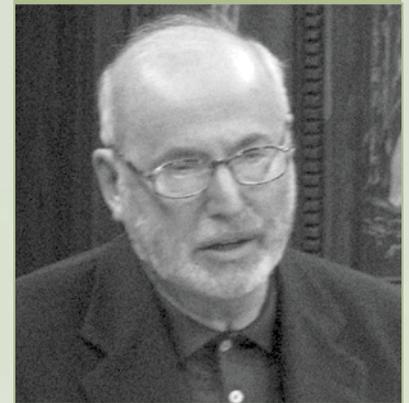


“ I woke up one morning and my despair had lifted. I decided to choose my time of death, rather than be institutionalized at great expense, and to slap destiny in the face by donating my heart, which cardiologists would love to have [...] I'm comforted by my decision; it has given me a sense of peace that I really needed, and now I savour every moment more intensely. ”

Nicole Gladu, suffering from post-polio syndrome, decided that, when the time came, she would go to Switzerland for assisted suicide – Excerpt from the hearing of September 7, 2010 in Montréal, general consultation

“ If the worst case scenario, which terrifies me, were to materialize, if I knew today that I would have help, the type of help I would want at that moment, if I knew for sure it would be there and accessible, then my quality of life, my life today, and that of my family, would be so much better. ”

Ghislain Leblond, Co-president of Collectif Mourir digne et libre, suffering from an orphan disease whose symptoms resemble those of Lou Gehrig's disease – Excerpt from the hearing of February 15, 2010 in Québec City, expert consultation



Does euthanasia have an impact on the family's grieving?

Death causes families to grieve, and one of the functions of palliative care is to promote healthy bereavement. We were touched by the testimonies of families who were beside their loved ones when they took their final breath. Palliative care hospices and units recount beautiful end-of-life stories of families brought closer together in the final days of a loved one, and even of friends who were able to reconcile before it was too late.

Unfortunately, some final moments are so horrible they haunt the deceased's family for years. We were shocked by some testimonies, because it was so clear the witnesses had not been able to grieve properly.

According to some witnesses, euthanasia can make it easier for families to grieve by making those final days more peaceful and humane. Of course, the sense of loss would still be as great, but it would also be more serene, because the end-of-life person would have requested and planned his own death. In addition, the sick person's family would be sure to be there for his last moments.

For others, euthanasia is a violent method that in no way helps the grieving process, because by accompanying the loved one to his death, the family begins the bereavement process prematurely. These participants also pointed out that bereavement associated with suicide is especially difficult, and that contributing, even if only tacitly, to the patient's process of asking for help to die is bound to leave scars on the family, including perhaps a sense of guilt.

We could not find any in-depth studies on the consequences of euthanasia for the grieving family. We took advantage of our mission to Belgium and the Netherlands to learn more about it. The doctors and nurses we met said they have not found a significant difference. However, according to them, discussing the decision to resort to euthanasia with the family can make the bereavement process easier. In addition, just as in the case of a "natural" death, the person usually spends his last moments with family and friends. In Belgium, we met the widow of a man who opted for euthanasia. She said that she believed she had fulfilled her duty by respecting and supporting her husband with his choice.

“ Twice the doctors told us that she had no more than 24 to 48 hours to live. Against all expectations, my mother regained consciousness.

The first question she asked the doctors was ‘Why am I still here?’

Please help me die.’ Faced with my mother’s insistence on wanting to die and the inability to do anything for her, one of her doctors then suggested she stop eating to speed things up.

Determined to die, that’s what she did. ”

Marie-Josée Gobeil, about the death of her mother from pancreatic cancer – Excerpt from the hearing of October 22, 2010 in Saguenay, general consultation



“ ... this whole period was a really special opportunity to get closer, to make him feel our love, share his passions and memories, but also to talk about the really important things in life. He reflected back on his life, all the good times, for which he was very grateful, and the challenges that made him a better person. It was a great journey, but it was also a journey that we took with him. ”

Nicoletta Toffoli, about the last moments of her uncle whom she considered as a father and who died of cancer – Excerpt from the hearing of October 13, 2010 in Montréal, general consultation

“ Yes, there were some beautiful moments, but my mother lived six months too long.

During the first six months of her illness, we had some good times, we learned some things, we said what

we needed to say to each other [...] Let me tell you: there are some images of my mother that I just can’t get out of my head.

Although it’s been two years, there are still nights that I go to bed and see that shrivelled body in front of me; I remember the smell of her those last days, when it was unbearable. ”

Marie-Josée Gobeil, about the death of her mother from pancreatic cancer – Excerpt from the hearing of October 22, 2010, in Saguenay, general consultation

“ It went very well, in the sense that he was very relaxed. It happened without a tear. My children told me afterwards that it was better for him and for me this way. Frankly, I'm glad we did it [...] the children agreed, the doctor at the rest home agreed. Everything took place very calmly. ”

Carmen Amores, whose husband Carlos Amores requested and obtained euthanasia – Excerpt from the meeting of July 5, 2011 in Brussels during the Committee's mission to Belgium

Can having recourse to euthanasia damage the relationship of trust between physician and patient?

A good doctor-patient relationship is essential. This is all the more true in a context where the patient is asked to make important decisions about the end of his life, because these decisions are based on information he receives from his physician. Trust is vital.

Some believe the trust in doctors and healthcare staff would be seriously compromised if euthanasia were legal. The fact of allowing this practice could be a source of anxiety for sick or elderly people; they might fear that they would be pressured by family or medical staff to ask for help to die or that they would be euthanized without their consent.

According to other testimonials, tough decisions are already being made, namely to stop treatment or administer palliative sedation. The relationship of trust between patient and doctor is not diminished in these situations, and there is no reason to believe that it would be any different with euthanasia. On the contrary, in countries where it is permitted, euthanasia has helped move the medical culture and the decision-making process towards a more balanced doctor-patient relationship. According to many, the ability to freely discuss all end of life options, including euthanasia, with one's doctor, and the assurance that one's wishes will be respected (provided the criteria are met) can only increase patient trust in physicians.

The merits of this last argument were confirmed on our mission to Europe. We were explained the kind of discussion that takes place between a physician who agrees to a request for euthanasia and his patient, and were impressed by what we heard. In fact, even the people we met who are opposed to euthanasia confirmed that patients do not feel threatened by the fact that it is practiced in the very place they are hospitalized.

Concern was expressed at the hearings about the repercussions of euthanasia on health professionals. A serious and highly significant act, euthanasia, they say, is bound to affect the people involved and could mark them for life. The European physicians we met were very honest in this regard. They confided that because euthanasia is such an emotionally charged act, it is difficult to carry out. Some also conceded that, on an emotional level, they could not handle more than a few requests a year. This clearly attests to the sensitivity and professionalism of the medical profession, a solid safeguard against the risk of abuse. One may wonder why these physicians would practice euthanasia, even when they are not obligated to do so. The answer is they believe it is their duty, when no positive outcome is possible, to support their patients right to the end, and to respect their wishes. In their view, not doing so would be tantamount to abandoning them.

While the practice of euthanasia may appear well founded, we must make sure that it in no way compromises investment in palliative care, that it does not negatively affect certain messages we send to society, particularly, regarding the fight against suicide, and that it never puts society's most vulnerable at risk.

Can the practice of euthanasia hinder the development of palliative care?

Some participants fear euthanasia will halt the development of palliative care, be it in terms of investment, training of health professionals or research. Euthanasia will be seen as an easy, inexpensive option.

Legitimate as this fear may be, this has not happened in the European countries where euthanasia has been legalized. Perhaps surprisingly, the exact opposite has occurred. The legalization of euthanasia has boosted the development of palliative care. The social consensus was to openly accept this practice as long as palliative care was accessible to more patients⁵⁶. Consequently, Belgium and the Netherlands have quality palliative care⁵⁷, much of which is offered at home.

Can the practice of euthanasia undermine the common good?

The concept of the common good was pervasive during the hearings and in our discussions. It was raised during the dialogue on autonomy, respect for life and development of palliative care. The common good is usually presented as a counterweight to individual rights. With regards to euthanasia, for some, the issues pertain to devaluing the right to life, the threat to vulnerable people, the consequences of the message left to future generations and suicide prevention.

Many participants invoked the common good to defend the interests of the most vulnerable members of our society, such as the sick, the elderly and the severely disabled. In their view, introducing euthanasia as an end-of-life option would undermine the value of life, particularly lives that could be deemed no longer useful according to a utilitarian view. As such, the "right to die" could insidiously turn into a "duty to die". People would come to view themselves as a burden on their families or on society and contemplate euthanasia as a solution.

⁵⁶ In Belgium, euthanasia and palliative care legislation were tabled at the same time. In the Netherlands, the legislation on euthanasia and assisted suicide was accompanied by measures to develop palliative care.

⁵⁷ In the Economist Intelligence Unit's "quality of death" ranking of 40 countries, the Netherlands and Belgium placed fifth and seventh respectively: *The Quality of Death: Ranking end-of-life care across the world*, Economist Intelligence Unit, [Online]: [http://www.eiu.com/site_info.asp?info_name=qualityofdeath_lienfoundation&rf=0].

⁵⁸ Meeting held in English.



“ As a doctor, for me euthanasia is a logical consequence of accompanying my dying patients and not standing by and watching the patient suffering and dying anyway and saying sorry I can't do anything.”⁵⁸

Dr. Rob Jonquière, practices euthanasia in the Netherlands – Excerpt from the meeting of July 1, 2011 in Amsterdam during the Committee's mission to the Netherlands



“ Is there a social benefit in promoting life that justifies forcing people to live out their lives until a ‘natural’ end, in pain? ”

Hélène Bolduc, President of the Association québécoise pour le droit de mourir dans la dignité – Excerpt from brief, general consultation

Some witnesses also fear that euthanasia will be used as a means to free up beds at a time when an aging population is placing growing pressure on the health system. As such, euthanasia would be practiced on people who are alone and vulnerable and who did not request it.

Others pointed out the contradiction between allowing euthanasia or assisted suicide and investing in suicide prevention, claiming that such practices could undermine all the efforts made over the years to fight against this scourge. Recognizing that death is an acceptable way of easing suffering and that committing suicide is an answer to adversity would only lead to more people taking their lives.

We were moved by the apprehension expressed in these testimonies. For this reason, we believe that we must proceed very carefully in this matter, never be complacent, and make sure not to send contradictory messages to the public. That said, we feel that because euthanasia would be practiced in a very structured medical framework and would only be used in exceptional cases, it would not undermine the importance of life. It would happen too infrequently to have a significant negative impact on society’s values relating to life and death. This was confirmed by the experiences of other countries where, as we have seen, euthanasia accounts for just 0.7% to 2% of deaths. What’s more, according to the people we met during the mission to Europe, euthanasia only shortens life by about 10 days on average. Moreover, the suicide rate has not increased in countries that have legalized euthanasia or assisted suicide⁵⁹. Lastly, in Québec, the right to refuse or stop treatment has not undermined the importance placed by society on fighting for life.

We were troubled by the accounts of sick people who feel like a burden on their families or on society. Although as a society we want everyone to feel like a full citizen, the reality is that despite every effort in this regard, some sick people may still have trouble seeing their families make sacrifices to take care of them or feel diminished by no longer being able to contribute to society as before. It is naturally our duty to make sure that sick people do not feel excluded from society.

Some participants asked questions about what kind of society we want, the values that will be passed on to future generations, and the moral legacy we will be leaving them. They expressed concern over the growing value placed on autonomy at the expense of solidarity. In an individualistic society, there is a real danger of withdrawal, and the risk of isolation and abandonment of its weakest members.

⁵⁹ It is interesting to note that the Association québécoise de la prévention du suicide is not opposed to euthanasia or assisted suicide, instead submitting important matters for consideration.



“ We must show, as well, there are solid secular arguments against euthanasia, for example, that legalizing euthanasia would harm the very important shared societal value of respect for life, and change the basic norm that we must not kill one another.”⁶⁰

Margaret Somerville, Professor, Faculty of Medicine, Faculty of Law, McGill University – Excerpt from brief, expert consultation

“ So, we have to be careful of the message we send to people in our society, especially in a society where performance, efficiency and the like are held in such high esteem. For me, this is a real danger.”

Dr. Louis Roy, Réseau de soins palliatifs du Québec – Excerpt from the hearing of September 28, 2010 in Québec City, general consultation



⁶⁰ Testimony given in English.

“ Here too, we have to fear the slippery slope.

The people or groups promoting ‘aid in dying’ loudly proclaim that strict guidelines will regulate this practice. Haven’t we already seen situations where the guidelines have been gradually changed to satisfy other requests that were not originally provided for? ”

The Assembly of Catholic Bishops of Québec – Excerpt from brief, general consultation



“ Euthanasia seriously undermines social solidarity, infringes on the rights of the weak and vulnerable, and puts them in danger. ”

Linda Couture, Director of Vivre dans la dignité – Excerpt from brief, general consultation

The common good is constantly being redefined as mentalities and values evolve. Thus, it can take various forms, including the promotion of individual rights such as autonomy. Without a doubt, compassion for and solidarity with someone who is suffering are also part and parcel of the common good. We believe that helping others while respecting their choices, even if we do not agree with them, is a form of social solidarity. It means respecting differences in people.

Lastly, we believe that euthanasia must not, under any circumstances, be viewed as a legitimate answer to the challenges of the aging population and pressures on the health system. As we adamantly and repeatedly stated during the hearings, we strongly disagree with the opinion of the very few witnesses who advanced this economic argument during the consultation⁶¹. Furthermore, we have full confidence in the professionalism of our doctors and nurses. In our opinion, the fear that economic considerations will drive their decisions is unfounded.

Can the practice of euthanasia lead to abuse?

Opponents of euthanasia are worried about potential abuse. Those in favour of an openness to this practice agree on the need for strict criteria to determine who can qualify to make such a request. Still, opponents are convinced these criteria, which may be restrictive at the outset, will expand over time. A number of witnesses drew a parallel with abortion to prove their point⁶². The experience of the Netherlands was also cited to back up their assertion. It was pointed out that at first only adults were eligible for euthanasia but that now minors age 12 and over also have access under certain conditions⁶³. As well, a petition is currently circulating in the country to allow people who are “tired of living” to qualify for euthanasia⁶⁴. This was the first aspect of the so-called “slippery slope” argument.

⁶¹ This argument, in any case, is contradicted by the fact that the expected number of requests for euthanasia will be so small that it could not possibly have a significant impact on public finances.

⁶² It should be mentioned, however, that the decriminalization of abortion was not accompanied by a legal framework of practice.

⁶³ This argument is based on false information. In fact, from the very outset, legislation on euthanasia in the Netherlands stipulated that adults and minors age 12 and over could have access under certain conditions. It also bears mentioning that this legislation was preceded by a period of tolerance for adults. Lastly, the legislation has never been amended since it was enacted.

⁶⁴ In fact, this petition pertains to the possibility of elderly people suffering from multiple ailments that are not life threatening when considered separately to be euthanized. According to the argument advanced by this petition, these afflictions considered as a whole respect the criteria provided by law. However, there is no political will to expand the law to this effect.

Those in favour of an openness to euthanasia are well aware of the gravity of the act and therefore consider it essential to establish guidelines to govern the practice and prevent the risks of abuse where the vulnerable are concerned. For example, we have to make sure the person has the ability and is capable of making a free and informed request. Opponents counter that these guidelines will not always be respected, pointing out that in Belgium, euthanasia has been carried out on people who only made the request verbally, despite the law requiring that consent be given in writing. As well, although attending physicians are required by law to seek the opinion of a second physician, this is not always done. This is the second aspect of the slippery slope argument.

This argument was weighed very carefully. This possibility was already a source of concern, and we therefore asked many questions on the matter during the hearings. We read the literature on the Belgian and Dutch experiences but were unable to discern a clear trend. The studies were often contradictory and at times controversial. The same official statistics were interpreted in diametrically opposed ways and led to different conclusions depending on whether the researcher was for or against euthanasia. Researchers are sometimes accused of producing biased results based on their personal beliefs. It was therefore difficult to form an opinion. The mission to Belgium and the Netherlands filled in the gaps.

Belgian and Dutch laws provide guidelines to structure the practice of euthanasia. By visiting these countries, we were able to learn how these guidelines, which have been in effect for several years now, are applied in medical practice. We were quite impressed by the Dutch “SCEN doctors” system⁶⁵, which we feel guarantees the independence of the second doctor charged with corroborating the attending physician’s diagnosis. We were also reassured when we saw how strictly the practice was controlled, as well as how carefully and seriously physicians and all medical staff approached this matter. The trivialization feared by certain witnesses has never materialized, in a society where the practice was tolerated long before it was legalized.

⁶⁵ This system is explained in greater detail in the next section.

“ ... First and foremost, I ask you to have faith in our health professionals [...] and their humanistic approach to the sanctity of life. And I think that it's the best path to take to arrive at appropriate care, on a matter as sensitive as end of life. [...] Don't think that it's easy for any doctor or nurse in Québec to be involved in an end-of-life decision, to make an end-of-life diagnosis or to take any sort of clinical action regarding the end of life. I'm convinced that Québec physicians and nurses will never make such decisions lightly and allow abuse. They will make sure each and every patient is properly cared for and offered the appropriate kind of relief. ”

As for the argument that physicians would be able to euthanize people who do not request it, what we found instead is that European doctors are reluctant to agree to this course of action, even if all the criteria are met, and will do so only once they are sure that all the possible care has been given and that the decision has been carefully thought out. In fact, in Belgium⁶⁶, the problem is the exact opposite: there are reports of people whose medical situation meets the criteria provided by law but who cannot find a doctor to comply with their request⁶⁷. Meanwhile, none of the doctors we met mentioned ever being pressured to perform euthanasia against their will.

As such, in the countries visited, we did not observe any abuse associated with the feared slippery slope⁶⁸. In fact, physicians and institutions that do not practice euthanasia, and even those opposed to it, told us the slippery slope has not materialized. Moreover, the annual reports of control boards, composed in part of opponents of euthanasia, have reported only a handful of problems over the years where certain formal procedures (second opinion, written request) were not followed. That said, no one has had to resort to the courts, and no private complaint has been reported, as the criterion for a free and informed request was met. In addition, the media has reported no cases of abuse, and polls show the public is still as favourable, if not more so, to euthanasia⁶⁹. Lastly, there is no popular movement or political will to go back to the way things were.

Of course, any human endeavour, regardless of its nature, involves risks. To deny this would be disingenuous. However, we firmly believe these risks can be eliminated by defining clear and strict guidelines. We are fortunate to be able to rely on the experiences of other countries and perfect their models. We are convinced that Québec society is ready to take up such a challenge. Moreover, the argument of abuse presupposes the complicity of physicians, nurses, health system administrators and patients' families. We feel this is highly improbable. We have full confidence in our health professionals and cannot imagine they would become agents of death overnight.

⁶⁶ Especially in the Walloon part of the country.

⁶⁷ Belgian doctors are entitled to conscientious objection.

⁶⁸ It bears mentioning that in its report, the expert panel of the Royal Society of Canada also concluded there was no abuse in these countries. Royal Society of Canada, *End-of-Life Decision-Making*, November 2011, 138 p.

⁶⁹ For example, the last survey in the Netherlands reported 85% support of the law.

Every day, these men and women are asked to make decisions and take actions with life and death implications for their patients. Every day, sick people make the decision to refuse yet another chemotherapy treatment, and families make the tough choice to stop force feeding their loved ones. No abuse has been reported since refusal and cessation of treatment was legalized and became common practice.

Instead, we find that therapeutic obstinacy still exists today. Some participants speculated that the reason for this may be fear of prosecution, despite the fact that it is legal to refuse or stop treatment. This fear may also explain why doctors hesitate to resort to palliative sedation, especially continuous sedation. Introducing euthanasia into the continuum of end-of-life care, by clarifying what constitutes appropriate care, could help eliminate this reticence.

Paradoxically, as some pointed out, the absence of legislation could encourage an unofficial practice of euthanasia, which opens the door to all manner of abuse. In fact, as we have seen, physicians concede that euthanasia is already practiced in Québec. Despite the confusion that may exist between increasing the dose of opiates, continuous palliative sedation and euthanasia, we heard enough to be persuaded that euthanasia is indeed going on, even if only rarely. The situation in Québec is the same as it was in Belgium and the Netherlands before euthanasia was legalized⁷⁰. Besides the potential for abuse, “unofficial” euthanasia is not governed by rules and specific expertise. Therefore, there is the risk of complications. Physicians who perform euthanasia do not necessarily know the best protocols.

Lastly, despite lobbying by certain associations, Belgian and Dutch laws have never been amended to expand the eligibility criteria for euthanasia since their enactment over a decade ago. The policymakers in these countries are clearly monitoring their legislation very carefully. We are convinced that it would be the same in Québec given our strict legislative process, in which public consultations play a prominent role.

In a democratic society such as ours, in which the National Assembly and the media provide effective checks and balances of government action, we are sure that any abuse would be denounced and thwarted. Moreover, the people and organizations opposed to any type of openness to euthanasia would be a part of the social control mechanism and provide one more safeguard.

⁷⁰ Physicians confided to us that they practiced euthanasia before the legislative changes.

“ So we have a meeting with the family, and it becomes clear they no longer want to continue treatment. So, as a clinician, I am faced with an intubation, which might extend the patient's life by 24, 48 or maybe 72 hours, and death, which will probably happen within an hour if I remove the tube. After I meet with the family, I go into the room with the respiratory therapist, I remove the tube, administer appropriate care and leave the room. I ask the family to come into the room. Less than an hour later, the patient dies surrounded by his family. That's what we call cessation of treatment. This is appropriate end of life care, and Québec hospitals have been doing this every day for the last 20 years. ”

The late Dr. François Desbiens, Director of Medical and University Affairs at the Agence de la santé et des services sociaux of Abitibi-Témiscamingue – Excerpt from the hearing of September 10, 2010 in Montréal, general consultation

OUR PROPOSAL: MEDICAL AID IN DYING

After studying the changes in social values, medicine and the law, and in light of our comprehensive review of the issues and the arguments raised by hundreds of witnesses and thousands of comments, we have come to the conclusion that an additional option is needed in the continuum of end-of-life care: euthanasia, in the form of medical aid in dying. Some suffering cannot be effectively relieved, and individuals who want to put an end to what they consider senseless, intolerable suffering face a roadblock that goes against Québec society's values of compassion and solidarity. Medical aid in dying would therefore become an option for this small number of patients in exceptional situations, provided the act is strictly controlled and limited, and the patient himself makes a free and informed request to this effect.

Although the term "euthanasia" is used in Belgium and the Netherlands, we noted during the public hearings that this term is emotionally charged⁷¹, and not everyone agrees on its use. But more importantly, it does not evoke the idea of support, which is central to our proposal. Over the course of the Committee's work, "medical aid in dying" is the expression that gradually emerged on its own. The word "aid" refers to the fundamental value of support, while "medical" indicates the type of support and implies the intervention of a physician and health professionals. We therefore opted for the expression "medical aid in dying".

Compatibility with changes in social values, medicine and the law

The medical aid in dying option is compatible with changes in social values, medicine and the law. Fuelled by diverse ideas, our social values have shifted from religious or ideological beliefs to notions of personal liberty, respect for autonomy, inviolability and integrity of the individual, all consistent with the concept of medical aid in dying. In the last 20 some years, these values have been expressed, for example, by the recognition of the right to refuse or stop treatment, decisions that often hasten death. In addition, opinion polls in Québec have long shown strong support in principle for medical aid in dying, which is corroborated by the answers to our online consultation.

Major scientific developments have equipped medicine with an impressive arsenal to fight disease and death. Today, an otherwise inevitable death can be delayed by days, weeks and even years. However, this can come at a price, namely uncontrollable chronic suffering that results in, according to some, unnecessarily prolonged agony. The medical profession wondered

⁷¹ Consider, for example, the involuntary euthanasia performed during World War II.

whether the time had come to rethink the approaches to end-of-life care, more specifically, to determine when it is best to forego curative treatment that could have an adverse effect on the patient in favour of palliative care, including palliative sedation, to relieve suffering. This type of care is today largely recognized and valued. These approaches, which focus more on providing relief than keeping the person alive at all costs, are consistent with the medical aid in dying option.

On the legal front, no doctor in Canada has ever been convicted by a jury for having performed euthanasia. In Québec, the Bar has no record of any such cases, prompting some to venture that the criminal rules are practically inapplicable. For its part, in 1994, the *Civil Code of Québec* enshrined the principles of autonomy, inviolability and integrity of the individual, in particular, the need for free and informed consent to undertake any medical treatment as well as the right to refuse or stop treatment, even if doing so hastens death. In view of all this, medical aid in dying looks more like an evolution than a revolution in Québec law.

Taking into account the issues raised

The medical aid in dying option takes into account the issues raised by the experts and witnesses at the general consultation as well as by the thousands of citizens who participated in the online consultation. It provides a solution to the issues of suffering and compassion in many end of life situations. It also addresses the fear of abuse. Finally, it meets a need that was stated with emotion and maturity, and is a safe course of action, provided the necessary precautions are diligently taken.

Despite its undeniable importance, palliative care is not always the right answer for all end of life persons, particularly those with uncontrollable pain. The medical aid in dying option would thus offer an alternative to this small number of people. It would not be in keeping with our social values to refuse such assistance just because palliative care is not uniformly accessible across the province. Based on the experiences abroad, we are convinced that medical aid in dying would in no way compromise the future development of palliative care.

Regarding the issues surrounding end-of-life practices, there seems to be a very fine line between continuous palliative sedation, refusal or cessation of treatment, and medical aid in dying. In all three cases, the end result is death, and in all three cases, the end-of-life patient is able to make

a free and informed decision to end what he considers intolerable and needless suffering. In this regard, despite the reticence of an age-old medical culture committed to maintaining life at all costs, the medical aid in dying option should, like continuous palliative sedation and refusal or cessation of treatment, be one of the choices available at the end of life.

This evolution in thinking in no way means diminishes respect for human life, especially the right and desire to live. However, it does invite us to attach great importance to a person's wish, made in a free and informed manner, to put an end to what he considers unbearable agony. Given that the will to live is deeply ingrained in human beings, this wish will seldom be made. On a related issue, the medical aid in dying option does not diminish the intrinsic dignity we hold by virtue of being human, regardless of the havoc wreaked by a disease; furthermore, it respects subjective dignity by acknowledging a person's right to consider his dignity compromised by his disease. Throughout their lives, people have the right to decide what fulfills their aspirations and values; this should also be true at the end of life. Lastly, many end-of-life persons, especially those suffering from degenerative diseases, would take tremendous comfort in knowing the medical aid in dying option exists, somewhat like an "emergency exit", to borrow the expression of one participant, if their situation were to become unbearable.

A number of points were raised concerning the potential abuses and the repercussions of an openness to euthanasia. These fears, while legitimate, were not substantiated based on what we found in the European countries where euthanasia is practiced. Our mission overseas allowed us to see for ourselves how the practice has evolved. What we typically heard, even from opponents, was that euthanasia has not led to any abuse of the vulnerable, that it has not impeded the development of palliative care—in fact quite the opposite—and that it has had a neutral and sometimes positive effect on family bereavement and on patient trust in physicians.

The issue of the common good, often presented as a counterweight to individual rights, came up frequently during the public hearings and our discussions. Among other things, fears were expressed that the "right to ask to die" could turn into a "duty to die" in order to bring relief to families or to free up beds, and that it would set back the fight against suicide. Here again, these fears have not materialized in countries where euthanasia has

been practiced for some time. Medical aid in dying does not endanger the common good; rather, it forms an integral part of it by offering one more option for those nearing the end of their lives, without posing a threat to society's most vulnerable members.

We are not saying there are no risks in allowing medical aid in dying, but we do believe that, just like Belgium and the Netherlands, Québec society has what it takes to avoid them. All the physicians we heard said they had never encountered any abuse associated with the fact that for the last 20 years, patients and families have been able to ask for the cessation of treatment, for example, unplugging a respirator.

On the matter of suicide prevention, we were very careful to take into account the comments of participants who were worried the use of the word "suicide" in the context of medical aid in dying could be detrimental to the fight against suicide. But beyond the term, assisted suicide, considered an individual act in time and space, does not reflect the values of medical support and safety that are inseparable from the medical aid in dying option, as we propose it. Moreover, assisted suicide certainly cannot be considered a form of care and therefore runs counter to one of the main principles that guided our thinking and our recommendations, namely that any openness in this regard should be situated in the context of a continuum of care.

Defining and structuring the medical aid in dying option: essential criteria and guidelines

How can we define and adequately structure the medical aid in dying option so that it reflects the changes in social values, medicine and the law, and adequately and safely responds to the issues raised by the public? Three main principles gradually emerged from our discussions and shaped our recommendations, as follows:

- 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 principles were useful in analyzing the models adopted by governments that have legislated euthanasia, particularly the Netherlands and Belgium. We are fortunate to be able to refer to their experiences, which can be used to tailor a model to Québec's reality. The principles above were

also essential to defining the Québec medical aid in dying option, in other words, specifying cases where a request may and may not be considered. The following recommendations stem from these three principles and reflect our circumspection in this matter. Any openness to medical aid in dying must be accompanied by unambiguous criteria and strict guidelines.

Who could request medical aid in dying?

This is a crucial question, and it is important to establish the criteria for medical aid in dying right from the start. Keeping in mind that this option must be a part of the end of life continuum of care, we recommend the criteria be clear and specific so as to facilitate assessment, but general enough to allow doctors to use their professional judgment in each case. Since it is impossible to list every possible disease and its conditions, it would be up to the attending physician to evaluate, with the patient, whether the medical situation meets the criteria.

Accordingly, anyone requesting medical aid in dying would have to fulfill all of the following criteria concomitantly:

1. The person is a Québec resident according to the *Health Insurance Act*;
2. The person is an adult able to consent to treatment under the law;
3. The person himself requests medical aid in dying after making a free and informed decision;
4. The person is suffering from a serious, incurable disease;
5. The person is in an advanced state of weakening capacities, with no chance of improvement;
6. The person has constant and unbearable physical or psychological suffering that cannot be eased under conditions he deems tolerable.

These criteria merit explanation. The reason for the residency criterion is to prevent people from coming to Québec solely for the purpose of obtaining help to die.

As for the requirement that the person himself make the request, this is one of the pillars of our proposal and, at the same time, an essential safeguard to prevent any risk of abuse. Therefore, the second and third criteria ensure that neither minors nor incompetent individuals⁷², nor their representatives, can

⁷² The section on advance requests for medical aid in dying would be a possible exception for incompetent individuals who, when they were still competent, expressed the wish to receive medical aid in dying in the event of irreversible unconsciousness.

make such a request. It goes without saying that the request must be based on a free and informed decision. This means the person has been thoroughly informed about his medical condition, the prognosis and possible courses of action, and his decision is made freely, without any outside pressure.

The issue of minors was not discussed at length during the hearings. We only heard two very poignant testimonies that focused more on palliative care and therapeutic obstinacy. We also did not hear from any experts on this topic. Consequently, although under the *Civil Code of Québec*, minors aged 14 and over are allowed to make decisions about their healthcare, we prefer to be cautious and restrict access to medical aid in dying to adults. In our opinion, this decision is too important to be made by anyone who has not reached what society considers to be the age of full majority. This point of view was shared by more than half of the respondents to the online questionnaire, with only 40% believing minors should have access to euthanasia.

The fourth and fifth criteria define the person's medical condition. Our goal is clear: medical aid in dying is reserved for people whose condition is irreversible and who are at the end of life. Determining whether a person is in fact at that stage is no easy task. Many factors must be taken into account, including the type of illness. For example, a terminal cancer patient may be deemed to be nearing the end of life when doctors estimate he has just a few days or weeks left. This is the most common scenario, since roughly 80% of the euthanasia cases in Belgium and the Netherlands involve cancer patients. However, it could be different for a patient with a degenerative disease. Life expectancy in such a case could be a few weeks or months or more, depending on the disease and on the individual's medical condition.

The last criterion acknowledges that physical pain and psychological suffering are equally important. Indeed, the latter is often wrongly considered less legitimate than physical pain, which can usually be clearly defined. However, the psychological distress experienced by end of life persons can at times be more unbearable than the physical pain.

RECOMMENDATION N^o 13

The Committee recommends that relevant legislation be amended to recognize medical aid in dying as appropriate end-of-life care if the request made by the person meets the following criteria as assessed by the physician:

- The person is a Québec resident according to the *Health Insurance Act*;
- The person is an adult able to consent to treatment under the law;
- The person himself requests medical aid in dying after making a free and informed decision;
- The person is suffering from a serious incurable disease;
- The person is in an advanced state of weakening capacities, with no chance at improvement;
- The person has constant and unbearable physical and psychological suffering that cannot be eased under conditions he deems tolerable.

Who would be able to provide medical aid in dying?

By definition, medical aid in dying could only be provided by a physician. Under their codes of ethics, physicians and nurses are entitled to conscientious objection, meaning they can refuse to perform an act that goes against their values. Of course, physicians and nurses⁷³ will retain this right where medical aid in dying is concerned.

However, a doctor who refuses to provide medical aid in dying for reasons of conscience will have the duty to help his patient find another who is prepared to do so, as quickly as possible, as already stipulated in the *Code of Ethics of Physicians*:

“A physician must, where his personal convictions prevent him from prescribing or providing professional services that may be appropriate, acquaint his patient with such convictions; he must also advise him of possible consequences of not receiving such professional services. The physician must then offer to help the patient find another physician.”⁷⁴

⁷³ In some cases, Belgian and Dutch nurses participate in euthanasia by placing a catheter.

⁷⁴ R.R.Q., c. M-9, r. 17, section 24.

This is a critical matter, because it is a key factor for providing access to medical aid in dying, as we saw in Belgium. Consequently, we invite the Collège des médecins to come up with a simple, effective mechanism to refer patients to physicians willing to provide medical aid in dying. For example, the directors of professional services in each institution could play a role in this regard.

How should a medical aid in dying request be formulated?

As we have said, the request for medical aid in dying would have to be made in a free and informed manner. For this to be possible, attending physicians would have to discuss life expectancy with their patients, as well as explain all the curative and palliative options available to them. The request would have to be repeated within a reasonable period of time, depending on the type of illness. Our goal here is to have physicians make sure the patient's wishes have not changed. It goes without saying that before providing medical aid in dying, the physician would have to ask, one last time, whether the patient was sure of his decision.

The request would have to be made in writing, and a straightforward, clear form should be designed to simplify the process. The person seeking medical aid in dying would have to sign and date the form, which the doctor would then place in the patient's medical file. If the person were unable to physically sign the form, because, for example, he had lost the use of his hands, it could be signed by an adult who would attest in writing to the person's verbal request. Of course, the request could be revoked at any time, in writing or verbally, in which case the form would be removed from the file and returned to the patient.

Control mechanisms are essential to ensuring compliance with the criteria and guidelines formulated. Below are a few suggestions in this regard, made with a view to protecting those who make a request for medical aid in dying, as well as the public, and ensuring that the criteria are always followed to the letter.

Which control mechanisms should be in place?

We propose two control mechanisms: the first, before the act, is the requirement to obtain a second opinion and a psychiatric evaluation, if necessary. The second, after the act, is a provincial entity charged with controlling all acts of medical aid in dying and assessing the process as a whole.

The first control: the role of the second physician

A physician who deems the person requesting medical aid in dying meets the criteria would have to seek a second opinion from another physician, who would examine the patient and ensure the criteria are respected. Obviously, the attending physician or the second physician should consult a psychiatrist if he has trouble evaluating the person's competence or psychological suffering, as the case may be.

The second physician must be competent with respect to the disease in question and be independent of both the patient and the attending physician. The second doctor would have to provide the attending physician with a written report on his conclusions. After the act, the attending physician would have to complete an official declaration of medical aid in dying, in which all the elements associated with the request and criteria are reported⁷⁵. This declaration would then be sent to the oversight entity.

RECOMMENDATION N° 14

The Committee recommends that relevant legislation be amended to include the following guidelines:

- All requests for medical aid in dying must be made in writing by way of a signed form;
- The request must be repeated within a reasonable period of time, depending on the type of disease;
- The attending physician must consult with another physician on whether the request meets the eligibility criteria;
- The physician consulted must be independent of the patient and the attending physician, and be competent with respect to the disease in question;
- The attending physician must complete a formal declaration of medical aid in dying.

⁷⁵ In Belgium, to avoid potential problems with insurers, physicians write "natural death" on the death certificate.

By imposing this obligation on the attending physician, we are making sure acts of medical aid in dying will be performed according to the established criteria. However, for this control mechanism to be truly effective, a structure must be put in place to guarantee the independence of the second physician. This will prevent consultations between colleagues accustomed to working together, a practice that could cast doubt on the rigour of the process. We invite the Collège des médecins to reflect on this matter but strongly suggest that Québec create an independent support and consultation entity similar to the one in the Netherlands.

The example of the Netherlands: *Support and Consultation on Euthanasia in the Netherlands (SCEN)*

In 1997, the Royal Dutch Medical Association set up *Support and Consultation on Euthanasia in the Netherlands (SCEN)*, a program aimed at structuring the consultation and decision-making process before accepting a request for euthanasia or assisted suicide. SCEN comprises 32 regional groups of 600 physicians trained for this purpose. The role of SCEN physicians is to provide independent consultations to attending physicians and to attest in writing that the legally prescribed criteria have been respected. SCEN trains the physicians as consultants under the prescribed procedure. The process in place ensures the physician consulted does not know the attending physician making the consultation request and meets with the patient in private.

The second control: a Québec entity charged with control and assessment

Since each institution's council of physicians, dentists and pharmacists (CPDP) is already responsible for assessing the quality of the medical acts performed there against the recognized standards, there is no doubt it will naturally serve as the first line of control after the act.

However, a control mechanism at the Québec level is also necessary in order to obtain an overall view of the situation. We therefore propose an entity be created to verify whether completed acts of medical aid in dying were performed according to the law and to investigate any deviations in this regard. We suggest this entity also be responsible for evaluating the medical aid in dying process.

This entity would be required to publish two types of reports: an annual report with statistics on acts of medical aid in dying and a five-year report on the implementation of medical aid in dying provisions. The latter could include recommendations on how to improve the process. As well, the Committee recommends this report be examined by the appropriate National Assembly committee.

RECOMMENDATION N^o 15

The Committee recommends that an entity be created to control and evaluate medical aid in dying, whose responsibilities would be to:

- Verify whether acts of medical aid in dying were carried out according to the conditions provided by law;
- Publish an annual report, including statistics, on acts of medical aid in dying;
- Publish, every five years, a report on the implementation of medical aid in dying provisions.

RECOMMENDATION N^o 16

The Committee recommends that the appropriate National Assembly committee examine the five-year report of the control and evaluation entity.

A new entity could be created based on the European model of evaluation and control committees, whose members include both proponents and opponents of euthanasia from different disciplines. That said, the suggestion made by the Québec Bar to entrust this role to the Bureau du coroner (Coroner's Office) merits consideration, as it would eliminate the need to create a new structure, even though we realize this responsibility is quite different from the duties the coroner's office currently performs.

Will advance directives for medical aid in dying be permitted?

Under the laws on euthanasia in Belgium and Luxembourg, any citizen can complete an advance directive requesting euthanasia if they ever became irreversibly unconscious, because they would not want to be kept artificially alive in such a state. According to the information compiled, knowing that medical aid in dying is available in such circumstances brings peace of mind to people who fear ending up in such a situation, either as the result of a serious accident or an illness that leads to an irreversible coma.

In Québec, individuals may draft advance medical directives concerning their healthcare in the event they are no longer able to make such decisions themselves. For example, they may decide that no treatment is to be given or continued if they are in an irreversible state of unconsciousness, even if it hastens death. In the case of irreversible unconsciousness, this can mean withdrawing food and water.

For this type of situation, we propose that competent adults be allowed to formulate an advance directive for medical aid in dying in the event they become irreversibly unconscious, based on the current state of medical science. This type of directive would be legally binding, and the application mechanisms would be similar to those proposed for advance medical directives. However, we would add a few other requirements.

In the interest of accessibility, and although a notarized form is always preferable, we suggest a mandatory, straightforward form be developed and used. This form would have to be signed in the presence of two witnesses, including a commissioner of oaths, who would attest that the request was free and informed. In addition, the individual would be able to designate one or more trusted persons who would ensure the directive was applied. If no person was designated, this role would devolve to the physician.

RECOMMENDATION N^o 17

The Committee recommends that relevant legislation be amended to recognize that an adult with the capacity to consent is entitled to give an advance directive for medical aid in dying in the event that he becomes irreversibly unconscious, based on the current state of medical science. This advance directive for medical aid in dying :

- Must be given in a free and informed manner;
- Is legally binding;
- Must take the form of a notarized act or an instrument signed by two witnesses, including a commissioner of oaths;
- May mention the name of one or more trusted persons who will ensure the directive is known and applied.

RECOMMENDATION N^o 18

The Committee recommends that relevant legislation be amended to include the following guidelines:

- The attending physician must consult another physician to confirm the irreversible nature of the unconsciousness;
- The physician consulted must be independent of the patient and the attending physician.

Moreover, the Ministère de la Santé et des Services sociaux should take steps to ensure advance directives for medical aid in dying appear in patients' medical files or are recorded in a register, such as the Québec Health Record, once it is up and running. It will be up to the attending physician to check whether such a directive exists in the patient's medical file or in the register. If so, he will have to obtain a second opinion as to the irreversible nature of the unconsciousness from another physician, who must be independent of the patient and the attending physician. Lastly, the health establishment's service quality and complaints commissioner will have to periodically check the register to ensure the advance directives are being respected.

RECOMMENDATION N° 19

The Committee recommends that the Ministère de la Santé et des Services sociaux:

- Take the necessary measures to ensure the advance directive for medical aid in dying appears in a person's medical file and is recorded in a register;
- Ensure that the physicians check for the existence of such a directive in patient medical files or in the register;
- Ensure that each establishment's service quality and complaints commissioner periodically verifies compliance with advance directives for medical aid in dying.

The legal framework required to implement the medical aid in dying option

In our proposal, medical aid in dying is the last option offered to end-of-life patients whose suffering cannot be alleviated. This option, endorsed by the Collège des médecins and this Committee, is consistent with an appropriate end-of-life continuum of care. It is an act performed by a physician within a medical framework which is carefully structured in accordance with strict criteria and which falls under Québec's healthcare jurisdiction.

The criteria and guidelines mentioned earlier to structure the practice of medical aid in dying constitute the proposed legal framework and should be incorporated into the law, in this case, the *Civil Code of Québec* and the *Act respecting health services and social services*.

Since Québec has jurisdiction in legislation governing professions, it can ensure medical practice is adapted to the new option of medical aid in dying under professional legislation and regulation as well as the codes of ethics and professional practice of the professional orders involved.

Although criminal law falls under the purview of the federal government, Québec is responsible for the administration of justice and application of criminal law. As such, the Attorney General of Québec decides whether to lay charges and prosecute. To ensure doctors have peace of mind when practicing their professions, the Attorney General of Québec should issue directives, in the form of "guidelines and measures", to the Director of Criminal and Penal Prosecutions so that physicians who provide medical

aid in dying in accordance with the criteria provided by law cannot be prosecuted. In fact, this recommendation was made by the Québec Bar and by lawyers who appeared before the Committee⁷⁶. The Royal Society of Canada also came out not long ago in favour of this approach⁷⁷.

RECOMMENDATION N^o 20

The Committee recommends that the Attorney General of Québec issue directives (in the form of “guidelines and measures”) to the Director of Criminal and Penal Prosecutions to ensure that a physician who provides medical aid in dying in accordance with the criteria provided by law cannot be prosecuted.

Québec followed a similar path for abortion in 1976. Although performing abortions was still a criminal offence at the federal level, social change in Québec made it difficult, if not impossible, to apply the law, with juries systematically returning not guilty verdicts. And more recently, England applied a similar approach, implementing a policy in 2010 aimed at prosecutors for cases involving aiding and abetting suicide. In Canada, the Attorney General of British Columbia adopted a directive following the Sue Rodriguez affair.

The framework proposed for implementing medical aid in dying would ensure the protection and safety of both patients and doctors who want to support them with such a decision. The following excerpts from the Québec Bar brief echo our thinking and will to act:

“It is essential to dispel the uncertainty that exists in the medical profession about the legality of medical assistance to die, because this uncertainty undermines the rights of end-of-life patients and encourages clandestine practices. It is important that physicians be able to work in a legal environment where the limits and options are well known and clear and allow them to provide their patients with care in accordance with ethical rules and good medical practice. [...]

⁷⁶ We are thinking here, for example, of Me Jocelyn Downie, Me Danielle Chalifoux, Me Pierre Deschamps, Me Diane Demers and Me Sarto Blouin.

⁷⁷ See note 68, p. 74.

Developing a meaningful legal framework is the best way to safeguard against the dangers of a slippery slope. The current legal vacuum resulting from the difficulties in applying the *Criminal Code* could be better filled by targeted ethical regulation and guidelines within legal rules applicable to the health system⁷⁸.

RECOMMENDATION N° 21

The Committee recommends that the Collège des médecins du Québec amend its Code of Ethics so that physicians may provide medical aid in dying in accordance with the criteria provided by law while confirming their right to conscientious objection and their obligation, in such a case, to refer their patient to another physician.

RECOMMENDATION N° 22

The Committee recommends that the Ordre des infirmières et infirmiers du Québec amend its Code of Ethics to allow its members to help provide medical aid in dying in accordance with the criteria provided by law, while, however, confirming their right to conscientious objection.

RECOMMENDATION N° 23

The Committee recommends that, based on the recommendations set out in the report of the Select Committee on Dying with Dignity, a bill be tabled in the National Assembly no later than June 2013.

COMPLEX ISSUES THAT REQUIRE DEEPER REFLECTION

The criteria that we propose for assessing requests for medical aid in dying exclude certain categories of individuals. For instance, individuals left severely disabled following an accident would not meet our criteria. As well, a person suffering from dementia caused by a degenerative brain disease would not be able to give an advance directive for medical aid in dying. These issues nevertheless caught our attention and were the subject of intense discussions during our meetings.

⁷⁸ Excerpt from the Québec Bar brief, general consultation, p. 114, 118 and 119.

The adversity suffered by people left severely handicapped as the result of an accident defies words. Beyond the loss of their physical capacities and independence, their ability to interact with others can also be severely hampered. While the majority manage to adjust to their new reality, the quality of life of quadriplegics, for example, is undoubtedly greatly affected.

We are very sensitive to this matter and sympathetic towards those living in this type of situation. However, despite extensive discussions, we remain very uneasy about allowing medical aid in dying in such cases. Unlike the exceptional scenarios for which we are proposing this openness, people who are severely disabled as the result of an accident are not at the end of their lives. As well, since they are not suffering from a disease, medical aid in dying cannot be conceived as the final step in the continuum of care. To do so would not be in keeping with the logic and principles that guided our approach. We therefore set this debate aside during this process, especially since not enough light was shed on the matter, which was only briefly discussed during the hearings. Moreover, no one in this situation came forward during the consultation to ask for openness in such cases. In addition, significantly fewer respondents to the online questionnaire supported this option for severely disabled accident victims.

We also carefully looked at the possibility of allowing people suffering from dementia caused by a degenerative brain disease such as Alzheimer's to give an advance directive for medical aid in dying. Under this scenario, individuals suffering from diseases associated with the progressive and irreversible loss of their cognitive faculties could draft an advance directive to receive medical aid in dying when the conditions they describe in the directive materialize and they can no longer express their wishes because their illness has made them unable to do so.

Some participants spoke of how they feared the prospect of having to live for months or years in an advanced state of decline without any possibility of escaping a situation they consider unbearable. Many of them had already helplessly watched the slow and inexorable decline in the cognitive and physical abilities of a loved one suffering from this type of disease. We were also touched by the comments of a medical specialist in the field who, although reluctant to speak out publicly, believed this option should be available in such cases, adding that, based on what he has seen, certain end-of-life conditions were especially difficult, and that he, for one, would like to have such a choice.

We were very moved by these testimonies and understand that for some, such an end of life would be meaningless, particularly in the advanced stages of the disease. The reality is that in the final stages of Alzheimer's, for example, people can end up bedridden, in a fetal position, unable to feed themselves, speak or even react to the presence of others.

This is a very complex question that raises important ethical issues. As well, assessing a person's medical situation in relation to the medical conditions described in an advance directive may prove difficult. Consequently, after much thought and discussion, we concluded that we did not receive enough input from experts during the consultation and therefore cannot express an opinion on this matter. We do however feel this topic merits further investigation and suggest that a multidisciplinary committee of experts (medical, legal and ethics) be created under the auspices of the Collège des médecins to study the question and propose solutions.

“ Knowing the long-term effects of the disease, I would like to have this option for myself [...]. In this way, I wouldn't have to go through the needless physical suffering and psychological anguish (the fear of becoming a burden on my family and the humiliation of being totally dependent on others), and could perhaps avoid being institutionalized [...] for care I don't want. I recently completed a mandate in case of incapacity as well as a request for help to die if the law so allows. ”

Comment of a physician included in an answer to the online questionnaire

RECOMMENDATION N° 24

The Committee recommends that a multidisciplinary committee of experts be created under the auspices of the Collège des médecins du Québec to determine whether it is possible for a person suffering from dementia caused by a degenerative brain disease to give an advance directive for medical aid in dying.

CONCLUSION

How should we respond to the suffering experienced by some people at the end of life? How should we respond to requests for help to die? These are the two questions we asked at the outset and answered with the help of many citizens, associations and experts who shared their thoughts with us during the consultations.

In order to respond to the suffering of end-of-life persons, Québec must improve access to palliative care, not just for cancer patients but for people suffering from degenerative diseases. Moreover, in-home palliative care must be expanded so as to be able to respect the wishes of most patients, which is to die in the comfort of their homes. To improve the quality of care offered, Québec must offer palliative care training to all healthcare workers and invest in research. Lastly, the practice of palliative sedation, so essential for refractory suffering, must be structured, so patients can benefit from best practices.

More generally, the debate on end of life got us to thinking about society's attitude towards death, which remains a taboo to this day. In addition to making it hard to have any sort of discussion on the topic, this attitude could lead to end-of-life decisions that are not necessarily consistent with what the person would have wanted. Aging and dying are a natural life process that must be accepted as part and parcel of the human condition. We have to learn to face death and be able to talk about it more openly with our loved ones. In this way, we will be able to plan the last leg of this journey according to our own values. To do so, Quebecers must be informed of their rights, such as the right to refuse or stop treatment, as well as of the means available to plan for this stage of life. We must also ensure that the wishes expressed in advance medical directives are respected.

In response to the second question, we have concluded that we must comply with requests for help to die made in very specific situations. A new option is definitely needed in the continuum of end-of-life care, because palliative care cannot ease all physical and psychological suffering. We propose that this option take the form of "medical aid in dying". This assistance involves an act performed by a physician in a medical setting following a free and informed request made by the patient himself.

This change is needed to offer people a more gentle death and a more serene end of life, including those who will never resort to medical aid in dying but who will know the option is available should their suffering become unbearable. The approach we are suggesting will also remove the legal uncertainties that exist today and that create difficult situations for patients, families and the medical profession. We are convinced Québec society is ready for this change. Medical aid in dying is consistent with the changes in our values, the law and medical practice. Lastly, after carefully studying foreign experiences, we can confidently say that allowing this practice would not harm society's most vulnerable, because there are ways to define and structure it to avoid any risk of abuse.

Dying with dignity is a key social issue that is increasingly taking centre stage both here and elsewhere. Just last year, cases were brought before the courts in Québec and British Columbia to recognize the right to assisted suicide, while the Royal Society of Canada published a report recommending the legalization of euthanasia and assisted suicide based on the conclusions of its expert panel⁷⁹. In France, a 2012 presidential candidate came out in favour of legalizing euthanasia. These are highly complex questions that follow social shifts. In Québec, we have been collectively reflecting on this issue since 2009 and have taken important steps forward in this regard. We hope this report lives up to the expectations placed on us.

We are confident that our recommendations will help strengthen our joint commitment to sick people, their families and the healthcare profession. Lastly, we believe the seriousness with which we approached this task and the widespread participation by Québec citizens will convince the government to follow through on our recommendations in a timely manner, out of respect for those approaching the end of their lives.

⁷⁹ See note 68, p. 76.

LIST OF RECOMMENDATIONS

RECOMMENDATION N^o 1 (p. 25)

The Committee recommends that the Ministère de la Santé et des Services sociaux obtain an assessment of the palliative care situation in Québec. This assessment should:

- Report on the existing resources across Québec;
- Report on needs and the resources required to meet them;
- Report on the state of palliative care in each region;
- Be regularly updated.

RECOMMENDATION N^o 2 (p. 28)

The Committee recommends that the Ministère de la Santé et des Services sociaux give priority to the development of in-home palliative care.

RECOMMENDATION N^o 3 (p. 33)

The Committee recommends that the Ministère de la Santé et des Services sociaux ensure that all healthcare professionals receive adequate training in palliative care.

RECOMMENDATION N^o 4 (p. 34)

The Committee recommends that the Ministère de la Santé et des Services sociaux create an administrative unit devoted to palliative care that would, among other things, ensure swift and full implementation of the *End-of-Life Palliative Care Policy*, more specifically:

- Providing earlier access to palliative care, as soon as required given the patient's clinical course;
- Providing access to palliative care to patients suffering from incurable diseases other than cancer;
- Keeping people suffering from incurable diseases in their home environment;
- Providing access to a private room;
- Sharing clinical information essential to a patient's medical treatment and setting up stable multidisciplinary teams.

RECOMMENDATION N^o 5 (p. 35)

The Committee recommends that the Ministère de la Santé et des Services sociaux send to the appropriate National Assembly committee, for its consideration, a report on the implementation of the *End-of-Life Palliative Care Policy* one year after publication of the report of the Select Committee on Dying with Dignity. The Ministère's report should contain an assessment of palliative care in Québec.

RECOMMENDATION N^o 6 (p. 35)

The Committee recommends that the *Act respecting health services and social services* be amended:

- To recognize the right of any individual to receive palliative care when warranted by his medical condition;
- To ensure that all healthcare establishments providing in-home or in-hospital end-of-life care include palliative care in their service offer.

RECOMMENDATION N^o 7 (p. 40)

The Committee recommends that the Collège des médecins du Québec develop a practice and ethical standards guide for palliative sedation.

RECOMMENDATION N^o 8 (p. 43)

The Committee recommends that relevant legislation be amended to recognize advance medical directives and that they:

- Be legally binding;
- Take the form of a notarized act or mandatory form signed before a witness;
- Be permitted to mention the name of one or more trusted persons who would ensure the advance medical directives are known and applied.

RECOMMENDATION N^o 9 (p. 43)

The Committee recommends that the Ministère de la Santé et des Services sociaux :

- Take the necessary measures to ensure advance medical directives appear in patients' medical files and are recorded in a register;
- Ensure that physicians check for the existence of such directives.

RECOMMENDATION N° 10 (p. 44)

The Committee recommends that the Ministère de la Santé et des Services sociaux put in place a mechanism encouraging citizens to periodically update their advance medical directives.

RECOMMENDATION N° 11 (p. 44)

The Committee recommends that methods of communication on end-of-life care planning be developed to educate the public and those working in health and social services on end-of-life issues.

RECOMMENDATION N° 12 (p. 45)

The Committee recommends that persons diagnosed with an incurable disease be given an information guide on their rights and the available services and resources.

RECOMMENDATION N° 13 (p. 82)

The Committee recommends that relevant legislation be amended to recognize medical aid in dying as appropriate end-of-life care if the request made by the person meets the following criteria as assessed by the physician:

- The person is a Québec resident according to the *Health Insurance Act*;
- The person is an adult able to consent to treatment under the law;
- The person himself requests medical aid in dying after making a free and informed decision;
- The person is suffering from a serious incurable disease;
- The person is in an advanced state of weakening capacities, with no chance at improvement;
- The person has constant and unbearable physical and psychological suffering that cannot be eased under conditions he deems tolerable.

RECOMMENDATION N° 14 (p. 84)

The Committee recommends that relevant legislation be amended to include the following guidelines:

- All requests for medical aid in dying must be made in writing by way of a signed form;
- The request must be repeated within a reasonable period of time, depending on the type of disease;
- The attending physician must consult with another physician on whether the request meets the eligibility criteria;
- The physician consulted must be independent of the patient and the attending physician, and be competent with respect to the disease in question;
- The attending physician must complete a formal declaration of medical aid in dying.

RECOMMENDATION N° 15 (p. 86)

The Committee recommends that an entity be created to control and evaluate medical aid in dying, whose responsibilities would be to:

- Verify whether acts of medical aid in dying were carried out according to the conditions provided by law;
- Publish an annual report, including statistics, on acts of medical aid in dying;
- Publish, every five years, a report on the implementation of medical aid in dying provisions.

RECOMMENDATION N° 16 (p. 86)

The Committee recommends that the appropriate National Assembly committee examine the five-year report of the control and evaluation entity.

RECOMMENDATION N° 17 (p. 88)

The Committee recommends that relevant legislation be amended to recognize that an adult with the capacity to consent is entitled to give an advance directive for medical aid in dying in the event that he becomes irreversibly unconscious, based on the current state of medical science. This advance directive for medical aid in dying :

- Must be given in a free and informed manner;
- Is legally binding;
- Must take the form of a notarized act or an instrument signed by two witnesses, including a commissioner of oaths;
- May mention the name of one or more trusted persons who will ensure the directive is known and applied.

RECOMMENDATION N° 18 (p. 88)

The Committee recommends that relevant legislation be amended to include the following guidelines:

- The attending physician must consult another physician to confirm the irreversible nature of the unconsciousness;
- The physician consulted must be independent of the patient and the attending physician.

RECOMMENDATION N° 19 (p. 89)

The Committee recommends that the Ministère de la Santé et des Services sociaux:

- Take the necessary measures to ensure the advance directive for medical aid in dying appears in a person's medical file and is recorded in a register;
- Ensure that the physicians check for the existence of such a directive in patient medical files or in the register;
- Ensure that each establishment's service quality and complaints commissioner periodically verifies compliance with advance directives for medical aid in dying.

RECOMMENDATION N° 20 (p. 90)

The Committee recommends that the Attorney General of Québec issue directives (in the form of "guidelines and measures") to the Director of Criminal and Penal Prosecutions to ensure that a physician who provides medical aid in dying in accordance with the criteria provided by law cannot be prosecuted.

RECOMMENDATION N° 21 (p. 91)

The Committee recommends that the Collège des médecins du Québec amend its Code of Ethics so that physicians may provide medical aid in dying in accordance with the criteria provided by law while confirming their right to conscientious objection and their obligation, in such a case, to refer their patient to another physician.

RECOMMENDATION N° 22 (p. 91)

The Committee recommends that the Ordre des infirmières et infirmiers du Québec amend its Code of Ethics to allow its members to help provide medical aid in dying in accordance with the criteria provided by law, while, however, confirming their right to conscientious objection.

RECOMMENDATION N^o 23 (p. 91)

The Committee recommends that, based on the recommendations set out in the report of the Select Committee on Dying with Dignity, a bill be tabled in the National Assembly no later than June 2013.

RECOMMENDATION N^o 24 (p. 93)

The Committee recommends that a multidisciplinary committee of experts be created under the auspices of the Collège des médecins du Québec to determine whether it is possible for a person suffering from dementia caused by a degenerative brain disease to give an advance directive for medical aid in dying.

APPENDIX I

EXCERPTS FROM THE MOTION TO SET UP THE SELECT COMMITTEE ON DYING WITH DIGNITY

"Motion to set up an *ad hoc* committee to consider the issue of the right to die with dignity and the terms for enforcing it, as the case may be; [...]

Regarding the two consultations held by the committees,

Resolutions regarding the first consultation

- That the Committee on Health and Social Services may begin its work, no later than 60 days after the present motion is adopted, by proceeding with special consultations and by holding public hearings with a view to considering the issue of the right to die with dignity; that, to this end, it may hear experts who will be selected in the deliberative meeting; and that these experts notably discuss the following issues in their statements: end-of-life conditions and care; the law and the terms and conditions that may eventually lay the framework for the right to euthanasia; any other considerations that may enlighten committee members; [...]
- That within 45 days of the end of the hearings, the committee produce a consultation paper designed to facilitate public participation in the general consultation that will be initiated by the *ad hoc* committee; that said document immediately be submitted to the *ad hoc* committee without being made public;

Resolution regarding the second consultation

- That the *ad hoc* committee examine the consultation document and that it be able to make any additions to it, as it sees fit;
- That said document be submitted to the National Assembly within 30 days of its receipt;
- That the general consultation may begin on approximately August 17, at the earliest, or within a reasonable amount of time in order to allow individuals and organizations to produce a brief;

- That the committee be able to devote periods of time to the public hearing, where the public will have expressed its interest to be heard by the committee despite not having submitted a brief;
- That the committee be able to meet outside the buildings of the National Assembly and Québec City;
- That the committee be able use videoconferencing as part of the hearings;
- That the committee carry out an online consultation in order to foster the broadest possible public participation [...].”

APPENDIX II

EXPERTS WHO PARTICIPATED IN THE SPECIAL CONSULTATION OF THE COMMITTEE ON HEALTH AND SOCIAL SERVICES

EXPERTS HEARD, WITH OR WITHOUT SUBMISSION OF BRIEF

Professional associations

Quebec Medical Association (015M)*

Collège des médecins du Québec (005M)

Fédération des médecins omnipraticiens du Québec (007M)

Fédération des médecins spécialistes du Québec (008M)

Physicians

Dr. Yvon Beauchamp (013M)

Dr. Howard Bergman and Dr. Marcel Arcand

Dr. Marcel Boisvert (011M)

Dr. François Desbiens (009M)

Dr. Jana Havrankova (002M)

Dr. Michel L'Heureux and Louis-André Richard of Maison Michel-Sarrazin (019M)

Dr. Bernard Lapointe (018M)

Dr. Hubert Marcoux

Dr. Annie Tremblay and Dr. Pierre Gagnon (029M)

Lawyers

Me Danielle Chalifoux and Me Denise Boulet (020M)

Me Diane Demers (022M)

Me Jocelyn Downie

*The numbers in parentheses refer to the numbers of the briefs on the National Assembly website.

Professors and university researchers

Jean-Pierre Béland, ethics and philosophy professor (023M)

Danielle Blondeau, nursing professor (025M)

Valérie Chamberland, social work researcher (010M)

Hubert Doucet, ethics professor (004M)

Bernard Keating, ethics professor

Isabelle Marcoux, psychology professor (030M)

Joane Martel, social services professor (026M)

Brian L. Mishara, psychology professor

David J. Roy, ethics researcher (028M)

Jocelyne Saint-Arnaud, nursing professor (014M)

Margaret Somerville, law professor (012M)

Other experts

Hélène Bolduc, president of the Association québécoise pour le droit de mourir dans la dignité (001M)

Yvon Bureau and Ghislain Leblond, co-president of the Collectif Mourir digne et libre (006M)

Comité national d'éthique sur le vieillissement et les changements démographiques of the Conseil des aînés (003M)

Danielle Minguy, president of the Alliance des maisons de soins palliatifs du Québec (017M)

Bérard Riverin and Elsie Monereau of the Association d'Entraide Ville-Marie (016M)

EXPERTS NOT HEARD BUT BRIEF OR PAPER SUBMITTED

Association québécoise d'établissements de santé et de services sociaux (024M)

Dr. Justine Farley, president of the Réseau de soins palliatifs du Québec (027M)

Le Phare, Enfants et Familles

Dr. François Primeau (021M)

APPENDIX III

LIST OF PARTICIPATING ORGANIZATIONS AND INDIVIDUALS IN THE GENERAL CONSULTATION OF THE SELECT COMMITTEE ON DYING WITH DIGNITY

ORGANIZATIONS AND INDIVIDUALS HEARD BEFORE THE COMMITTEE (EITHER BY WAY OF A BRIEF OR A REQUEST TO BE HEARD)

Organizations

Afeas (037M)*

Afeas régionale Montréal-Laurentides-Outaouais (205M)

Albatros Est-de-l'Île-de-Montréal (218M)

Assembly of Catholic Bishops of Quebec (036M)

Quebec Association of Baptist Churches (080M)

Spina Bifida and Hydrocephalus Association of Quebec (152M)

Association des médecins catholiques de Montréal (206M)

Association des retraitées et retraités de l'éducation et des autres services publics du Québec (181M)

Association du Québec pour l'intégration sociale (182M)

Association étudiante pour la justice sociale (141M)

Association québécoise pour la défense des droits des personnes retraitées et préretraitées – Laval (164M)

Association québécoise de défense des droits des retraités et des préretraités – Centre-du-Québec (204M)

Association québécoise de défense des droits des retraités et des préretraités de la MRC de Joliette (216M)

Association québécoise de défense des droits des retraités et des préretraités, section Trois-Rivières (133M)

* The numbers in parentheses refer to the numbers of the briefs on the National Assembly website.

Association québécoise de gérontologie (183M)
 Association québécoise de prévention du suicide (120M)
 Association québécoise des directeurs et directrices d'établissement d'enseignement retraités (052M)
 Association québécoise des retraité(e)s des secteurs public and parapublic (099M)
 Association québécoise d'établissements de santé et de services sociaux (083M)
 Association québécoise pour le droit de mourir dans la dignité (190M)
 Association québécoise pour le droit de mourir dans la dignité – Mauricie (136M)
 Québec Bar (229M)
 Quebec Life Coalition (103M)
 Carpe Diem – Centre de ressources Alzheimer (184M)
 Chambre des notaires du Québec (230M)
 Knights of Columbus Quebec (186M)
 Coalition des médecins pour la justice sociale (188M)
 Coalition humaniste des étudiants en médecine (112M)
 Collectif de Femmes Engagées d'Alma (102M)
 Collectif Mourir digne et libre (165M)
 Comité des résidents of the Montréal Chest Institute (059M)
 Conseil pour la protection des malades (074M)
 Conseil québécois des gais et lesbiennes (108M)
 Corporation Albatros Inc. (202M)
 Cote des Neiges Presbyterian Church (028M)
 English Speaking Catholic Council (030M)
 Fédération des médecins omnipraticiens du Québec (212M)
 Fédération des Mouvements Personne d'Abord du Québec (208M)
 Fédération interprofessionnelle de la santé du Québec (151M)
 Vaudreuil–Soulanges Health Care Foundation (086M)
 L'Envolée (194M)
 Forum des citoyens aînés de Montréal (069M)
 Maison Aube-Lumière (249M)
 Maison de soins palliatifs de la Rivière-du-Nord (070M)
 Maison de soins palliatifs de l'est-de-l'Île-de-Montréal (219M)
 Maison Mathieu-Froment-Savoie (142M)

Maison Michel-Sarrazin (125M)
 NOVA Montreal (138M)
 Office des personnes handicapées du Québec (121M)
 Ordre des infirmières et infirmiers du Québec (134M)
 Ordre des médecins vétérinaires du Québec (130M)
 Ordre des psychologues du Québec (226M)
 Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec (197M)
 Palliaco des Sommets (124M)
 Regroupement provincial des comités des usagers (093M)
 Réseau de soins palliatifs du Québec (115M)
 Réseau FADOQ (215M)
 Service des soins spirituels du CSSS de Saint-Jérôme (097M)
 Bruyère Continuing Care (127M)
 English-speaking parish of St. Augustine of Canterbury in Saint-Bruno-de-Montarville (239M)
 Table de Réflexion et d'Action de Retraités et d'Aînés de la MRC Rivière-du-Nord (110M)
 Table régionale des aînés des Laurentides (265M)
 Vive la Vie (001M)
 Living with Dignity (203M)

Individuals

Véronique Angers (098M)
 Flor Del Pilar Arana
 Irene Armano (175M)
 Marthe Asselin Vaillancourt
 Drs. Joseph Ayoub, André Bourque, Catherine Ferrier, François Lehmann, José Morais and others (023M)
 Barbara Bagshaw (072M)
 Lorraine Baker
 Gregory Barrett (148M)
 John Zucchi and others (137M)
 Élisabeth Beauchesne (135M)
 Jean-Pierre Béland (158M)
 Julie Bélanger (015M)

Pierre A. Bélanger (012M)
Cristina Benetti, Mary Grace Griffin and other (191M)
Lisette Benoit (025M)
Ida Bilodeau (178M)
Paul Biron (087M)
Dr. Agathe Blanchette
Sarto Blouin (140M)
Dr. Marcel Boisvert (042M)
St-Jean Bolduc (096M)
Hélène Bonin
Julie Bonneville (035M)
Francis Boudreau (153M)
Jeffrey Brooks (170M)
Laurence Brunelle-Côté
Christian Caillé
Joseph Caron (123M)
Me Danielle Chalifoux (228M)
François Champoux (051M)
Thérèse Chaput, Robert Marsolais and Denise Nadeau (068M)
Nicole Charbonneau Barron (156M)
Elisabeth Chlumecky (113M)
Alexandre Chouinard
Marlène Coulombe
Michel Couture, represented by Linda Couture and Antoine Couture
Vincent G. Cuddihy (201M)
Isabelle Cyr
André Dagenais (111M)
Dr. Michelle Dallaire (129M)
Madeleine Dalphond-Guiral (064M)
Dr. Serge Daneault (258M)
Suzanne Danis
Monique David (159M)
Thomas De Koninck (095M)
Maria Del Pilar Sarmiento Hernandez and Sandrine Futchá (155M)
Me Diane L. Demers (071M)

Dr. François Desbiens (167M)
Pierre Deschamps
Louis DeSerres (192M)
Ploa Desforges
Jean Deslauriers (193M)
Anna Di Nunzio
Paola Diadori
Louis Dionne (094M)
Hubert Doucet (063M)
Doris Dubreuil (046M)
Robert Duchesne
Onil Dumont (058M)
Benoît Élie (217M)
Dr. Sherif Emil
Enante Emilus (109M)
Rouleau family (077M)
Edmond Ferenczi (006M)
Catherine Filion
Dominique Foisy-Geoffroy
Clarissa Foley
André Fortin (213M)
Mgr Pierre-André Fournier (196M)
Aline Fredette
Pierre Gagné (079M)
Bertrand Gagnon (195M)
Glen Gagnon
Jocelyne Gagnon (032M)
Doris Germain-Gagnon (041M)
Ghislaine Gillet (039M)
Martin Giroux
Nicole Gladu (082M)
Marie-Josée Gobeil
Me Allan J. Gold (261M)
Adela González Casal (180M)
Jacques Grand'Maison (003M)

Maria Cecilia Grava, Mariane Hamel, Christiane Beauregard, Barbara Desjardins, Cristina Ardelean, Martine Leduc, Adriana Di Donato, Francesca Aleotti and Nicoletta Toffoli (081M)

Mary Grace Griffin

Richard Haber

Carmen Hardy (271M)

Dr. Jana Havrankova (056M)

Jacqueline Hébert (009M)

Michael Hendricks (060M)

Lucienne Jetté and Jacques Vincent (085M)

Sheila Jones (118M)

Brigid Kane (062M)

Grazina Kieller Ilczuk

Isabelle Krauss (091M)

Dr. Louise La Fontaine (033M)

Doris Labrecque (107M)

Robert Labrecque (198M)

Jean-Claude Lachapelle

Daniel Laflamme (116M)

Carole Lafrance (100M)

Élise Lalonde (154M)

Alain Lampron (233M)

Geneviève Laplante (038M)

Geneviève Lavoie (157M)

Colombe Le Houx

Danielle L'Écuyer (168M)

Michel Rousseau, Michelle Leduc, René Rouleau, Yvon Poitras and Johanne Frenette (117M)

Christine Leduc (187M)

Diane Leduc (250M)

Alain Legault

Ted Lender (061M)

Maria G. Lepore (128M)

Daniel Lévesque

Josette Lincourt (088M)

Agostino Lucarelli and others (106M)

Joan B. Lusignan (161M)
Gillian Lusignan
Patrick Mahony (252M)
Giuseppe Maiolo
Dr. Réal Major (004M)
Zoé Major
Dr. Aline Mamo and others (150M)
Odile Marcotte (149M)
Gilles Marsolais (073M)
Lorraine Mazzella (072M)
John McCallum, Randal Cowie, Dave Bowie, Phil Anderson and John W. Fossey (019M)
Teresa McConnon (055M)
Physicians from the Geriatric Department of McGill University (210M)
Physicians and nurses caring for cancer patients who oppose euthanasia and assisted suicide (207M)
Jean Mercier (211M)
Marguerite Mérette (146M)
Brian L. Mishara (235M)
Guylaine Morin
Michael Newman
Nicholas Newman (119M)
William A. Ninacs
Éric Normandeau
Gus Olsthoorn (008M)
Sonia Ouellet
Adam Pasamanick (139M)
André Pelletier (254 M)
Maxime Plamondon (048M)
Danielle Émilie Poirier (264M)
André Prévost (010M)
Dr. François Primeau (014M)
McGill University professors opposed to euthanasia and assisted suicide (137M)
Palliative care program, Oncology Department, McGill University (209M)
Philip Raphals (176M)

Sara Susan Raphals (177M)
Jean-Noël Ringuet (020M)
Eugenia Rivas
André Rochon (160M)
Marie-Dominique Rouleau
Odette Royer, Marjolène Di Marzio, Huguette Ruel, Stéphanie Béchard,
Claude Proulx and Steeve Gauthier (089M)
Carmen Sansregret (105M)
Paule Savignac
Robert Senet (047M)
Line Simard
Georges Sobolweski (026M)
Margaret Somerville (045M)
Frédéric Sparer
Dennis Stimpson (104M)
Diane St-Onge (199M)
René Théberge (031M)
Laurier Thériault (122M)
Luc Thériault (266M)
Inés Maria Tillard (200M)
Linda Tremblay (066M)
Silvia Ugolini (166M)
Natalie Valle (147M)
Rénald Veilleux (053M)
Élizabeth Verge (067M)
Dr. Louise Villemure (101M)
Georges Villeneuve
Vaclav Vychytil (092M)
Ouanessa Younsi

ORGANIZATIONS AND INDIVIDUALS NOT HEARD, BUT BRIEF SUBMITTED

Organizations

Association des juristes catholiques du Québec (259M)
 Association for Reformed Political Action Canada (024M)
 Association québécoise de défense des droits des retraités et des préretraités – Québec (234M)
 Canadian Society of Palliative Care Physicians (145M)
 Centre de recherche et d'expertise en gérontologie sociale du CSSS Cavendish (273M)
 Christian Legal Fellowship (163M)
 ChristianGovernance (132M)
 Collège des médecins du Québec (050M)
 Comité national d'éthique sur le vieillissement et les changements démographiques du Conseil des aînés (227M)
 Confédération des organismes de personnes handicapées du Québec (189M)
 Covenant Health (143M)
 Culture et Foi (Outaouais-des-Deux-Rives) (016M)
 DeVeber Institute for Bioethics and Social Research (172M)
 Fédération des médecins spécialistes du Québec (214M)
 Institute of Marriage and Family Canada (084M)
 Catholic Organization for Life and Family (131M)
 Respect for Life – Education Movement (011M)
 VieCanada – LifeCanada (126M)
 REAL Women of Canada (090M)

Individuals

Michel Allaire (222M)
 Éric Beaudoin (262M)
 France Beaudoin (017M)
 Isabelle Bégin-O'Connor (076M)
 Chantal Bélanger (021M)
 Robert Bikerdike (272M)
 Danielle Blondeau (044M)

Jacques Blouin (057M)
Dr. Antoine Boivin (231M)
Dr. Marcel Boulanger (256M)
Gaston Bourdages (224M)
Vicky Brunet-Girard (245M)
Christina Calder (171M)
Jacques Carrier (270M)
Robert Clément (013M)
Marie-Reine Côté (236M)
Carolle Cotnoir (257M)
Émilie Courval (241M)
Linda Couture (269M)
Gilles de Lafontaine (018M)
Carole Deschênes (114M)
Marie-Ève Desgagné-McLean (267M)
Me Margaret K. Dore (144M)
Jean-Yves Dubé (237M)
Christian Duchesne (268M)
Jean Duchesneau and Louise Duchesneau (221M)
Dr. Catherine Ferrier (185M)
Éric Folot (007M)
Nicole Fortin (232M)
François Gaumond (240M)
Christopher B. Gray (022M)
Charles André Horth (255M)
Monique Khouzam-Gendron (260M)
Tom Koch (173M)
Laurence Labelle (247M)
Dianne Laheurte (049M)
François Lapierre (002M)
Guylaine Larose (220M)
André Ledoux (040M)
Claude Lemieux (253M)
Petia Lichkova (174M)
Elizabeth Lier (248M)

Claude Magny (027M)
Gilles Marleau (029M)
André Mathieu (263M)
Madeleine Mayer (078M)
Claudette Melançon (225M)
Sabrina Mercier (244M)
Ward O'Connor (075M)
Parishioners of Sainte-Angèle-de-Saint-Malo (179M)
Jocelyne Pichette (238M)
Marie-Pier Plouffe (243M)
Julie Prévost (169M)
Julio Quintero (251M)
Suzanne Raymond (034M)
Carl Rodrigue (162M)
Miodrag Roksandic (054M)
Sabrina Rondeau (242M)
Maurice J. Roy (005M)
Gabrielle Soucy (065M)
Valérie Tanguay (223M)
Kariane Thibault (246M)
Liane Vignola (043M)

INDIVIDUALS WHO PARTICIPATED DURING THE OPEN MIC PERIODS

Geneviève Arsenault
Max Bauchet
Monique Beaudoin
Pierre Beaudry
Claudette Beaulieu
Lise Beaulieu
Marie Bégin
Gaétane Bergeron
Réjean Bergeron
Dr. Paul Clifford Blais
Raymond Blouin

Ève Boisly
Edna Boiselle
Marie-France Bouchard
Nicole Bouchard
Gaston Bourdages
Nicole Brunet
Gaston Carmichael
Hélène Charpentier
Paul Chénard
Valérie Clift
Allan Conway
Anita Cormier
Shelley Corrin
Marie-Thérèse Costisella
Marlène Côté
Hélène Couture
Marie Couture
Lise Cuillerier
Katherine Dadei
Louise De Brouin
Priscille De Galembert
Marie-Ève Desgagné
Martin Desrosiers
Lise Dolbec
Marie-Andrée Dorais
Teresa Doyle
Danielle Drolet
Yves Fecteau
Gloria Fex
Martin Fortier
Patrice Fortin
Jean-Yves Gagnon
Gisèle Gauthier-Simard
Diane Gauvin
Angela Ghezzi

Anne Godbout
André Godin
Pierre Goulart
Maria Cecilia Grava
Jean-François Gravel
Robert Greig
Louise Hamel
Amy Hasbrouck
Michelle Houle
Danielle Hudon
Evelyl Huglo
Don Ivanski
Francine Jinchereau
Marie-Thérèse Kazeef
Monique Khouzam-Gendron
Jocelyne Kilpatrick
Marc-Antoine L'Heureux
Christine Lachance
François Lagarde
Jacques Lalanne
Roxanne Laliberté
Sylvain Lamontagne
Pauline Landry
Daniel Langlois
Lyne Larose
Pauline Leblanc
Louise Leclerc
Diane Leduc
Thérèse Légaré
Claude Lemieux
Ginette Lemieux
Élizabeth Létourneau
Paul Marchand
Rachel Marcotte
France Maxant

Denise Ménard Hamel
Marthe Meyers
Normand Michaud
Roger Millaire
Cindy C. Morin
Lorette Noble
Lunine Norbal
Laurence Normand-Rivet
Victor Olaguera
Danielle Ouellette
Marie-Claude Pastorel
Marcel Pennors
Suzanne Philips-Nooteens
Lucie Plante
Marie-Michelle Poisson
Huguette Potvin
Jeanine Pruner
Claude Quintin
Andréa Richard
Jeannine Richard
Louise Rives
Jean Sicotte
Françoise Simard
Thomas Somcynsky
Patrick St-Onge
Théa Stoina
Julie Sullivan
Valérie Tanguay
Marie-Hélène Vachon
Angelo Zanchette
Maximilian Zucchi

APPENDIX IV

Results of the Online Consultation

PRESENTATION

In an effort to elicit the broadest response possible, the Select Committee on Dying with Dignity used various ways to allow everyone to be heard. One way was an online questionnaire, available on the National Assembly website for those who could not or did not wish to submit a brief or a request to be heard.

The quantitative results of this questionnaire were compiled at the end of the consultation period and are presented here in the form of graphs and pie charts. We also felt it important to present the highlights of the results. Although the online consultation is not a scientific poll, the significant number of respondents certainly gives an undeniable value to the answers received and indicates some trends in Québec society.

HIGHLIGHTS

Respondent profile

- A total of 6,558 respondents completed the online questionnaire.
- Of this number, 3,820 (58.2%) were women and 2,738 (41.8%) were men.
- 29% were under age 30, and 49% were between 40 and 59.
- Nearly 50% were from the administrative regions of Montréal, Montérégie and Capitale Nationale.

Questions about euthanasia

- In all, 74% agree with the legalization of euthanasia under certain conditions, and 25% disagree.
- As for who should be allowed to request euthanasia, adults capable of deciding for themselves (79%) and people who make the request in advance in anticipation of incapacity (79%) were the top two answers. Minors capable of deciding for themselves (40%) constitute the category that received the least support.

- As for situations that might justify a request for euthanasia, 80% feel euthanasia should be made available to people with an incurable illness who suffer from unbearable psychological and physical pain. The situation that received the least support is that of people who are severely handicapped following an accident (64%), while people with a degenerative and incapacitating illness received 70% of support.
- Fifty-nine percent feel that society as a whole supports the legalization of euthanasia, and 82% are of the opinion that lawmakers should take society's views into account when considering the legalization of euthanasia.

Questions about assisted suicide

- In all, 71% agree with the legalization of assisted suicide under certain conditions, while 27% disagree.
- As for who should be allowed to request assisted suicide, adults capable of deciding for themselves was the top answer (77%), just as for euthanasia. Again here, minors capable of deciding for themselves (40%) constitute the category that received the least support.
- Much like for euthanasia, 77% feel assisted suicide should be made available to people with an incurable illness who suffer from unbearable psychological and physical pain. The situation that received the least support is that of people who are severely handicapped following an accident (65%), again much like euthanasia, while people with a degenerative and incapacitating illness received 69% of support.
- Half of the respondents feel that society as a whole supports the legalization of assisted suicide, and 81% are of the opinion that lawmakers should take society's views into account when considering the legalization of assisted suicide.

Arguments in favour of euthanasia and assisted suicide

- The argument in favour of euthanasia and assisted suicide with which respondents agree the most (77%) is as follows: "Since it is legal for a person to refuse or request an end to treatment, even if it results in death, it should be legal to request assisted death". This is also the most commonly invoked argument by those in favour of legalizing euthanasia (94%) and assisted suicide (95%).
- The argument in favour of euthanasia and assisted suicide with which respondents agree the least (56%) is as follows: "The fact that assisted death is illegal may encourage artificial prolongation of life".

- Nearly one third of **those against legalizing** euthanasia and assisted suicide nevertheless agree with the following statement: “The current legislative framework does not reflect clinical realities. This causes confusion among healthcare professionals and the public. Changes to legislation are therefore necessary”.

Arguments against euthanasia and assisted suicide

- The argument against euthanasia and assisted suicide with which respondents agree the most (48%) is as follows: “Sick and elderly individuals worried about being a burden to their loved ones may request assisted death”.
- The argument against euthanasia and assisted suicide with which respondents agree the least (15%) is as follows: “Legislation is not necessary, as only a tiny minority of the ill will request legalized assisted death”.
- Among the **respondents against legalizing** euthanasia and assisted suicide, the argument that receives the most support, from nearly three-quarters of them, is the following: : “Human life is sacred, and there is no justification for ending it intentionally”.
- Approximately 40% of **those in favour of legalizing** euthanasia and assisted suicide nevertheless agree with the following statement: “Sick and elderly individuals worried about being a burden to their loved ones may request assisted death”.

Respondent profile*

- Fifty-six percent of respondents who are palliative care volunteers agree with legalizing euthanasia and assisted suicide. This is 17% less than the overall support for legalizing euthanasia and 15% less than the overall support for legalizing assisted suicide.
- Forty-eight percent of respondents who are palliative care volunteers agree with the following statement: “Palliative care cannot always relieve patients of unbearable pain and suffering. Assisted death may therefore provide a solution”, while 66% of all respondents concur with this statement.

* Respondents were asked to check the box or boxes that best reflected their situation, i.e. citizen with a personal interest in the topic of dying with dignity; person with a terminal or degenerative disease; friend or relative of a person with a terminal or degenerative illness; person who has accompanied a loved one (friend or relative) in the final stages of life; palliative care volunteer, healthcare professional, member of an activist group in favour of or opposed to euthanasia and assisted suicide, and researcher interested in euthanasia and assisted suicide.

- Sixty-nine percent of health professional respondents agree with legalizing euthanasia, and 64% are in favour of assisted suicide. This is 5% less than the overall support for legalizing euthanasia and 7% less than the overall support for legalizing assisted suicide.
- The following table shows the position of health professional respondents regarding certain arguments pertaining to their work:

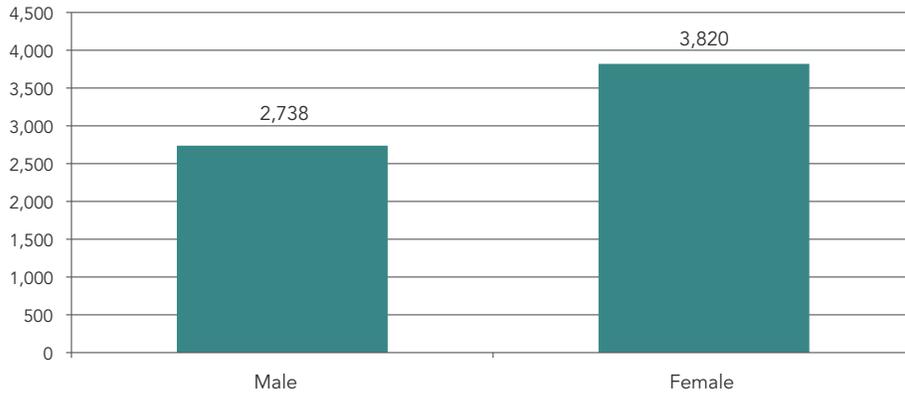
	HEALTH PROFESSIONALS		ALL RESPONDENTS	
	Agree	Disagree	Agree	Disagree
Those in favour of legalizing assisted death (euthanasia, assisted suicide) typically invoke the arguments below. What is your opinion on each of them?				
Palliative care cannot always relieve patients of unbearable pain and suffering. Assisted death may therefore provide a solution.	64%	35%	75%	24%
The fact that assisted death is illegal may encourage artificial prolongation of life.	69%	39%	66%	30%
The current legislative framework does not reflect clinical realities. This causes confusion among healthcare professionals and the public. Changes to legislation are therefore necessary.	72%	24%	75%	18%
Legal oversight would prevent people from choosing assisted death in secret.	69%	38%	74%	21%
Those who disagree with legalizing assisted death (euthanasia, assisted suicide) typically invoke the arguments below. What is your opinion on each of them?				
Doctors will not do everything possible to keep patients alive.	24%	71%	21%	73%
Assisted death legislation may hinder government efforts to provide the necessary level of support to the seriously ill and dying.	36%	59%	31%	63%
The criteria for assisted death requests would not always be respected.	34%	57%	29%	60%

- Individuals with a terminal or degenerative disease were significantly more in favour of legalizing euthanasia (91% versus 74% for all respondents) and assisted suicide (85% versus 71% for all respondents). Most of these respondents believe that anyone with a degenerative and incapacitating illness should be able to ask for assistance to die (85% versus 70% for all respondents).
- Respondents aged 60 and over were the least in favour of legalizing euthanasia and assisted suicide (12% less than for all respondents), but a majority was still in favour of legalization (62% for euthanasia and 59% for assisted suicide).
- Compared with respondents overall, those under age 18 were less amenable to allowing minors capable of deciding for themselves to make a request for assistance to die (6% less for euthanasia and 7% less for assisted suicide).

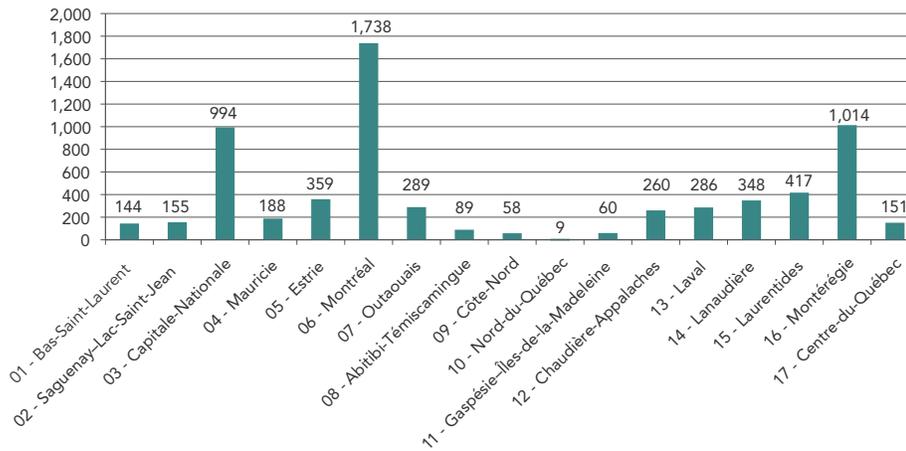
COMPILATION OF RESULTS

Respondent Profile

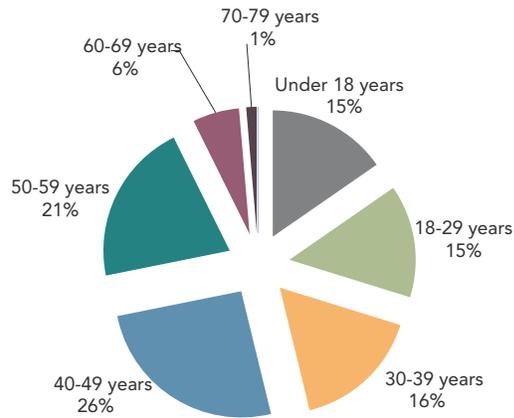
BREAKDOWN BY SEX



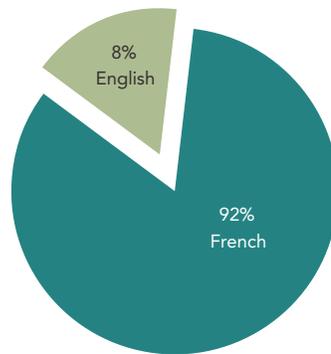
BREAKDOWN BY REGION



BREAKDOWN BY AGE

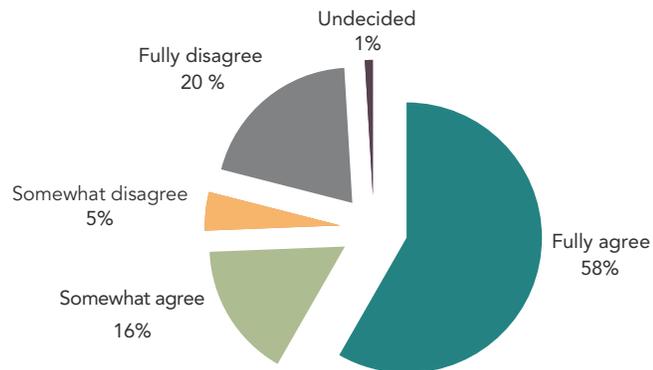


BREAKDOWN BY LANGUAGE OF COMPLETED QUESTIONNAIRE

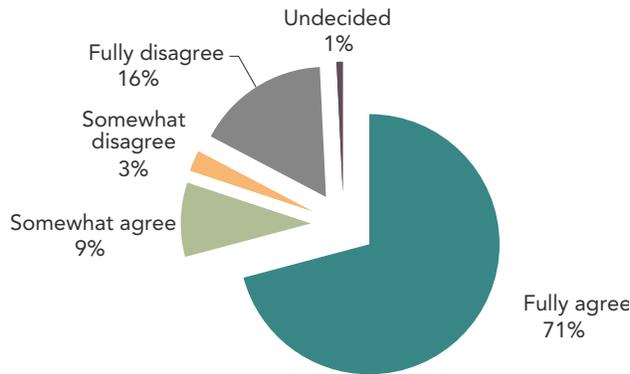


Questionnaire Answers

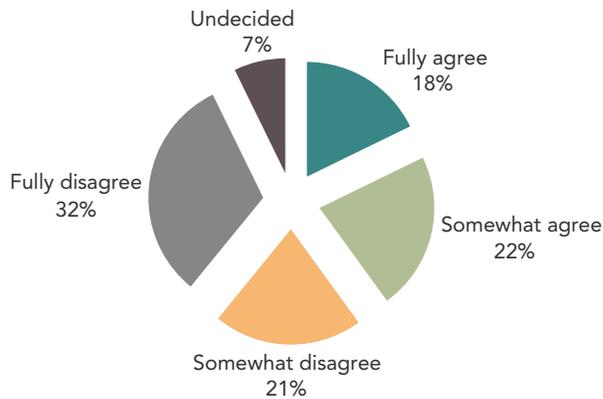
QUESTION 1 - DO YOU AGREE OR DISAGREE WITH THE LEGALIZATION OF EUTHANASIA UNDER CERTAIN CONDITIONS?



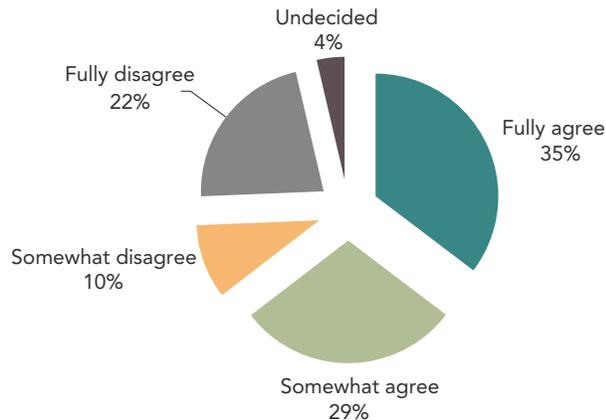
QUESTION 2 - WHO SHOULD BE ABLE TO REQUEST EUTHANASIA, PROVIDED THEY HAVE A VALID REASON?
Adults capable of deciding for themselves.



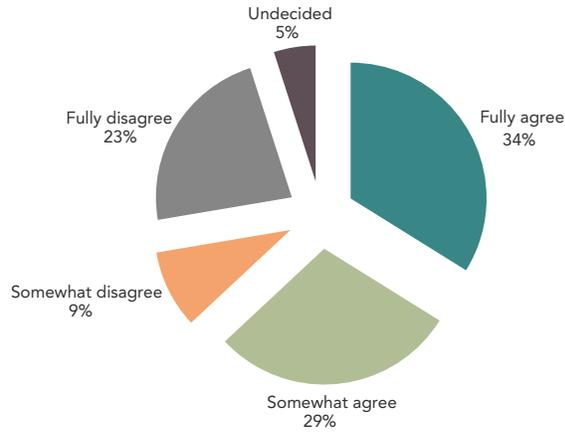
QUESTION 2 - WHO SHOULD BE ABLE TO REQUEST EUTHANASIA, PROVIDED THEY HAVE A VALID REASON?
Minors capable of deciding for themselves.



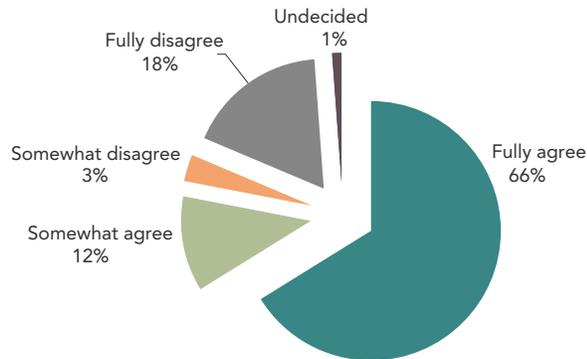
QUESTION 2 - WHO SHOULD BE ABLE TO REQUEST EUTHANASIA, PROVIDED THEY HAVE A VALID REASON?
Families of persons incapable of deciding for themselves.



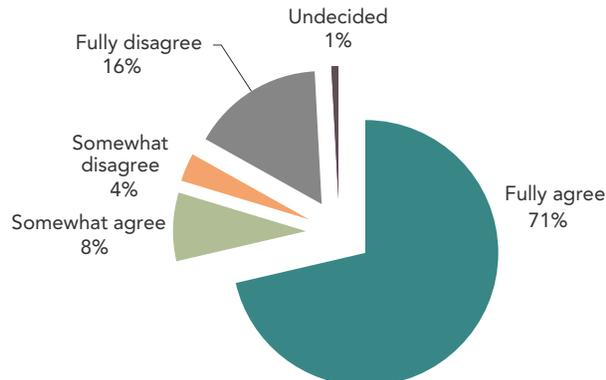
QUESTION 2 - WHO SHOULD BE ABLE TO REQUEST EUTHANASIA, PROVIDED THEY HAVE A VALID REASON?
Parents or guardians of a minor.



QUESTION 2 - WHO SHOULD BE ABLE TO REQUEST EUTHANASIA, PROVIDED THEY HAVE A VALID REASON?
People who make the request in advance in anticipation of incapacity.

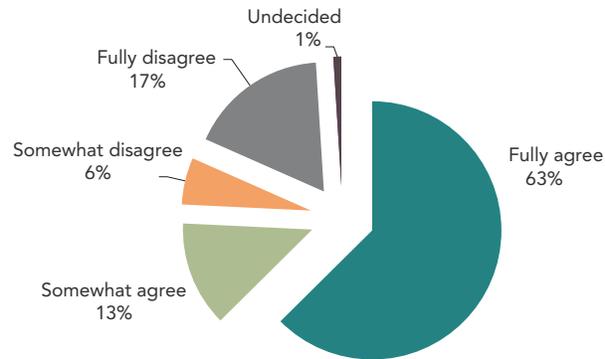


QUESTION 3 - IN YOUR OPINION, IN WHICH OF THE FOLLOWING SITUATIONS MIGHT A EUTHANASIA REQUEST BE JUSTIFIED?
People with an incurable illness who suffer from unbearable psychological and physical pain.



QUESTION 3 - IN YOUR OPINION, IN WHICH OF THE FOLLOWING SITUATIONS MIGHT A EUTHANASIA REQUEST BE JUSTIFIED?

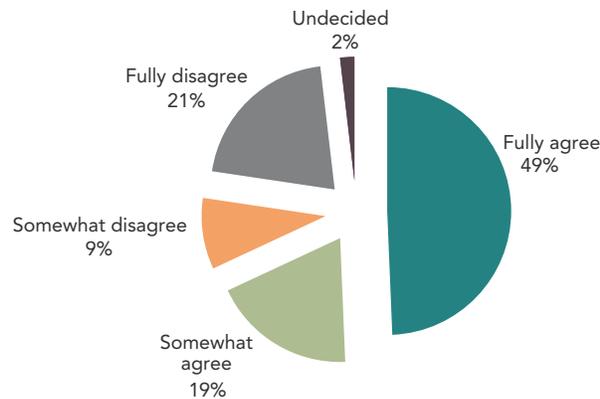
People in the final stages of a terminal illness who know they will experience intolerable pain.



QUESTION 3 - IN YOUR OPINION, IN WHICH OF THE FOLLOWING SITUATIONS MIGHT A EUTHANASIA REQUEST BE JUSTIFIED?

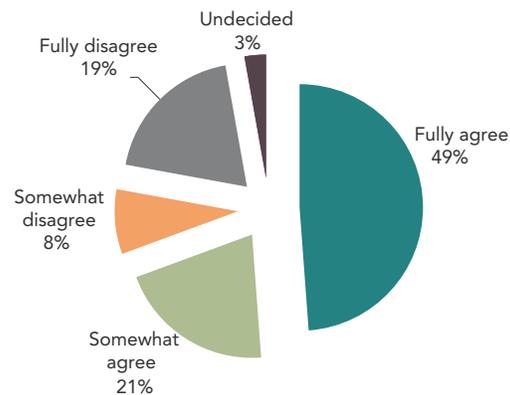
People whose death is imminent and inevitable.

Though their physical pain is treatable, they no longer wish to live.



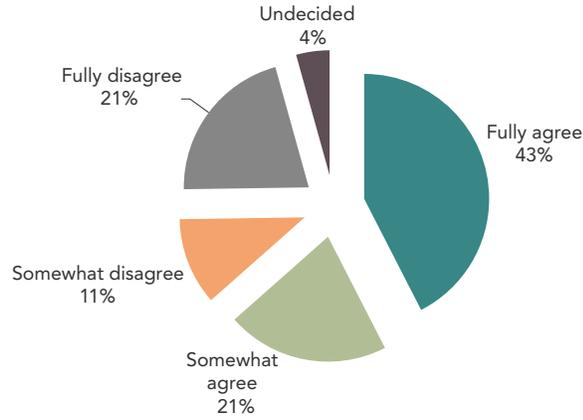
QUESTION 3 - IN YOUR OPINION, IN WHICH OF THE FOLLOWING SITUATIONS MIGHT A EUTHANASIA REQUEST BE JUSTIFIED?

People with a degenerative and incapacitating illness.



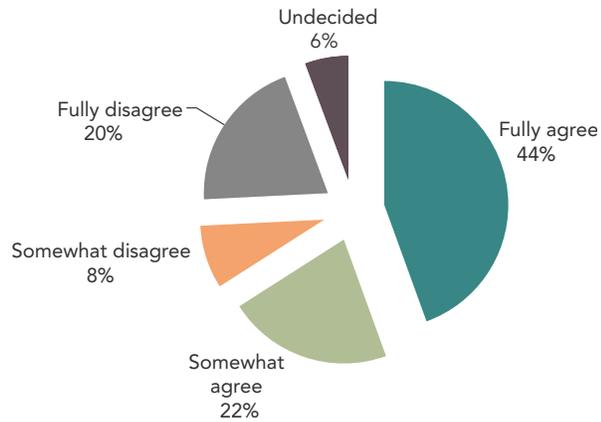
QUESTION 3 - IN YOUR OPINION, IN WHICH OF THE FOLLOWING SITUATIONS MIGHT A EUTHANASIA REQUEST BE JUSTIFIED?

People who are severely handicapped following an accident.

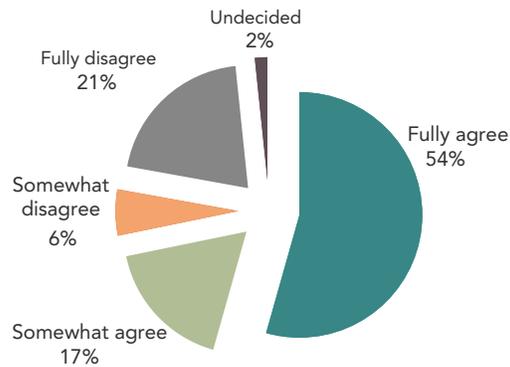


QUESTION 3 - IN YOUR OPINION, IN WHICH OF THE FOLLOWING SITUATIONS MIGHT A EUTHANASIA REQUEST BE JUSTIFIED?

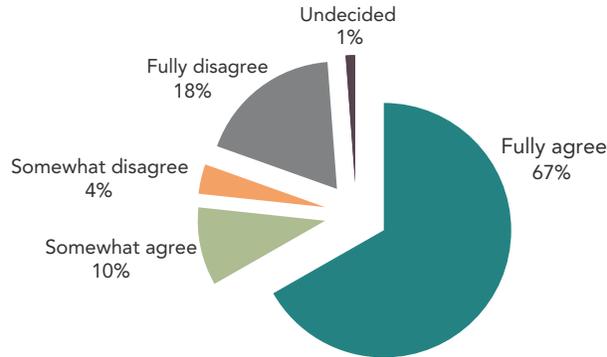
Children with a serious and incurable terminal illness.



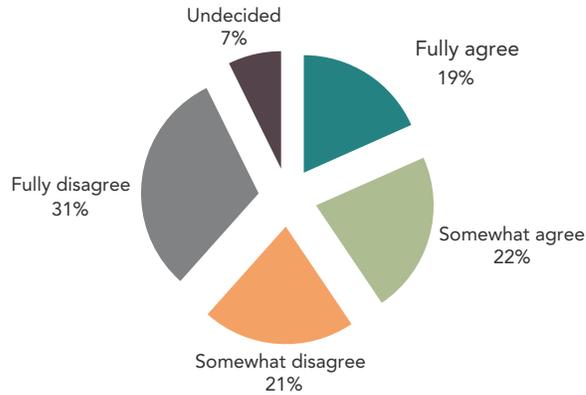
QUESTION 4 - DO YOU AGREE OR DISAGREE WITH THE LEGALIZATION OF ASSISTED SUICIDE UNDER CERTAIN CONDITIONS?



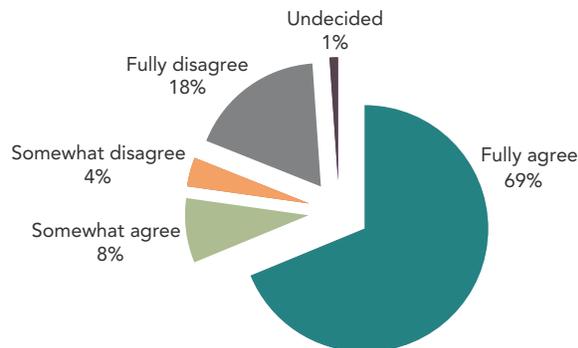
QUESTION 5 - WHO SHOULD BE ABLE TO REQUEST ASSISTED SUICIDE, PROVIDED THEY HAVE A VALID REASON?
Adults capable of deciding for themselves.



QUESTION 5 - WHO SHOULD BE ABLE TO REQUEST ASSISTED SUICIDE, PROVIDED THEY HAVE A VALID REASON?
Minors capable of deciding for themselves.

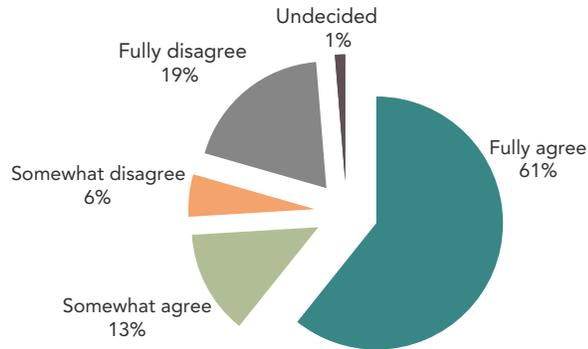


QUESTION 6 - IN YOUR OPINION, WHICH OF THE FOLLOWING SCENARIOS MIGHT JUSTIFY A REQUEST FOR ASSISTED SUICIDE?
People with an incurable illness who suffer from unbearable psychological and physical pain.



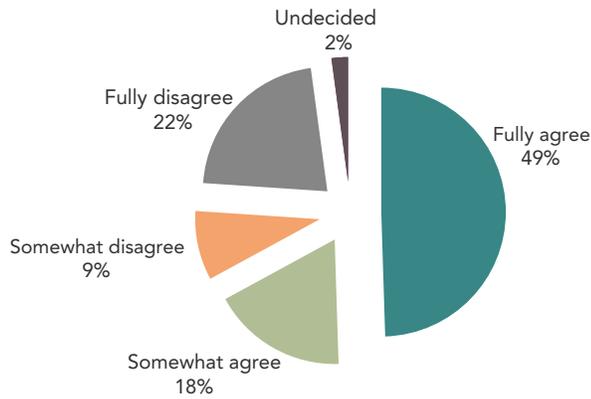
QUESTION 6 - IN YOUR OPINION, WHICH OF THE FOLLOWING SCENARIOS MIGHT JUSTIFY A REQUEST FOR ASSISTED SUICIDE?

People in the final stages of a terminal illness who know they will experience intolerable pain.



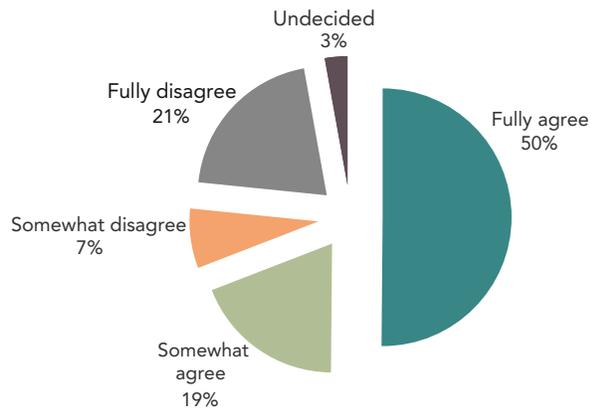
QUESTION 6 - IN YOUR OPINION, WHICH OF THE FOLLOWING SCENARIOS MIGHT JUSTIFY A REQUEST FOR ASSISTED SUICIDE?

People whose death is imminent and inevitable. Though their physical pain is treatable, they no longer wish to live.

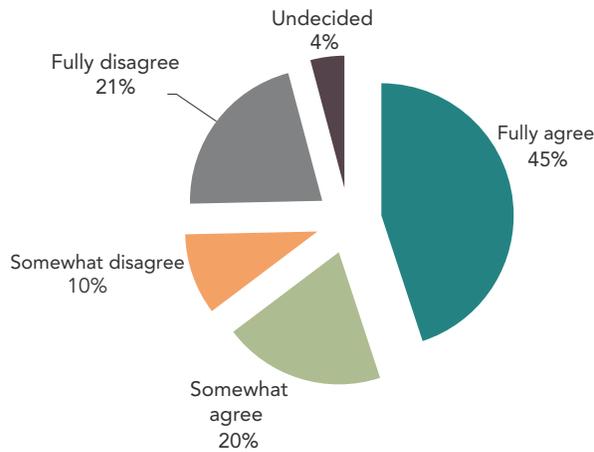


QUESTION 6 - IN YOUR OPINION, WHICH OF THE FOLLOWING SCENARIOS MIGHT JUSTIFY A REQUEST FOR ASSISTED SUICIDE?

People with a degenerative and incapacitating illness.

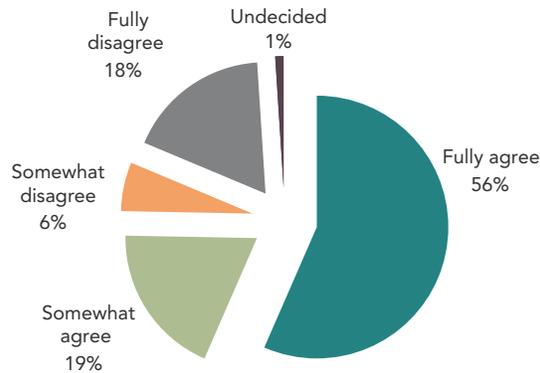


QUESTION 6 - IN YOUR OPINION, WHICH OF THE FOLLOWING SCENARIOS MIGHT JUSTIFY A REQUEST FOR ASSISTED SUICIDE?
People who are severely handicapped following an accident.

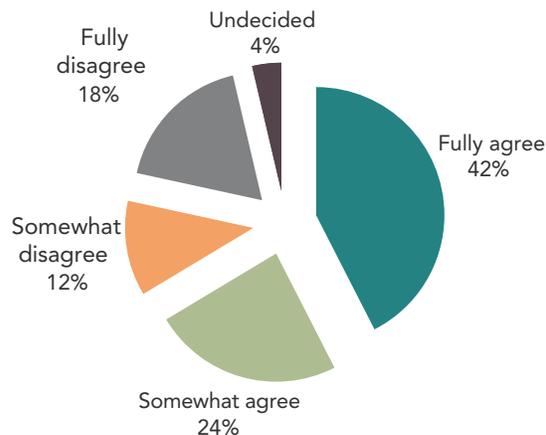


QUESTION 7 - THOSE IN FAVOUR OF LEGALIZING ASSISTED DEATH (EUTHANASIA, ASSISTED SUICIDE) TYPICALLY INVOKE THE ARGUMENTS BELOW. WHAT IS YOUR OPINION ON EACH OF THEM?

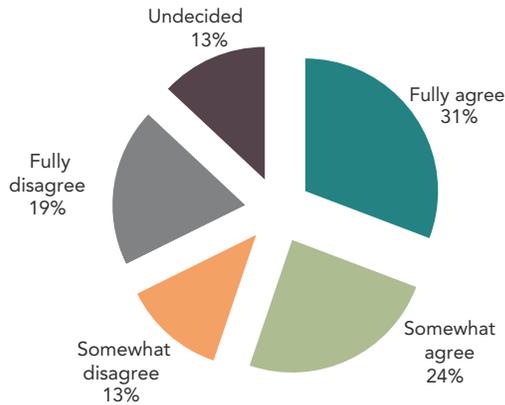
Palliative care cannot always relieve patients of unbearable pain and suffering. Assisted death may therefore provide a solution.



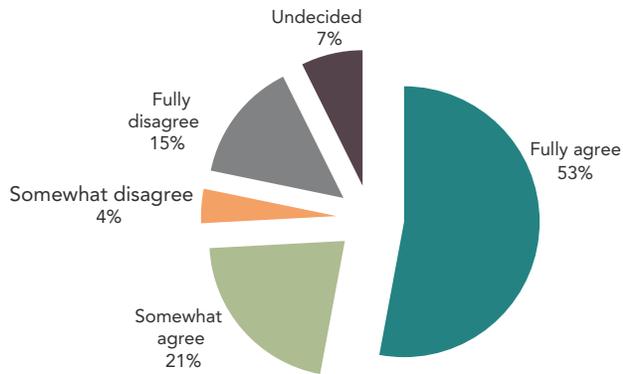
The fact that assisted death is illegal may encourage artificial prolongation of life.



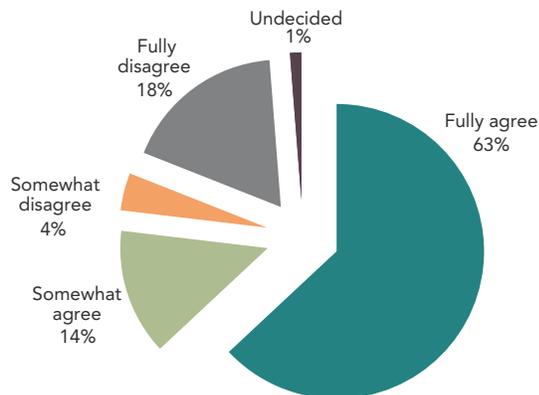
If euthanasia were legal, there would be less suicide among the elderly.



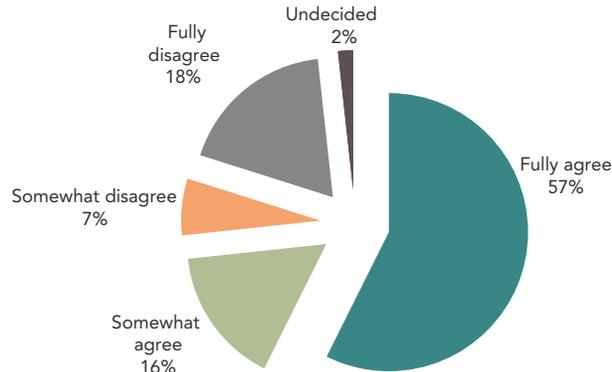
The current legislative framework does not reflect clinical realities. This causes confusion among healthcare professionals and the public. Legislative changes are therefore necessary.



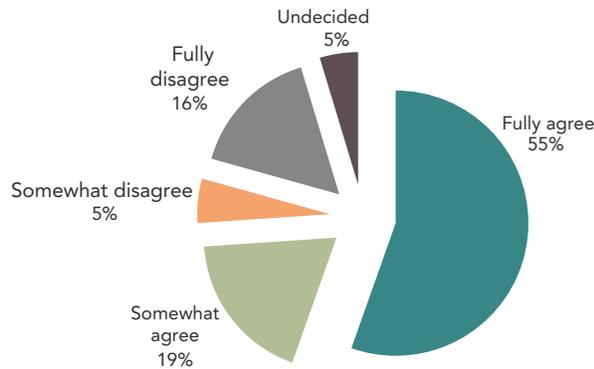
Since it is legal for a person to refuse or request an end to treatment, even if it results in death, it should be legal to request assisted death.



People have free will and should ultimately be able to decide when and how to die if their quality of life becomes intolerable.

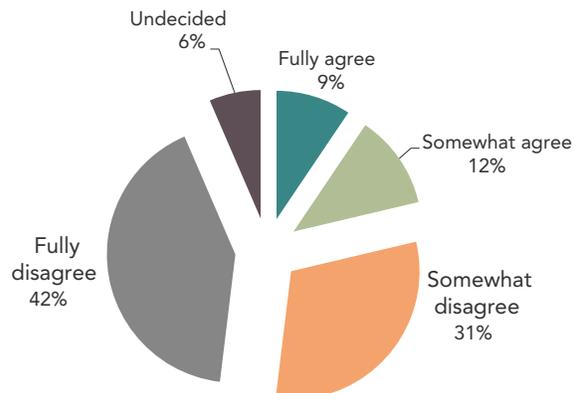


Legal oversight would prevent people from choosing assisted death in secret.

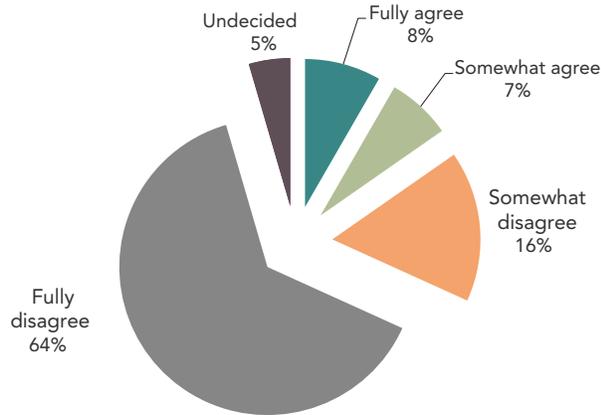


QUESTION 8 - THOSE WHO DISAGREE WITH LEGALIZING ASSISTED DEATH (EUTHANASIA, ASSISTED SUICIDE) TYPICALLY INVOKE THE ARGUMENTS BELOW. WHAT IS YOUR OPINION ON EACH OF THEM?

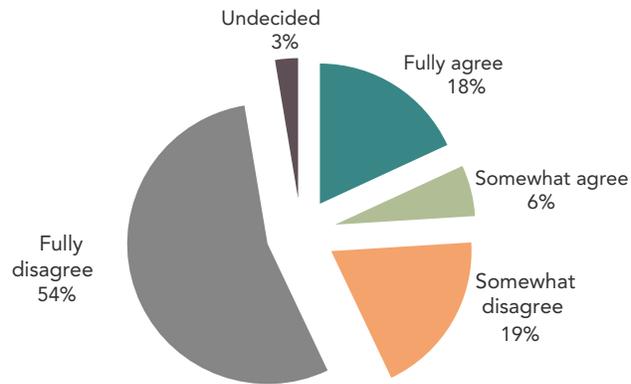
Doctors will not do everything possible to keep patients alive.



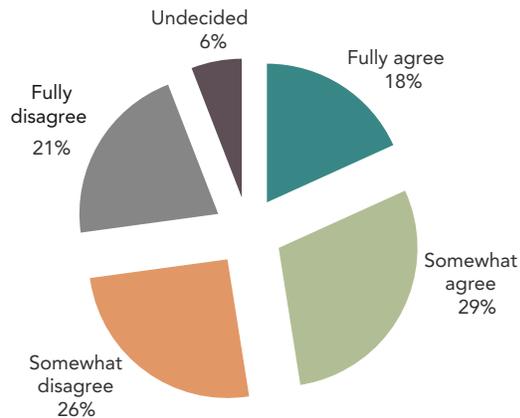
Legislation is not necessary as only a tiny minority of the ill will request a legalized assisted death.



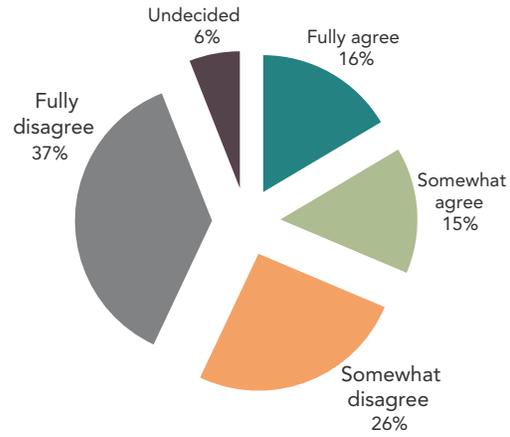
Human life is sacred and there is no justification for ending it intentionally.



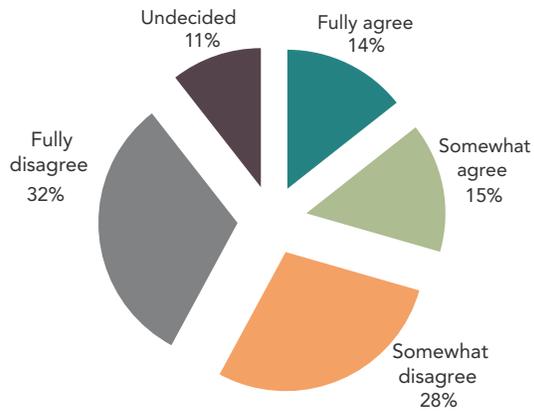
Sick and elderly individuals worried about being a burden to their loved ones may request assisted death.



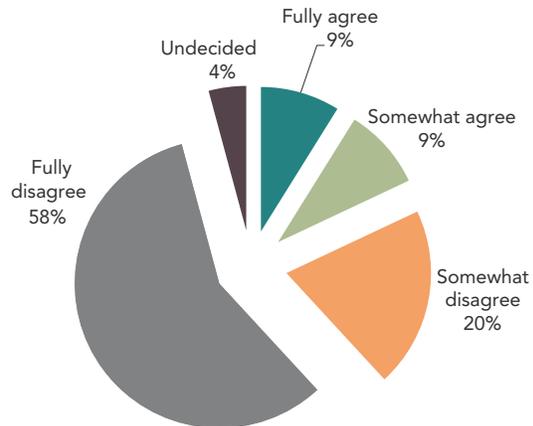
Assisted death legislation may hinder government efforts to provide the necessary level of support to the seriously ill and dying.



The criteria for assisted death requests would not always be respected.



A dying person is not capable of making a free and informed decision.



QUESTION 9 - IF EUTHANASIA OR ASSISTED SUICIDE HAD TO BE LEGALIZED, WHICH WOULD YOU CHOOSE?

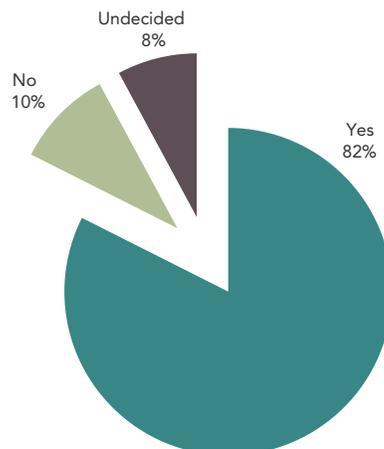
Some respondents found this question biased, because it did not offer the option to answer “neither one.” We therefore decided not to take the answers to this question into consideration. Some felt we were forcing the hand of those opposed to legalizing euthanasia and assisted suicide, because they could not move on to the next question unless they answered question No. 9. Our rationale for proceeding in this manner was to prevent respondents from inadvertently returning incomplete questionnaires; consequently, every question had to be answered.

Our goal was to find out, regardless of the respondents’ convictions, i.e. for or against legalization, which of the two practices they would pick if one of them were to be legalized. We never intended to sway their answer. That said, we admit the question could have been more clear, and an additional choice should have been provided.

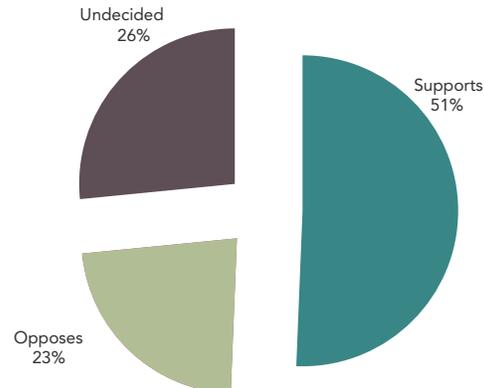
QUESTION 10 - DO YOU THINK THAT SOCIETY AS A WHOLE SUPPORTS OR OPPOSES THE LEGALIZATION OF EUTHANASIA?



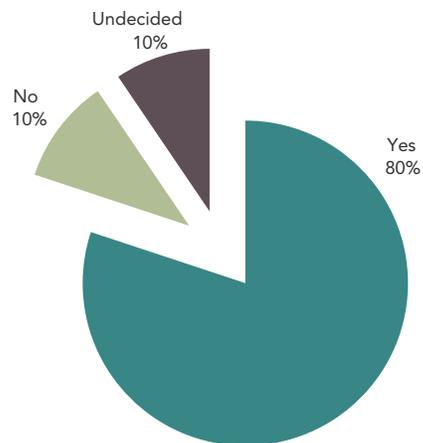
QUESTION 11 - IN YOUR OPINION, SHOULD LAWMAKERS TAKE SOCIETY'S VIEW INTO ACCOUNT WHEN CONSIDERING THE LEGALIZATION OF EUTHANASIA?



QUESTION 12 - DO YOU THINK THAT SOCIETY AS A WHOLE SUPPORTS OR OPPOSES THE LEGALIZATION OF ASSISTED SUICIDE?

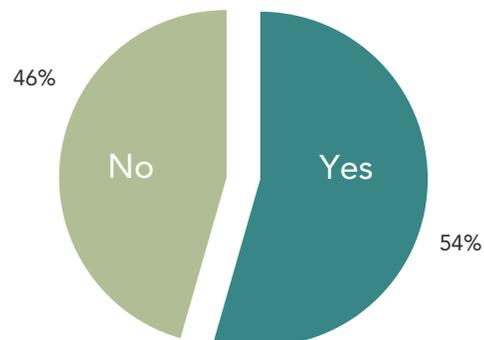


QUESTION 13 - IN YOUR OPINION, SHOULD LAWMAKERS TAKE SOCIETY'S VIEW INTO ACCOUNT WHEN CONSIDERING THE LEGALIZATION OF ASSISTED SUICIDE?



Reading of the consultation document

QUESTION 14 - HAVE YOU READ THE COMMITTEE'S CONSULTATION DOCUMENT ON THE ISSUE OF DYING WITH DIGNITY?



APPENDIX V

Foreign Experiences with Euthanasia and Assisted Suicide and the European Mission Agenda

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The Netherlands

Background

1980s	Euthanasia is still illegal, but case law is made up of not guilty verdicts against physicians who practice it (Supreme Court decisions in 1984 and 1986 in highly publicized cases).
1984	The Royal Dutch Medical Association comes out in favour of euthanasia.
1991	The Rummelink Commission, charged with investigating euthanasia and other medical decisions involving termination of life, concludes there were approximately 2,300 euthanasia cases in 1990, accounting for 1.8% of deaths that year.
EARLY 1990s	Discussions between the Justice and Health Departments lead to regulatory arrangements whereby doctors continue to be protected from prosecution for performing euthanasia.
1994	Dutch Parliament approves the Public administration regulation concerning termination of life. Although it does not legalize euthanasia, the regulation guarantees immunity to physicians who practice it in accordance with the stipulated "due care criteria."
1998	The government sets up termination of life on request and assisted suicide regional review committees and stipulates the methods of oversight.
1999	The Ministers of Justice and Health table a bill in the Lower House of Netherlands Parliament aimed at legalizing euthanasia, called "termination of life on request," and assisted suicide. The measure is adopted by the Lower House in November 2000 by a vote of 104 to 50 and in the Senate in April 2001 by a vote of 46 to 28.
2002	The <i>Termination of Life on Request and Assisted Suicide Act</i> comes into force on April 1, 2002.

The Termination of Life on Request and Assisted Suicide Act at a glance

- Under the Dutch Penal Code, euthanasia and assisted suicide are still criminal offences but physicians who act according to the law are exempt from criminal prosecution.
- The new provisions of the *Termination of Life on Request and Assisted Suicide Act* set out the due care criteria and confirm that the medical act performed in compliance with the law does not constitute a homicide or a crime against the person.
- Patients must be at least 12 years of age. Sick children between the ages of 12 and 16 require parental consent. Youths between 16 and 17 can make the decision, but the parents must still be involved in the discussions with the physicians.
- The six due care criteria are deemed to have been respected when the physician:
 - Is satisfied that the patient's request is voluntary, well considered and repeated;
 - Is satisfied that the patient is suffering from severe physical or mental pain with no prospect of relief;

- Has informed the patient of his situation and further prognosis;
 - Has discussed the situation with the patient and come to the joint conclusion that there is no other reasonable solution;
 - Has consulted at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the criteria of due care;
 - Exercises due medical care and attention in terminating the patient's life or assisting (he must be present in person) in his suicide.
- The patient does not necessarily have to be in the terminal phase of an illness. In effect it is deemed that a patient's unbearable suffering may be without prospect for improvement when it is due to an incurable disease or affliction and physicians agree that nothing more can be done to relieve the symptoms.
 - The request is almost always made orally and does not necessarily have to be in writing. A written request is taken into consideration when the patient has lost the ability to express his will (he is aphasic, for example) and he previously had a discussion with his doctor and meets the due care criteria.
 - In order to prevent people from coming to the Netherlands to die, the law stipulates that there must be a relationship of trust between the patient and his attending physician. As such, non-residents cannot take advantage of this law.

Euthanasia typically involves the intravenous administration of a barbiturate, which puts the patient to sleep, followed by the injection of a neuromuscular blocker. If the patient ingests the barbiturate himself and the ingestion causes death, it is called assisted suicide. If the injection of a neuromuscular blocker follows, it is a combination of the two.

Moreover, under the *Funeral Act*, a physician who practices euthanasia or assisted suicide must submit a report (a detailed questionnaire of 20 sections) to the medical examiner, who must then send the information to the regional review committee. There are five regional committees. The committee must inform the government if it deems that the physician has failed to respect the due care criteria imposed by law.

Application

- The regional review committee's 2010 annual report revealed the following:
 - 3,136 cases were reported, compared to 2,636 in 2009, 2,331 in 2008 and 1,815 in 2003;
 - There were 2,910 cases of euthanasia, 182 of assisted suicide and 44 of a combination of the two;
 - The breakdown of categories of physicians who reported euthanasia or assisted suicide are as follows:
 - general practitioner: 2,819 cases
 - specialist doctor in a hospital: 193 cases
 - geriatrician: 15 cases
 - resident: 9 cases
 - The places where euthanasia or assisted suicide were performed are as follows:
 - patient's home: 2,499
 - long-term care facility: 109 cases
 - specialized nursing home: 127 cases
 - other locations (home of a family member): 219 cases
 - The illnesses break down as follows:
 - cancer: 2,548 (2,153 in 2009)
 - cardiovascular disease: 158 (54 in 2009)
 - nervous system disease: 75 (131 in 2009)
 - other afflictions: 237 (168 in 2009)
 - multiple illnesses: 118 (130 in 2009)
 - start of dementia: 25 cases (12 in 2009)
- From one year to the next, euthanasia and assisted suicide account for, respectively, approximately 2% and 0.1% of all deaths. Some 80% of all terminations of life are performed in the home of the patient, often after the patient has received palliative care.
- Lastly, in 2007, the government published a report on application of the law since it came into force. This report concluded that the law has fulfilled its objectives and has not led to a slippery slope of abuse or misuse. A new evaluation will be published in 2012.

Report on the mission to the Netherlands

Based on the data compiled during the mission to the Netherlands and an analysis of the information collected during the mandate, the Committee notes the following:

Strong social acceptance

- Support from the public and the medical profession is constantly growing. As such, according to the latest poll commissioned by the Ministry of Health (July 2011), 85% of people are in favour of the law, 10% are undecided and 5% are against (compared to 7% in the last survey). What little opposition exists is limited to fears that euthanasia will be extended to people with dementia and to seniors who are not suffering from a terminal illness but are “tired of living” due to a combination of physical and psychological suffering that has become unbearable and without hope of being relieved. A petition signed by 113,000 people was tabled in Parliament to recognize “tired of living” as a criterion, but a survey showed that only 30% of the public and 20% of doctors support such a reason.
- All the people we met believe that the law does not need to be amended in any way and that the due care criteria adequately structure the practice of euthanasia.
- For their part, the representatives of the Kuria hospice whom we met refuse to practice euthanasia but will refer a patient who makes such a request. Like all its opponents, they consider that euthanasia is now part of the continuum of end-of-life care. They recognize that there will always be people with unbearable pain that cannot be alleviated, even by the best palliative care units. They further believe that, after 30 years, this practice is now well structured and that there is no risk of abuse.
- Another physician that we met, Dr. Paul Lieveise, is against euthanasia, mainly because he believes in the sanctity of life. He also believes that medicine can relieve most pain. However, he works in a hospital where euthanasia is practiced and he will not protest it. He respects colleagues who do not share his views.
- The representatives of the Dutch Association for the Right to Die with Dignity with whom the Committee delegation met believe that a good number of euthanasia requests are refused because the medical profession is still reluctant to perform it.

The control and evaluation process is very rigorous

- In 1997, the Royal Dutch Medical Association set up *Support and Consultation on Euthanasia in the Netherlands* (SCEN), a program aimed at structuring the consultation and decision-making process before accepting a request for euthanasia or assisted suicide. SCEN comprises 32 regional groups of 600 physicians trained for this purpose. The role of SCEN physicians is to provide independent consultations to attending physicians and to attest in writing that the legally prescribed criteria for due care have been respected.
- A part of the SCEN mandate is to train the physicians as consultants. This program ensures that the physician consulted does not know the attending physician making the consultation request and that the consultant meets with the patient in private. In most cases, the independent consultant is a SCEN physician. SCEN physicians handle about 3,700 consultations a year and according to statistics, 20% of cases do not meet the criteria (for example, the suffering is not untreatable or the request was not well thought out).
- The five regional review committees carefully analyze the detailed form completed by physicians following an act of euthanasia or assisted suicide. The place of death determines which committee will evaluate the act. Each committee is made up of three members – a lawyer (the president), a doctor and an ethicist – and each member has a replacement. The committee secretary (a lawyer) plays an advisory role during the deliberations. Mandated to help the committees with their work, the secretariats report to the Ministry of Health. The committees publish a joint annual report. The statistics show that each year, about 10 physicians fail to comply with the due care criteria. In these cases, the patient's request was medically justified but certain procedures were not correctly followed by the doctor (for example, the drug and dose used was not indicated on the declaration of euthanasia form). No doctors have been prosecuted for violation of the law since it was enacted.
- The doctors who perform termination of life use the methods, means and doses indicated in the joint opinion of the Royal Dutch Medical Association for the Advancement of Pharmacy and the Scientific Institute of Dutch Pharmacists. The standards call for the intravenous administration of a coma-inducing substance, followed by a muscle relaxant. The standards also specify which products to use and which ones to avoid.

The feared abuses have not materialized

- The Royal Dutch Medical Association assesses the Dutch experience as follows:
 - “Quality of death” has improved and there are fewer inhumane ends of life;
 - The offer and quality of palliative care has improved substantially since 2002 and is now among the best in the world. In-home palliative care is especially well developed;
 - Euthanasia and assisted suicide are only contemplated as a last resort, when all other possible care has been provided;
 - The control and evaluation methods as well as the level of transparency are excellent;
 - The public’s trust in doctors is high and constantly growing;
 - There is no less respect for life than before;
 - The slippery slope has not materialized, i.e. euthanasia has not increased among people over age 80, the disabled, the chronically ill, the economically disadvantaged or other groups included in this argument;
 - Annually, there are about 8,000 explicit requests that meet the criteria: approximately one third of those who make a request will receive help to die. The other cases can be explained as follows: the patient may die before the act is performed; the request may be rejected because it has not been well thought out or the suffering is not intolerable; or the person does not follow through on his request, oftentimes because the comfort obtained by knowing that this option is available is sufficient to allow him to wait for a “natural death.”
- The opponents we met recognize that most people are in favour of euthanasia and are not asking that the law be revisited. They also acknowledge that the relationship of trust between patients and physicians has improved. Both proponents and opponents believe that there has not been any abuse and that the potential for abuse by doctors and nurses is nil because:
 - Doctors find it difficult to perform such an act. And it becomes increasingly difficult to do so even if a doctor only performs one or two acts of euthanasia a year;

- Health professionals are trained to keep patients alive and to improve their quality of life. Their priority is always to help the patient die a natural death;
- Any abuse will be quickly denounced by other health professionals, the families and the media.
- The healthcare system, in particular the palliative care system, is fully insured and available to everyone. Every citizen has a family doctor. In-home care is very developed, and roughly 75% of all acts of euthanasia are performed at home, usually by the family doctor.
- Euthanasia is neither a patient's right nor a doctor's duty. A patient may make the request, but there is no guarantee that it will be honoured. Doctors and nurses retain the right to conscientious objection (5% of doctors say that they would refuse to perform euthanasia). Health institutions can also state that they are against euthanasia and that they refuse to perform it.
- It is true that in the beginning, there were about 500 cases per year where people received a form of help to die without their consent. However, studies commissioned by the Ministry of Health showed that they did not entail euthanasia per se. The cases involved dying persons who received higher doses of morphine to relieve and shorten their suffering. The Ministry of Health deemed that these cases had to be considered as euthanasia, because the physician's intent was, among other things, to shorten suffering with a drug (morphine), which is not intended for this purpose. The Ministry believes that inadequate use of morphine has stopped since the Royal Dutch Medical Association published directives on the appropriate protocols for palliative sedation.
- It is believed that life is shortened by less than one week in half of the cases and only 8% of patients had a life expectancy of more than one month.

Euthanasia is expected to increase in the future

The people we met unanimously agreed that the number of euthanasia cases will increase in the years ahead for the following reasons:

- More people know about the law;
- Physicians no longer hesitate to report the act;
- The aging of the population will lead to an increase in the prevalence of cancer and other serious diseases;

- Autonomy is very important to aging baby boomers, and as such, they will refuse to die a death deemed inhumane and will want to control the end of their lives.

The reason why palliative sedation is on the rise

It is true that palliative sedation is on the rise. The reason is because the practice has become better known and because the Royal Dutch Medical Association has issued directives in this regard. Palliative sedation is administered when a patient has refractory symptoms and has less than two weeks to live.

The law does not prohibit a doctor from complying with the request of a patient in the early stages of dementia who is still competent

In 2009, there were 12 termination of life cases involving individuals in the early stages of dementia. In 2010, there were 25. The individuals in question were in the early stages of the disease and understood their symptoms, which cause personality changes and difficulty with orientation. In each case, the doctors were able to demonstrate that the request was voluntary and well considered, that there was no prospect for improvement, and especially, that the suffering was unbearable. The individuals were keenly aware that the disease would lead to a complete loss of self and total dependence. The number of such cases is expected to increase in the future.

Certain allegations must be refuted

There is absolutely no basis to the following two allegations, heard on various occasions during the Committee's public hearings:

- That seniors will leave the Netherlands for Germany because they are afraid of being euthanized against their will. This baseless allegation appeared in what is commonly referred to as the "Leonetti report," the outcome of an assessment of the law on patient rights and end of life;
- That Els Borst, the Minister of Health in 2002, said she regretted having introduced the law. When the Committee delegation met with her, she denied ever making such a statement and had only good things to say about the experience in the Netherlands.

Belgium

Background

- Unlike the Netherlands, there was no long period of legal tolerance of euthanasia in Belgium before it was legalized in 2002.
- The *Euthanasia Act* is the outcome of the initiative taken by six senators of the political majority in 1999. It took three years of consultations and parliamentary work to arrive at a compromise. During the debate that preceded adoption of the law, several polls showed strong public support for euthanasia, which was also endorsed by experts from different spheres. However, the Catholic Church, the heads of medical organizations and various legal experts opposed the practice.
- A first vote held in the Senate in October 2001 approved the euthanasia law proposal by 44 in favour, 23 against, and 2 abstentions. A second vote, held in the House of Representatives in May 2002, endorsed the bill by 86 for, 51 against, and 10 abstentions. The law came into force in September 2002.
- Without amending its Penal Code, Belgium therefore introduced a specific legal provision in 2002 legalizing euthanasia. The legislation was motivated by a desire to respect the wishes of the sick but also to establish strict controls for the proper practice of euthanasia in order to put an end to clandestine practices.

The Euthanasia Act at a glance

- Crimes against the person, including any action by a third party causing or leading to the death of another, are punishable criminal offences under Belgium's Penal Code. Under this code, the administration of a lethal substance causing death is prohibited and carries a sentence of life imprisonment.
- However, under the *Euthanasia Act*, euthanasia is a medical act not covered by the Penal Code but subject to the control and oversight mechanisms of medical practice. The Belgian law defines euthanasia as an act practiced by a physician intentionally ending the life of a person at that person's request. The Federal Control and Evaluation Commission concluded in its initial report, covering 2002 and 2003, that medically assisted suicide "falls into the category of euthanasia as defined by the law."

- The criteria are as follows:
 - The patient must have attained the age of majority or be an emancipated minor (i.e. age 15 and over) and be legally competent and conscious at the moment of making the request;
 - The request must be voluntary, well considered and repeated, and not the result of any external pressure;
 - The patient's request must be in writing;
 - The patient must be in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident;
 - The physician must inform the patient about his health condition and life expectancy, and about all the possible therapeutic and palliative courses of action and their consequences;
 - The physician must obtain a second opinion about the serious and incurable character of the disorder. The physician consulted must be independent of the patient as well as competent to give an opinion about the disorder in question. He examines the patient and reports on his findings;
 - If the patient's death is not imminent (i.e. in the next few days, weeks or months), the attending physician must furthermore consult a psychiatrist or a specialist in the disorder in question, who must draft a report and consult the healthcare team. At least one month must elapse between the patient's written request and the act of euthanasia.
- Advance directives for euthanasia are permitted:
 - Every legally competent person of age, or emancipated minor, can draw up an advance directive instructing a physician to perform euthanasia in the event he is no longer able to express his will and if the physician ensures that the patient suffers from a serious and incurable disorder, caused by illness or accident, and the patient is no longer conscious, and this condition is irreversible given the current state of medical science;
 - The advance directive must be composed in writing in the presence of two witnesses of legal age, at least one of whom has no material interest in the death of the patient. In the advance directive, one or more person(s) taken in confidence can be designated in order of preference, to inform the attending physician about the patient's will.

Each person of confidence co-signs the form. The patient may, at any time, amend or revoke the advance directive. An advance directive is only valid if it is drafted or confirmed no more than five years prior to the person's loss of ability to express his wishes;

- The royal decree of April 27, 2007 determined the manner in which advance directives are registered and communicated to physicians by way of the National Register. For example, to be valid, the directives must be drafted in accordance with the prescribed form. Registration of directives began on September 1, 2008. By the end of 2009, the register had 11,175 names.
- Euthanasia is performed under the control of the Federal Control and Evaluation Commission, which is made up of 16 members: 8 physicians, of whom at least 4 are university professors, 4 lawyers and 4 members drawn from groups that deal with the problem of incurably ill patients. The Commission informs the Crown if conditions have not been fulfilled (such a decision may be made by a two thirds majority) and reports to the legislative chambers every two years.
- The law stipulates that "any person who dies as a result of euthanasia performed in accordance with the conditions established by this Act is deemed to have died of natural causes for the purposes of contracts he had entered into, in particular insurance contracts."

Application

- The last report submitted to the legislative chambers covers 2008 and 2009.
- The number of reported euthanasia cases has increased from year to year in Belgium, from 235 in 2003 to 704 in 2008 and 822 in 2009. The next report, for 2010 and 2011, will be published in 2012.
- In 2008 and 2009, death by euthanasia accounted for 0.7% of all deaths. Less than 1% of cases (12 cases in two years) were characterized as "medically assisted suicides" because the death occurred by ingesting a barbiturate and no subsequent injection of a neuromuscular blocker.
- 97% of requests came from conscious persons and 3% from advance directives (14 cases in 2008 and 22 cases in 2009).

- In a majority (52%) of euthanasia cases, the act was performed in the patient's home or in a rest home. This is consistent with the frequently expressed wish of terminating one's life at home. This proportion is greater than the 49% reported in 2006-2007.
- All the afflictions were serious and incurable:
 - 79% involved cancer;
 - 6% were terminal progressive neuromuscular diseases (for example, Creutzfeldt-Jakob or Huntington's disease);
 - The other afflictions were broken down as follows: non-progressive neuromuscular diseases (1%), non-cancerous pulmonary diseases (3%), cardiovascular diseases (4%), kidney disease (1%), neuropsychological diseases (2%) and multiple illnesses (2%);
 - The report underscores that there were no cases of AIDS/HIV.
- Seventy-three percent of the cases involved patients aged 40 to 79 and 25% involved patients over age 79.
- Ninety-two percent of the cases involved patients whose death was imminent. Most were suffering from generalized or seriously disabling cancer. Among the 8% of cases involving patients whose death was not imminent (116 cases in the two years), most entailed terminal progressive neuromuscular disease with quadriplegia or severe multiple paralyses, and exceptionally, serious neurological damage caused by a disease or an accident. Only 12 of the euthanasia cases for cancer involved patients whose death was not imminent. These statistics are consistent with those in previous reports.
- Of the 1,526 cases reported in 2008 and 2009, 1,478 persons complained of physical pain (e.g. cachexia, pain, dyspnoea, dysphagia, exhaustion, hemorrhage, digestive tract obstruction, paralysis, sores, repeated transfusions) and 1,279 persons complained of mental suffering (e.g. dependence, despair, loss of dignity).
- None of the declarations pointed to violations of the substantive conditions set out in the law.
- The Commission "confirms its previous opinions, where it found that the law has not resulted in serious problems or abuses that require new legislation".

- In 2009, 80% of the declarations came from the Flemish region and 20% from the Wallonia region (18% in 2008). These statistics were explained as follows:
 - Differences in how well the public or doctors are informed;
 - Different socio-cultural attitudes;
 - Differences in end-of-life medical practices;
 - The fact that when the law was enacted, Flanders set up a forum of physicians (“LEIF-artsen”) trained as independent consultants, as required by the law, similar to the SCEN physicians in the Netherlands. This type of forum was only recently created in French Wallonia. Some 100 physicians are now part of the EOL Forum (end of life).
- Based on epidemiological surveys, the clandestine practice of euthanasia is rare. However, widely used end-of-life medical practices (the use of high doses of morphine, palliative sedation) create certain ambiguities that may ultimately explain differences in the number of reported euthanasia cases and the number of end-of-life medical acts that may hasten death but that are not considered euthanasia by physicians.
- In 96% of cases, death was brought about by inducing deep unconsciousness through intravenous injection (usually Pentothal), and if death did not occur within a few minutes, by administering a neuromuscular blocker. This is the most appropriate way of fulfilling the conditions for proper euthanasia: a rapid, calm death, without suffering.
- The Federal Control and Evaluation Commission examines, on a monthly basis, the registration forms completed and sent by physicians each time euthanasia is performed. The registration document must be sent to the Commission within four business days of the euthanasia. The Commission verifies whether the euthanasia was performed in accordance with the conditions and procedure stipulated by law.
- The Belgian Ministry of Health Web site offers an advance directive for euthanasia template, a euthanasia registration form, a brochure for physicians explaining certain aspects of the law, and all the Commission reports submitted to the legislative chambers.

Report on the Belgian mission

Based on the data compiled during the mission to Belgium and an analysis of the information collected during the mandate, the Committee notes the following:

An important debate before the law was enacted

- The topic of euthanasia was debated for a number of years before the law was enacted. A first public consultation was held across the country and received extensive media coverage.
- The government then tabled a bill and proceeded with another public consultation.
- The concurrent enactment of two other laws, one on patient rights and the other on palliative care, facilitated adoption of the law on euthanasia.
- When the legislation was being drafted, its authors contemplated the possibility of requiring an ethics committee to sign off on all euthanasia requests. However, this possibility was rejected for fear of making the process cumbersome and the risk of judicialization. According to the people we met, experience has shown that two physicians is enough in most situations, and three in cases where death is not imminent.

Strong support

- Support from the public and the medical profession is very strong and continues to grow.
- Initially opposed to euthanasia, the Order of Physicians now claims to be neutral but has amended its Code of Ethics, removing the section prohibiting physicians to help terminate a life.
- What little opposition exists is limited to concerns regarding dementia and extension of the law to seriously ill newborns and minors between the ages of 14 and 15.

The absence of abuse and the debate on accessibility

- Everyone agrees that there has been no abuse. No slippery slope has materialized. There has been no increase in euthanasia cases among the vulnerable such as the handicapped, the chronically ill, and seniors. In fact, advanced age is not in and of itself a factor in euthanasia since 73% of the cases involved patients between the ages of 40 and 79 and 25% involved patients over the age of 79.
- Some claim that the real problem is that too many doctors refuse euthanasia requests because of their personal reluctance. Consequently, not everyone will have access to euthanasia even if they meet the criteria because doctors refuse to discuss this option or direct them to another physician. The feeling is therefore that a doctor who invokes conscientious objection should be required to refer the patient to another physician, which is not the case right now.
- Two proposals are currently under study:
 - The first is to expand the criterion concerning minors to give the same rights to persons aged between 14 and 15. The Committee delegation met with Christine Defraigne, the senator behind this proposal. She believes it is unlikely the law will be expanded in the near future due to the political context;
 - The second is to increase the validity of advance directives from five to ten years to avoid penalizing people who forget to renew them.
- The situation is still unclear regarding accessibility for people with some form of dementia. Some believe that those in the early stages of dementia should have easier access to euthanasia. Some of these individuals end their lives prematurely because they do not believe their advance directives for euthanasia will be respected.
- There is unanimous agreement that there is no risk of trivialization, because physicians find it difficult to perform euthanasia. It is also believed that abuse and misuse will be promptly denounced by physicians, families and the media.
- No one has been prosecuted since the law came into force. Physicians have received reprimands regarding communication and procedural problems. However, the central conditions of the law have been respected.

- There has been no “suicide tourism,” because under the legal requirements, the physician must have treated the patient on an ongoing basis for a sufficient period of time. To do so means the patient necessarily resides and receives care in Belgium.
- As for the suicide rate, everyone agrees that there has been no impact in either direction.
- Everyone also agrees that there is no need to amend the law and that the criteria stipulated adequately structure the practice of euthanasia.
- Lastly, euthanasia has not affected life insurance policies.

Euthanasia is on the rise

The number of euthanasia cases is growing slowly but steadily. This trend is expected to continue in the years ahead due to the aging of the population, the increase in cancer and degenerative diseases, and greater awareness of the law. The fact that baby boomers want to control the end of their lives and avoid an inhumane death may also explain this projection.

Three controversies explained: undeclared euthanasia, euthanasia without patient consent, and the practice of palliative sedation

- There is an explanation for the high number of undeclared cases of euthanasia in the first few years after the practice was legalized. Physicians who administered high doses of morphine stated that they did so in the hope of relieving the patient’s suffering but also to hasten death without immediately causing it. They therefore did not declare this act as euthanasia. However, according to the Ministry of Health, these cases were indeed euthanasia because the intent was, among other things, to hasten death. We now believe that the number of undeclared acts of euthanasia is almost nil, because the use of morphine at end of life as well as the practice of palliative sedation and euthanasia is now well structured.
- It is false to say that many patients are euthanized without their consent. These patients receive continuous palliative sedation when they are unable to express consent, when they are dying, and when the doctor and family believe that it is the best way to ease their suffering.
- Palliative sedation is on the rise because it is more widely known. However, according to some, physicians all too often prefer palliative sedation over euthanasia because it is not controlled and requires no documentation.

Good news about palliative care and in-home care

- Although he had no official substantiating data, Federal Control and Evaluation Commission rapporteur Marc Englert believes that at least 50% of the 4,000 people who have died by euthanasia since 2003 received palliative care beforehand. Euthanasia is always a last resort, once all possible care has been provided.
- Over 50% of euthanasia cases take place in home and this proportion is growing steadily.
- Palliative care has developed rapidly in Belgium since 2002 and is now considered among the best in the world. A concerted effort has been made to make this type of care available to end-of-life persons, a fact substantiated by the number of medical reports relating to euthanasia cases that indicate patients had received palliative care in the weeks or months leading up to their deaths. Belgium has developed mobile palliative teams in hospitals and implemented in-home palliative care.
- Some believe that the bereavement process is easier for the family when the sick person's death is carefully thought out and calmly discussed with the patient, doctor and family members.
- The people we met view palliative care and euthanasia as complementary.
- Everyone agrees that the doctor is there to help the patient die and not to end his life. This is why it is agreed that just like palliative care, euthanasia can fit into the continuum of appropriate end-of-life care.

Luxembourg

Background

- In Luxembourg, the new legal framework applicable to the end of life since 2009 was the outcome of a long process of reflection within society that began in 1996 in the Chamber of Deputies and within the Special Ethics Commission established by Parliament.
- The *Law on Euthanasia and Assisted Suicide* was voted on by the members in December 2008 (30 in favour, 26 against and 1 abstention) and came into force in March 2009.
- The *Law relating to palliative care, advanced instructions and end-of-life accompaniment* was unanimously passed and enacted at the same time as the Law on Euthanasia and Assisted Suicide.

The Law on Euthanasia and Assisted Suicide at a glance

- Crimes against the person, including any action by a third party causing or leading to the death of another, are punishable criminal offences under Luxembourg's Penal Code.
- The *Law on Euthanasia and Assisted Suicide* states that: "The physician who complies with a person's request for euthanasia or assisted suicide shall not be subject to criminal prosecution or civil action."
- Euthanasia and assisted suicide are considered medical acts that must comply with the control and oversight mechanisms of medical practice. Therefore, when it is carried out in accordance with the law, the act is not considered a homicide or a crime against the person.
- The criteria are as follows:
 - The patient must be of majority age and legally competent and conscious at the moment of making the request;
 - The request must be voluntary, well considered and repeated and not the result of any external pressure;
 - The patient's request must be in writing;
 - The patient must be in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident;

- The physician must inform the patient about his health condition and life expectancy, and discuss the possible therapeutic and palliative courses of action;
- The physician must consult another physician about the serious and incurable character of the disorder. The physician consulted must be independent of the patient as well as of the attending physician and must be competent to give an opinion about the disorder in question. He examines the patient and prepares a report on his findings.
- It is possible to draft end-of-life provisions (the equivalent of advance directives on euthanasia in Belgium).
 - Every legally competent person of age can establish end-of-life provisions instructing a physician to perform euthanasia in the event he is no longer able to express his will and if the physician ensures that the patient suffers from a serious and incurable disorder, caused by illness or accident, and the patient is no longer conscious and this condition is irreversible given the current state of medical science;
 - The provisions may be reiterated, adapted and withdrawn at any time. An adult person of trust may be named to inform the attending physician of the patient's will. The provisions are recorded in the patient's medical file and registered with the National Commission for Control and Assessment. Every five years, the Commission must seek confirmation from the person. Doctors are responsible for finding out from the Commission whether such provisions exist.
- Physicians who perform an act of euthanasia must submit a registration document to the nine-member Commission, which verifies whether the conditions and procedures were respected.
- Every two years, the Commission submits a report to the Chamber of Deputies containing the following:
 - An information brochure intended for the general public to explain and clarify certain interpretations of the law;
 - The forms used by the Commission:
 - The registration form that physicians must complete;
 - The request for euthanasia or assisted suicide;
 - The end-of-life provisions.

Application

- Submitted in March 2011, the first report of the National Commission for Control and Assessment detailed the results of the 21 months between the second quarter of 2009 and the fourth quarter of 2010.
- Five cases of euthanasia took place during this 21-month period in this country whose population was then 512,000.
- No assisted suicides were reported.
- The Commission considers that application of the law did not give rise to any major difficulties or abuse that would require new legislation. No declaration contained doubtful points that may have contravened any substantive or formal conditions of the law and therefore no case was forwarded to the Collège medical or to the Court of Justice.
- All the euthanasia cases involved people suffering from cancer.
- Six hundred eighty-one people registered their end-of-life provisions.
- The Commission made the following recommendations:
 - Medical schools should include training to teach future doctors how to handle end-of-life situations, including palliative care and the correct use of euthanasia. The same should be encouraged for post-graduate education and professional development;
 - When admitting new patients, hospitals and long-term care facilities should routinely inquire whether they have end-of-life provisions.
- According to the Luxembourg Association for the Right to Die with Dignity, some patients saw their request for euthanasia refused by their attending physician and looked in vain for another doctor willing to comply with their request.

Switzerland

Background

- Euthanasia is illegal in Switzerland.
- The Penal Code contains a long-standing provision that prohibits assisted suicide unless the assistance is given without selfish motives. This practice has been tolerated for more than 60 years.
- Things began to change a few years ago with the emergence of assisted suicide organizations such as Dignitas. These entities operate outside the state-regulated health system. The absence of a specific legislative framework explains why these associations can advertise their services and even offer them to foreigners.
- In July 2008, the Swiss government called on the Department of Justice and Police to prepare a report on the need to update the rules on assisted suicide. The Federal Council wanted a criminal standard to strictly regulate assisted suicide. A long social debate followed on whether assisted suicide should be more strictly regulated or banned altogether.
- In June 2011, the Federal Council concluded that this regulation was not necessary and that the current legislation was enough to prevent abuse. Thus, the government believes that the Penal Code, the Therapeutic Products Act, the Narcotics Act and professional rules of conduct provide effective sanctions. Moreover, the government believes that there is no reason to act against “suicide tourism” because the existing rules are such that few foreigners can come to Switzerland for assisted suicide. The government confirmed its intent to focus on promoting suicide prevention and palliative medicine.

Provisions of the Swiss penal code concerning assisted suicide

- For Swiss society, the government’s role is first and foremost to ensure respect of the freedom and autonomy of individuals making end-of-life decisions.
- Article 114 of the Penal Code prohibits voluntary euthanasia (terminate a life on request) but imposes a less severe sentence than for other homicides. The minimum sentence for murder and involuntary manslaughter is 10 years and 1 year respectively, while there is no minimum sentence for euthanasia.

- Article 115 pertains to assisted suicide and stipulates that anyone who, for selfish reasons, incites or helps someone to commit suicide will be sentenced to a term of imprisonment. Assisted suicide is therefore permitted if the person is motivated by unselfish reasons. Article 115 does not require the presence of a physician, which is a significant departure from the laws of other countries that allow assisted suicide. In this case, it is assisted suicide and not “medically” assisted suicide.
- Assisted suicide involves providing a person with a lethal substance to end his life. The substance must be prescribed by a physician after he has examined the patient.
- Following assisted suicide, a report must be filed with the police and the death certificate must indicate the cause of death.

Application

- There are a few associations in Switzerland that respond to requests for assisted suicide. Exit and Dignitas are the best known. The latter is different from the others in that it accepts requests from residents and foreigners alike, which is why it stirs controversy. Generally speaking, these associations are viewed favourably by the public.
- Exit was created in Geneva in 1980 and today has 70,000 members in Switzerland. Memberships rose sharply in 2009 (2,000 new members), undoubtedly due to the Federal Council’s draft regulation. In 2010, Exit helped 257 people die, compared to 217 in 2009, 167 in 2008 and 179 in 2007. The average age of the requester was 76. Most cases involved people with cancer.
- Dignitas was created in 1998 by the controversial Dr. Ludwig A. Minelli. It has 5,600 members around the world. Dignitas helped 195 people die in 2006, compared to 97 in 2010. By the end of 2010, 12 years after its creation, the organization had helped a total of 1,138 people with incurable illnesses or unbearable disabilities, including 592 from Germany, 115 from the United Kingdom, 118 from Switzerland, 102 from France, 19 from Italy, 18 from the United States and 16 from Spain. Seventy percent of the people who made a request for assisted suicide did not follow through with the act.
- Most of the suicides take place in people’s homes or on the premises of the associations. However, this practice has been permitted by some teaching hospitals and long-term care facilities since 2006 but under strict conditions. That said, staff members are forbidden from being directly involved.

The United States

- In the U.S., the individual states have jurisdiction in criminal, civil and health matters.
- The American electoral process allows them to put draft legislation to the public by way of a referendum.
- Opponents of Oregon's assisted suicide law, adopted in 1997, took steps to ensure that the federal government would quash the state's initiative. After several attempts to limit the ability of the states to act in this area and a protracted legal battle, the case ended up before the Supreme Court, which in January 2006 held that a state has the right to prohibit or allow euthanasia or assisted suicide, American law being first and foremost a right of the states.
- Since 1994, bills on euthanasia or assisted suicide have been tabled in 25 states.

Oregon

- The *Death with Dignity Act* was enacted in Oregon on October 27, 1997.
- A public debate went on for several years before a first referendum was held, the outcome of a citizen initiative in 1994 (51% of the population voted in favour while 49% voted against). The referendum pertained to Ballot Measure 16, under which terminally ill adult residents of Oregon with a prognosis of less than six months to live can obtain a prescription for medication for the purpose of committing suicide. An injunction delaying enactment of the law was lifted in October 1997.
- This bill was hotly contested by, among others, the Catholic Church and certain physician associations and pro-life citizen groups. A second referendum aimed at repealing the law and adopted in the interim was rejected by the majority of the population in 1998 (60% voted in favour of maintaining the law while 40% voted for repeal).
- The law allows assisted suicide under certain conditions but not euthanasia.
- The patient must be an adult; must be capable; and must be suffering from a terminal disease, which is defined in the law as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months." Since it is a suicide, the patient must remain capable right through to the end.
- The person must be a resident of Oregon.

- The physician must inform the patient of, among other things, his diagnosis, prognosis, feasible alternatives including the curative care available for his illness and suffering, and the probable result of taking the medication to be prescribed.
- The patient must make the request verbally and in writing, and then verbally repeat it in order to confirm that his decision is informed and made of his free will.
- At least 15 days must elapse between the two verbal requests.
- The opinion of a second physician is required to confirm the diagnosis and prognosis as well as the ability of the person in question to make this decision.
- The law is extremely clear on the process the physician must follow. In so doing, it creates the conditions for civil, professional and criminal immunity for physicians who choose to help their patients die.
- The physician must make sure that the process complies with the statutory requirements, in particular with the formalities, including the declarations and forms to complete.
- The law acknowledges the right of any health professional to refuse to participate in an assisted suicide, for any reason whatsoever.
- The patient alone must take the lethal medication but a physician may be present.
- The Public Health Division receives and processes declarations and reports and verifies compliance with the provisions of the law. It prepares an annual report on the situation. These reports have been produced since 1997 in Oregon. Since that year, 525 patients have died after ingesting the prescribed medication in accordance with the rules.
- The 2010 annual report shows that 96 people availed themselves of the law (compared to 95 in 2009 and 88 in 2008), i.e. they obtained a prescription for lethal medication. Of those, 59 ingested the medication while 6 others obtained a prescription in 2009, for a total of 65 deaths by assisted suicide in 2010 (59 in 2009 and 60 in 2008). These 65 deaths account for 0.2% of all deaths.
- In 2010, 96.9% of patients died at home and 92.6% received palliative care.

Washington State

- A first referendum on assisted suicide called “Initiative 119” was rejected in 1991 in Washington by a margin of 54% to 46%.
- In 2008, a second referendum, called the “Washington Initiative 1000, Aid-In-Dying” was held following a campaign headed by former Governor Booth Gardner, who has Parkinson’s disease. The initiative passed by a margin of 58% to 42%.
- The Washington *Death with Dignity Act* came into force on March 5, 2009.
- The law allows assisted suicide under certain conditions but not euthanasia.
- Patients must be adult residents of Washington and have less than six months to live.
- The conditions are the same as in the Oregon law.
- The first annual report covers the period from the law’s enactment on March 5, 2009 to December 31, 2009.
- Of the 63 people who received a prescription, 36 died after ingesting the medication.
- The second annual report, for 2010, states that 87 people received a prescription and 51 died after ingesting the medication.
- 90% died at home and 84% were receiving palliative care.

Montana

In December 2009, the Supreme Court of Montana, in a 4 to 3 decision, recognized the right of a terminally ill person to end his life by ingesting medication prescribed by a physician. At the same time, the Court ruled that state law protects doctors from prosecution because the act cannot, in its view, be perceived as against public policy.

England, Wales and Northern Ireland

- In the United Kingdom, England and Wales, Northern Ireland and Scotland all have directors of public prosecutions.
- The *Suicide Act* of England and Wales, which dates back to 1961, decriminalized suicide. It prohibits euthanasia and assisted suicide but provides that the director of public prosecutions can use his discretion when deciding whether to prosecute a person who helped another commit suicide.
- A recent highly publicized case led to a new policy concerning criminal prosecutions in England, Wales and Northern Ireland. In July 2009, after examining the appeal of Debbie Purdy, a British citizen suffering from multiple sclerosis who was contemplating suicide and wanted to know if her husband would be prosecuted if he helped her die, the House of Lords asked the Director of Public Prosecutions to clarify when an individual might face prosecution. In September 2009, the Director published an interim policy that states that persons who help a relative die will probably not be prosecuted if the act was motivated by compassion and if the patient's will is beyond doubt. The Director then launched an extensive consultation to which 5,000 responses were received from the public and health associations and professionals.
- In February 2010, the Director of Public Prosecutions came out with new guidelines outlining 22 factors to determine whether a person who abets a suicide will be prosecuted. The Director collaborated with the Director of Public Prosecutions of Northern Ireland, who published similar guidelines at the same time.
- Assisted suicide is a criminal offence punishable by up to 14 years' imprisonment but the new policy for prosecutors makes it less likely that charges will be laid against persons helping a family member commit suicide out of compassion (and not for money, for example), provided the latter clearly expressed his will. The final policy states, notably, that there should not be prosecution if the victim made a clear, definite and informed decision to commit suicide. However, prosecutors are encouraged to prosecute if the victim, for example, was a minor, and if the person abetting the suicide benefited in some way from the death or if he was paid for his assistance.
- These guidelines do not concern euthanasia. Persons who perform euthanasia will be prosecuted for homicide.
- The Parliament of Scotland, for its part, rejected a bill in 2010 to legalize assisted suicide.

British Columbia

- In the wake of the Sue Rodriguez affair, the Attorney General of British Columbia published guidelines in 1993 on the prosecution of those who, for compassionate reasons, help a sick person die. According to these guidelines, Crown counsel will only prosecute when there is a substantial likelihood of conviction and where prosecution is required in the public interest. The factors to be considered include the provable intention of the person who helped a loved one die and, in cases involving physicians and their patients, expert medical opinions as to generally accepted ethical medical practices.
- The public interest criterion involves consideration of the following factors:
 - Society's interest in supporting proper professional and ethical standards for healthcare professionals;
 - Society's interest in protecting vulnerable persons;
 - Society's interest in protecting the sanctity of human life, while recognizing this does not require life to be preserved at all costs.
- To our knowledge, there is no official or unofficial report on the experience of British Columbia.
- An assisted suicide case is currently before the Supreme Court of British Columbia. This case, funded by the British Columbia Civil Liberties Association, concerns five plaintiffs who are asking the Court to allow physicians to help their patients die. Observers compare this case to the Sue Rodriguez affair and believe it is quite likely to soon end up before the Supreme Court of Canada.

The debate elsewhere in the world

- In 1996, Australia's Northern Territory, one of the country's six member states, briefly legalized medically assisted suicide and euthanasia. The *Rights of the Terminally Ill Act* contained numerous criteria and statements concerning the level of acceptable suffering. Section 4 stated the fundamental orientation of the law: a patient who, in the course of a terminal illness, is experiencing pain, suffering and/or distress to an extent unacceptable to the patient, may request the patient's medical practitioner to assist the patient to terminate the patient's life. In 1997, a bill to repeal the Northern Territory law was adopted by the House of Representatives and by the Australian Senate (under section 122 of the Australian constitution, the Commonwealth Parliament has full power to adopt legislative provisions that prevail over territorial laws). In the meantime, only four people were able to avail themselves of the law.
- In Colombia, the country's highest court ruled in 1997 that a physician could not be prosecuted for helping an individual commit suicide because he was suffering from an incurable disease and if he had given his consent.
- Euthanasia and assisted suicide have been the topic of debate in the parliaments of several countries in recent years, namely Canada, the United Kingdom, Australia and five of its six member states, France and Bulgaria.
- Associations in favour of euthanasia first sprang up in the 1930s in England and in the United States. These were followed by dying with dignity associations in the 1970s. In all, 46 such associations from 27 countries have come together under the World Federation of Right to Die Societies, which today has 500,000 members around the world.
- A number of countries have legalized cessation of treatment at the patient's request, outlawed therapeutic obstinacy and instituted initiatives to accompany end-of-life patients. In some countries, the law recognizes the binding effect of advance medical directives.

The case of France

The Committee learned the following during its mission to France.

- Jean Leonetti, a minister and practicing cardiologist, chaired the parliamentary mission on end-of-life accompaniment in 2004. Following the highly publicized case of Vincent Humbert*, the president of the National Assembly, at the urging of several members, organized this mission of information to study potential legislative reforms. Composed of 31 members, representative of the entire French political spectrum, the mission proceeded with 81 hearings, held in 5 rounds. It also travelled to Belgium and the Netherlands. The report, titled *Respecter la vie, accepter la mort* [Respect Life, Accept Death], was unanimously adopted.
- This mission led to the adoption of the *Loi relative aux droits des malades et à la fin de vie* [Law on patient rights and end of life] (the “Leonetti law”) in April 2005, whose fundamental principles are as follows:
 - No unreasonable obstinacy when treatment is futile or excessive;
 - If the physician finds that he can only relieve the patient’s suffering with a life-threatening treatment, he must inform the patient, the person of trust named by the patient, the family or loved ones;
 - When the time comes to limit or stop treatment of an unconscious patient, the people mentioned above must be consulted;
 - The patient is entitled to cease treatment, including artificial nutrition;
 - Any person can provide advance medical directives to express his wishes in the event he becomes unconscious. Such directives are valid for three years and can be withdrawn at any time.
- In 2008 Jean Leonetti chaired a second mission, this one mandated to assess the law on patient rights and end of life. This mission was created following the highly publicized case of Chantal Sébire**. In December of that year, Jean Leonetti delivered his report, dubbed the “Leonetti report”, to the Prime Minister, in which the legalization of euthanasia was rejected in favour of expanding palliative care.

* A young man who unsuccessfully pleaded with the president of the Republic, in a now famous letter, to allow him to die. The man was left a quadriplegic, mute and nearly blind following a car accident. His request was refused.

** A woman suffering from a very rare sinus cancer made a request to President Sarkozy and to the courts for “the right to die with dignity” without having to leave the country. Her request was denied.

- In this new report, Leonetti recommends creating an “observatory of end-of-life medical practices” to study the impact of expanding palliative care services in the years ahead (70% of people requiring palliative care do not currently have access).
- The Observatoire national de la fin de vie [national end-of-life observatory] was created in May 2010. Mandated to “report on the end-of-life situation and needs”, the observatory will make it possible to answer many questions, for instance, how have medical practices evolved since the law of April 22, 2005? When should palliative care begin? How can the government find out the number of unlawful, clandestine cases of euthanasia being performed?
- According to the people we met during the mission, the law shows that medical paternalism, still all too present in France, is slowly giving way to the primacy of patient autonomy.
- The Comité consultatif national d'éthique pour les sciences de la vie et de la santé [National Consultation Ethics Committee on Life Sciences and Health] has long called for, albeit unsuccessfully, the creation of a “euthanasia exception” that would be applied to “borderline situations or extreme cases recognized as such” by physicians following a “freely expressed, repeated request made orally at the time or previously in a document” by a patient when palliative care proves to be ineffective.
- According to surveys, more than 80% of French citizens are in favour of euthanasia.
- In legal practice, most cases are either dismissed or the penalties are symbolic.
- The Association for the Right to Die with Dignity has 47,700 members organized in some 100 delegations. The advocacy committee is made up of high-profile members, including the former prime ministers Laurent Fabius and Michel Rocard.

- In November 2009, for the first time, a public debate was held in the National Assembly on a bill on the right to die with dignity. In January 2011 a new parliamentary debate unfolded in the Senate, this time involving three bills tabled by three different political parties. Meeting on January 18th, the Senate's Social Affairs Committee studied the three bills and adopted one (25 for, 19 against, 2 abstentions). This bill stipulated that:

“Any capable adult in an advanced or terminal stage of a serious and incurable disease or an illness resulting from an accident causing him physical or mental suffering that cannot be eased, or that he deems unbearable, may request [...] medical assistance allowing, by way of a deliberate act, a rapid, painless death.”

- However, the bill was rejected in a plenary session by a margin of 170 to 142. This about-face came following an intense debate fuelled by an open letter from Prime Minister François Fillion to the *Le Monde* newspaper in which he came out against euthanasia, against therapeutic obstinacy and in favour of developing palliative care.
- This issue is currently being debated in the 2012 presidential campaign. President Sarkozy has come out against euthanasia legislation, while socialist party candidate François Hollande has included the following proposal in his “60 promises to France :”Any adult suffering from a terminal or an incurable disease causing unbearable physical and mental pain that cannot be relieved may ask, under strict and specific conditions, for medical assistance to die with dignity.”

EUROPEAN MISSION AGENDA

(June 29 to July 5, 2011)

DELEGATION

Maryse Gaudreault, MNA for Hull and Chair of the Committee

Véronique Hivon, MNA for Joliette and Vice-Chair of the Committee

Francine Charbonneau, MNA for Mille-Îles and member of the Committee

Monique Richard, MNA for Marguerite-D'Youville and member of the Committee

Robert Jolicoeur, Research Officer

Anik Laplante, Committee Clerk

FRANCE (June 29 and 30)

- Meeting with Régis Aubry, President of the Observatoire national sur la fin de vie, and Lucas Morin, Director of the Observatoire
- Meeting with Jean Leonetti, deputy
- Meeting with senators who are against the bill to legalize euthanasia
- Meeting with senators who are in favour of the bill to legalize euthanasia
- The Chair gave a speech on the Committee during the first Congrès francophone d'accompagnement et de soins palliatifs [Francophone conference on accompaniment and palliative care] in Lyon.

THE NETHERLANDS (June 30 and July 1)

- Meeting with Dr. Paul Lieveerse, anesthesiologist and pain specialist, and president of the CMF association, which lobbies for the right to life
- Meeting with representatives of the Ministry of Health, Ministry of Justice and the South Holland and Zeeland Control Board.
- Meeting with Heleen Dupuis, Senator

- Meeting with representatives of the Royal Dutch Medical Association (KNMG)
- Meeting with Els Borst, former Minister of Health
- Meeting with representatives of the Netherlands Right to Die Association (NVVE)
- Visit to the Kuria hospice and meeting with its representatives

BELGIQUE (July 3, 4 and 5)

- Meeting with Dr. Philippe Mahoux, Senator
- Meeting with Léon Favyst, President of RSW, the Flemish association for the right to die with dignity
- Meeting with Me Jacqueline Herremans, President of ADMD, Belgium's association for the right to die with dignity, and member of the Federal Control and Evaluation Commission; and with Professor Marc Englert, member and rapporteur of the Federal Control and Evaluation Commission.
- Meeting with Me Jean-Christophe André-Dumont, President of Jurivie
- Meeting with Edouard Delruelle, Assistant Director of the Centre for Equal Opportunities and Opposition to Racism
- Meeting with a representative from the Ministry of Health
- Visit of the supportive care unit of the Institut Jules Bordet and meeting with Dr. Dominique Lossignol and his team
- Meeting with Christine Defraigne, Senator
- Meeting with Carmen Amores, whose husband asked for and obtained euthanasia
- Meeting with Dr. Marianne Desmedt, head of the continuous care unit at the Saint-Luc university clinics and member of the Federal Control and Evaluation Commission; and with Professor Jean-Marie Maloteaux, President of the Commission d'éthique biomédicale hospitalo-universitaire des cliniques universitaires Saint-Luc [Hospital-University Biomedical Ethics Board of the Saint-Luc university clinics]



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