



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Consultation on Legislative Options for Assisted Dying

A submission to the External Panel by the Canadian
Hospice Palliative Care Association

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Introduction

The way we die is changing. Across Canada, we are seeing a wave of change in care for people faced with frailty and/or chronic life-threatening illnesses and choices at end of life. Palliative care services – once only offered in the last days or weeks of life to people designated as dying – need to be better integrated with treatment services to enhance people’s quality of life throughout the course of their illness or the process of aging.

Despite the fact that most Canadians would prefer to die at home and that only a small proportion need intense tertiary care in the last days or weeks of life, most (67%) still die in hospital.¹ It is crucial that a palliative approach to care is delivered by interprofessional teams, with access to specialists as needed, and supported with the skills, knowledge and confidence to meet the wishes of individuals and their families to live well until dying whether at home, in long-term care settings, in residential hospices or hospitals.

While the recent Supreme Court decision on the issue of physician-assisted death has captured media attention, a relatively small number of Canadians are likely to meet the criteria for those services. However, everyone has the potential to benefit from the growing willingness to acknowledge that dying is part of living, and that people deserve and should receive the integrated palliative approach to care at all stages along their illness trajectory and in all settings of care.

It would be a shame if a Canadian were to choose physician-assisted death when their pain and symptoms are poorly managed and they were never referred to hospice palliative care.

We need to make sure our government is focused on delivering quality end-of-life care services along a full spectrum of illness trajectories options before physician-assisted death.

All patients deserve access to information about end of life options, including physician-assisted death.

A *need* for change

For universal access to quality end-of-life programs for all Canadians to become viable, we must understand why the integrated palliative approach to care is so crucial.

An integrated palliative approach to care means we need to think differently about care as people near the end of life based on a number of relevant issues.

1. **Significant changes in illness trajectories.** Canadians are now more likely to survive heart attack or a cancer diagnosis, and to live for several years with chronic illnesses or increasing frailty. Although *when* people will die is less predictable, they will still experience the same losses throughout their illness trajectory (e.g. pain, loss of mobility and other functions, physical and mental limitations, loss of roles

and relationships). They and their families would benefit from palliative care services such as psychosocial support and pain and symptom management that can enhance quality of life. Being diagnosed as “close to death” should no longer be the trigger for Canadians to receive these services.

2. The cost of “futile” treatments at end of life. Growing data on the cost of health care services show that our health systems spend a significant amount on procedures in the last days or weeks of a person’s life that offer little benefit and sometimes increase the person’s discomfort. A closer look at these interventions have shown that many occurred simply because many people did not have advance care plans and health care providers were hesitant to have open transparent conversations with individuals and families about the prognosis or the benefits and risks of those interventions.

3. Increasing health care costs and pressure to manage them. Faced with rising health care costs and pressure to manage and control budget increases, health care systems are making concerted efforts to reduce the use of costly hospital services and provide more care in the community. This disconnect between the care that people want and need and the care that they actually receive is due largely to a shortage of community providers who are skilled in the palliative approach to care and the lack of supports for family caregivers who – given changing illness trajectories – are often providing care for a loved one for years.

4. Consumer advocacy. As our population ages, more people are speaking out about the kind of care they want as they near end of life. They are advocating for services that focus on quality of life as well as options that allow them to die “at home” wherever that may be.

5. A growing focus on advance care planning. Over the past few years, a number of Canadian jurisdictions have actively promoted advance care planning – encouraging primary care providers to talk to their patients about the kind of care they want. However, the process itself raises expectations that the home-based and community-based care people want will be available as they age – which is currently not the case in many parts of Canada. Those expectations are another pressure for change.

To address these issues, the Quality End-of-Life Care Coalition (made up of 36 national associations and organizations) and the Canadian Hospice Palliative Care Association advocated and received funding from the Government of Canada to create *The Way Forward*. This national initiative worked with federal/provincial/territorial governments, the non-profit and charitable sector and communities to move beyond the politics of health care by leveraging existing networks of agencies and organizations to develop a national framework for action.

A *need* for an action plan

The CHPCA believes that we need national leadership and coordination of a fully funded national framework or commission to ensure universal access to hospice palliative care.

The Way Forward developed practical and implementable tools and resources to help policy makers, health planners and service providers make changes and make them more quickly, including:

- a clear definition of the integrated palliative approach to care
- a policy paper that explained the concept and the rationale for the integrated palliative approach
- a summary of the literature
- descriptions of innovative models of the integrated palliative approach to care already in place and working around the world
- analyses demonstrating the cost-effectiveness of the palliative approach to care
- surveys of Canadians, family physicians and nurses working in primary care to understand their attitudes and perspectives
- a framework or roadmap to implementing the integrated palliative approach to care with clear action steps for sectors, health care settings and providers.

A *need* for awareness and knowledge

While all patients deserve access to information regarding ALL end-of-life options, there is a dire need to educate Canadian citizens on hospice palliative care options available to them at end of life.

Comprehensive hospice palliative care can help alleviate many of the factors that may cause people to consider physician assisted death, particularly the burden on loved ones, depression and adequate pain and symptom management.

While great strides have been made within the hospice palliative care field, there is still a lack of understanding and conversation taking place between physicians and patients regarding end-of-life options.

Doctors are not well-trained to engage in end-of-life conversations resulting in unclear goals of care, the burden of stress and anxiety placed on caregivers and an overall lack in fulfilling the wishes on how patients would like to live out their final days.

We are calling on federal leadership to advocate and fund a nation-wide framework or commission that includes an awareness campaign on hospice palliative care.

To engage Canadians, we must use all types of media, including social media and story-telling. We must find champions who are already comfortable talking about death, such as spiritual leaders and enlist the support of patient advocacy organizations. We must also make use of tools and resources already developed to disseminate knowledge to the hospice palliative care community to educate both physicians and patients.

To shift attitudes within the healthcare system, we must educate and support healthcare providers to help them overcome their own fear of loss, dying and death. An integrated palliative approach to care should be part of all healthcare providers' education.

Only once conversations about death and dying are fully transparent and end-of-life options are fully understood and discussed, will we be able to properly manage requests for physician-assisted death.

The CHPCA believes the following key messages:

- Hospice palliative care does not include physician assisted death.
- Hospice palliative care does not hasten or prolong death.
- Hospice palliative care strives to end suffering not life.
- Canadians need universal access to hospice palliative care including good pain and symptom management.
- All patients deserve access to information about end-of-life options, including physician-assisted death.

A *need* for transparency and accountability

Physician-assisted death will greatly impact the illness trajectory of elderly and sick Canadians and their caregivers.

We must ensure that this new development is introduced in an appropriate way that does not impinge on programs and services already available within the hospice palliative care community.

Moreover, a structured and unified action plan must be presented to the Canadian public including those all those working within the hospice palliative care field, explicitly establishing norms of practice that should be followed when carrying out physician-assisted death. The following factors should be considered in preparing legislation regarding physician-assisted death:

How will we protect our medical service providers?

Allied healthcare professionals must be protected including physicians and nurses in such a way that their decisions are respected and alternative options presented should they choose not to administer a physician-assisted death.

How will this legislation impact hospices and their staff?

Hospices across Canada must be allowed to opt out of the provision of physician-assisted death and if they choose to allow this on site that they be given appropriate options to have a team of certified healthcare professionals come in to administer / take part in the physician-assisted death.

What steps will be required to grant a patient permission to go through with physician-assisted death?

Legislation must be put in place assuring that specific requirements are met for a patient to be granted the physician-assisted death. More than one person should be conducting the competency assessment. We must ensure that trained professionals are used during these consultations and are able to adeptly analysis a patient's illness trajectory to see if physician-assisted death is truly the only option to alleviate a patient's suffering.

The patient should be considered end of life palliative and have no other viable treatments available to help alleviate pain and suffering. They should be over 21 to make the decision themselves and careful precautions should be taken with those in young adulthood.

A “cooling off period” should be established between the request and the provision of PAD. The Oregon model would be good to follow, which has already been in place for over 15 years.

How will legislation and regulations be introduced?

The federal government will need to be responsible for developing universal legislation in regards to physician-assisted death that provincial governments can follow. There needs to be one set of regulations and norms of practice that should be followed nation-wide.

Will physicians and healthcare institutions be able to opt-out?

All institutions and physicians should be given the option to opt-out of providing PAD granted they are willing to provide a referral to the patient.

How will this legislation take into account family caregivers and loved ones during the decision to go through with a physician-assisted death?

The CHPCA believes that the issue of whether or not substitute decision makers will have the power to request a physician-assisted death on behalf of the patient if it is outlined in their advance care plan will have to be left to the expertise of legal experts. If this decision-making ability is granted, it is crucial that all Canadians are educated about advance care plans in order to lessen the burden of the decision.

What resources will be available to those considering a physician-assisted death?

Our government and healthcare system must put into place and use resources that explicitly outline the implications of a physician-assisted death for both patients and loved ones.

Clear information and readily available guidelines must be available to all Canadians in order to inform them of their options. These resources should be led by an awareness campaign put out by the federal government and distributed amongst the provinces to utilize.

These resources must also outline other alternative options available to patients with a chronic disease that could potentially help improve their quality of life without ending it.

What will be the implications to consider after a physician-assisted death?

Legislation and policy put into place regarding physician-assisted death must take into account several factors after it has been administered. If physician-assisted death is not necessarily being written on the expired patient’s death certificate then we will need to keep record on this. Counseling support for loved ones after the physician-assisted death has taken place should be a priority.

Next *steps*

The CHPCA will continue to be a catalyst for change. Until all Canadians have access to the integrated palliative approach to care across settings and people are comfortable having conversations about the kind of care they want towards the end of life, these organizations will keep pushing. Federal, provincial,

territorial governments and regional health organizations and professional colleges/associations need to continue to support health-care providers through the change management process and culture shift.

Only once all Canadians are fully educated on the end-of-life options available to them can we expect to have a healthcare system in which physician-assisted death can be properly administered.

There also needs to be a much closer integration between two inter-related initiatives: the integrated palliative approach to care and advance care planning. Each needs the other to actually meet Canadians' expectations that they will have the kind of care they want and need when faced with a life-threatening chronic disease or frailty, and each needs to be fully and effectively engaged in by Canadian citizens and professionals.

In *closing*

The CHPCA is calling on the federal government take an active stance for a legislative response to *Carter V. Canada* while ensuring universal access to hospice palliative care for all Canadian citizens. More specifically, the CHPCA would like to see the following objectives achieved:

- A federally commissioned frame work for hospice palliative care that would work towards ensuring universal access to for all Canadian citizens.
- A national awareness campaign for hospice palliative care including Advance Care Planning (www.advancecareplanning.ca) which would inform Canadians of the options available to them at end of life.
- The protection of Canadian health care workers in the hospice palliative care field including the option for them to opt out of providing physician-assisted death should they choose to.
- Clear and informed legislation regarding physician-assisted death developed federally to be enacted by provincial institutions based on a model that takes into account all factors mentioned in the “transparency and accountability” section of this document.
- Readily available access to resources and information for physicians, caregivers and patients regarding their end-of-life care options and physician-assisted suicide.

All patients deserve access to information about end-of-life options, including physician-assisted death.

About the Canadian Hospice Palliative Care Association

What the CHPCA stands for

The CHPCA serves as the national voice for Hospice Palliative Care in Canada. Advancing and advocating for quality end-of-life / hospice palliative care in Canada, its work includes public policy, public education and awareness. Established in 1991, its volunteer Board of Directors is composed of hospice palliative care workers and volunteers from Canadian provinces and territories as well as members-at-large.

How the CHPCA operates

The CHPCA strives to achieve its mission through the following:

- Collaboration and representation;
- Increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers;
- Development of national standards of practice for hospice palliative care in Canada;
- Support of research on hospice palliative care;
- Advocacy for improved hospice palliative care policy, resource allocation and supports for caregivers.

Who the CHPCA represents

With a membership of over 3,000 people, the CHPCA represents a myriad of Canadians including aging seniors, those with chronic and terminal illnesses and the thousands of Canadian caregivers that are looking after their ailing loved ones.

The CHPCA also works to serve as a voice for Canadian health care workers including nurses, physicians working in palliative care, volunteers, and hospice palliative care workers.

ⁱ Wilson, D., Cohen, J., Deliens, L., Hewitt, J., & Houttekier, D. (n.d.). The Preferred Place of Last Days: Results of a Representative Population-Based Public Survey. *Journal of Palliative Medicine*, 502-508.