Association québécoise pour le droit de mourir dans la dignité

Brief on Bill C-7

An Act to amend the Criminal Code (medical assistance in dying)

Presented to the

Standing Committee on Justice and Human Rights

Federal Government

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(AQDMD.org)

Dear Members of Parliament,

Thank you very much for this opportunity to discuss Bill C-7 with you.

My name is Georges L'Espérance and I am the President of the Association québécoise pour le droit de mourir dans la dignité (AQDMD), a citizen organization whose mission is to protect the right of every person to a dignified death in keeping with their values.

> *The mission of the AQDMD is to promote recognition for the right of every competent adult who has prepared an advance medical directive (AMD) to have, when the time comes, an end of life that is consistent with his or her own values of dignity and freedom and to ensure respect for that individual's personal desire to receive medical assistance in dying (MAID), regardless of his or her cognitive status at that time. (http://aqdmd.qc.ca/documentation-in-english/)*

As a retired neurosurgeon, I myself administer MAID. In that capacity, I participate in a private discussion group in Quebec that is composed solely of physicians who offer this final compassionate and ethical care, which provides for highly judicious and informative dialogue. The following remarks represent a strong consensus among us and feed the AQDMD's deliberations on behalf of our fellow citizens.

By way of context, in Quebec, between 1 April 2019, and 31 March 2020:

- 1 776 people received MAID, representing 2.6% of total deaths.
- 76% had cancer.
- Neurodegenerative diseases are now the second most prevalent diagnostic category.

We believe the changes required by the Baudouin decision to be a significant step forward for our patients and all citizens. The few years that the law has been in place have shown how seriously it is applied across the country, with the utmost respect for the dignity of those who request MAID as well as protection for the most vulnerable.

All the other C-14 criteria are adequate and clear, for both patients and caregivers, and "*safeguards already in place in the legislation are sufficient to ensure that the system can provide medical assistance in dying to individuals who are entitled to it.*" *(Baudouin decision, paragraph 621).*[i]

Some observations on Bill C-7

I would like to take this opportunity to thank Minister Lametti and his team for having listened to practitioners and citizens, which is reflected in his bill.

The key principles that should guide all discussions remain central:

1. Self-determination of the person.
2. Respect for expressed wishes and values.
3. Dignity in living and in dying.
4. Ability to decide for oneself when expressing one's wishes.

The relaxation of certain elements, as presented in Bill C-7, is particularly helpful for people who are alone. This includes the following:

1. Written request for MAID in front of a single independent witness.

2. Allowing a person whose occupation is to provide health or personal care to act as an independent witness.

3. Repeal of the 10-day cooling-off period. This relaxation is the result of simple clinical logic. Our patients who request MAID most often have a long history of illness and are perfectly aware of their situation. This 10-day waiting period (C-14) is superfluous and useless for these seriously ill patients, not to mention the additional and inhuman suffering endured by some patients as a result.

4. The waiver of final consent immediately prior to care is also a response that corresponds to the clinical reality we all experience. Our patients will no longer have to refuse pain medication in order to remain lucid, nor fear losing their competency as a result of delirium.

We fully agree with the prior written waiver clause, as well as subclauses 3.3 and 3.4 concerning the person's demonstration by words, sounds or gestures that they are refusing administration of the substance.

However, we suggest that this last safeguard in subclause 3.4 be reviewed in two years based on experience gained, and possibly repealed.

There are still 3 major areas where we feel improvements should be brought to C-7.

A. The criterion of "Reasonably Foreseeable Natural Death" as the second element of an assessment

We ask that the concept of "reasonably foreseeable natural death" be removed as a safeguard from C-7. All of the other criteria found in C-14 have proven that the "most vulnerable" in Canada do not require further protections to ensure their fair and safe access to MAID.

Moreover, as doctors and nurses working in the field, we will once again be confronted with a vague, non-medical concept, because life expectancy is a notion involving averages rather than specific individuals. This measure is useless and redundant when all other criteria are met.

Should Parliament nevertheless choose to retain this measure, it should at least remove the minimum 90-day assessment period, for the same reasons as those mentioned for the 10-day period: patients who have a chronic pathology that meets the other criteria have had ample time to reflect on their situation for years. It is an insult to their intelligence and their suffering to force them to reflect even longer on their condition. Moreover, what criteria was this 90-day period based on? Why not 10 days, 20 days, 100 days, etc.? This number appears to be completely random—and it bears repeating—unnecessary for patients who meet all the other criteria.

The revocation of this natural death criterion will ensure compliance with the framework of the 6 February 2015 Supreme Court decision and the right to self-determination, and will also allow for more consistent access across Canada by subjecting the MAID decision to a strict, objective, peer-reviewed medical process.

I note for the record a single excerpt from the decision of Justice Baudoin, who conducted a lengthy analysis of the issue of vulnerability.

> *[252] Vulnerability should not be understood or assessed on the basis of a person's belonging to a defined group, but rather on a case-by-case basis, at least for the purposes of an analysis under section 7 of the Charter. In other words, it is not the person's identification with a group characterized as vulnerable – such as persons with disabilities, Indigenous persons or veterans – that should bring about the need to protect a person who requests medical assistance in dying but, rather, that person's individual capacity to understand and consent in a free and informed manner to such a procedure, based on his or her specific characteristics.*

B. Medical assistance in dying and patients who have a mental health condition only

As worded, **C-7 specifically excludes mental illness**. However, mental illness is a real illness involving real suffering that may be intolerable and resistant to treatment. Excluding mental health can only lead to more legal challenges, which is unacceptable for the patients concerned.

With all due respect for those citizens, and because the issues are complex, **we suggest removing this exclusion clause and retaining a 12-month non-application period** during which the professional orders of all the provinces would work together under a legal obligation to define a common clinical framework. There is an immediate need to develop the medical criteria for access to MAID for people with a serious mental health problem that is recurrent and resistant to therapy. The association des psychiatres du Québec has completed a comprehensive report on this subject and should be releasing its findings shortly.

People with mental health problems suffer just as do those with physical pathologies. We must take the time to do things right, however: expert opinions (psychiatrists, psychologists, social workers, frontline workers dealing with the homeless); review of the evidence (already done at the federal level);[ii] consultation with community groups. A goal of 8 to 10 months seems realistic and achievable, with respect for these citizens, while establishing additional benchmarks to the current criteria.

With a view to guiding future decisions, a few observations and questions regarding mental health pathologies and medical assistance may help shed some light.

- Mental illness is a real illness involving real suffering that may be intolerable and resistant to treatment.
- The Canadian and Quebec charters of rights establish the almost absolute principle of patient autonomy and the patient's right to accept or refuse treatment(s).
- In our democratic societies, psychiatric treatments, with the exception of seismotherapy (electrotherapy), are minimally or not at all invasive in the usual sense of the word. How far can we go in obliging psychiatric patients to receive other treatments without their consent if they no longer want them?
- How do we develop a reasonable definition for therapeutic resistance?
- What is the justifiable qualitative AND quantitative limit when the final request is for euthanasia? What is the temporal limit and should there be one: 10 years? 15 years? 25 years of mental health disorders and inability to function in society?
- And within this framework, it would seem impossible to set a (necessarily random) biological age for requesting MAID, because it would immediately be challenged as age discrimination.
- Which psychiatric diagnoses would meet a restrictive definition of an intolerable, incurable disease that engenders unbearable psychological suffering?
- And how far do we go if there are numerous serious suicide attempts?

- And how do we balance the risk of undignified or horrific suicide (gun, fall, subway, etc.) with the possibility of a gentle and controlled death??
- How can we be attentive to those lobbying for the protection of patients with mental health problems who want mental pathology to be recognized, and rightly so, as an illness in the same way as physical pathologies, as well as to the anti-suicide lobbies who fear the normalization of suicide and MAID in those same psychiatric patients, again often rightly so?

C. Cognitive neurodegenerative pathologies

First of all, it is absolutely essential to clarify and explain that cognitive neurodegenerative pathologies are physical and organic, rather than mental, in the usual sense of the term.

Any competent person who has received a diagnosis of cognitive Alzheimer-type neurodegenerative disease should be allowed to indicate in their written advance medical directives, with witness certification, that they wish to receive MAID at the time they deem appropriate, consistent with their values and regardless of their cognitive state at that time.

This was in fact a specific recommendation in the February 2016 report of the Special Joint Committee on Physician-Assisted Dying.

RECOMMENDATION 7

> That the permission to use advance requests for medical assistance in dying be allowed any time after one is diagnosed with a condition that is reasonably likely to cause loss of competence or after a diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable. An advance request may not, however, be made, prior to being diagnosed with such a condition. The advance request is subject to the same procedural safeguards as those in place for contemporaneous requests.

In Quebec, the expert panel[iii] established by the Ministère de la Santé et des Services sociaux tabled its report in October 2019. The report was the subject of broad and almost unanimous consensus in Quebec at a forum on the subject.[iv]

In closing, I would like to reiterate here the AQDMD's firm and unshakeable position in favour of an **absolute prohibition, with potential criminal sanctions, on administering MAID to persons who have always been incompetent** (mental disability) or persons who have become incompetent without having signed an advance medical directive, because that would be nothing short of eugenics.

Georges L'Espérance, Neurosurgeon
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[i] *Truchon c. Procureur général du Canada*.

[ii] The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition.

[iii] L'aide médicale à mourir pour les personnes en situation d'inaptitude : le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence, [French only].

[iv] Forum national sur l'évolution de la Loi concernant les soins de fin de vie, [French only].