

Abridged memorandum presented by H el ene Bolduc,
President, *Association pour le droit de mourir dans la dignit e* (AQDMD)
to the *Commission de la sant e et des services sociaux*:
“Special consultations and public hearings on
Bill 52, An Act respecting end-of-life care”
Quebec, September 25, 2013 memorandum

Introduction

Bill 52 is the result of a remarkable democratic process undertaken by Quebec parliamentarians. The report of the Select Committee on Dying with Dignity is noteworthy in several respects. It is an extensive and nuanced societal statement on a matter which we must all acknowledge, citizens and caregivers alike.

Bill 52 deals with the sum total of end-of-life-care. Four years of sustained efforts preceded this bill specifically dedicated to end-of-life-care, palliative sedation and medically assisted death. As representatives of the *Association qu eb ecoise pour le droit de mourir dans la dignit e* (AQDMD), we will not deal here with the full scope of Bill 52 with which we are in complete agreement. But we do add our voice to the many who concur that the bill is the very basis to any approach respectful of a person’s dignity at the end of his/her life.

We have chosen to limit our memorandum to a few modifications to what is generally known as medically assisted death within the overall context end-of-life care that are proposed to Quebecers.

In broad terms, Bill 52 is impeccable as it adheres to fundamental bioethics principles, notably:

1. Respects a patient’s autonomy to the extent that it does not infringe on the rights of others.
2. Demands that a sense of caring be manifested to patients, acknowledging that they are the best judges of what that means to them.
3. Demonstrates principles of societal justice by ensuring access to all, but without any imposition on anybody by anyone.

Mission

The AQDMD is a citizen association of some 500 volunteer members representing a broad spectrum of our society. Since 2007, our Association has been defending the fundamental right to die with dignity. In this context, we actively advocate that such

values as liberty, dignity and compassion, justice and individual autonomy be respected, specifically in the key and sensitive matters regarding end-of-life and our respective deaths.

Our position is that any person suffering from a terminal illness as well as any person experiencing unbearable physical and/or psychic pain in the context of a severe pathology without reasonable therapeutic hope be able to obtain if requested the medical assistance required to ensure a dignified end-of-life and gentle death.

We underline in particular that medically assisted death is on solid humanitarian, philosophical and political grounds in the sense that it corresponds to our collective values as per: the Charter of Rights and Freedoms, the individuals' freedom to choose and the respect of those individual choices. In the final analysis, it is the recognition of an individual's right to autonomous decision-making.

In dealing with such sensitive matters and in willingly committing itself to not only reducing pain, but also the unbearable suffering of certain individuals at the end of their lives, Quebec is part of a vast societal movement that now includes several European countries and American states. Quebec is thus not an exception in this matter, but is at the forefront of public policies.

In spite of the significant progress achieved, the best palliative care cannot control all end-of-life suffering notably that caused by debilitating conditions or perceived as such by patients in hopeless situations.

Several scientific works have demonstrated that the complementarities between palliative care and medically assisted death have a positive effect on patients by reducing the anxiety of eminent death. Knowing that medically assisted death is available, if we so request it, helps us to live our final moments.

Specific Comments

We have submitted the few modifications, additions and points of clarification which we suggest should be included in Bill 52. We wish here to draw the legislators' attention to three items in particular:

1. Section 26: Criteria to obtain medical aid in dying

The criteria to obtain medical aid in dying only apply to end-of-life patients. However, what about those individuals suffering from constant and severe physical or psychic pain, but whose death is not eminent?

We cannot leave such persons to themselves on the grounds that they have not yet reached the end of their lives. One has but to think of the overwhelming and permanent consequences of neurodegenerative illnesses or neurovascular accidents.

We must be aware and understand what is important to these individuals and respond to their overall and invasive distress and suffering, as well as to their pain. Nobody has the right to decide for them what they should do or to refuse them what they perceive as the right thing to do.

For those individuals whose very humanity is breaking down as well for those who are

aware of being gradually trapped in a body that is becoming foreign to them, we must have the courage and humane understanding to reconsider our current response in forcing them to live against their will.

The suggested modifications to section 26 are as follows:

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

- (1) be of full age, be capable of giving consent to care or having clearly and freely indicated his/her choice in this matter in his/her advance medical directives, be an insured person within the meaning of the Health Insurance Act (chapter A-29)
- (2) suffer from an advanced medical state of irreversible decline in capability without any expectation of improvement;
- (3) suffers constant and unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable, and that is the result of a severe or incurable medical or accidental pathological process;

The patient must request medical aid in dying himself/herself, 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 it; if the professional countersigning is not the attending physician, the signed form is given to the attending physician.

In the case of an individual who is incapable of signing consent to care form, the advance medical directives stand in lieu of such a form.

2. Advance medical directives

- a) Sections 45 and 52: Advance medical directives for incapable persons
- b) Section 46: Advance medical directives form in use

As stated by the *Barreau du Québec*, we propose that advance medical directives pertaining to medical care, including end-of-life care, and written while the person was deemed capable, be respected should that person become incapable. To this end, over and above the suggested modifications to section 26, we propose that sections 45 and 52 be modified as indicated below.

With regard to section 46 concerning the advance medical directives form, we believe that a person should choose the type of form and format that fits his/her needs.

a) Requested modifications to sections 45 and 52:

45. A person of full age who is capable of giving consent to care may specify, in advance medical directives what care, including end-of-life care, required by their state of health they consent or do not consent to, in the event that they become incapable of giving consent.

In addition to instructions relating to care, including end-of-life care, the directives may include the names of one or more trusted persons who are to give them, at the appropriate time, to the attending physician or to another health professional providing care to the person.

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.

b) Requested modifications to section 46:

46. Advance medical directives are given by notarial act en minute or in the presence of witnesses on the form prescribed by the Minister or on a form or in a way that is agreeable to him/her at the time of decision-making.

3. Sections 14 and 65: waiver for palliative care hospices

Sections 14 and 65, as written, undermine access to end-of-life care by including a waiver for palliative care hospices and certain facilities. What will be the effective likelihood of a patient receiving medically assisted death in facilities that we feel are systematically opposed (or at least their spokespersons) to medically assisted death?

The conscientious objection of any individual is a recognized inalienable right and we understand that this debate may be more prevalent in palliative care circles. We know, on the other hand, that many of their caregivers agree with medically assisted death, but the relative discretion concerns us as it raises the possibility of failure to the smooth implementation and continuity of end-of-life care.

We believe that institutions such as palliative care hospices or health centres which receive significant public funding should not be exempted from the obligation to offer the complete range of care provided by Bill 52 which states the patient's decision is to be respected. In our opinion, this clearly includes medically assisted death which the bill considers as a necessary, justified and ethical care and clearly respectful of human beings. We reiterate that such an institutional obligation does impose any individual obligation on health professionals who are free to act according to their convictions and beliefs. We however underline that the exercise of that freedom must not be at the expense of any patient's right to request otherwise, especially since the latter is far more vulnerable than the former. We thus suggest that any institution receiving public funds be held accountable for making available to patients who so request medical assistance in dying the effective and practical medical assistance in dying as provided by a health professional whose own ethics and empathy are compatible with this humanitarian goal.

Requested modifications to sections 14 and 65:

14. End-of-life care are offered in the premises of a palliative care hospice.

It seems to us that section 65 is incompatible with Bill 52's objectives. We believe that it is unacceptable that general and specialized hospital centres not offer the range of care pursuant to the mission of such centres. We suggest that this waiver be deleted.

~~65. 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. Such an institution must inform persons of the end-of-life care it offers before admitting them.~~

Conclusion

Time and efforts will be required to clarify the situation and properly inform both health professionals and the population in general as, during this long debate, a number of opponents circulated false information to raise unwarranted fears, based more often than not unfortunately on malicious demagoguery. By way of their alarmist discourse, unwarranted to repeat, these individuals managed to instill concerns and fears in elderly persons' advocacy groups and in the most vulnerable persons themselves. It is thus our duty as an Association, but also as reasonable citizens, to support elected members in order that Bill 52 reassures all concerned. Clearly, denying a person's right to liberty, dignity and autonomous decision-making is no way to reassure anybody about securing a dignified end-of-life.

Opposing such humane concepts as palliative care on the one hand and medically assisted death on the other is a road to nowhere, for one does not prevent the other and the recognition of the latter does mean the disappearance of the former.

The members of our Association think that Bill 52, including medically assisted death, equates significant progress over the now impracticable status quo.

We hope that our participation to the present Parliamentary Commission will have contributed to the improvement of this bill. The *Association québécoise pour le droit de mourir dans la dignité* will be front and centre in the necessary and essential educational tasks to be carried out.

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Abridged memorandum endorsed by the Board members of the AQDMD.