

**Brief presented by Hélène Bolduc,
President of the Association québécoise pour le droit de
mourir dans la dignité (AQDMD)**

**to the Committee on Health and Social Services:
Special consultations and public hearings on Bill 52,
an Act respecting end-of-life care**

Quebec, September 25, 2013

Introduction

The report tabled by the Dying with Dignity committee is a remarkable work of thoughtful reflection that is admirable in several respects. A robust and nuanced document, it captures the present societal debate regarding this issue and we, citizens and practitioners, must all take note of it.

Bill 52 addresses the full spectrum of end-of-life care. Four years of sustained efforts went into this outstanding bill, dedicated to end-of-life care, terminal palliative sedation, and medical assistance in dying. As representatives of the Association québécoise pour le droit de mourir dans la dignité (AQDMD), we will not be addressing, at this moment, all aspects of the bill with which we, like most Quebecers, are in full agreement. We are therefore adding our voice to all those that express this sentiment: this is the very foundation of an approach that respects the dignity of each person in this last part of their life.

In this brief, we have opted to address only one issue: the addition of what is commonly called “medical assistance in dying” to the spectrum of end-of-life care offered to Quebecers.

The AQDMD has been defending the fundamental right to die with dignity since 2007. In this context, we are advocating for an active approach to respecting the values of freedom, dignity and compassion, justice, and personal autonomy, all in a particularly important and delicate period: the end of life and death of every individual.

In its major points, this bill is outstanding, in that it respects the main principles of bioethics:

- 1) Respect for the patient's autonomy, insofar as the rights of others are not violated,
- 2) Requiring a compassionate approach and recognizing that only the patient can define this compassion.
- 3) Including an element of societal justice, in that every person may have access to it, but no one is obligated to use it.

It is worth noting that, presently, terminal palliative sedation is the only response to requests for medical assistance in dying (MAID) during inhuman end-of-life stages, which goes against all three of these principles.

We want it to be possible for any person to receive, if this is their wish, the medical assistance required to ensure a dignified end of life and a gentle death, if they are suffering from a terminal illness or experiencing unbearable physical and/or psychological pain (suffering) caused by a grievous illness, where there is little reasonable therapeutic hope.

We do not expect to see a unanimous response to this kind of topic. But it is important for us to underscore our unconditional agreement with the report published by the Committee on Dying with Dignity, which was unanimously accepted by the National Assembly, as seen on p. 53:

“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.”

Statistics do not generate ethical principles; common sense does, however, naturally align with them.

The AQDMD is a 500-member citizens' association that brings together people from all walks of life. Our approach to a “good death” is, in part, based on work carried out by the Royal Society of Canada regarding this same issue.

From their work, we concluded that medical assistance in dying has solid foundations, in terms of human, philosophical and political concepts, in that it aligns with the foundations of our collective life: respect for the Charter of Rights, freedom of choice for all individuals, and respect for the choices that these individuals have expressed. In other words, it is a matter of recognizing every person's right to decision-making autonomy.

Furthermore, following the work of the Committee and of the Royal Society of Canada, which both sent representatives to study, on-site, how medical assistance in dying is performed in jurisdictions that have implemented the practice, it is no longer possible to legitimately assert that these jurisdictions do not apply these laws with care and compassion. Similarly, without making a long list here, all serious studies allow us to contradict the "slippery slope" argument or any statement of that kind: real-life experience, on the contrary, is coloured by humanism and empathy.

By addressing this delicate question and by committing to a desire to reduce not only the pain, but also the unbearable suffering that some people experience until the very end of their life, when living with an illness that they deem to be debilitating and without real hope of improvement, Quebec is working within a great humanist movement that now includes several European countries and American states. The province may not be exceptional, but it is at the forefront of public policy in this regard.

Despite important advances, even the best palliative care cannot control all end-of-life pain, let alone the suffering caused by debilitating conditions or those perceived as such by patients in a hopeless situation. Future debates should start from these observations, rather than circling back to questions that have, by now, been reviewed in detail and been endorsed, for strictly medical matters, by the best medical journals in the Western world.

We, the members of the Association québécoise pour le droit de mourir dans la dignité, believe that we represent the many Quebecers and their families who are without a voice, who have experienced or will experience a difficult end of life, be it physical, psychological, or moral, and who will be reassured by the opportunity to end their suffering, even if they do not act on this choice, thus moving away from the medical paternalism of the last century, which has no place in modern medicine.

We do have questions, however, regarding the following two topics:

- 1. What will a patient's actual opportunity to receive medical assistance in dying look like**, when faced with what appears to be, in our view, systematic obstruction by the Quebec palliative care network (or at least by its spokespersons), which opposes medical assistance in dying?

Conscientious objection is the recognized, inalienable right of every person and we understand that this debate has especially disrupted the palliative care community.

On the other hand, we are aware that several medical professionals in this field agree with medical assistance in dying, but their relative discretion in the group concerns us and makes us fear that successful implementation may fail when it comes to the full spectrum of end-of-life care.

We believe that an institution, such as a palliative care centre, that receives significant public funding and that must provide universal service, notwithstanding the beliefs of patients and medical professionals, should not be allowed to avoid this new requirement to offer the full range of care covered by this bill, which claims to respect the patient's decision. This, of course, includes medical assistance in dying, which we consider to be a healthcare service that, though infrequently used, is nevertheless necessary, justified, ethical, and, above all, respectful of human beings.

We should add that such an institutional obligation does not include the individual obligation of the professional, who will always have his or her free will and convictions; but the free will of one individual cannot and must not obscure and especially not sacrifice that of another person, especially given that the patient is by far the most vulnerable.

As the President of the Quebec Medical Association (QMA), Dr. Laurent Marcoux courageously stated in the last meeting of the Canadian Medical Association in August 2013: "It is a societal decision, and we are at service of society. In Quebec, we have been having this discussion for four years, and the overwhelming majority of the population would like for us to go so far as to allow assistance in dying." He reminded his peers that two out of three Quebec physicians consider that medical assistance in dying is appropriate end-of-life care.

Thus, we suggest that the institution have an obligation of means and of results; more specifically, it must make medical assistance in dying available to people who request it, in a real and practical manner, and have it administered by a professional whose ethics and empathy will be compatible with this noble goal.

We believe it would be relevant to emphasize here that what is sacred is not the patient's life, but rather the living person, a human being who makes an enlightened decision for themselves, who exercises full autonomy and requests medical help for this purpose, to end their days in a peaceful manner and at a time that they deem it relevant for themselves. Medical help is often what has led a person to lead a life or a form of survival that has been

worthwhile, but that now brings them more disadvantages than benefits, in their personal view. Should the same medical system not be the one that would help this person leave a life that has become intolerable? The patient should be allowed to make this judgment, and no one else.

Only medicine, in the broad sense, can provide compassionate, empathetic, effective, gentle help: any other method used by a patient who has been left to their own devices, isolated, will inevitably be brutal and without dignity, as we cast aside our societal duty to help the most vulnerable among us.

What will a patient who is hospitalized, suffering, and on the verge of death, do when faced with a healthcare team that immediately refuses to hear his or her request? Would this not be, precisely, a loss of true compassion, a holistic compassion that includes all values and beliefs, without regard for those of the practitioner, who would be attributing power to himself or herself over the last days of a fellow human?

And of course, as stated by Dr. David Lambert, an orthopedic surgeon suffering from metastatic prostate cancer, on August 20, 2013, there can be no assistance in dying without informed consent, which is the means of protection against abuse and the “slippery slope” effect. (“There can be no aid in dying without informed consent, which is the means of protection against abuse. Consent is absolutely necessary. It is the bulwark against the slippery slope, the shield for the mentally impaired. Those who wish to do so can submit an advanced medical directive outlining their preferences, and this will be preserved in a central registry.”—The Gazette)

We also wish to emphatically denounce the ignominious assimilation that causes some people to state that allowing medical assistance in dying amounts to justifying suicide, which at its core is a personal tragedy experienced by a person of any age struggling with severe depression: it is the antinomy of medical assistance in dying requested by a competent person, who has the capacity to consent, and performed within well-defined guidelines.

Likewise, any reference to ethnocidal tragedies is not only an affront to history and to its victims but is also utterly false by the very nature of these monstrous abuses, characterized by a complete lack of choice.

2. We also have concerns about persons experiencing intolerable living conditions.

We must not look away from those who are trapped in their bodies, on the grounds that they are not at the end of their life: we need only point to neurodegenerative diseases or massive and permanent neurovascular accidents. We must listen to them, to understand what is important to them, and to be receptive to their distress and overall, pervasive suffering, and not only to their pain. This has been clearly demonstrated in the Committee's report and it is unnecessary to reiterate this point here. No one has the right to decide what is right for these persons, nor to deny them what they believe to be fair.

The clinical experience of physicians who are members of the AQDMD, and certainly of several others—perhaps even of the majority, if one is to rely on surveys published by the Collège des Médecins du Québec and by the medical federations—prevents us from sharing the opinion of legal experts who have opted to postpone studying cases of severe dementia, which causes patients to forget loved ones and to take on early childhood behaviours that can sometimes be incongruous and devastating.

If a competent adult writes out their wishes and requests medical assistance in dying, if applicable, to spare them and their family the agony of this loss of identity, it then becomes immoral not to recognize the value of their last significant decision. This strikes us as incompatible with the solidarity and compassion owed to each person and denies the primacy of their personal values, established in the introduction of Bill 52. It is disturbing to note that the will of a deceased person is respected for years after their death, but that this same person would be denied an end of life with dignity, which they expressed with informed consent. There is no redemption for suffering that has already been experienced.

Note that four European countries and as many American states have already passed legislation that meets the needs expressed by individuals. Despite some alarmist rhetoric, there is no abuse in these countries or states and the evidence on this is clear. We are certain that those who are vulnerable, elderly, and/or very old face no risks, because the established safeguards are strict and deliberate.

The humanist values behind this fight are not a red herring from a Quebec society worried about the future of its health system. Nor is it the effect of a selfish fad that rejects old age, as demonstrated by statistics in countries or states that allow assisted dying.

For these persons experiencing a deterioration in the very foundation of their humanity, and for persons who are aware of their progressive confinement in a body that is becoming foreign to them, our current response—to keep them alive against their will—should be called into question, in our view, with courage and humanity.

3. Doctors, caregivers, and the Bill.

Some people have voiced opinions about the contradiction between medicine (the Hippocratic oath) and medical assistance in dying, going so far as to suggest that it may be an inconsistent concept.

Medicine has bypassed or shelved the Hippocratic Oath whenever new science and changes in society have made it justifiable; legislation has confirmed the constant evolution of autonomy for every person and for their values, as demonstrated in the Ménard Report.

In our opinion, it is worth noting that an individual becomes a physician not for himself or herself, but for others. In *Oneself as Another*¹, philosopher Paul Ricoeur examines the decisional conflict that arises between a patient who cannot take it anymore and is asking for his suffering to be shortened, and a physician who feels obliged to respect the patient's life more than the patient's will. Ricoeur highlights the asymmetry which then arises in the patient-doctor relationship, characterized by a weakened and dependent patient, faced with his healthy doctor who is backed by the authority of science. A rebalancing can be achieved with more compassion, which he calls "solicitude," allowing a "different kind of exception to take shape, one differing from the exception in my favor, namely, the exception on behalf of others."

This solicitude does not make the physician a simple executor of the wishes of the dying person, but a solidary acolyte in maintaining the integrity of the patient, anchored to the very integrity of the physician, acting as "oneself as another." Essentially, the physician's conscience is the voice of the person in need, towards whom compassion dictates above all that "my loyalty lies with the Other."

And of course, mirroring the autonomy of the patient, no physician and no caregiver will ever have to go against their own convictions, no more in this matter than for abortion, for instance. The physician will, however, need to inform their patient of their limitations in this area and ensure that the patient can access the requested services by providing a referral: it will happen the same way in this area as in any other field of medicine and there is absolutely nothing coercive here.

The following is an excerpt from a speech made by one of our guests of honour, Mr. Denys Arcand, Knight of the National Order of Quebec and Companion of the Order of Canada, at our 5th anniversary last October:

¹ Paul Ricoeur, *Oneself as Another* (Paris: Seuil, 1990), p. 312.

“The right to die with dignity is another step to be taken in the long struggle to recognize the rights of each individual. This struggle has been going on for centuries and has given rise to many battles. We are saying that our life belongs to us and belongs only to us and demanding the right to end it when intolerable and inhuman suffering makes prolonging this life unreasonable.”

We represent a majority of Quebecers, who would be appeased if this bill, with the few changes that we are submitting to you, were passed by this Legislative Assembly.

Conclusion

An information and education campaign will be necessary, both for medical professionals and the general public, because detractors in this long-held debate have conveyed false information by instilling fears that were unfounded and, unfortunately, often based on malicious demagoguery.

Through this alarmist and unfounded—it bears repeating—rhetoric, these people allowed a certain fear to permeate groups defending the elderly and more vulnerable persons; it is our duty, as a group, but also as reasonable citizens, to support elected officials to ensure that the bill will reassure them on all fronts. But denying a fundamental right to autonomy is certainly no way to ensure the dignity of a person’s end of life.

A moral and professional obligation places the person who is suffering (physically and psychologically) above one’s personal beliefs, whatever they may be.

To put two very human concepts in opposition, with palliative care on one side and medical assistance in dying on the other, is a dead end: one does not prevent the other and recognizing this second approach will in no way cause the disappearance of the first. Moreover, according to all studies published on the topic in the countries that allow it, few people do in fact resort to MAID: but the opportunity is there, with clear guidelines, and it is called “having a choice.”

To be human, unlike all other living organisms, is to make choices throughout one’s life, and this must include choices about the final moments, whether this means days, weeks, months, or even years, which is the case for debilitating illness that medicine can prolong with no end, except the one a person chooses for himself or herself.

And the alternative to the inexorable final decline, whether it is short or long, is the opportunity—not the obligation—to leave gently, according to one’s own convictions, not those of practitioners.

As an association that has been interested in the issue for several years, we want to draw the attention of legislators to certain more general points that we consider to be important.

The members of our association believe that Bill 52, including medical assistance in dying, is a significant step forward on the status quo that has become impracticable, that it represents a remarkable step forward for the well-being of the minority of the most overwhelmed and vulnerable population, in a continuum with the best possible palliative care, which we hope will flourish.

There is obviously a need for regulatory agencies, but they must above all consider the choice of the patient and not the wishes of the institution that is hosting the patient.

Implementing this legislation, particularly in terms of medical assistance in dying, will require an information and education campaign, especially for medical professionals. Resources, awareness campaigns, and training programs will be needed, so that the new legislation can seamlessly be integrated into practical healthcare services.

Our association will be on the front line, contributing to this necessary and essential educational effort.

Hélène Bolduc, President
Association québécoise pour le droit de mourir dans la dignité
514-341-4017
info@aqdmd.qc.ca

Persons who contributed to writing this brief:

- Marcel Boisvert, MD, MSc
- Georges L'Espérance, MD, MSc, neurosurgeon
- Mr. Jean Mercier, PhD, professor of public policy, department of political science, Laval University

Brief endorsed by the members of the AQDMD Board of Directors

APPENDIX I

AMENDMENTS requested by the AQDMD for Bill 52, Act respecting end-of-life care

Section 14:

The section should read as follows: (underlined)

End-of-life care must be offered in palliative care hospices.

Section 26:

The following changes are requested:

26. Only a patient who meets all the following criteria may obtain medical aid in dying:

(1) be of full age and capable of giving consent to care or have clearly and freely expressed their choice in this respect, through advance medical directives and be an insured person within the meaning of the Health Insurance Act (chapter A-29);

(2) be in an advanced state of irreversible decline in capability, with no prospect of improvement;

(3) be experiencing constant and unbearable physical or psychological suffering that cannot be relieved or treated, with medical care, in a manner the patient deems tolerable, and that is caused by a grievous and incurable physical illness or injury. (Affidavit in Leblanc case—Barreau du Québec)

As stated in this excerpt from the report published by the Special Committee on Dying with Dignity, March 2012, on page 84:

“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.”

The patient must request medical aid in dying themselves, in a free and informed manner, by means of the form prescribed by the Minister. The form must be dated and signed by the patient or, if the patient is physically incapable of doing so, by a third person. The third person may not be a minor or an incapable person of full age or a member of the team responsible for caring for the patient.

The form must be signed in the presence of a health or social services professional who countersigns; if the professional countersigning is not the attending physician, the signed form is given to the attending physician.

In the case of a person who is unable to consent to care, advance medical directives serve the purpose of such a form.

Section 28. c):

The following addition is suggested:

(With the applicant for medical assistance in dying, the physician must conduct discussions) “at reasonably spaced intervals given the progress of the patient’s condition.”

We should plan to involve the DSP ² or the CPDP ³ to counter unreasonable delays caused by a reluctant professional.

Section 46:

The section reads as follows:

“Advance medical directives are given by notarial act *en minute* or in the presence of witnesses on the form prescribed by the Minister.”

We suggest that everyone should be able to select their form according to their needs and choose the method that suits them.

We therefore suggest this addition:

(...) on the form prescribed by the Minister or with a form or a method that suits the applicant at the time that the decision is to be made.

² DSP: director of professional services.

³ CPDP: Council of Physicians, dentists and pharmacists.

Section 52:

The section should read as follows: (underlined)

52. When a person is incapable of giving consent to care, clearly expressed instructions relating to care, including end-of-life care, that are recorded in the advance medical directives register or filed in the person's record carry, for all health professionals having access to the register or record, the same weight as wishes expressed by a person capable of giving consent to care.

Section 65:

Section 65 reads as follows:

“Despite section 8, an institution which, on *(insert the date of coming into force of section 8)*, operates a general and specialized hospital centre and, within the range of care that may be offered pursuant to the mission of such a centre, only offers palliative care may continue to offer that care exclusively.”

We feel that section 65 is incompatible with the objectives of this bill. It is our belief that it is unacceptable for general and specialized hospital centres to not offer the full range of end-of-life care.

We therefore suggest that this exception be removed.