

Towards a Person-Centred Approach to End-of-Life Care in Canada: Dying With Dignity Canada's Submission to Health Canada's Consultation on Palliative Care

Introduction

Dying With Dignity Canada (DWDC) is pleased to participate in Health Canada's consultation on palliative care. As the leading organization defending Canadians' end-of-life rights, we bring insights and values that we believe will be invaluable in informing a new national framework for end-of-life care in this country.

Any future national strategy for end-of-life care must be person-centred: that is, when it comes to making decisions about the shape of a new national framework, the rights, the interests and the wishes for care of the individual must come first. Thankfully, there has been a growing movement, in Canada and elsewhere in the West, towards making public healthcare more "patient-centred" or "person-centred." The creation of the provincial [Office of the Patient Ombudsman](#) in Ontario, for example, as well as other bodies aimed at ensuring the system is accountable to the people it serves, signals a significant evolution in how we as a society think about the role of the person both in their own medical decision-making and the development of public policy governing the provision of healthcare.

Despite these developments, we in Canada do not have a standard, generally agreed-upon definition of person-centred care, let alone one that is tailored for the end-of-life context. In our view, laying out specific criteria of what constitutes person-centred care will be a crucial first step in the development of a national framework for end-of-life care. Indeed, we are encouraged by the fact that Health Canada is seeking feedback on the topic of person-centred care as part of its public consultation on palliative care.

The body of our submission does not advance a fully fleshed-out definition of what constitutes person-centred end-of-life care. Instead, it outlines a set of principles that must guide the creation of the national framework on end-of-life care if it is to be truly person-centred. In addition, it lays out a series of recommendations on how to improve access to a full range of legal end-of-life options and how to empower Canadians to ensure better end-of-life outcomes for themselves and for their loved ones.

Principles of person-centred care

At Dying With Dignity Canada, we believe the rights, 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 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.”

Though any national framework for end-of-life care should be designed with these values in mind, this list is not detailed enough to serve as an adequate template for a new definition of person-centred care. Conversely, the [following 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, may represent a better starting place in the development of a definition that could undergird the creation of the national framework.¹ These principles address a range of factors that affect the well-being of the person in care — both in terms of the objective quality of their care and their subjective experience of it:

- **“Respect for patients’ values, preferences, and expressed needs**
 - Treating individuals with respect, in a way that maintains their dignity and demonstrates sensitivity to their cultural values
 - Keeping individuals informed about their condition and involving them in decision making
 - Focusing on the person’s quality of life, which may be affected by their illness and treatment.”
- **“Coordination and integration of care**
 - Coordinating and integrating clinical and patient care and services to reduce feelings of fear and vulnerability.”
- **“Information and education**
 - Providing complete information to individuals regarding their clinical status, progress, and prognosis; process of care; and information to help ensure their autonomy and their ability to self-manage, and to promote their health.”
- **“Physical comfort**
 - Enhancing individuals’ physical comfort during care, especially with regard to pain management, support with the activities of daily living, and maintaining a focus on the hospital environment (e.g., privacy, cleanliness, comforts, accessibility for visits).”
- **“Involvement of family and friends**

¹ “Clinical Best Practices Guidelines.” *Registered Nurses Association of Ontario*, May 2015. http://rnao.ca/sites/rnao-ca/files/FINAL_Web_Version_0.pdf, 85.

- Acknowledging and respecting the role of the person's family and friends in their health-care experience by: 1) accommodating the individuals who provide the person with support during care; 2) respecting the role of the person's advocate in decision making; and 3) supporting family members and friends as caregivers, and recognizing their needs.”
- **“Continuity and transition in coordination of care**
 - Alleviating anxiety about the person's ability to self-manage after discharge by: 1) providing information regarding medication, physical restrictions, nutrition, etc.; 2) coordinating ongoing treatment and services and sharing this information with the person and their family; and 3) Providing information regarding access to supports (e.g., social, physical, and financial) on an ongoing basis.”
- **“Access to care**
 - Ensuring, mainly with respect to ambulatory: 1) access to multiple health-care settings and services; 2) availability of transportation; 3) ease of scheduling and availability of appointments; and 4) access to specialists and specialty services when needed.”

Applying the Picker Principles to end-of-life care in a Canadian context would serve as a strong basis for a new national definition of person-centred end-of-life care. Even better, they could form a foundation for a new national framework that would guarantee Canadians fair, timely access to a full range of compassionate care options, including palliative care and medical assistance in dying. Moreover, in order to be fully person-centred, any national framework for end-of-life care must reflect the [five program criteria laid out in the *Canada Health Act*](#), especially the tenets stipulating comprehensiveness, universality, portability and accessibility in the administration of public healthcare.²

Recommendations

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 just 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 does not 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

² *Canada Health Act*, 2nd session, 32nd Parliament of Canada, 1984. S. 7.

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*](#).³

This is only a small snapshot of one hospital network's experience with MAID, and the team's findings do not necessarily reflect what is occurring in other healthcare settings. However, the UHN report does speak to the complementary relationship between palliative care and assisted dying. On one hand, people who access MAID typically require 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 does not go far enough to alleviate the person's suffering.

Yet, despite the growing body of evidence suggesting a positive, complementary relationship between palliative care and MAID, a small group of influential voices in the medical establishment is striving to drive a wedge between these two essential end-of-life options. Critics, including many self-identified opponents of the right to an assisted death, argue that the legalization of MAID generally detracts from, or leads to underinvestment in, palliative care. This argument is empirically untrue; in jurisdictions where assisted dying is legal, the implementation of MAID is associated with increased investment in palliative care. In addition, some commentators have used the [World Health Organization's definition of palliative care](#) to argue that clinicians or facilities that specialize in palliative care should have no role in the provision of MAID. This argument is flawed and, in certain instances where it is presented, disingenuous. The WHO definition does state that palliative care "intends neither to hasten nor postpone death."⁴ It is true that assisted dying is neither synonymous with nor a subcategory of palliative care (which, unlike MAID, is not by definition an end-of-life intervention). However, nothing in the WHO's definition suggests that MAID is in inherent opposition to the principles of palliative care or that a person should not explore a request for MAID while receiving palliative care. In fact, the availability of MAID can help achieve some of the objectives of palliative care. For example, for some individuals, having access to MAID alleviates some of the psychological suffering they experience as a result of the progression of their medical condition or the prospect of dying in a manner that is not of their choosing.

³ Li, Madeline, et al., "Medical assistance in dying — Implementing a hospital-based program in Canada." *The New England Journal of Medicine*. Vol. 376, No. 21 (2017): 2085.

⁴ "WHO Definition of Palliative Care." *World Health Organization*.
<http://www.who.int/cancer/palliative/definition/en/>.

In our view, drawing ideological battle lines separating palliative care and MAID does nothing to bring us closer to a more person-centred model of end-of-life care. Rather, efforts to create or reinforce institutional barriers between palliative care and MAID imposes real-life harms upon already-suffering individuals who require the pain relief, emotional care and social support that palliative care provides, and who also want to explore a request for MAID. A number of those harms, and recommendations on how to address them, are discussed in the next section of our submission.

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 opinion 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 occur in a hospital setting, including 45 per cent of all cancer deaths, according to the Canadian Cancer Society.⁵

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](https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf)

⁵ "Right to Care: Palliative Care for All Canadians." *Canadian Cancer Society*, Jan. 3, 2016. <https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf>, iii.

[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.⁶ These recommendations should be taken into serious consideration as part of the development of a national framework for end-of-life care:

- **“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

⁶ Ibid., iv-v.

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 is 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 principles of person-centred care as well as many of the values enshrined in the WHO's definition of palliative care.

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 a person's 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.⁷ 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.⁸ These numbers suggest that most of us have not given any instructions about how our care should proceed if we were to

⁷ “Advance Care Planning in Canada: National Framework.” *Hospice Palliative Care Association of Canada*, Jan. 2012. <http://www.advancecareplanning.ca/wp-content/uploads/2016/08/ACP-Framework-2012-ENG.pdf>, 2.

⁸ “Canadians want palliative and end-of-life care support — but they don't know how or where to access it.” *Canadian Newswire*, Jan. 23, 2014. <https://www.newswire.ca/news-releases/canadians-want-palliative-and-end-of-life-care-support---but-they-dont-know-how-or-where-to-access-it-513600071.html>.

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

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 must be taken 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.

Conclusion

The establishment of a national framework for end-of-life care is a once-in-a-generation opportunity to improve how we as a country care for people who are dying. We encourage Health Canada, along with its federal and provincial-territorial partners, to use the recommendations we have outlined in this report to outline a strategy for end-of-life care that is truly person-centred. We are grateful for the opportunity to provide our input, and we ask that the federal government invite Canadians to provide their feedback on a draft of a national framework once it has been prepared. After all, it is the future of their rights, their interests, their lives and their deaths that is ultimately at stake.