Brief on Bill C-7

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

submitted to the

Standing Senate Committee on Legal and Constitutional Affairs

Pre-study of Bill C-7

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To the Honourable Senators,

Thank you for this opportunity to address Bill C-7 (PL 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 association that aims to protect every person's right to die with dignity, according to 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 state at that time. (https://aqdmd.org/)

As a retired neurosurgeon, I myself administer MAID and, as such, I am a member of a private discussion group in Quebec; it includes only doctors who provide this final compassionate and ethical care, which allows for a highly judicious and informative dialogue. The following remarks represent a strong consensus within the group and feed the AQDMD's critical reflection for our fellow citizens.

A word on context.[1] In Quebec, from April 1, 2019, to March 31, 2020:

- 1776 people received MAID, i.e., 2.6% of overall deaths
- On average, MAID was administered 18 days after the official request
- 76% of recipients had cancer
- Neurodegenerative disease is now the second most prevalent diagnostic category

The overwhelming majority of MAID recipients were given 6 months or less to live (86%) and most (74%) were given 3 months or less. Only 5% of MAID recipients had a terminal prognosis of more than 6 months (Figure 3.7). These rates are similar to those seen in 2018–2019.

We consider the changes requested by the Baudouin judgment 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 other C-14 criteria are adequate and clear, both for patients and practitioners, and "safeguards already in place in the legislation are sufficient to ensure that the

[1] Annual report of the Commission on end-of-life care. From April 1,2019 to March 31, 2020.

system can provide medical assistance in dying to individuals who are entitled to it."*(Baudouin Decision, paragraph 621).*[2]

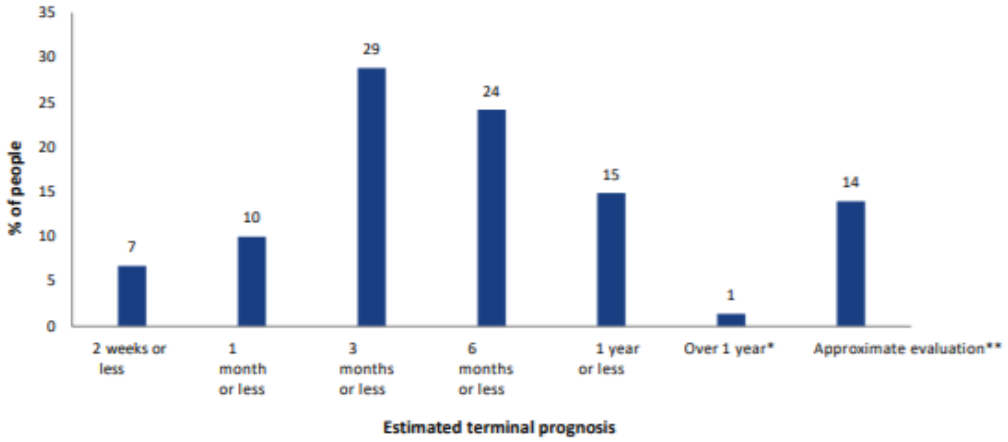
CLARIFICATION

As the debates in the House of Commons and the media continue, I believe two factual clarifications are in order.

1. Physical neurodegenerative diseases

The vast majority of people (70%) with **a neurodegenerative disease** who received MAID were given 6 months or less to live and just under half (46%, Figure 4.3), were given 3 months or less. Just over one quarter (16%) had a terminal prognosis of more than 6 months. (The following figures are taken from the reports cited)

Figure 4.3
Percentage of people with a neurodegenerative disease who received MAID relative to their estimated terminal prognosis



* Considering the information submitted, the Commission found that these people were at the end of their lives.

** These terminal prognoses varied from "a few weeks" to "a few months" in most cases, without additional details.

2 http://citoyens.soquij.qc.ca/php/decision.php?ID=ABDC24B668988D804B23D496876FB98A&captchaToken=03AGdBq25rgplFTECldb-BAIUM7Q6G82IwgftEpoHsLHCRxHqYJ7_td9K6UhCpBZmuVcAHsmxoptr5JDvKjdohWXzATK-4gDZ2jTEFUY7jbA7baJZkyvK0QrOtZc-Yijax_sR0tcOQ1nRhXh28wVigV4kFgZ2cR1U7X85p0G51W38GcCP0EH3eXUs0qb42hEdhBjXTme0rPkx4Ij9vLjxPriiEx60VSB6XMFySSSvu36fn9xHjZ3XClC3aIOVGBKj9FHos4wlWge0gdxdBYlMPnG2EcQSNdkH-Es9YPKU27ar_mSgUAWXnuJ0lDsbwLtIEStprIk0tOw8yJ7fdvDclSjn4gBV8FElbge3jmxY1EtNnbd16ejBN2BypMe_whi5NalXHrSf4gYZpdVwefGkhB4dvcVHwegTC1bUWElIZ6HtIcbTAnwT5RYI-hEYPf2uyCKrAl2Gm7DGNSvf3zC7ya9ru1KEelK8mmuoPeUPWCTyBdw1WOIr9M8hSWsMNqC5kqzLeFHuD-HzO5awXH9OOUfkgkLxVZ6CBuw

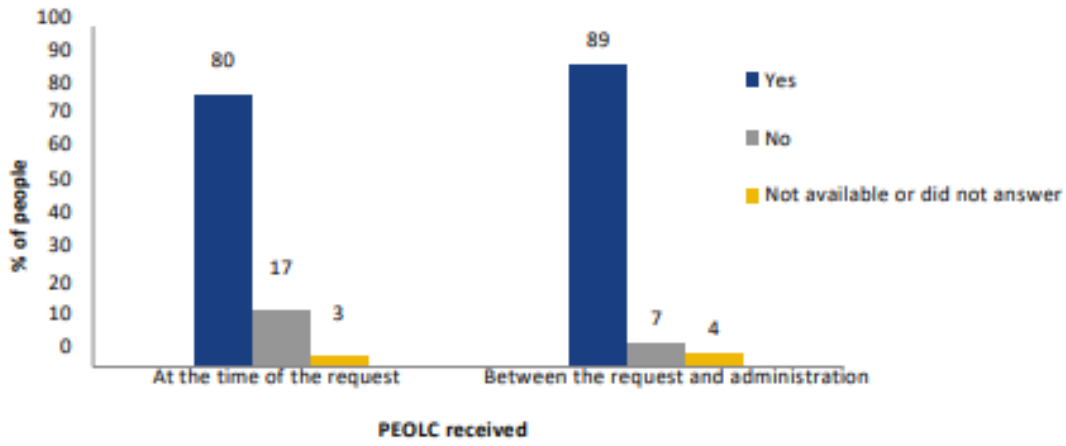
Overall, this figure shows that most people with neurodegenerative diseases received MAID while in the terminal phase of the disease.

This may come as a surprise, given that these people were well aware of the inevitable progression that the disease would follow and the irreversible decline in their capability and that they could have requested and received MAID earlier because the Act does not specify a prognosis associated with the end-of-life criterion.

2. Palliative care and MAID

As shown in Figure 6.11, **80% of people who received MAID were receiving end-of-life palliative care (PEOLC)** when they applied for MAID.[3] Furthermore, 89% had received it between the time they requested MAID the time it was administered.[4] Of those who were not receiving PEOLC at the time of their MAID request, 59% received it afterwards. In some cases where PEOLC was not received, the institution specified that the patient had refused care.

Figure 6.11
Percentage of MAID recipients who also received PEOLC



The all-too-frequent claim that patients request MAID because they are not receiving palliative care simply does not hold water given the data.

Why would patients who are in high-quality palliative care or even in palliative care centres ask for MAID if the palliative care were an end-all solution? Such a

[3] Report on the state of end-of-life care in Quebec from December 10, 2015, to March 31, 2018. Quebec Commission on end-of-life care, 2019.

[4]

claim stems from medical paternalism, and perhaps even religious considerations.

It is essential to remember that palliative care and medical assistance in dying are not in contradiction, nor are they mutually exclusive. MAID is a part of palliative care and is just an additional way of responding to our patients and to citizens.

Observations on Bill C-7

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

The principles that should guide all conversations remain at the heart of this debate:

1. Self-determination for every person
2. Respect for expressed wishes and values
3. Dignity in both life and death
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 before an independent witness.

2. Allowing a person who provides health care services or personal care, as their primary occupation, to act as an independent witness.

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

4. The waiver of final consent immediately prior to treatment is yet another response that has met the clinical reality that we all experience. Our patients will no longer have to refuse pain medication, in order to maintain their capacity to consent, or fear losing their decision-making capacity due to delirium.

We fully agree with the advance written waiver clause as well as sections 3.3 and 3.4 concerning the person's demonstration, through words, sounds, or gestures, of a refusal to have the substance administered.

However, we suggest that this final safeguard in 3.4 be revised 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 part of an assessment

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

Moreover, as physicians 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. If all the other criteria are met, this measure becomes unnecessary and redundant.

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 all other criteria have had ample time to reflect on their condition 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.

> We often hear the example of a person who has become quadriplegic after an accident and requests MAID some weeks afterwards. This example is pure demagoguery: no doctor would sign such a request because the other safeguard conditions would not be met.

Revoking this natural death criterion will make it possible to respect the framework provided by the February 6, 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.

For the record, I would like to recall one excerpt from the decision rendered by Judge Baudoin, who assessed, at length, 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 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 whose sole medical condition is a mental illness

As worded, **C-7 specifically excludes mental illness**. However, mental illness is a real illness that causes real suffering, which can sometimes be intolerable and resistant to any 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), consultation with community groups.[5] A goal of 8 to 10 months seems realistic

[5] %99uhttps://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-Where-a-Mental-Disorder-is-the-Sole-Underlying-Medical-Condition.pdf

and achievable, with respect for these citizens, while establishing additional benchmarks to the current criteria.

In order to guide future decisions, some considerations regarding mental health and medical assistance may shed light on the issue.

- Mental illness is a real illness that causes real suffering, which may be intolerable and resistant to any treatment.
- The Canadian and Quebec Charters of rights establish the near absolute principle of patient autonomy and this person's right to accept or refuse treatment(s).
- In our democratic societies, psychiatric treatments, with the exception of sismotherapy (electrotherapy), are minimally invasive or not invasive in the usual sense of the word. How far can we go, in obligating psychiatric patients to undergo more treatments without their consent if they no longer want to receive them?
- How do we develop a reasonable definition for therapeutic resistance?
- What is the justifiable qualitative AND quantitative limit if 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 should we go if there have been several 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, it is absolutely essential to clarify that cognitive neurodegenerative pathologies are physical and organic, and not mental, in the usual sense of the term.

Any person with decision-making capacity who has been diagnosed with a cognitive neurodegenerative disease, like Alzheimer's disease, should be able to have advance medical directives drawn up, signed by a witness, stating that they wish to receive MAID at a time that they deem appropriate, consistent with their values, regardless of their cognitive state at that time.

This was in fact a specific recommendation in the February 2016 report by the Special Joint Committee on Physician-Assisted Dying (Senate/Commons). (https://www.parl.ca/DocumentViewer/en/42-1/PDAM/report-1)

> **RECOMMENDATION 7**
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> *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 will be subject to the same procedural safeguards as those in place for immediate requests.*

In Quebec, the expert panel[6] established by the Ministère de la santé et des services sociaux submitted its report in October 2019; it was almost unanimously accepted in Quebec during a forum on the issue[7].

In closing, I would like to reiterate here the AQDMD's firm and unwavering position in favour of an **absolute prohibition, under penalty of criminal sanctions, of administering MAID to persons who have always been unable to provide consent** (intellectual disability) or for persons who have lost the capacity to consent without having made an advance request, because it becomes a matter of eugenics.

On behalf of the Board,

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[6] https://publications.msss.gouv.qc.ca/msss/fichiers/2019/19-828-04W.pdf [French only]

[7] https://www.msss.gouv.qc.ca/professionnels/soins-et-services/forum-national-sur-l-evolution-de-la-Loi-concernant-les-soins-de-fin-de-vie/programmation/ [French only]

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