



The Time to Meet the Needs of Dying Canadians is Now!

A Pan-Canadian Partnership for Palliative and End-of-Life Care

Recommendations for Federal Government Action (Summarized)

1. Develop a pan-Canadian comprehensive consultation, involving not only Health Canada, and other relevant federal government departments, such as Human Resources and Skills Development, First Nations and Inuit Health, Veterans Affairs and Corrections, but also provincial, territorial and community governments, with the creation of an action plan as its immediate goal.
2. Develop a broad-based advisory committee to offer guidance and direction in the development of new policies and strategies.
3. Recognize the need for more research to understand end-of-life care issues. Continue to support the necessary research by making available initiative and research grants and contribution funding in the form of a multi-level partnership.

The Quality End-of-Life Care Coalition of Canada (QELCCC) believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice.

The QELCCC is pleased that, as stated by the Honourable Tony Clement, Minister of Health, Canada's new government recognizes the importance of providing quality health care to those facing the end-of-life¹. Due to the activities of the (now discontinued) National Strategy for Palliative and End-of-Life Care, as well as the research funding through Canadian Institute of Health Research, some significant progress in national end-of-life care policy has been made. Notwithstanding, the QELCCC believes that achieving quality end-of-life care for all Canadians requires an on-going, well-funded, sustainable national approach to palliative and end-of-life care. The QELCCC welcomes the opportunity to work together in partnership with Canada's new government and other concerned organizations and agencies to achieve this goal.

Meeting the Needs of Canadians

The QELCCC estimates that **only 25% of Canadians who need palliative and end-of-life care services currently have access** to appropriate programs and services. Given the urban, rural and remote demographics of Canada, there are marked regional differences in the level of access, leaving the majority of individuals and their families without much-needed care and support.

Canadians need increased access to coordinated, integrated, comprehensive and accessible hospice palliative and end-of-life care services. This can be addressed through: research, policy

¹ Honourable Tony Clement, Minister of Health, 2007 National Hospice Palliative Care Week Letter of Greeting

development and best practices, knowledge transfer, knowledge translation and dissemination. Resources, programs, education and funding are key areas that must be addressed to develop tools that will meet the growing palliative and end-of-life care needs of Canadians. Finally, those tools must be accessible to all Canadians.

Support is critical for all Canadian families dealing with a loved one's life-limiting illness. The QELCCC recognizes the positive impact of the Compassionate Care Benefit (CCB). However even with the recent broadening of the CCB definition of family, it does not provide all of the support necessary to family caregivers nor does it reach all Canadian family caregivers. Approximately 36% of family/friend caregivers (including those providing palliative care) in the community are over the age of 70² and are therefore not eligible for the Compassionate Care Benefit. What they need most may be access to respite care or bereavement support. A variety of programs and services must exist to ensure that all Canadian families are adequately supported.

Benefiting all Canadians

While palliative and end-of-life care programs benefit individual patients by allowing them to gain more control over their lives, and manage pain and symptoms more effectively, they also benefit all Canadian families through the fundamental support offered for family caregivers³. The Canadian Hospice Palliative Care Association estimates that each death in Canada affects the immediate well being of an average of five other people, or more than 1.25M Canadians each year. Caregiving spouses suffer increased mortality and can have complicated grief leading to depression, placing more pressure on limited health care resources. Ample support for caregivers and families, both during their loved one's illness, as well as during bereavement, can help to minimize negative effects on the health of caregivers and families.

Providing palliative and end-of-life care offers positive benefits for non-palliative Canadian patients as well. While the growing trend for Canadians is to choose to die at home, the unfortunate reality is that 75% of deaths still take place in acute care hospitals and long-term care facilities.⁴ Not only is this contradictory to the wishes of the majority of patients, it can negatively impact the provision of timely health care to other patients, through increased patient

Factors Impacting Hospice Palliative Care

- In 2007, 259,000 Canadians will die.¹
- By the year 2020, the number of deaths will increase to more than 330,000 per year.²
- Since chronic diseases account for 70% of all deaths³, in 2007, up to 181,300 Canadians, and up to 231,000 by 2020, will need access to hospice palliative care services and programs.
- 75% of deaths take place in acute care hospitals and long-term care facilities.⁴

¹ Deaths – 2004, [Statistics Canada](#), Catalogue No. 84F0211. p.6

² Projections for Canada, Provinces and Territories – 2000-2026, [Statistics Canada](#), Catalogue No. 91-520, p.124

³ Rachlis, Michael. Presentation to the Local Health Integration Networks (LHIN) Education Session, Toronto, Ontario, April 6, 2006

⁴ Quality End-of-Life Care: The Right of Every Canadian, Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology, Final Report, June 2000, <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm>

² Website: <http://www.ccsmh.ca/en/caregivers.cfm>

³ Definition: *Informal and Family Caregivers* are family members, loved ones, or friends and neighbours who provide support or care for the dying family member, loved one, or friend. The CHPCA's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (2002)* defines 'Informal Caregivers' as, "not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice. They may be family members or friends."

⁴ Quality End-of-Life Care: The Right of Every Canadian, Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology, FINAL REPORT, June 2000, <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm>

wait times for acute care beds occupied by palliative patients. Increasing palliative and end-of-life care services and programs will decrease wait times for acute care beds for other patients.

Current studies indicate that there is no economic impediment to increasing hospice palliative care services and programs. In fact, it has been demonstrated that providing comprehensive and community-based palliative care services results in increased palliative care service delivery and cost neutrality, primarily through the decrease in use of acute care beds.^{5,6}

Federal Leadership in Action

Leveraging the excellent work already accomplished through Health Canada's Secretariat on Palliative and End-of-Life Care, the QELCCC recommends that Health Canada demonstrate that end-of-life care is a priority, by implementing the following initiatives:

1. Develop a **pan-Canadian comprehensive consultation**, involving Health Canada and other relevant government departments, such as Human Resources and Skills Development, First Nations and Inuit Health, Veterans Affairs and Corrections and diverse stakeholder communities. Use the results of the consultation to create an action plan that includes incomplete work items from the original 2002 five-year action plan (created at the National Action Planning Workshop on End-of-Life Care) still deemed relevant, redefined priorities and structure, and any potential new areas identified through the consultation process.
2. Create a **broad-based advisory committee** (with representation from federal, provincial and territorial governments, as well as community, cultural and professional organizations), and through its guidance, direction and agreement, develop a clear plan to begin the implementation of the new partnership. Use this action plan to guide the longer process of engaging multi-levels of stakeholders, focusing on front-line activities that engage the public and stakeholders across Canada through projects, awareness campaigns, education and research initiatives. Finally, ensure that evaluation mechanisms are in place to monitor the effectiveness of these projects, campaigns and initiatives.
3. Make available **grants and contribution funding**, to facilitate the implementation and uptake of initiatives, campaigns and pilot projects.

The QELCCC believes that a pan-Canadian partnership on palliative and end-of-life care needs to be sustainable over the long-term. A vital leadership role exists for the federal government to ensure that quality end-of-life care services are integrated into the health system, are coordinated with other health services, are comprehensive in nature and effectively use health care dollars. More efficient utilization of health care resources will benefit not only palliative care patients and their families directly, but also all Canadian patients indirectly, helping to ensure that the level of care they need is available when they need it.

Partnership in Action

The QELCCC will engage with the federal, provincial and territorial governments, as well as with other national, community and cultural groups to support future activities that address the

⁵ K. Fassbender et al. *Journal of Palliative Medicine* 2005; 19: 513_520

⁶ Bruero, Eduardo. *Journal of Palliative Care* 2000; 16:16-22

palliative and end-of-life care needs of all Canadians. These partnerships would support actions which include:

- Ensuring access to coordinated, integrated, comprehensive and accessible hospice palliative and end-of-life care services (including acute care, long-term care, residential hospice and home care settings)
- Raising public awareness of critical issues that Canadians face regarding death and dying
- Promoting an environment where Canadians can become informed and make educated decisions with regard to their end-of-life care needs, and those of their loved ones
- Promoting interdisciplinary research that increases the base for evidence-based decision making and creates research networks
- Ensuring that policy is in place to make end-of-life care a priority, which will support the development and adaptation of best practices for care providers across Canada

We believe that it is only through partnership, under strong federal leadership that the Canadian health care system can ensure all Canadians the right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice.

Submitted by the following member organizations of the Quality End-of-Life Care Coalition of Canada:

ALS Society of Canada	Canadian Lung Association
Alzheimer Society of Canada	Canadian Medical Association
Canadian AIDS Society	Canadian Nurses Association
Canadian Arthritis Patient Alliance	Canadian Pharmacists Association
Canadian Association of the Deaf	Canadian Society of Palliative Care Physicians
Canadian Association of Occupational Therapists	CARP: Canada's Association for the Fifty-Plus
Canadian Association for Pastoral Practice and Education	Catholic Health Association of Canada
Canadian Association of Social Workers	Childhood Cancer Foundation
Canadian Breast Cancer Network	Candlelighters Canada
Canadian Cancer Society	Heart and Stroke Foundation of Canada
Canadian Caregiver Coalition	Huntington Society of Canada
Canadian Healthcare Association	Long Term Care Planning Network
Canadian Home Care Association	National Council of Women of Canada
Canadian Hospice Palliative Care Association	The GlaxoSmithKline Foundation
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