

Société Alzheimer Society

CANADA

MEDICAL ASSISTANCE IN DYING

Position statement

Background Information

Dementia is a progressive disease that will eventually lead to death. Because dementia is very different than other life-limiting illnesses, the needs of people with dementia at the end of life are unique and require special considerations.

Due to the progressive, degenerative nature of dementia, people with the disease will eventually become unable to make decisions about treatment and their own care. Family members and health care professionals often have to make difficult decisions on behalf of the person with dementia. People with dementia should make their wishes known to their family members (or a substitute decision maker in some provinces) when they are still capable. A written advance care plan can guide families when the person with dementia is no longer able to express their wishes for health and personal care decisions.

What is medical assistance in dying?

Medical assistance in dying (MAID) is the administration by health care teams (physicians, nurses, pharmacists and other health care professionals) of medications or substances to end the life of a person, at her/his request, in order to relieve suffering by hastening death. *(Other terms used include physician-assisted death, physician-assisted dying, physician-assisted suicide, physician-hastened death, etc.)*

What is the issue?

The significant outcome of the Supreme Court decision of February 6, 2015 is that physician-assisted dying will no longer be considered murder under the Criminal Code of Canada. This means that a competent adult with *enduring and intolerable suffering* can request MAID by clearly consenting to terminate her/his life.

Capacity and consent

While a person with dementia will not be deemed incapable to make decisions for herself immediately at the time of diagnosis, due to the progressive nature of dementia, specific skills will be lost during the course of the disease, including the capacity to consent to treatment including MAID. Therefore, a diagnosis of dementia does not render someone immediately incapable.

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To consent - in this instance, to MAID - the person needs to be capable of retaining and understanding new information, analyzing the information and making an informed decision. Consent must be clearly expressed and voluntary - at the time that medical assistance in dying is provided - and the person's ability to make decisions must be carefully assessed to ensure that she/he is able to understand the information provided and the consequences of making a decision to end their life.

All of these abilities (i.e. retaining, understanding and analyzing information and making informed decisions) may be impaired in people with dementia and consent will not be possible at the time of medical assistance in dying or throughout the mandated period of reflection (during which a person can withdraw her/his consent).

Consequently, the law does not consider people with dementia competent to make a decision to end their life, at the end of their life. Furthermore, the Alzheimer Society believes that if a person is not deemed competent, then she/he is extremely vulnerable and the risk of abuse is simply too great.

Our position:

Given the progressive nature of dementia, wishes, values and beliefs may change, skills are lost and the ability to make decisions is greatly reduced. MAID should only be possible when a person is deemed competent at the time of MAID.

However the Special Joint Committee On Physician-Assisted Dying (Parliament of Canada) has recommended "that the permission to use advance requests for MAID be allowed any time after one is diagnosed with a condition that is reasonably likely to cause loss of competence or after a diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable"¹.

The Alzheimer Society of Canada believes that because we cannot predict future suffering, providing **advance consent**² for MAID should not be possible for people with dementia. The Alzheimer Society believes that people with dementia need to be safeguarded as they will be extremely vulnerable at the end of their life. People with dementia do not have the **capacity to make an informed decision and consent** to end their life at the later stages of the disease.

In view of this position, the Alzheimer Society of Canada:

- Aims to reduce the stigma and stereotypes around Alzheimer's disease and other dementias, stressing that living a satisfying life doesn't end with a diagnosis and that is it possible to continue to live well with the disease.

¹ Medical Assistance in Dying: A Patient-Centred Approach - Report of the Special Joint Committee on Physician-Assisted Dying available at <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&DocId=8120006&File=18>

² In this case, provide consent for assisted death in prediction of grievous and irremediable suffering due to life-limiting illnesses - Advance consent often requires a mandated "period of reflection" that allows patients several opportunities to withdraw their consent, which is different than consent in the here and now.

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- Urges those who develop the new legislation to take into account the complex circumstances and vulnerability of people with dementia and limit the harm and risk that MAID could represent.
- Urges people with dementia to make their wishes for their future care known, preferably through **advance care planning**³, as soon as possible after diagnosis. It's important that families plan together while the person with dementia is able to fully participate in decision-making about their care to ensure the best possible **quality of life**.
- Calls for improved **quality hospice palliative care** that is available to all Canadians with dementia as they near the end of their life. The right to access quality palliative care will help minimize unnecessary suffering and improve the **quality of dying** for people with life-limiting illnesses.

Additional resources:

- *A dignified death for dementia patients: Who makes that call?* André Picard, The Globe and Mail, published February 16, 2016; available at <http://www.theglobeandmail.com/opinion/a-dignified-death-for-dementia-patients-who-makes-that-call/article28760956/>
- *Life goes on after diagnosis of Alzheimer's*, Jim Mann, Vancouver Sun, February 12, 2016; available at <http://www.vancouversun.com/opinion/letters/gravitational+waves+link+discovery/11720885/story.html>

For more information on advance care planning:

- Planning for the future, Alzheimer Society of Canada, available at <http://www.alzheimer.ca/en/Living-with-dementia/Planning-for-the-future>.
- Speak Up Campaign on advance care planning in Canada, available at <http://www.advancecareplanning.ca/>

³ Advance care planning: is the process of planning for a person's future health-care where the person has conversations with close family and friends about their values and beliefs.