
BACKGROUND

There is urgent need for a right to palliative care in Canada. Palliative care is understood to be a vital component of comprehensive health care throughout the life course. However, palliative care is neither reasonably assessable to all Canadians nor consistently provided across all Canadian jurisdictions. Nationally and internationally the Parliament of Canada expressly supports strengthening palliative care services; however access to palliative care across Canada has not materially improved. Now, with the Supreme Court of Canada’s decision to legalize physician assisted death, there has never been a greater need for a right to palliative care in Canada.

What is Palliative Care?

Palliative care is a relatively recent health care model, developed out of a changing medical landscape. It emerged in Canada in the 1970’s when “greater attention and priority was devoted to managing the pain and other symptoms of cancer patients.”¹

The World Health Organization defines Palliative care as “an approach that improves the quality of life of patients (adults and children) and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”² End-of-life care is among the critical components of palliative care.³ Rather than focus on curing a patient’s condition, palliative care focuses on maintaining quality of life for the patient and his or her family. Care is designed to minimize pain and maximize comfort for patients and their families.

¹ Federal, External Panel on Options for a Legislative Response to *Carter v. Canada, Consultations on Physician-Assisted Dying Summary of Results and Key Findings Final Report* (Her Majesty the queen in Right of Canada, 15 December 2015) at 122- 123 [The External Panel].

² WHO, *Strengthening of palliative care as an component of integrated treatment within the continuum of care*, EB134.R7, session 134th, Agenda item 9.4., 23 January 2014 [WHO].

³ *Ibid.*

Palliative care takes a multidisciplinary approach to patient care. It is provided by a team of specialists that may include: physician, nurse, pharmacist, social worker, spiritual counsellor, bereavement support worker, home care worker, nutritionist, physiotherapist, occupational therapist, volunteers and informal caregivers.⁴ A multidisciplinary approach allows a palliative care team to address physical, emotional, spiritual, existential and social concerns that arise with advanced illness, by developing a care plan to relieve suffering in all areas of a patient and his or her family's lives.

The benefits of palliative care are numerous: “[e]mpirical research has found that palliative care is associated with better outcomes for patients (symptom management, quality of life, overall satisfaction), family caregivers (reduced burden) and the healthcare system (reduced hospital admissions).”⁵ Research indicates that palliative care is more cost-effective than hospital care. The daily average cost of a hospice, palliative care bed is roughly \$460 per day compared to the \$1,100 per day expense of a hospital bed.⁶

Palliative Care in Canada

There is no right to palliative care in Canada.

No Federal Model to Fund or Implement Palliative Care in Canada

The two-tiered legislative approach to health care in Canada, as set out in the federal *Canada Health Act* (CHA),⁷ results in inconsistent availability of palliative care services across Canada. Both federal and provincial governments fund health care services; provincial governments receive money from the federal government via the Health Transfer payments set out in the CHA. The provinces must allocate health care funds in accordance with the CHA's guidelines.

The CHA contains five governing principles: reasonable accessibility, public administration, comprehensiveness, universality, and portability⁸. The criterion of reasonable accessibility, comprehensiveness, universality and portability only apply to insured health services.

⁴ *The External Panel, supra* note 1 at pg 123.

⁵ *Ibid.*

⁶ Ontario, Auditor General of Ontario, *2014 Annual Report of the Office of the Auditor General of Ontario* (Ontario, 2014) at pg 265 [AGO Report].

⁷ RSC, 1985, c. C-6 [CHA].

⁸ ss. 12, 8, 9, 10 and 11 respectively in the CHA, *supra* note 7.

Palliative care is not specified as an insured health service in the CHA. Therefore, provincial governments have defined it as falling under the CHA's definition of "extended health care services". Because the onus is on each province to determine if and how 'extended health care services' will be funded, and the criterion of reasonable accessibility, comprehensiveness, universality do not legally apply, Canada does not have a consistent approach to the delivery and availability of palliative care. This leaves palliative care programs at the mercy of budget cuts within the regions that the care is administered.

Canada's Current Palliative Care System

Palliative care in Canada is often described as a "patchwork quilt" or as "a work in progress."⁹ As few as 16-30% of all Canadians have access to some level of palliative care.¹⁰ Experts report that palliative care is required in 90% of all deaths.¹¹ Despite this, reports estimate that "the health system is currently unable to provide palliative care to 70% of those in need."¹²

The Special Joint Committee on Physician-Assisted Dying (the Committee), appointed by the Parliament of Canada to make recommendations on the legislative response to *Carter v. Canada*, heard from many witnesses who identified a need for adequate palliative care in Canada.¹³ The Committee found that "many Canadians do not have access to high quality palliative care when they need it."¹⁴

The federally appointed External Panel on Options for a Legislative Response to *Carter v. Canada*¹⁵ noted: "[u]nquestionably, too many Canadians and their families do not have access to good quality palliative care and hence, have less than ideal and sometimes even tragic end-of-life experiences."¹⁶ As a result, end of life patients are unnecessarily hospitalized; 60% of deaths occur in hospitals despite the fact that many of these deaths are "not sudden and could have been planned to occur elsewhere".¹⁷

⁹ *The External Panel, supra* note 1 at pg 124.

¹⁰ *Ibid.*

¹¹ *The Way Forward Framework: A roadmap for an integrated palliative care approach* (March 2015), page 9 [The Way Forward].

¹² *Improving Access to Palliative Care in Ontario* (McMaster University, 2013) pg 6 [McMaster Health Forum].

¹³ Federal, Report of the Special Joint Committee on Physician-Assisted Dying, *Medical Assistance in Dying: a Patient-Centred Approach* (Parliament of Canada, February 2016) pg 15 [The Special Joint Committee].

¹⁴ *Ibid* at pg 33.

¹⁵ 2015 SCC 5, [2015] 1 S.C.R. 331 [Carter].

¹⁶ *The External Panel, supra* note 1 at pg 124.

¹⁷ *AGO Report, supra* note 6 at pg 264.

Closely linked to accessibility and service provision is labour availability. Notably, by international standards Canada has fewer doctors specializing in palliative care than comparable countries such as the United States and Australia:

Out of approximately 77,000 physicians in Canada, a recent survey identified just 51 palliative care specialists, as well as 123 family physicians whose practices focus on palliative care. The survey also identified another 931 family physicians and specialists (e.g., oncologists, pediatricians) who provide some palliative care as part of their practices, *but two-thirds of this group reported having no training in palliative medicine.*¹⁸

Populations particularly vulnerable and often under-served at the end of life include people living outside of urban centres, indigenous people, children and new Canadians.¹⁹ In its recommendations, the Committee specifically highlighted the need to ensure “culturally and spiritually appropriate end-of-life care services, including palliative care” services are available to the Canadian Indigenous population.²⁰

Access to Palliative Care in Canada Has Not Materially Improved

In many instances the federal government and its appointed bodies have reviewed Canada’s provision of palliative care and made recommendations. But movement beyond broad visions and loosely defined milestones and towards specific targets has not materialised.

With the rare support of all parties, the Parliament of Canada passed Motion-456 on May 28, 2014, which called for a Pan-Canadian Palliative and End-of-life Care Strategy. This strategy would work with the provinces and territories on “a flexible, integrated model” of palliative care that:

- (a) takes into account the geographic, regional, and cultural diversity of urban and rural Canada as well as Canada’s First Nation, Inuit and Métis people;
- (b) respects the cultural, spiritual and familial needs of all Canadians; and
- (c) has the goal of

¹⁸ *The External Panel, supra* note 1 at pg 124 (emphasis our own).

¹⁹ *The External Panel, supra* note 1 at pg 124.

²⁰ *The Special Joint Committee, supra* note 13 at pg 33 (recommendation 18).

- i. ensuring all Canadians have access to high quality home-based and hospice palliative end-of-life care,
- ii. providing more support for caregivers,
- iii. improving the quality and consistency of home and hospice palliative end-of-life care in Canada,
- iv. encouraging Canadians to discuss and plan for end-of-life care.²¹

In March 2015, the federal government funded the report “The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care” (The Way Forward).²² This report discusses the benefits inherent in an integrated approach to palliative care. The report states that a “system-wide shift” is required to achieve integrated palliative care. This shift would facilitate the understanding that palliative care is an extension of health care rather than a form of boutique care only required for some individuals.

Many of the recommendations in The Way Forward focus on accessibility and universality. It recommends integrated palliative care be available to patients and families at appropriate times in their lives or during an illness *in all care settings*.²³ The report discusses that all health care practitioners should be providing many elements of palliative care, separate from complex palliative care skills that will require extensive training.²⁴

The Way Forward sets out a vision for palliative care in Canada including a number of goals and principles, none of which are binding. Under the report’s Framework in Action for Federal, Provincial and Territorial Governments, it suggests, amongst others, that legislation and regulations be created, and policy expectations for all care settings and providers be established. To date, no legislation has been enacted further to this federally funded report.

Almost two years after Motion-456 was passed, on February 25, 2016, the Special Joint Committee on Physician-Assisted Dying recommended: “that Health Canada re-establish a Secretariat on Palliative and End-of-Life Care; and that Health Canada work with the provinces and territories and civil society to develop a flexible, integrated model of palliative care by implementing a pan-Canadian palliative and end-of-life strategy with dedicated funding, and developing a public

²¹ Pan-Canadian Palliative and End-of-life Care Strategy 41st Parliament, Private Members’ Motion-456, 41st Parliament, 2nd Session.

²² *The Way Forward*, *supra* note 11.

²³ *Ibid* at pg 14.

²⁴ *Ibid* at pg 16.

awareness campaign on the topic.”²⁵ On the issue of palliative care, the Special Joint Committee found that Canada “could and needs to do more in this area.”²⁶

The Parliament of Canada has yet to initiate a pan-Canadian palliative and end-of-life strategy, nor enact a legislative response to integrated palliative care.

Post-Carter, Lack of Alternative Care Creates Urgent Vulnerabilities

Physician assisted death was never intended as a substitute to palliative care. Even Wanda Morris, past-CEO of Dying with Dignity Canada stated: “[n]obody should have to choose an assisted death because the medical system has failed to give them other options.”²⁷

In 2015, the Supreme Court of Canada found the prohibition against physician assisted death was unconstitutional.²⁸ Federal legislation to regulate physician assisted death will be in force no later than June 6, 2016.

Canadians suffering pain, whether physical, emotional, spiritual, existential or social, may now seek physician assisted death when their pain is more appropriately addressed with palliative care. Studies show that patients with fractured dignity are significantly more likely to report a desire for death, loss of will to life, depression, hopelessness and anxiety.²⁹ These same studies find that terminal patients who receive state-of-the-art palliative care are less vulnerable to assaults on their sense of dignity.³⁰

Palliative care and physician assisted death are not mutually exclusive. The three committees established to consider the legislative outcome of *Carter* heard extensive evidence and made findings specifically related to palliative care.³¹ Significantly, all three committees found access to quality palliative care across Canada must be increased despite new access to physician assisted death.

The Special Joint Committee views access to palliative care as an important consideration in assessing whether a patient gave informed consent to physician

²⁵ *The Special Joint Committee, supra* note 13 at pg 33 (recommendation 19).

²⁶ *The Special Joint Committee, supra* note 13 at pg 33.

²⁷ *The External Panel, supra* note 1 at pg 122.

²⁸ *Carter, supra* note 15.

²⁹ HM Chochinov, Dignity in the Terminally Ill: a developing empirical model” (2002) 54(3) 433-443.

³⁰ *Ibid.*

³¹ *The Special Joint Committee, supra* note 13 at pg 33, *The External Panel, supra* note 1 at 121- 125, Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying at pg 20.

assisted death.³² The Committee heard many witnesses discuss palliative care as a safeguard to reducing vulnerabilities experienced by patients. Adequate palliative care and full information about alternative care must be provided to ensure a patient's decision for physician assisted death is "genuine choice."³³

The External Panel agreed: "[p]hysician-assisted dying must not become an indication of the system's failure to provide adequate end-of-life care. There appeared to be overall consensus among those who expressed their views to the Panel that a truly informed decision can be made only when the individual is aware of and understands meaningful alternatives."³⁴

The province of Quebec recognized its obligation to confer a right to palliative care as an essential element of its *Act Respecting End-of Life Care*,³⁵ which came into effect in December 2015.

If the Federal Government Will Not Legislate, Canadians with disabilities are prepared to Mount A *Charter* Challenge for a Right to Palliative Care

It is anticipated that the legislated response to the Supreme Court's decision will be that physician assisted death will immediately become an insured service under the CHA. The lives of Canadians are threatened every day that physician assisted death is available and palliative care is unavailable. Granting the right to one without the other makes people vulnerable to making choices they would not willingly have made. Palliative care must be a Canada-wide right.

If the federal government will not include a national right to palliative care in its legislative response to *Carter*,³⁶ the Council of Canadians with Disabilities and the Canadian Association for Community Living are prepared to challenge the federal government's decision to exclude palliative care from the legislated response to *Carter*. The decision to exclude palliative care will negatively affect the choices of all people and it is particularly discriminatory against persons with disabilities and the elderly. The decision to exclude palliative care threatens the life, liberty and security of person of all Canadians, as well as their right to equality.³⁷

³² *The Special Joint Committee*, *supra* note 13 at pg 18.

³³ *The Special Joint Committee*, *supra* note 13 at pg 16.

³⁴ *The External Panel*, *supra* note 1 at pg 121.

³⁵ RSQ c S-32.0001.

³⁶ *Carter*, *supra* note 15.

³⁷ "The Right to Palliative Care Think Paper" (2015) <http://www.bakerlaw.ca/wp-content/uploads/The-Right-to-Palliative-Care-Think-Paper.pdf>

Canadians with disabilities are requesting that all Canadians join with them in requesting that the federal government confer a right to needed palliative care as part of its legislative response to the Supreme Court of Canada's decision in *Carter*³⁸.

³⁸ *Carter*, *supra* note 15.