



EXECUTIVE SUMMARY

End-of-Life Decision Making:

Policy and Statutory Progress (2011-2020)

October 2020

A Report by the Policy Briefing Committee of the Royal Society of Canada Expert Panel Report (November 2011)



End-of-Life Decision Making: Policy and Statutory Progress (2011-2020)

Executive Summary

Overarching Findings of the 2011 Expert Panel

- Clarification is needed of the legal, ethical, and clinical status of withholding and withdrawing potentially life-sustaining treatment, especially where mature minors are concerned, and where treatment is withheld or withdrawn unilaterally by physicians.
- Research, education, and governmental resources are needed to facilitate advance care planning (including advance directives) by members of the public.
- Initiatives are needed to ensure better access to palliative care and to expand palliative care beyond cancer care to other areas of need.
- Legal guidelines and educational programs are needed regarding the administration of potentially life-shortening symptom relief.
- Legal clarification, clinical guidelines, and public education are needed regarding the practice of terminal sedation.
- Canada should have a permissive yet carefully regulated and monitored system with respect to the provision of assisted suicide and voluntary euthanasia.

Impact of the 2011 Expert Panel Report

- The Report has been cited numerous times in the scholarly end-of-life literature, in policy documents, and in the media.
- The Report was cited by the trial judge in *Carter v Canada (Attorney General)*, the case that led to the legalization of Medical Assistance in Dying (MAiD) in Canada.
- There have been many subsequent developments in end-of-life policy and law in Canada that align with the Report's recommendations.

Policy and Statutory Developments since the 2011 Expert Panel Report

Good progress:

- Research on advance care planning
- Resources to facilitate advance care planning
- Legalization of MAiD through Bill 52 (Quebec) and Bill C-14 (federal Parliament)

Moderate progress:

- Efforts to expand access to palliative care

Limited progress:

- Some attempts to clarify the legal status of withholding and withdrawal of potentially life-sustaining treatment, the mature minor rule for end-of-life decision-making, and unilateral withholding and withdrawal of potentially life-sustaining treatment
- No attempts by governments, prosecutors, or regulators to clarify the legal status of terminal sedation, except in Quebec

No progress:

- No guidelines or educational initiatives regarding potentially life-shortening symptom relief

Tracking Policy and Statutory Progress Since 2011

Expert panel recommendations on withholding and withdrawal of potentially life-sustaining treatment

Limited progress:

There has been no clarification of the legal status of withholding and withdrawal of potentially life-sustaining treatment by statutory amendment or by prosecutorial guidelines. However, the need for such clarification is now arguably less pressing due to statements made by the courts and by the federal Justice Department counsel. Legislators and government departments did not address the need for clarification with respect to the mature minor rule for end-of-life decision making. However, other organizations have offered clarifications for their members, clients, or communities. There remains a need to resolve the differential treatment of MAiD for mature minors and other health care decision making (including decisions with the consequence of ending life) for mature minors. The Expert Panel's concerns about the confusion, conflict, and controversy surrounding unilateral withholding and withdrawal of potentially life-sustaining treatment remain valid and inadequately addressed.

Expert Panel Recommendations on Advance Directives

Good progress:

More research has been conducted into advance care planning and efforts have been made by both governmental and non-governmental actors to develop resources to foster such planning.

Expert Panel Recommendations on Palliative Care

Moderate progress:

Progress has been made by governments, health care institutions, and health care providers toward ensuring that high quality palliative care is accessible to individuals that need and want it, including expanding palliative care beyond cancer.

Expert Panel Recommendations on Potentially Life-Shortening Symptom Relief

No progress:

The concerns that motivated the Expert Panel's recommendations regarding potentially life-shortening symptom relief remain valid and have not yet been addressed.

Expert Panel Recommendations on Terminal Sedation

Limited progress:

The concerns identified in the Expert Panel Report remain valid and have not yet been addressed anywhere other than in Quebec (and, even in Quebec, only for a subset of the types of sedation identified in the Report).

Expert Panel Recommendations on Assisted Suicide and Voluntary Euthanasia

Good progress:

MAiD has been legalized in Canada, under carefully circumscribed circumstances, first by statute in Quebec (Bill 52) and then by amendments to the *Criminal Code* (Bill C-14). However, many of the concerns identified by the Expert Panel remain valid:

- Exclusion of persons not at the "end of life" (Quebec) or whose natural death is not "reasonably foreseeable" (*Criminal Code*);
- No provision for advance requests;
- Exclusion of mature minors;
- 10-day waiting period.

The federal government took further steps toward bringing the law closer to the Expert Panel recommendations in Bill C-7. If passed as introduced, it would allow for advance requests for MAiD by persons who have been assessed and found eligible where their natural death has become reasonably foreseeable and would eliminate the waiting period for such persons. However, other significant inconsistencies with the Expert Panel recommendations would still remain, especially the exclusion of mature minors. There is also an explicit exclusion of persons with mental illness from the eligibility criterion of serious and incurable illness. Furthermore, Bill C-7 stipulates a 90-day waiting period for those whose natural death has not become reasonably foreseeable. There also remains a need for a national oversight commission to monitor and report annually and publicly on MAiD in Canada. The federal government has undertaken to study the issues of advance requests and mature minors further in its five-year review of the legislation.

Ongoing Policy and Statutory Challenges

Withholding and withdrawal of potentially life-sustaining treatment

Meeting the Expert Panel recommendations would require the following steps:

- provision of a statutory clarification by all provincial/territorial governments that do not currently provide clarity with respect to consent and mature minors;

- the federal government making a choice between permitting MAiD for mature minors (through amendments to the *Criminal Code*) and justifying treating decision making about MAiD differently than other health care decision making (including decisions with the consequence of ending life) for mature minors;
- provincial/territorial governments clarifying when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment;
- health care professional regulators (other than Manitoba, Ontario, and Quebec) amending their policies to make it clear when, if ever, health care professionals have the legal authority to unilaterally withhold or withdraw potentially life-sustaining treatment;
- health care regulators providing clinicians with more guidance in this area;
- health care professional educational institutions providing education to trainees and practitioners in this area.

Palliative care

Efforts are still needed to ensure that high quality palliative care is accessible to individuals who need and want it and that palliative care continues to be expanded beyond cancer.

Potentially life-shortening symptom relief

Efforts are still needed to clarify the legal and clinical status of the use of potentially life-shortening symptom relief for individuals who are experiencing enduring, intolerable, and irremediable suffering but are not eligible for MAiD.

Terminal sedation

To meet the Expert Panel recommendations the federal government would need to revise the *Criminal Code* to make it clear that palliative sedation in circumstances where it *will* hasten death is MAiD for the purposes of the *Criminal Code*, and is subject to the same procedural conditions and requirements as other forms of MAiD, and that palliative sedation in circumstances where it only *may* hasten death is not MAiD for the purposes of the *Criminal Code*.

The ongoing areas of concern—which include differences in clinical and legal definitions of palliative sedation, lack of data concerning its incidence and prevalence, as well as the ambiguities concerning what does and does not hasten death—indicate the need for collaboration between government, legal bodies, health care professional regulators, and clinicians in establishing legal and clinical standards that are clear to patients, clinicians, and the courts.

Assisted suicide and voluntary euthanasia (now known as MAiD)

Meeting the Expert Panel recommendations would require the following steps:

- the federal Parliament amending the *Criminal Code* and the Quebec National Assembly amending their *Act respecting end of life care* to permit respecting requests for MAiD made while capable but in advance of loss of capacity;
- the federal Parliament and Quebec National Assembly each amending their legislation to allow mature minors to access MAiD;

- the federal Parliament *not* amending the MAiD legislation to exclude all persons with mental illness as their serious and incurable illness, disease, or disability;
- the federal Parliament amending the MAiD legislation to remove the 10-day waiting period for all and *not*, as proposed, adding a 90-day waiting period for patients whose natural death is not reasonably foreseeable;
- the Colleges of Physicians and Surgeons and Colleges of Nurses that have not already done so including a duty of effective referral or transfer of care in their professional standards;
- the federal Parliament establishing a national oversight commission to monitor MAiD requests, work collaboratively with the Quebec's End of Life Care Commission and report annually and publicly on MAiD in Canada.