

**PALLIATIVE CARE IN CANADA –
CHA’S PERSPECTIVE**

**Brief Submitted to the
Parliamentary Committee on
Palliative and Compassionate Care**



**Canadian Healthcare Association
Association canadienne des soins de santé**

November 2010

About the Canadian Healthcare Association

The Canadian Healthcare Association (CHA) is Canada's only federation of provincial and territorial health associations and organizations and is a leader in developing and advocating for health policy solutions that meet the needs of Canadians. For almost 80 years, CHA has been a recognized champion for a sustainable and accountable quality health system that provides access to a continuum of comparable services throughout Canada, while upholding a strong, publicly-funded system as an essential, foundational component of this system. We have earned a solid reputation as an independent, non-partisan, highly respected organization.

We invite you to visit our website, www.cha.ca, to learn more about our solutions to health system challenges.

Selected recommendations from CHA policy briefs

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Improve the lives of informal caregivers.

A. New provision in CPP/QPP for caregivers

CHA recommends the creation of a provision in the CPP/QPP to allow for adjustment in pension calculation for Canadians who have taken time from the workforce to provide informal care or permit those caregivers who leave the labour force to continue to contribute to CPP/QPP.

B. Compassionate Care Benefit

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Home Care in Canada: From the Margins to the Mainstream – May 2009

Provide appropriate supports to both formal and informal (usually family) caregivers.

Caregivers are performing a valuable service — and they deserve more support.

CHA recommends forms of support could be undertaken at a national level, including:

- **recognition of the caregiver role and its importance to society;**
- **establishment of minimum standards for respite care;**
- **easier access to information and training; and**
- **greater social supports for caregivers.**

New Directions for Facility-Based Long Term Care – October 2009

Address end-of-life care.

CHA recommends that:

- **long term care homes should become palliative care centers of excellence given that 39% of all deaths occur in facility-based long term care in Canada and there is a growing preference among residents to remain there during their last days rather than being transferred to a hospital. There is a need to raise the knowledge quotient of all long term**

care staff in end-of-life care. This investment in people will promote a culture of caring that benefit not only the dying resident but all residents in facility-based long term care.

- Adequate public funding for appropriate end-of-life care must be available.**
- Identify appropriate health services in the year of death: palliative care rather than aggressive medical treatment, the promotion of advance directives, the continuation of care in facility-based long term care rather than costly transfers to hospitals near the time of death, and culturally-sensitive and humane practices throughout the health care system.**

PALLIATIVE CARE IN CANADA – CHA’S PERSPECTIVE

Palliative care (end-of-life care) was developed to address the unmet needs of dying individuals and their loved ones. Its purpose is to neither hasten nor postpone death but to provide relief from pain and suffering during the end of a person’s life. Palliative care integrates the medical, psychological and spiritual aspects of care and offers a valuable support system to help relatives and friends cope during the bereavement period.

A progress report undertaken by the Quality End-of-Life Care Coalition in 2008 found that 60 percent of deaths in Canada still occur in hospitals, while most people have indicated that they would prefer to die at home. And home can mean a private dwelling, a retirement home or a long term care home.

In the case of the latter, health care professionals have recently recognized the need for increased education in palliative care and some have even expressed a lack of competence in the delivery of end-of-life care. In spite of the emergence of palliative care leading practices and advances in pain and symptom management, front line staff concur that there is still a need for more training in palliative care¹. A cross-sectional survey of 426 directors of nursing assessed the current practice of end-of-life care in Ontario long term care homes. Staffing levels were viewed by a majority of the respondents as being inadequate to provide quality end-of-life care². A similar survey was completed by 275 medical directors representing 302 long term care homes in Ontario with identical results. Most medical directors (67.1%) reported insufficient staffing levels as an impediment to the provision of palliative care. Further barriers to effective end-of-life care included the heavy time commitment required and a lack of needed equipment. This is significant as long term care homes should become palliative care centers of excellence given that there is a growing preference among residents to remain there with family and friends during their last days rather than being transferred to a hospital.

There is a dearth of information about the quality of palliative care in Canada but if major studies were conducted they would likely reveal major variances across the country. Notwithstanding the fact that some organizations provide exceptional end-of-life care, there is an urgent need to raise the knowledge quotient of all staff engaged in palliative care. This investment in people will promote a culture of caring that benefits not only the dying person but all person accessing healthcare services in Canada.

It must be said that we have taken several strides forward in the care of dying persons. Prince Edward Island’s *Integrated Palliative Care Initiative* was recognized by the Health Council of Canada in 2005 as a leading practice because of its collaborative practice among disciplines and care sites, coordinated entry to the programs, client- and family-focused approach, and for its use of a common palliative care assessment tool.

But there is still considerable work to be done in this field.

¹ Kortes-Miller, K., Habjan, S., & Kelley, M.L. (2007). Development of the palliative care education program in rural long-term care facilities. *Journal of Palliative Care*, 23(3), 154-162.

² Brazil, K., Krueger, P., Bedard., M., Kelley, M. L., McCainey, C., Justice, C., & Taniguchi, A. (2006). Quality of care for residents dying in Ontario long-term care facilities: Findings from a survey of directors of care. *Journal of Palliative Care*, 22(1), 18-25.

All activities should be done in a culturally appropriate and sensitive manner. Ideally, palliative care protects the individual's spirit. This requires an understanding that while there is erosion of the human body, the spirit remains.

How critical is the connection between spirituality and palliative care?

Researchers in the United States studying a random sample of cancer survivors found that spiritual care was more important to the individual's quality of life than support groups, counseling sessions or even spousal support.

In 2006, the Canadian Hospice Palliative Care Association (CHPCA) issued *The Pan-Canadian Gold Standard for Palliative Home Care*. Two years later, the Coalition issued a revealing progress report. It assessed the progress made by several jurisdictions across Canada in giving Canadians access to a range of palliative home care services (case management, nursing, personal care, pharmaceuticals). It noted that all jurisdictions had made significant progress. Yet only six (British Columbia, Alberta, Manitoba, Ontario, New Brunswick and Nova Scotia) had policies on providing 24/7 nursing and personal care services and only four (Saskatchewan, Ontario, New Brunswick and Newfoundland and Labrador) had policies ensuring round-the-clock access to case management.

There is a large discrepancy between the number of people who prefer to die at home and the number who actually do so. While it is not always possible or appropriate for people to die at home, it should become the norm for those who can die with comfort in the place they call 'home'. Large numbers of Canadians die in hospital and for various reasons, including a shortage of palliative care professionals and programs, and a lack of 24/7 case management support. The Canadian Institute for Health Information noted in 2007 that the variation in care suggests that an integrated, systematic approach to end-of life care does not yet exist in Canada.

Senator Sharon Carstairs has been advocating for a national palliative care strategy since 1995 when she was involved in the Special Senate Committee on Euthanasia and Assisted Suicide. Today, there is significant drive for a pan-Canadian approach given the absence of a national palliative care strategy. Advocates for change speak to the need for federal guidelines, standards, nationally funded research, and a public education campaign to advise Canadians of the range of choices they have for end-of-life care. In June of this year, the Senate of Canada tabled the report, *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*, which contained 17 recommendations for governments to work together to provide funds for research, public education and a national strategy.

"Despite some remarkable gains we have observed over the years, there is still much more to be done to ensure that every Canadian has access to quality hospice palliative and end-of-life care regardless of where they live," stated Sharon Baxter, Executive Director of the CHPCA at the time of report's release this past summer. "Currently in Canada, at best there is still at least 70% of Canadians who do not have access to palliative care, and with an aging population, the health care system must be prepared to meet the increasing demand."

The last word on the role of federal government in palliative care comes from Dr. Martin LaBrie, a palliative care consulting physician and a clinical assistant professor in the division of palliative medicine at University of Calgary. Quoted in the *Calgary Herald* on November 21, 2010, Dr. LaBrie stated: "Alberta is one of the best provinces in the country for palliative care, but we do need some direction from the federal government for a standard of care."

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