Commission sur les soins de fin de vie

Bill C-7, An Act to amend the Criminal Code (medical assistance in dying)

Brief submitted to the House of Commons Standing Committee on Justice and Human Rights

November 5, 2020

CONTEXT

The Commission on End-of-Life Care (Commission sur les soins de fin de vie) was created by the Government of Quebec to examine all issues related to end-of-life care in Quebec. Its mandate is not to decide what care is made available to Quebeckers by the National Assembly, but rather to ensure access to appropriate end-of-life care, and in particular to ensure that all medical aid in dying (MAID) cases meet the criteria of the *Act respecting end-of-life care*. Although the Commission reports to the Quebec Minister of Health and Social Services, it fulfills its mandate independently.

Since December 10, 2015, the Commission has assessed the reports of close to 6,000 cases of MAID administered to Quebeckers and has compiled and analyzed the data submitted by the physicians who administered MAID. It has drawn findings and lessons from these unique stories of people with serious and incurable diseases enduring constant, intolerable and unappeasable suffering (Figure 1).

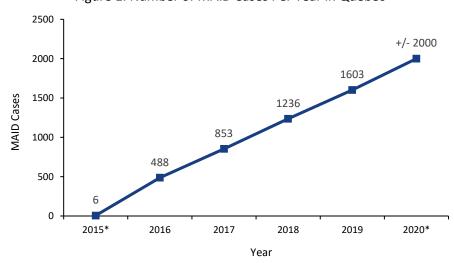


Figure 1. Number of MAID Cases Per Year in Quebec

Based on all the reports submitted to the Commission over the past five years and the descriptions they contain of the clinical presentations of individuals who received MAID, the Commission has data allowing it to infer certain probable effects of the *Criminal Code* amendments proposed in Bill C-7 on the administration of MAID in Quebec.

The Commission will refrain from commenting on Bill C-7's exclusion of persons with mental disorders, since this is outside its jurisdiction. The Commission will also not comment on the possibility of administering MAID to individuals incapable of giving consent. In fact, the issue of MAID for those incapable of giving consent was the subject of a report by an expert panel¹ and a national forum on January 27, 2020. Discussions and consultations are ongoing.

^{*} For 2015: December 10 to 31. For 2020: Estimate.

¹ Expert panel, 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, Government of Quebec, 2019, 157 pp. [Online].

The Commission will simply comment on its experience over the past five years on five specific objectives of Bill C-7 concerning persons at the end of life who have received MAID due to a serious and incurable physical illness:

- 1. repeal of the requirement that natural death be reasonably foreseeable;
- 2. repeal of the requirement of at least 10 clear days between the day of the request and the day that MAID is administered;
- 3. waiver of final consent;
- 4. The duality of the assessment and safeguard processes, which are different depending on whether the MAID application is for those whose natural death is reasonably foreseeable and for those whose natural death is not reasonably foreseeable; and
- 5. The safeguard mechanism of an assessment and oversight committee.

1. REPEAL OF THE REQUIREMENT THAT NATURAL DEATH BE REASONABLY FORESEEABLE

In the Commission's view, repealing reasonably foreseeable natural death as an eligibility requirement will not result in a sudden increase in MAID for individuals suffering from a serious and incurable disease, disability or illness.

MAID accounts for a minority of annual deaths in Quebec (2.6% of deaths in 2019–2020). According to Commission data, people who officially applied for MAID did so at an advanced stage of their disease. Of those who received MAID, 76% had a prognosis of three months or less and 88% had a prognosis of six months or less (Figure 2). MAID applications are submitted very close to the expected time of death. This is true not only for cancer patients, but also for those with a neurodegenerative disease that progresses more slowly (Parkinson's, multiple sclerosis and amyotrophic lateral sclerosis; Figure 3).

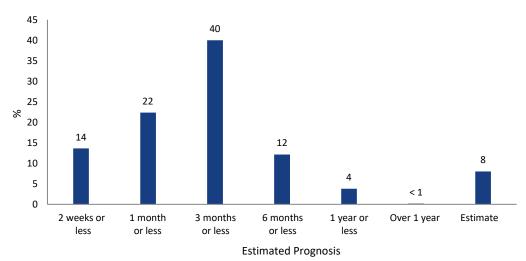


Figure 2. Percentage of Patients Who Received MAID, By Prognosis

50 43 45 40 35 30 25 24 25 % 20 15 15 15 15 10 10 5 01 0 2 weeks 1 month 3 months 6 months 1 year Over 1 year **Estimate** or less or less or less or less or less **Prognosis** ■ Cancer ■ Neurodegenerative Disease

Figure 3. Percentage of Cancer Patients (n = 3,564) or Those With a Neurodegenerative Disease (n = 436) Who Received MAID, By Prognosis

If adopted, Bill C-7 will provide access to MAID for many individuals with serious and incurable medical conditions who would have years or even decades left to live. Individuals with a disability or severe chronic disease, such as Ms. Gladu and Mr. Truchon, would be eligible for MAID once the reasonably foreseeable natural death requirement is repealed. However, the Commission is unable to estimate by how much the number of MAID applications and MAID cases would grow. Some fear that this number would be considerable and would take us down the slippery slope to death on demand. This is not the Commission's view.

First, the requirement that there be enduring, intolerable and unappeasable suffering and "advanced state of irreversible decline in capability," which are still in Bill C-7, would restrict the number of individuals eligible. Even in countries where euthanasia is not restricted to individuals at the end of life or whose death is expected in the near future (Belgium and the Netherlands), the number of euthanasia cases remains low. The slippery slope has therefore not been observed. Lastly, further to *Baudouin* (October 2019), which allows persons whose natural death is not reasonably foreseeable to obtain a judgment from the Superior Court of Quebec in order to receive MAID, a very small number of individuals took that approach.

2. REPEAL OF THE 10-DAY WAITING PERIOD BEFORE ADMINISTERING MAID

While Quebec's *Act Respecting End-of-Life Care* does not specify a particular waiting period, federal law requires a period of 10 clear days between the application and administration of MAID. According to data submitted to the Commission and evidence gathered from physicians who have administered MAID, this 10-day waiting period often causes terrible and unnecessary suffering for individuals and their loved ones.

In fact, more than half (53%) of individuals received MAID within 10 days of applying for it, not only because they feared losing the capacity to consent to MAID or because death was imminent, but also because of unappeasable suffering (Figures 4 and 5).

The Commission therefore supports the repeal of this mandatory waiting period as proposed in Bill C-7.

Figure 4. Percentage of Individuals by Waiting Period (Clear Days)

Between Application and Administration of MAID

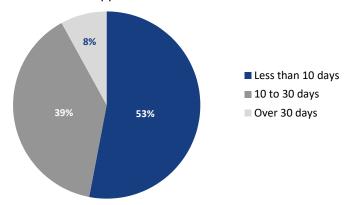
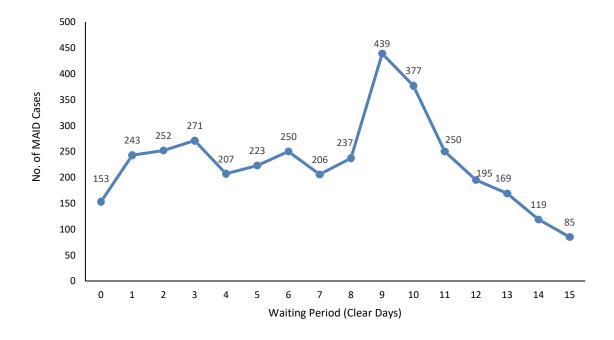


Figure 5. Time Between Application and Administration of MAID (Clear Days) for MAID Administered Between 0 and 15 Days After Application Form Was Signed



3. WAIVER OF FINAL CONSENT

The Commission notes from the reports analyzed that roughly one-quarter of the forms (26%) state that the patient refused the prescribed pain medication out of fear that taking the medication would compromise their ability to consent at the time MAID was administered. This causes undue suffering to these individuals deemed eligible for MAID.

The Commission therefore supports the repeal of the requirement for consent given at the time of MAID administration proposed by Bill C-7 for persons whose natural death is reasonably foreseeable and who have been deemed eligible for MAID by two independent practitioners.

4. DISTINCTION BETWEEN ASSESSMENT PROCESSES AND SAFEGUARDS BASED ON WHETHER OR NOT A PERSON'S NATURAL DEATH IS REASONABLY FORESEEABLE

People at the earliest stage of a serious and incurable disease want to know how long they have left to live. Aware of the difficulty of giving a reliable prognosis, medical professionals provide a prognosis to the best of their knowledge. Usually, medical professionals can provide a fairly accurate answer for individuals with a limited prognosis. Medical professionals should therefore have little difficulty assessing whether or not the natural death of an individual applying for MAID is reasonably foreseeable.

Having to determine which assessment process and safeguard should be applied, based on whether or not natural death is reasonably foreseeable, should therefore not be a problem.

The Commission believes that the assessment processes and safeguards should be separate, depending on whether or not natural death is reasonably foreseeable, as proposed in Bill C-7.

Individuals at end of life / with a reasonably foreseeable natural death

The closer the person is to death, the more accurate the prognosis. According to the 6,000 MAID reports reviewed by the Commission, physicians do not appear to have much trouble assessing MAID applications for individuals at the end of life, whose prognosis is generally estimated to be less than six months (up to one year in some cases), and the process in place is clear and has been well established for the past five years. Bill C-7 maintains the status quo for these individuals applying for MAID. The Commission believes that the current assessment mechanisms and safeguards must remain in place for MAID applications concerning individuals whose natural death is reasonably foreseeable, including, in particular, clearly specifying in their report the individual's diagnosis and serious and incurable condition, the advanced and irreversible decline of their capacities, and their persistent, constant, intolerable and unappeasable physical or mental suffering.

Individuals not at end of life / with a reasonably foreseeable natural death

The Commission does not have experience with those individuals whose natural death is not reasonably foreseeable who will be applying for MAID, since they were not previously eligible. There have been too few cases authorized by the Quebec Superior Court for the Commission to provide an informed opinion.

The Commission agrees with Bill C-7's proposal to establish a specific process for MAID applicants whose natural death is not reasonably foreseeable. Both the assessment process and the safeguards should be adapted to these cases. These MAID applications often require more complex assessments, requiring the involvement of another practitioner with expertise in the condition causing the person's suffering and the current and expected decline in capacity.

5. SAFEGUARD BY AN ASSESSMENT AND OVERSIGHT COMMITTEE

Quebec's National Assembly decided to create an independent commission on end-of-life care. It looked to Belgium and the Netherlands, which introduced such a safeguard mechanism in 2002, when they adopted their respective laws on euthanasia. These commissions must ensure that each euthanasia complies with the statutory requirements.

Based on its five years of experience and nearly 6,000 MAID cases analyzed in Quebec, and faced with the expansion of MAID eligibility to include individuals whose natural death cannot reasonably be foreseen, the Commission on End-of-Life Care draws these conclusions:

- All MAID providers must report the MAID administered, describe the complete clinical picture justifying MAID, and ensure that each report is carefully verified by competent multidisciplinary experts.
- The Commission's experience with 6,000 post-MAID reviews and, where appropriate, feedback to physicians and institutions to request missing information, explanation or justification, help prevent potential abuses and reassure the public.
- The Commission's feedback to physicians who administered MAID confirms that they acted in accordance with the Act.
- The provincial experiences in Quebec and Ontario appear to confirm that each post-MAID review must be conducted by a competent, independent, effective and efficient review body.
- The Commission on End-of-Life Care is able to evaluate, in real time, how the use of MAID is progressing and quickly identify new trends.