

DWDC Letter-Writing Toolkit: Voice Your Choice for a Patient-Centred Approach to End-of-Life Care in Canada

The federal government is inviting Canadians to participate in a public consultation on the future of end-of-life care. According to Health Canada, the public's submissions will help inform a new national framework for palliative care.

Dying With Dignity Canada firmly supports the government's decision to get Canadians' thoughts on what a national framework for palliative care could look like. We encourage our supporters to weigh in and to help advocate for an approach to end-of-life care that puts the person — their rights, needs and choices — first.

DWDC has developed a toolkit designed to help you make a letter submission to Health Canada. This document offers suggestions on how to format your letter and ideas on what you might want to bring to the government's attention. We hope that our toolkit will help you make the best of this incredible opportunity to improve the quality and the accessibility of end-of-life care for all Canadians.

How to submit your letter

Once you're finished writing your letter, please send it to Health Canada's End of Life Care Team. Here's how to get in touch:

- **Email:** End.of.life.care.Soins.fin.de.vie@hc-sc.gc.ca (If you plan to include your letter as an attachment, please send a Microsoft Word or Adobe PDF file)
- **Mailing address:** Let's Talk Palliative Care, The End of Life Care Team, c/o Venetia Lawless, 200 Eglantine Drive, A.L. 1904D, Ottawa, ON, K1A 0K9

The deadline for submissions is July 13, 2018. When you're done, please let us know by sending an email to consultation@dyingwithdignity.ca. Not only do we love hearing from our supporters, but your feedback helps us gauge the effectiveness of our human-rights advocacy efforts.

Your letter

To Health Canada's End-of-Life Care Team,

Executive Summary:

Briefly summarize your key recommendations and concerns in two or three bullet points. Sample prompts include:

- *“A national strategy for end-of-life care must include...”*
- *“Canadians deserve a national approach to end-of-life care that puts the person first.”*
- *“Palliative care is not necessarily a substitute for access to assisted dying, and vice versa. Both are essential options on a continuum of care at end of life. Canadians deserve fair access to both.”*

Body of your letter:

In clear, concise language, include your opinions, comments and recommendations for the future of end-of-life care in Canada. To convey your point, you may wish to include personal stories, or examples of the kind of care you would like to have at end of life.

In your own words, you may wish to highlight the following ideas and recommendations:

1. Above all, Canada should adopt a “person-centred” approach to end-of-life care.

At Dying With Dignity Canada, we believe the rights, the interests and care needs of suffering Canadians must be the central focus of a national strategy for end-of-life care. Even though many groups advocate for “person-centred” or “patient-centred” care, there is currently no standard, agreed-upon definition of what these terms mean. However, a passage from Health Quality Ontario’s [“Quality Statement on Palliative Care for Adults with a Progressive, Life-Limiting Illness”](#) lays out the basic values that drive a person-centred approach to end-of-life care:

- “Individualized, person-centred care consists of care and treatment that is customized for each person based on their values, wishes, goals, and unique health needs.”
- “The person with the progressive, life-limiting illness drives the care provided.”
- “A person-centred approach involves a partnership between patients and their health care professionals.”

You may also wish to consult this list [adapted from the Picker Principles of Patient-Centred Care](#), which were created by the Picker Institute in Europe in collaboration with the Harvard Medical School. You may find this list helpful as you compile your own.

- Respect for patients’ values, preferences and expressed needs (their rights and wishes must be at the forefront)
- Coordination and integration of care (in order to, as much as possible, reduce feelings of fear and vulnerability in the patient)
- Information and education (to ensure that the patient can make informed decisions about their care)
- Physical comfort (enhancing the person’s physical comfort by, for example, managing their pain, supporting them with the necessities of daily living, maintaining a clean environment, etc.)

- Involvement of family and friends (respecting that patients often want to involve loved ones in their care, including in the decision-making process)
- Continuity and transition in coordination of care (alleviating anxiety around discharge or transfer by providing relevant information; coordinating care with the individual, their loved ones and/or other healthcare professionals; and providing information regarding access to social supports)
- Ensuring access to care

Ultimately, all the suggestions in this toolkit are aimed at promoting a person-centred approach to end-of-life care. In your submission, you may wish to provide a more detailed list of what this concept means to you.

2. Canadians must have access to a full range of end-of-life care options, including high-quality palliative care and medical assistance in dying.

At Dying With Dignity Canada, we believe that giving the suffering individual access to a full range of options is a hallmark of person-centred end-of-life care. No matter where they live, and no matter their income or ability to pay, Canadians should have access to high-quality palliative care *and* medical assistance in dying (MAID) — not one or the other.

Simply put, palliative care and assisted dying are two essential options on a spectrum of care at end of life. Having palliative care doesn't eliminate the need for access to MAID, and vice versa. This is supported by the fact that many, potentially most, people who end their lives with medical assistance will have received some sort of palliative care treatment before they die. Take, for example, the experiences of the people who requested MAID at the four hospitals in Toronto's University Health Network. Of the 28 patients who were approved for MAID in the 12-month period between March 8, 2016 and March 8, 2017, 27 (96 per cent) were receiving palliative care, according to [a May 2017 paper published in the *New England Journal of Medicine*](#).

This is only a small snapshot of one hospital network's experience with MAID, and the team's findings don't necessarily reflect what's going on in other healthcare settings. However, the UHN report does speak to the relationship between palliative care and assisted dying. On one hand, people who access MAID typically need some form of palliative care as they approach end of life; on the other hand, though suffering people obviously benefit from the pain relief and emotional support that palliative care provides, it sometimes doesn't go far enough to alleviate the person's suffering.

3. Health Canada must work together with the provinces and territories to break down barriers that prevent Canadians from dying where they want, in a manner that is dignified to them.

a) *Barriers to dying at home*

According to public opinions polls on the topic of end-of-life care, most Canadians say that, when the time comes, they would like to die in the comfort of their own home. In reality, though, the majority of deaths in Canada (65 per cent) occur in a hospital setting, including 45 per cent of all cancer deaths, according to the Canadian Cancer Society.

In order to adopt a person-centred approach to end-of-life care, we must break down barriers that prevent Canadians who want to die at home from being able to do so. Some of those barriers include:

- Insufficient home care coverage for people who are living with life-limiting illnesses
- Insufficient financial, educational and emotional supports for families and caregivers
- Failure on the part of the healthcare system to engage the person on their wishes for care at end of life

b) *Barriers to palliative care*

Although data about palliative care in Canada is inconsistent, one thing is clear: not everyone who needs palliative care is getting it when they need it, and the ability to access it can vary from one part of the country to the next. Improving access will be a complex, enormous task, one that any national strategy for end-of-life care should be aimed at tackling. However, the Canadian Cancer Society, in its 2016 paper "[Right to Care: Palliative Care for All Canadians](#)" laid out five goals or objectives that stakeholders, including the federal government, should pursue in order to improve the quality of care for people at end of life. You may wish to include these goals in your submission. They are:

- **"Guarantee access to quality palliative care to all Canadians** in federal and provincial/territorial legislation."
- **"Develop and implement measurable palliative care standards** to ensure access to quality palliative care. At the same time, a plan for ongoing and consistent data collection should be developed to enable us to understand the state of palliative care, make improvements and hold healthcare decision makers accountable."
- **"Train healthcare providers** to ensure we have sufficient palliative care specialists and that all healthcare professionals can provide basic palliative care and know when a referral to formal palliative care is needed."

- **“Support patients and family caregivers** by ensuring they have the information and tools needed to engage in advance care planning, undertake being a family caregiver and be knowledgeable about palliative care.”
- **“Provide appropriate funding for palliative care.** Federal and provincial/territorial governments should work together to establish a financing plan and create a national palliative care transition fund to ensure the changes needed to improve palliative care in Canada can take place.”

c) Institutional barriers to assisted dying

Currently, a number of barriers in the healthcare system make it difficult for suffering Canadians to access their right to medical assistance in dying. In some cases, the delays created by one or more barriers to access mean that a person whose health situation is very fragile may lose out on their opportunity to have an assisted death — they lose capacity or die without medical assistance while waiting to be assessed. In order to break down unfair barriers to assisted dying access, the federal government, in collaboration with provinces and territories, must:

- Ensure that all publicly funded healthcare facilities that care for dying Canadians allow medical assistance in dying on their premises
- Require doctors and nurse practitioners who oppose assisted dying to, in a timely manner, refer patients who request it to a willing clinician or third-party agency
- Remove barriers that currently discourage clinicians from including assisted dying as part of their practice (for example, by implementing fair rates of compensation for MAID-related work and streamlining the paperwork involved in assessing for and providing MAID)
- Launch a public education campaign about the right to medical assistance in dying, so Canadians can make informed decisions about their care

It should be noted that improving access to assisted dying would function to improve access to high-quality palliative care. That's in part because, in some cases, people are refusing to accept palliative-care beds in facilities that don't allow assisted dying, out of fear that they will have to leave in order to receive MAID. People who are receiving palliative care in facilities that ban MAID have to transfer off-site to access — or in some cases, even be assessed for — assisted dying, subjecting them to additional unwanted, unnecessary suffering. Thus, allowing public healthcare facilities to ban MAID on-site violates the principle of person-centred care.

4. Health Canada must work together with the provinces and territories to develop a national framework for advance care planning.

Completing an advance care plan is one way to help ensure that your wishes for care at end of life are followed. According to [the Hospice Palliative Care Association of Canada's proposed National Framework on advance care planning](#), an advance care plan is a “capable person’s documented expression with respect to the continuation or discontinuation of medical treatment” when the person has lost the ability to speak for themselves. An advance care plan serves as a guide for a person’s substitute decision-maker when it comes time to give consent to or refuse treatment on the incapacitated person’s behalf. In cases where a substitute decision-maker has not been appointed or is not available, healthcare professionals can use an advance care plan to assess which medical interventions, if any, would be in accordance with the person’s wishes.

Unfortunately, relatively few Canadians have advance care plans. According to [a 2014 survey conducted by polling firm Harris-Decima](#), about one in eight (13 per cent) adult Canadians had completed an advance care plan. One in three (34 per cent) had talked with loved ones about their wishes for care at end of life. These numbers suggest that most of us have not given any instructions about how our care should proceed if we were to become incapacitated. As a result, many Canadians end up receiving treatment measures (such as emergency cardiopulmonary resuscitation) that they would decline if they had the ability to speak for themselves.

Even in cases where a person has written down or otherwise expressed their wishes, their directives are not always respected because of flaws and inconsistencies in the system. It doesn’t help that the rules and regulations for advance care planning differ from one province or territory to the next.

Possible steps that the federal government could take to ensure that Canadians communicate their wishes for care, and that their wishes are respected, include:

- Conduct a pan-Canadian study on the patchwork of rules that govern advance care plans in the different provinces and territories
- With the provinces and territories, develop and implement national standards for advance care planning
- Launch a national public education campaign on advance care planning, encouraging Canadians to complete advance care plans
- Engage healthcare professionals on how to get patients thinking about their wishes for care long before they experience a decline in their health

5. The federal government must take steps to remove unfair and possibly unconstitutional restrictions that exist in the federal assisted dying law.

Assisted dying is a right in Canada for individuals who are suffering intolerably from a grievous and irremediable illness and who clearly consent to the termination of life. In the two years since Parliament legalized assisted dying, more than 4,000 Canadians have availed themselves of this option.

However, Bill C-14, the federal assisted dying law, contains restrictions that are unfair and that likely violate the *Canadian Charter of Rights and Freedoms*. For example, the ban on advance requests for assisted dying discriminates against people with conditions, such as dementia, that rob victims of their capacity as a matter of course. The ban on advance requests has also led terminal cancer patients — those who have already been approved for assisted dying — to forego proper pain treatment, out of fear that they will lose the ability to provide final consent for MAID. Allowing them to make a legally binding advance request for MAID would help ensure that they could have access to their right to MAID without compromising the quality of their care at end of life.

Steps that the government must take in order to respect the rights of Canadians who have been discriminated against under the federal assisted dying law include:

- Health Canada, together with the federal Department of Justice, must develop a mechanism by which suffering Canadians could consent to MAID via an advance request.
- The federal government must take steps to respect the end-of-life rights of other groups who are unfairly discriminated against under Bill C-14, including mature minors and individuals whose primary underlying condition is a mental illness.

Your conclusion

Briefly summarize the main points of your letter. In a sentence or short paragraph, reiterate the main points you made in the executive summary.

Finish your letter by thanking Health Canada for their consideration. You may also wish to remind them that the voices, experiences and rights of ordinary Canadians must be at the heart of any serious examination of the future of end-of-life care in this country.