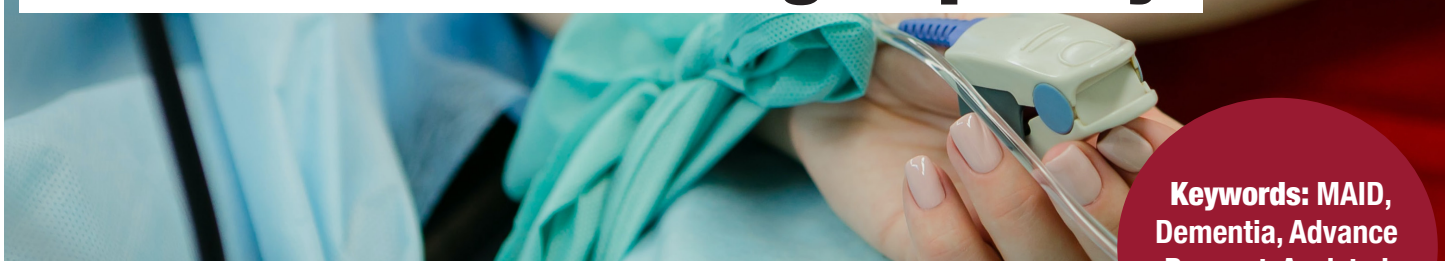


# An advance request: Accessibility of Medical Assistance in Dying (MAID) for patients who lose decision-making capacity



**Keywords: MAID, Dementia, Advance Request, Assisted Suicide**

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## ABSTRACT

Since the legalization of Medical Assistance in Dying (MAID) in Canada in 2016, there have been discussions regarding the extension of this service to patients who lose decision-making capacity but have made a prior advance request for physician-assisted suicide. Both caregivers and physicians have shown some support for allowing patients to make advance requests for MAID. The proposed changes to the legislation would remove the mandatory 10-day waiting period for patients whose deaths are imminent and would include a waiver of final consent for those who lose decision-making capacity following their MAID request. There are important ethical considerations as well because as the inclusion criteria becomes broader, the subjectivity in the decision to implement MAID rises. Determining clear eligibility criteria and strong safeguards is essential for the safe and equitable implementation of this procedure.

## RÉSUMÉ

Depuis la légalisation de l'aide médicale à mourir (« Medical Assistance in Dying, MAID ») au Canada en 2016, des discussions ont eu lieu concernant l'extension de ce service aux patients qui perdent leur capacité de décision mais qui ont fait une demande préalable de suicide médicalement assisté. Tant les soignants que les médecins ont montré un certain soutien pour permettre aux patients de faire des demandes en avance pour le service. Les modifications proposées à la législation supprimeraient la période d'attente obligatoire de dix jours pour les patients dont le décès est imminent et comprendraient une dérogation au consentement définitif pour ceux qui perdraient leur capacité de décision à la suite de leur demande d'aide à mourir. Il y a également d'importantes considérations éthiques car plus les critères d'inclusion sont larges, plus la décision de mettre en œuvre le programme d'aide médicale à mourir est subjective. La détermination de critères d'éligibilité clairs et de mesures sécuritaires solides est essentielle pour une mise en œuvre sûre et équitable de cette procédure.

## MEDICAL ASSISTANCE IN DYING (MAID) IN CANADA

On February 6th, 2015, the Supreme Court of Canada unanimously ruled that the prohibition of physician assisted dying was unconstitutional, as it violated the

Canadian Charter of Rights and Freedoms (1). Following this decision, the Province of Quebec adopted the first MAID legislation, Bill 52, which had been passed on June 5th, 2016 (2). Six months later, the Canadian parliament created a similar legislation, Bill C-14, which allowed

physicians and nurse practitioners to provide MAID (3).

In order to qualify for MAID, a patient must be eligible for health services funded by the Canadian government, be at least 18 years of age, be capable of giving informed consent and be suffering from an incurable medical condition (3). In the fall of 2019, a Quebec Superior Court Judge ruled that certain sections of the federal and provincial laws were unconstitutional on the grounds that the eligibility criteria were too restrictive (4). Justice Christine Baudouin ruled in favor of two Quebecois citizens with incurable degenerative diseases who were denied access to MAID on the grounds that their deaths were not “reasonably foreseeable” (4). Since this was seen by many as limiting these patient’s rights to a dignified death, these cases sparked a nationwide discussion regarding the question of broadening the eligibility criteria for patients seeking MAID.

Specifically, there have been discussions regarding the lack of accessibility of MAID for patients who lose decision-making capacity due to major neurocognitive disorders or other medical ailments. The expert panel working group, a collection of individuals from varying disciplines assembled to prepare a report for the Government of Canada regarding the nuances of MAID, describe an advance request as “a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under circumstances outlined in the request after the person has lost decisional capacity” (5). Currently, it is not possible to make advance requests for MAID should an individual become incapable throughout the course of their illness. However, on February 24th 2020, a new bill was introduced which proposed a waiver of final consent for those already approved for MAID. This bill would allow for an arrangement between patients and their practitioner to waive final consent if the patient was at risk of losing decision-making capacity before their chosen date to receive MAID and “whose natural death is reasonably foreseeable” (6). The new legislation would also extend the previous 10-day reflection period to take place over 3 months unless the loss of capacity is imminent (6).

### LIMITATIONS FOR PATIENTS WITH ADVANCED STAGES OF DEMENTIA

The Alzheimer’s Society of Canada has released a 2019 statement expressing their view that patients should have

the ability to access MAID through advance requests (7). This demonstrates a change in opinion since their 2016 position statement (8). In order to further investigate the wishes for advance requests, the province of Quebec has conducted several studies to assess the opinions of informal caregivers and physicians (9-10). Informal caregivers, mainly spouses or adult children of patients with dementia, showed support for extending MAID to patients with Alzheimer’s disease who lose decision-making capacity. Surveys demonstrated that 68% of respondents agreed that MAID should be extended to patients with advanced Alzheimer’s disease who had previously completed a written request (9). This agreement increased to 91% if the patient was also in the terminal stages of their disease and was showing signs of distress (9). Compared to informal caregivers, physicians appeared to be less in favor of increasing access to MAID. One study demonstrated that only 45% of physicians supported extending access to MAID for patients suffering from advanced dementia in the presence of a written request. However, support increased to 71% if the patient was also demonstrating signs of distress (10). It would be important to explore the reasons why physicians may be less in favor of MAID in individuals with advanced dementia compared to informal caregivers. It is possible that the emotional burden of actively ending an individual’s life discourages physicians from supporting MAID to the same extent of caregivers. Furthermore, it is possible that family understand their loved ones better than physicians and witness the patient’s suffering firsthand, which could lead them to be more comfortable with decisions regarding the implementation of MAID. Another factor which would be important to explore is the impact of caregiver burnout on end-of-life decision making. Overall in both studies, there was significantly less support for access to MAID when no prior request was expressed (10).

### MAID IN OTHER PARTS OF THE WORLD

Currently, there are four countries that allow for advanced euthanasia requests: the Netherlands, Belgium, Luxembourg and Colombia (5). In Belgium and Luxembourg, this procedure is limited to individuals who have given prior written consent and whose condition has progressed to a state of irreversible coma (10). In contrast, the law in the Netherlands requires patients to be conscious at the time of euthanasia and there is no guarantee that a patient who has made an advance request will be provided with

the service (5). Although legally permitted, there are no available statistics on advance requests for euthanasia in Colombia (5).

In the United States, there is a different approach to assisted suicide. In the few states where MAID is permitted, physicians are responsible for prescribing a lethal dose of barbiturates but cannot legally be involved in its administration. According to the 2018 Data Summary from Oregon, 249 individuals filled Death With Dignity Act prescriptions in 2018 and 11 had prescriptions from previous years, but only 169 individuals were confirmed to have ingested the medication (11). Based on these numbers, there are over 90 patients who completed the process for acquiring a lethal prescription, but who did not ingest the medication. In Canada, however, the administration is almost exclusively conducted by care providers. This raises the question as to whether or not certain patients in Canada who are eligible for MAID would have opted against completing the process had they been responsible for self-administering the lethal substance.

### KEY CONSIDERATIONS FOR MAID

There are numerous key elements that should be examined when assessing the ethical questions pertaining to advance requests for MAID. Firstly, there is an emotional burden placed on health care providers and patient families responsible for life ending decisions. Furthermore, although some patients with Dementia develop Behavior and Psychological Symptoms of Dementia (BPSD), many continue to appear quite content during the terminal stages of their disease. In these cases, it seems unreasonable to complete a MAID request despite the patient's prior wishes.

Health care providers have also expressed the challenge of characterizing intolerable suffering among patients whose communication is limited (12). When creating advance requests, it is not feasible that every possible situation be addressed, leaving large amounts of uncertainty regarding the timing of MAID implementation. Furthermore, the expert panel working group expresses concerns regarding the stigmatization of incapacity as well as the potential for abuse in the context of external pressures, such as systematic lack of resources for long-term care (5). Indigenous elders contacted by the expert panel for their input argue that, instead of spending resources to increase accessibility

of MAID, these resources should instead be focused toward improving quality and access of medical care in underserved areas (5). A new safeguard included in the proposed bill to amend the current legislation addresses this, stating that "the person must be informed of available and appropriate means to relieve their suffering [...] and must be offered consultations with professionals who provide those services" (6). There is also no consensus as to the acceptable amount of time that can elapse between the request for MAID and the completion of the request (5). Furthermore, there is no agreement as to whether or not patients could make advance requests prior to being diagnosed with a severe and incurable illness (5).

Although there are numerous hesitations regarding advance requests for MAID, making this option accessible to patients ultimately offers advantages. It allows for greater patient autonomy and self-determination. It creates opportunities for people to dictate the context of their death and could remove stresses surrounding potential loss of capacity to make decisions for one's own care needs. Although sufficient literature is lacking, there is also speculation that offering advance requests for MAID would prevent premature suicide. Some believe that patients may take their lives prematurely, while they are still competent, in order to prevent their perceived suffering of terminal stage dementia (5). Contrastingly, a systematic review concluded that dementia may not confer a significant overall risk to suicidal behavior, and thus, MAID may not cause premature loss of quality life years among patients with dementia (13). Furthermore, due to the mandatory 2-week waiting period between the MAID request and the procedure, certain patients may lose their ability to provide consent, thereby restricting their access.

### FUTURE DIRECTIONS FOR MAID IN CANADA

There are arguments both for and against advance requests for MAID. With the proposed amendments to the current legislation, we must explore the reasoning behind such requests and consider the possible implications of revising current laws. It is important to acknowledge the motivations underlying advance MAID requests and determine if they may be mediated by other factors such as existential anxiety or perception of being burdensome to family members, which could potentially be mediated. Additionally, we must consider whether patients with

advanced dementia suffer intractably, since this becomes impossible to assess with 100% certainty during advanced stages of the disease. If we consider infants who demonstrate limited knowledge of the world around them, we can conclude that although they are reliant for their basic needs and lack the ability to communicate effectively, we do not interpret this as suffering. Alternatively, we can argue that for patients who seem to be in frequent and visible agony, that perhaps there is a subset of patients with dementia that may meet the criteria for irremediable suffering. In this subset of patients who do not respond to medical management, it may be reasonable to consider an advance request for MAID. For the subset of patients who do complete a request for MAID, but who lose capacity over the course of their illness, it is likely reasonable to uphold the patient's prior MAID request. Determining the criteria for this, however, is difficult and will imply a certain amount of subjectivity. Paradoxically, changing the legislation to include a wider range of patients increases the burden on health care providers and increases uncertainty, which may reduce the number of physicians willing to provide MAID, in turn, decreasing its accessibility. We find ourselves faced with the question of identifying the limit of precedent autonomy.

## CONCLUSION

The introduction of MAID in Canada has increased the ability to dictate the circumstances surrounding one's own death. The proposed amendment to the legislation would allow the patients who make prior requests for assisted suicide, but then lose decision-making capacity during the course of their illness, to waive their final consent and access the procedure. Although discussed in the expert panel on MAID, no consensus was made regarding what specific criteria would need to be met in order for individuals to qualify for advance requests and what safeguards would need to be put in place (5). With this in mind, I believe there is still considerable discomfort in discussing the ethical considerations of assisted suicide and further exploration of the ethical considerations and the values of our society is warranted. I predict, if advance requests become available in Canada, that the criteria will be restrictive, and that the time frame between making the advance request and implementing the procedure will be relatively short.

## ACKNOWLEDGEMENTS

Thank you very much Dr. Brendan Lier for your support with this publication and your invaluable insight and teaching in the field of bioethics.

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