

Dying With Dignity Canada – Speaking Notes: Advance Requests for MAID

Helen Long, CEO and Senator James Cowan, Member of the Board of Directors

Dying With Dignity Canada or DWDC is a national human-rights charity, which for the past 42 years, has been committed to protecting end-of-life rights, and helping Canadians avoid unwanted suffering. For Canadians this is not an academic debate, it is about compassion, avoiding suffering and fundamental rights.

Every day we hear from individuals and families as they navigate end-of-life choice, including but not limited to medical assistance in dying or MAID. In developing our position, we sought out the insights and lived experience of healthcare practitioners, individuals with physical disabilities and mental disorders, first person advocates, and other volunteers within the MAID community.

We believe that everyone should have both the right to live and the right to choose their end-of-life. We encourage the government to continue to invest in increasing access to palliative care and to providing additional supports for people living with disabilities and mental disorders. At the same time, we strongly support the statement made by Dr. Stefanie Green last week, that MAID and community resources for mental health, palliative care and disability supports be developed and supported in parallel.

By far the most frequently asked questions we receive are those related to advance requests for MAID. An advance request involves a competent person making a written request that could be honoured later, after they lose the capacity to make medical decisions for themselves. It would allow an individual to describe in writing, a future state in which they would like to access MAID.

We know through multiple Ipsos polls, that Canadians support advance requests. Those results have been consistent over time and in line with those from government consultation in the spring of 2020. Ipsos polling in April 2022 indicates that 85% of Canadians support an advance request for those diagnosed with a grievous and irremediable condition and 77% of Canadians support an advance request without a diagnosis.

Canadians tell us they are concerned about their capacity to provide informed consent to MAID due to a family history of neurocognitive conditions such as dementia or Parkinson's. Or that an accident, or other medical problem that could result in diminished mental capacity. Advance requests for MAID would allow those - **who so choose** - to avoid a life of grievous and irremediable pain and suffering if loss of capacity occurs. DWDC believes that advance requests should be allowed with or without a diagnosis of a serious and incurable disease.

Canadians already have the right to provide advance direction regarding treatment options through Personal Care Directives. The same right for an advance request for MAID would allow those who

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anticipate a loss of capacity to ensure that the guiding principles of their lives are respected when they can no longer speak for themselves.

Our MAID laws have been driven by Canadians whose desire for dignity, autonomy and self-determination have led them to fight for the right to make decisions that align with their own personal values. People like Sue Rodriguez, Kay Carter, Gloria Taylor, Audrey Parker, Jean Truchon and Nicole Gladu. Today, we hear from people like Pamela Cross, Katherine Hammond and the Eusanio Sisters whose experience with capacity eroding conditions motivate them to speak up and support changes to the law.

DWDC recommends that the assessment of eligibility for MAID, including the requirement of intolerable suffering as described in the advance request, be completed by healthcare practitioners when made aware of an advance request prepared previously by an individual who has since lost capacity. The advance request should be documented in a manner consistent with the current process and include a personal statement that outlines the values and interests that are central to the person's life and at the core of their identity. That statement must be considered by the practitioners when making their assessment.

Time does not allow us to go through the details of the careful safeguards which we have outlined in our brief, but we implore you as committee members to review them in detail.

Some clinicians have pointed out that individuals who have lost capacity and reach the point of what their advance request describes as suffering intolerable to them, may not appear to be suffering at that time. However, the purpose of the advance request for MAID is to respect the previously expressed wishes of the person when they were competent. The safeguards and decision-making process ensure that the individual meets the criteria for assisted dying and MAID would not proceed if the individual exhibits conscious indication of resistance or refusal.

There is no evidence that access to MAID in Canada, or in other jurisdictions, has had a negative effect on societal values pertaining to individuals with capacity loss. Rather, it has brought more attention to end-of-life care in general, including palliative care, and to the need to ensure that all citizens can live and die well.

Thank you for your time today, we would be happy to answer any questions you might have.

