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POLICY BRIEF

MARCH 2025

The Risks of Advance Requests for Medical Assistance in Dying (MAiD)

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A previous version of this brief (published December 2024) reported a different estimate of national compliance issues. The brief has been updated as of March 2025 to correct this estimate to a new range based on data from Quebec and Ontario.

ISSUE

The Government of Canada is conducting a consultation on advance requests for medical assistance in dying (MAiD). An advance euthanasia request[1] would allow patients to request MAiD prior to losing decision-making capacity at some point in the future. This would allow a practitioner to administer MAiD at an unknown future date without the patient's express final consent. Advance euthanasia requests introduce heightened risks for patients and providers, including significant risks of wrongful deaths. Few international jurisdictions allow euthanasia on the basis of an advance euthanasia request, and thus empirical data on the practice is limited.

Despite the risks, the province of Quebec has unilaterally proceeded with allowing MAiD for patients who lack capacity to consent based on advance euthanasia requests. This will result in Quebecois dying in circumstances that are contrary to the exceptions permitted under the Criminal Code. The federal government should take strong action to protect the lives of Canadians by acting on the following recommendations.

RECOMMENDATIONS

The Government of Canada should:

- Challenge the Government of Quebec's decision to contravene criminal law on advance euthanasia requests;
- Not introduce any federal legislation to expand MAiD through advance euthanasia requests;
- Commit to enhancing and enforcing safeguards in current MAiD practice for patients facing a loss of capacity in order to protect the most vulnerable Canadians;
- Investigate and address problems with current MAiD practice, including the inadequacy of safeguards, documented problems of non-compliance, and inadequate social and health supports causing Canadians to opt for a premature death.

[1] For clarity and to avoid confusion with similar terms, this brief uses the term "advance euthanasia request" rather than "advance request".

BACKGROUND

Currently, the Criminal Code requires patients to provide final express consent to the clinician immediately before euthanasia is administered. **This was instituted as a procedural safeguard** as it provides an opportunity for patients to withdraw their request for MAiD and reaffirm their consent. However, this safeguard was eroded through the creation of exceptions to final consent in Bill C-7 in 2021.[2] Specifically, the Criminal Code currently allows:[3]

For Track 1 patients, whose natural deaths are reasonably foreseeable:

- A patient approved for MAiD who is at **risk of imminently losing their capacity to consent (such as losing consciousness) before the date they planned to receive MAiD may waive their final consent and still receive MAiD on that date,** even if consent cannot be affirmed immediately before death (S. 3.2). In such cases, the waiver of final consent is null if the patient demonstrates refusal or resistance to the procedure (S. 3.4).

For Track 2 patients, whose natural deaths are ***not*** reasonably foreseeable:

- A patient approved for MAiD is still required to provide express final consent but, importantly, **the 90-day period between their first assessment and their receipt of MAiD can be reduced to provide MAiD sooner** if concern exists about the imminent loss of a person's capacity to consent (S. 3.1).

For patients self-administering MAiD:

- In the very rare cases (<7 cases/year)[4] where patients opt to self-administer a substance through assisted suicide, they may make arrangements in writing to allow the practitioner to administer a second substance if complications with self-administration arose and the person could not consent immediately before death (S. 3.5).

Allowing the waiver of final consent is already deeply problematic. Advance euthanasia requests would be much more problematic, as detailed further below. For the sake of clarity, advance euthanasia requests should be differentiated from ***advance directives.*** Fundamentally, advance directives to cease or withdraw treatments, or not attempt resuscitation, can be appropriate in some situations where a patient is dying – but these are ***materially different*** than a directive to consent to being killed at a future date under certain conditions. As described by the Council of Canadian Academies in their government-commissioned report, "advance directives do not compel a third party to decide that another person is ready to die, though the withdrawal or withholding of treatment may certainly result in death", in contrast to an advance euthanasia request whereby "a third party…must, based

[2] "C-7 (43-2) - Royal Assent - An Act to Amend the Criminal Code (Medical Assistance in Dying)," C-7 § (2021), https://www.parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent.

[3] Legislative Services Branch, "Consolidated Federal Laws of Canada, Criminal Code," October 10, 2024, https://laws-lois.justice.gc.ca/eng/acts/C-46/section-241.2.html?txthl=consent+final.

[4] Health Canada, "Fourth Annual Report on Medical Assistance in Dying in Canada 2022" (Health Canada, October 26, 2023), 21, https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022.html.

on a documented request, determine the exact timing and circumstances of a person's death".[5] Moreover, advance directives to cease or withdraw treatments can be ethically complex and challenging to navigate. There are already existing concerns about how they can and sometimes are used against persons living with disabilities, as a result of stigma and ableist biases from healthcare providers.[6] The introduction of advance euthanasia requests, whereby the clinician would directly and intentionally end the life of the patient, would be even more fraught – particularly for vulnerable Canadians.

CONSIDERATIONS

Consideration 1: The MAiD system already has problems that require investigation, enhanced safeguards, and better monitoring. These documented compliance issues warrant more effective federal enforcement measures, instead of an acceleration of expansion.

- Canada has the world's fastest-growing assisted dying program, and is the second highest in the world in terms of MAiD deaths as a percentage of total deaths. As noted in Cardus's August 2024 report on the subject, MAiD was intended to be for exceptional cases, but has become increasingly normalized.[7] Furthermore, this growth in deaths has been continually underestimated by Canadian officials.[8] This growing rate of MAiD deaths should be a signal to investigate the functioning of the current system as well as the sources of suffering driving demand for MAiD.

- Reports have documented Canadians opting for MAiD due to social suffering, rather than suffering related to their medical condition.[9] The Office of the Chief Coroner of Ontario has provided data and case information showing how Track 2 MAiD is impacting marginalized Canadians.[10]

- Compliance with regulations is not independently reviewed in most cases and MAiD reports are based solely on the self-reported data of MAiD assessors and providers.[11] This creates inherent challenges for both monitoring and enforcement.

[5] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying" (Ottawa, ON: The Expert Panel Working Group on Advance Requests for MAID, Council of Canadian Academies, 2018), 39, https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf.

[6] Gabrielle Peters, "Reality, Not Religion, Is the Reason People Need MAiD-Free Health Care," *Policy Options*, April 26, 2024, https://policyoptions.irpp.org/magazines/april-2024/maid-free-health-care/.

[7] Alexander Raikin, "From Exceptional to Routine: The Rise of Euthanasia in Canada" (Cardus, August 2024), https://www.cardus.ca/research/from-exceptional-to-routine/.

[8] Raikin, "From Exceptional to Routine."

[9] Ramona Coelho et al., "The Realities of Medical Assistance in Dying in Canada," *Palliative & Supportive Care* 21, no. 5 (October 2023): 871–78, https://doi.org/10.1017/S1478951523001025.

[10] MAiD Death Review Committee, Office of the Chief Coroner, "MAiD Death Review Committee (MDRC) Report 2024 – 2: Complex Medical Conditions with Non-Reasonably Foreseeable Natural Deaths" (Government of Ontario, 2024); MAiD Death Review Committee, Office of the Chief Coroner, "MAiD Death Review Committee Report 2024 - 3: Navigating Vulnerability in Non-Reasonably Foreseeable Natural Deaths" (Government of Ontario, 2024); Office of the Chief Coroner, "Medical Assistance in Dying (MAiD): Marginalization Data Perspectives" (Government of Ontario, 2024).

[11] Jaro Kotalik, "Monitoring of MAID: Deficits of Transparency and Accountability," in *Medical Assistance in Dying (MAID) in Canada: Key Multidisciplinary Perspectives*, ed. Jaro Kotalik and David W. Shannon, vol. 104, The International Library of Bioethics (Cham: Springer International Publishing, 2023), 115–26, https://doi.org/10.1007/978-3-031-30002-8.

- Quebec's Commission sur les soins de fin-de-vie has documented, each year, cases of non-compliance, including cases where the commission disagrees with the assessors and providers over the eligibility of patients who died through MAiD. Other than indicating that summaries of concerns are sent to the province's physician and nursing regulatory bodies, the Commission provides no further details as to the consequences of non-compliance and measures of enforcement.[12]

- Leaked documents from Ontario's Office of the Chief Coroner have documented 428 cases of non-compliance in the province, including some MAiD providers exhibiting a "pattern of noncompliance" despite feedback from the Coroner's office.[13] 178 compliance issues were identified by the Coroner's Office in 2023 alone, with 25% of MAiD providers receiving communications from the Coroner's Office on compliance issues.[14] No Ontario assessors or providers were reported to law enforcement for their alleged violations of the Criminal Code.

- A lack of similar review functions in other provinces results in a data gap as to how many cases of non-compliance are occurring each year across the country, but estimations based on the data from Quebec and Ontario could mean there have been between 300 to 1300 compliance issues nationally since 2016 and an unknown number of wrongful deaths as a result.[15] Given that data is self-reported by MAiD providers, compliance issues and wrongful deaths may be significantly higher, but we lack independent mechanisms to verify their self-reports.

- Significantly heightened safeguards would be needed for advance euthanasia requests, as attested to by the Council of Canadian Academies in their commissioned study of the issue,[16] but ongoing, current issues with safeguards and the lack of adequate monitoring and enforcement must be addressed ***first*** to avoid compounding the problems. As noted by the Council of Canadian Academies' study, there is a lack of sufficient data to understand the impacts of introducing advance MAiD requests, but they note that Canada's aging population is anticipated to result in a growth of neurological conditions affecting capacity, which would likely yield increased demand for advance euthanasia requests over time.[17]

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[12] Commission sur les soins de fin de vie, "Rapport Annuel d'activités: Du 1er Avril 2023 Au 31 Mars 2024" (Gouvernment du Québec, 2024), https://csfv.gouv.qc.ca/fileadmin/docs/rapports_annuels/csfv_rapport_activites_2023-2024.pdf.

[13] Raikin, Alexander, "A Pattern of Noncompliance," *The New Atlantis*, November 11, 2024, https://www.thenewatlantis.com/publications/compliance-problems-maid-canada-leaked-documents.

[14] Raikin, Alexander, "A Pattern of Non-Compliance."

[15] Calculated using total deaths of MAiD as of 2023 (60,301), the 99.5% compliance rate in Quebec (or 0.5% non-compliance) and the aforementioned 428 cases of non-compliance in Ontario (or 2.3% non-compliance, when calculated against the 18,376 total MAiD deaths in Ontario as of 2023). Commission sur les soins de fin de vie, "Rapport Sur La Situation Des Soin de Fin de Vie Au Quebec: Du 1er Avril 2018 Au 31 Mars 2023" (Gouvernment du Québec, February 18, 2025), https://csfv.gouv.qc.ca/fileadmin/docs/rapports_sfv/csfv_rapport_2018-2023.pdf; Health Canada, "Fifth Annual Report on Medical Assistance in Dying in Canada, 2023," December 11, 2024, https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2023.html.

[16] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," chap. 6.

[17] Council of Canadian Academies, 39–41, 136–37.

Consideration 2: Advance euthanasia requests compromise – rather than protect – informed consent for MAiD and may contradict the present agency of a patient in favour of their past decision.

- **Patients diagnosed with dementia, even in the early stages, may be unable to make an informed decision regarding an advance request.** As described by researchers, "Although the patient suffering from initial symptoms of dementia may project himself into future worsened conditions, he will not be able to fully understand those cognitive, emotional, and behavioral alterations inevitably associated with a different stage of the disease."[18] As a result, the decision does not account for a patient's capacity to adapt to a diagnosis or condition and no longer wish to die.
    - Furthermore, early diagnosis is typically rare; as such, patients usually will be experiencing symptoms – including depression – while making decisions for advance requests.[19]
- **Strong stigma continues to exist against conditions like dementia and Alzheimer's Disease, which may significantly impact a patient's understanding of what life could be like for them in that situation.**[20] In one study, patients recently diagnosed with Huntington's disease had fears about what would constitute suffering in the future – such as requiring help to shower– but, as they progressed in their condition, they found such circumstances did not actually produce the suffering they had feared.[21]
    - Additionally, **quality of life is often underestimated by outsiders,** with patients with dementia still identifying as having a good quality of life.[22] Patient perspectives may not be well understood by others, even amongst family. [23] Family, caregivers and medical personnel may incorrectly interpret behaviours that express a will to live and not die, if the patient is no longer able to express themselves verbally. This creates significant challenges, as those interpreting their wishes must discern "between their documented wishes, as stated in an advance directive, and their current interests, as conscious and alert beings, although with diminished competency."[24] Clinicians would also need to navigate the potential of coercion or elder abuse driving an advance euthanasia request, to which persons with dementia are already more vulnerable.[25]

[18] Nicola Di Fazio et al., "European Countries' Different Legal Orientation About End-of-Life Issues in Patients Affected With Neurological/Psychiatric Diseases: Does Italian Law n.219/2017 Provide Adequate Options for This Fragile Category of Patients?," Frontiers in Psychiatry 12 (September 24, 2021): 3, https://doi.org/10.3389/fpsyt.2021.675706. This research applies to 'advanced treatment provisions' (ATPs) more generally, but is arguably more significant when it is an advance request for euthanasia.

[19] Di Fazio et al., "European Countries' Different Legal Orientation About End-of-Life Issues in Patients Affected With Neurological/Psychiatric Diseases."

[20] Gwendolien Vanderschaeghe et al., "Amnestic MCI Patients' Perspectives toward Disclosure of Amyloid PET Results in a Research Context," *Neuroethics* 10, no. 2 (2017): 281–97, https://doi.org/10.1007/s12152-017-9313-z.

[21] Marina R. Ekkel et al., "Patient Perspectives on Advance Euthanasia Directives in Huntington's Disease. A Qualitative Interview Study," *BMC Medical Ethics* 23, no. 1 (October 10, 2022): 101, https://doi.org/10.1186/s12910-022-00838-0.

[22] G. Livingston et al., "Successful Ageing in Adversity: The LASER-AD Longitudinal Study," *Journal of Neurology, Neurosurgery, and Psychiatry* 79, no. 6 (June 2008): 641–45, https://doi.org/10.1136/jnnp.2007.126706.

[23] Carlos Gómez-Vírseda and Chris Gastmans, "Euthanasia in Persons with Advanced Dementia: A Dignity-Enhancing Care Approach," *Journal of Medical Ethics* 48, no. 11 (November 1, 2022): 15, https://doi.org/10.1136/medethics-2021-107308.

[24] Gómez-Vírseda and Gastmans, 14.

[25] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 86.

- Decisions to make an advance request may also be **influenced by fears of being a burden** to their family, caregivers, and community. Research has pointed to interest in euthanasia linked to a fear of being a burden.[26] This is of particular relevance given that existing data shows a significant number of MAiD recipients report a source of suffering driving their request for MAiD as feeling like a burden (35.3% in 2022).[27] This is significantly higher in Quebec – 47% - compared to the rest of Canada,[28] creating even more concerns as to Quebec's unilateral decision to proceed with this expansion.

- **Patients may die based on their advance euthanasia request even if the request no longer represents their current wishes at the time of their death.** If patients lose capacity and are unable to revoke their consent, they may receive MAiD contrary to their present wishes. **This creates a conflict between the patient's past autonomy and present autonomy,** requiring the MAiD practitioner to adjudicate between them: "the one [intention] expressed by the still-competent person in the form of an AED [advance euthanasia directive], anticipating unknown situations; or the one expressed in non-cognitive ways—through utterances or behavioral expressions—by the present person with advanced dementia?"[29]

  - Importantly, the use of advance euthanasia requests could come into conflict with established "human rights principles, including the UN Convention on the Rights of Persons with Disabilities, which stresses the importance of involving individuals with decision-making disabilities in decisions for as long as possible, rather than relying solely on an AED [advance euthanasia directive]." [30]

Consideration 3: Few jurisdictions allow advance euthanasia requests and, consequently, the state of knowledge on their use is limited. Jurisdictions that do allow euthanasia without final consent based on an advance euthanasia request/directive are navigating significant ethical, legal and practical problems.

- All but a few international jurisdictions **do not allow** for euthanasia without final consent, on the basis of an advance request or directive to receive euthanasia.

  - Belgium and Luxembourg allow for the use of euthanasia without final consent ***only*** where a patient with an advance euthanasia directive has become ***irreversibly unconscious.*** They also require these directives to be registered in a national registry.

  - In the Netherlands, by contrast, ***some degree of consciousness is required*** to receive euthanasia as a result an advance euthanasia directive (AED).

[26] Vanderschaeghe et al., "Amnestic MCI Patients' Perspectives toward Disclosure of Amyloid PET Results in a Research Context."

[27] Health Canada, "Fourth Annual Report on Medical Assistance in Dying in Canada 2022," 31.

[28] Commission sur les soins de fin de vie, "Rapport Annuel d'activités: Du 1er Avril 2023 Au 31 Mars 2024," 30.

[29] Gómez-Vírseda and Gastmans, "Euthanasia in Persons with Advanced Dementia," 6.

[30] Djura O. Coers et al., "Navigating Dilemmas on Advance Euthanasia Directives of Patients With Advanced Dementia," *Journal of the American Medical Directors Association*, October 10, 2024, 6, https://doi.org/10.1016/j.jamda.2024.105300.

- Spain and Colombia also allow for the possibility of advance directives related to euthanasia, but limited English-language research is available on its use. [31]

- Overall, as highlighted by the Council of Canadian Academies report, **there is "little empirical evidence" to evaluate the practice** of providing euthanasia without final consent based on an advance euthanasia request.[32]

  - The Netherlands' experience has highlighted the complexities in evaluating whether patients with advance euthanasia directives qualify.[33] Concerns have been flagged in a number of cases studied by euthanasia review committees as not meeting the established criteria.[34]

  - Furthermore, there are significant practical challenges with interpreting behavior and communications (verbal or otherwise) that run contrary to the wishes expressed in an advance euthanasia directive; researchers note that, in such cases, physicians interpreting a desire to continue living will 'suspend' the directive.[35] Regardless, in the Netherlands, research has pointed to doctors experiencing pressure to provide euthanasia in cases of dementia, with the requests most often coming from the family rather than the patient, raising questions about how negative views of dementia and stigma may influence such requests.[36]

- Despite these issues in the Netherlands' use of euthanasia, the possibility of abuse may be significantly higher in Canada due to several procedural factors:[37]

  - Unlike the Canadian law, the Netherlands' "due care" criteria requires the doctor to conclude that there is "no prospect of improvement" and, "together with the patient,…no

[31] Tamara Raquel Velasco Sanz et al., "Spanish Regulation of Euthanasia and Physician-Assisted Suicide," Journal of Medical Ethics 49, no. 1 (January 1, 2023): 49–55, https://doi.org/10.1136/medethics-2021-107523; Miguel Paradela López and Alexandra Jima González, "Analyzing the Spanish Euthanasia Law: Achievements and Inconsistencies of the Legal Assistance to Die," Revista de Bioetica Y Derech 58 (2023): 147–64, https://doi.org/10.1344/rbd2023.58.39990; Luis Espericueta, "First Official Report on Euthanasia in Spain: A Comparison with the Canadian and New Zealand Experiences," Medicina Clínica (English Edition) 161, no. 10 (November 24, 2023): 445–47, https://doi.org/10.1016/j.medcle.2023.06.021; Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 113. As noted in the Council's report, Columbia does not have requirement around consciousness for receiving euthanasia and also allows surrogate decision makers to request euthanasia on behalf of a patient or, conversely, withdraw a request.

[32] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 86.

[33] D. O. Coers et al., "A Qualitative Focus Group Study on Legal Experts' Views Regarding Euthanasia Requests Based on an Advance Euthanasia Directive," *BMC Medical Ethics* 25, no. 1 (October 24, 2024): 119, https://doi.org/10.1186/s12910-024-01111-2; Coers et al., "Navigating Dilemmas on Advance Euthanasia Directives of Patients With Advanced Dementia"; Djura O Coers et al., "Dealing with Requests for Euthanasia in Incompetent Patients with Dementia. Qualitative Research Revealing Underexposed Aspects of the Societal Debate," *Age and Ageing* 52, no. 1 (January 1, 2023): afac310, https://academic.oup.com/ageing/article/52/1/afac310/6969134.

[34] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 133.

[35] Coers et al., "Navigating Dilemmas on Advance Euthanasia Directives of Patients With Advanced Dementia," 6.

[36] Jaap Schuurmans et al., "Euthanasia Requests in Dementia Cases; What Are Experiences and Needs of Dutch Physicians? A Qualitative Interview Study," *BMC Medical Ethics* 20, no. 1 (October 4, 2019): 66, https://doi.org/10.1186/s12910-019-0401-y.

[37] This is not to endorse the safeguards of the Netherlands' system, as there are significant concerns that continue to be raised with the administration of euthanasia there.

reasonable alternative".[38] This is a higher bar than Canada's mere requirement to discuss alternatives, without a requirement to have actually tried such means of relieving suffering.

- Furthermore, Regional Euthanasia Review Committees in the Netherlands provide an independent mechanism after each euthanasia death to ensure compliance from assessors and providers – and a heightened level of review in complex cases.[39] Canada failed to institute a national review program and as noted previously, the provincial review functions that exist lack transparency and clear mechanisms of enforcement.

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[38] Regional Euthanasia Review Committees, "Euthanasia Code 2022: Review Procedures in Practice" (Regional Euthanasia Review Committees, Government of the Netherlands, July 2022), https://english.euthanasiecommissie.nl/the-committees/euthanasia-code-2022.

[39] Regional Euthanasia Review Committees.