



Position Statement: Advance Requests for Medical Assistance in Dying

SUMMARY

Canada has created a legal framework for medical assistance in dying (MAiD), but certain elements of eligibility criteria and procedural safeguards remain unsettled. One of these elements is the framework for Advance Requests.

Under the current law, a person in the advanced stages of dementia will likely not be able to legally consent to MAiD. The ability to make an advance request would circumvent this problem. The Special Joint Parliamentary Committee on Medical Assistance in Dying (AMAD) has resumed its review of MAiD – including advance requests. The subject of MAiD is complex and there is a diversity of views within our community. As the public debate and the legal framework has evolved, so have the positions of the Alzheimer Society of Canada.

People living with dementia must have the same rights as other Canadians – including the right to a timely diagnosis; to participate in advance care planning; access to high-quality health and palliative care, and to make an advance request for a medically assisted death if that is their desire. Advance Requests represent one possible end-of-life treatment option within an advance care plan.

It is essential to include the views of people living with dementia in any change to legislation or policy – including decisions affecting their health and life. Respect for the basic rights, dignity and well-being of people living with dementia must be paramount, no matter the stage of their condition. People living with dementia should not be excluded from the rights extended to other Canadians because of a diagnosis. That includes access to end-of-life care and options for individualized support. The Alzheimer Society believes that people living with dementia should have personal autonomy in making decisions about their care – including the right to make an advance request for medical assistance in dying.

The Alzheimer Society of Canada supports the right of people living with dementia to make an advance request for a medically assisted death.

ISSUE DESCRIPTION

Canada’s framework for MAiD does not include a framework for making Advance Requests - a process with safeguards to allow an individual to make a request before decision-making capacity is lost.

The Special Joint Parliamentary Committee on Medical Assistance in Dying (AMAD) has resumed its statutory review of the provisions of the Criminal Code relating to Medical Assistance in Dying and its application – including Advance Requests.

This review needs to respect the individual autonomy of people living with dementia and ensure that they have the same rights as other Canadians – including the right to a timely diagnosis, to participate in advance care planning and to make an advance request for a medically assisted death.

BACKGROUND

MAiD

Canada is one of a small number of jurisdictions to allow some form of medical assistance in dying (MAiD). In 2016, the Parliament of Canada passed legislation¹ providing a legal framework for MAiD in response to a Supreme Court of Canada decision². This legislation permitted a health-care professional to administer or prescribe medications or substances to a person at their request in order to end that person’s life. The framework was modified in 2021 so that the requirement for a person’s natural death to be reasonably foreseeable in order to be eligible for MAiD. This change was made in response to a decision by the Superior Court of Quebec³.

MAiD has been the subject of public debate for many years, and even with the creation of a legal framework, certain elements of eligibility criteria and procedural safeguards remain unsettled. One of these elements is the framework for Advance Requests.

The Special Joint Parliamentary Committee on Medical Assistance in Dying (AMAD) has resumed its statutory review of the provisions of the Criminal Code relating to Medical Assistance in Dying and its application – including advance requests.

Advance Requests for MAiD

Canada’s MAiD framework requires that express consent is provided in order to receive medical assistance in dying. As a result, those who are unable to provide express consent or who do not possess decision-making capacity are ineligible for MAiD.

The idea of an Advance Request for MAiD would establish a process and safeguards to allow an individual to make a request for MAiD before decision-making capacity is lost, with the intention that the request be acted upon under circumstances outlined in the request after the person has lost decision-making capacity.

An advance request for MAiD differs from a personal care directive in an advance care plan – a process that includes designation of a substitute decision-maker and a Power of Attorney to outline wishes for end-of-life care and make a will.

Considerations for People Living with Dementia

People living with dementia must have the same rights as other Canadians, including the right to a timely diagnosis, to participate in advance care planning and to make an advance request for a medically assisted death.

Policies should respect individual autonomy and the person-centred approach outlined in the *Canadian Charter of Rights for People with Dementia*⁴, a document crafted by the Society's Advisory Group of People with Lived Experience of Dementia, whose members represent different walks of life from across the country.

Under the current law, a person in the advanced stages of dementia will likely not be able to legally consent to MAiD. Consent to MAiD requires the person to be capable of retaining and understanding new information, analyzing the information, and making an informed decision. The effects of dementia in its advanced state may impair a person's capacity to make an informed decision about their end-of-life care.

The ability to make an Advance Request would address this problem, but these requests are not permitted. The current law states that a person requesting MAiD must have the capacity to provide consent immediately prior to the procedure. Advance consent often requires a mandated period of reflection that allows for opportunities to consider their decision and withdraw their consent.

Every person will experience dementia in their own way. While symptoms and duration can vary from person to person, it is common for individuals to live well with dementia for many years. A person's wishes, values, and beliefs may change over time. It can also be difficult to predict future circumstances. Expansion of MAiD to permit advance requests for people living with dementia will require greater clarity as to how such requests will be applied, including safeguards for vulnerable people. When considered at the systems level, individuals need supports for advance care planning, professional counselling, and access to palliative care.

Advance Care Planning and Palliative Care

Advance Requests represent one end-of-life treatment option within an advance care plan.

Advance care planning helps ensure that plans for future health care are carried out in accordance with the values and beliefs of the person living with dementia. That is why it is important for people living with dementia to make their wishes known to their family members — or a substitute decision maker in some provinces — while they are still capable of doing so.

For advance care planning to be truly effective, options and services need to be available. Canadians living with dementia are less likely to be referred to palliative care teams, are prescribed fewer palliative care medications, and have more difficulty accessing end-of-life care than those diagnosed with other life-limiting illnesses⁵. This can exacerbate psychological symptoms and result in poorly managed symptoms and lower quality of life. Improving access to palliative care is imperative.

Advance care planning helps ensure that people receive the end-of-life care that they want and choose. Putting a plan in place as soon as possible after diagnosis means that palliative care — care that may address physical as well as emotional and spiritual needs at any point during an illness —

can start earlier, improving the quality of living and dying for people with dementia and their family. Advance care planning can also reduce stress for family members, guiding them when their loved ones with dementia are no longer able to communicate their wishes for health and personal care decisions.

How the Alzheimer Society is engaged on MAiD and Advance Requests

The Alzheimer Society provides Canadians living with dementia the support and information they need to make informed decisions about their care, including at the end of life.

The subject of MAiD is complex and there is a diversity of views within our community. As the public debate and the legal framework has evolved, so have the positions of the Alzheimer Society of Canada. We have sought out input from individuals and provincial Societies, and we provided funding to support research⁶ to better understand the views of people living with dementia and their caregivers.

Ultimately, the right of persons with dementia to advocate for access to MAiD, including through advance requests should be respected.

RECOMMENDATIONS

- The Alzheimer Society of Canada supports the right of people living with dementia to have autonomy over decisions affecting their health and life. This includes the right to make an advance request for a medically assisted death should they choose.
- Adequate resources and supports are needed for advance care planning, professional counselling, and access to quality long-term care and palliative care.

ABOUT

The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities across Canada, the Society provides information, programs and services to those living with a diagnosis and their caregivers. The Alzheimer Society Research Program is Canada's leading funder of research into better understanding the causes of dementia, improving treatment and care, and towards finding cures.

¹ Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) https://laws-lois.justice.gc.ca/eng/annualstatutes/2016_3/fulltext.html

² Carter v. Canada (Attorney General) <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>

³ Truchon c. Procureur général du Canada, 2019 QCCS 3792
<https://www.canlii.org/fr/qc/qccs/doc/2019/2019qccs3792/2019qccs3792.html>

⁴ <https://alzheimer.ca/en/take-action/change-minds/canadian-charter-rights-people-dementia>

⁵ A Dementia Strategy for Canada: Together We Aspire, 2019 <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>

⁶ Extending Medical Aid in Dying to Incompetent Patients: A Qualitative Descriptive Study of the Attitudes of People Living with Alzheimer's Disease in Quebec <https://id.erudit.org/iderudit/1084452ar>

L'aide médicale à mourir pour les personnes atteintes d'un trouble neurocognitif majeur : analyse des commentaires de participants à une enquête <https://id.erudit.org/iderudit/1084450ar>