



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging

Submitted by:
Canadian Hospice Palliative Care Association
Annex B – Saint-Vincent Hospital
60 Cambridge Street North
Ottawa, ON K1R 7A5

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Preamble

Thank you to the Special Senate Committee on Aging for inviting Canadians to participate in this critical discussion on Canada's aging population and the issues that the evolution in demographics will bring about. The Canadian Hospice Palliative Care Association (CHPCA) is grateful for this opportunity to present its concerns and recommendations to this committee. The CHPCA would like to also take this opportunity to express its appreciation to Senator Sharon Carstairs and Senator Wilbert Keon, who have already completed some excellent work in drawing attention to the issue of hospice palliative care in Canada.

In any discussion related to aging, the issue of hospice palliative care must be addressed, as care at the end of life is a key issue for our society. It is also a key issue for our federal government as it cross-cuts many government departments, such as health care, human resources, housing and taxation. The federal government is responsible for health care for aboriginal people and prisoners, so aboriginal and northern affairs and corrections are also affected. As noted in the Special Senate Committee on Aging Interim Report, "It is projected that by 2031, about one in four Canadians will be 65 years of age or over."¹ Natural effects of aging combined with an increase in chronic disease means that the majority of Canadian seniors will need access to hospice palliative care programs and services.

Background

Mission Statement

The Canadian Hospice Palliative Care Association (CHPCA) is the national association that provides leadership in hospice palliative care in Canada. The CHPCA offers leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.

The CHPCA strives to achieve its mission through:

- collaboration and representation;
- increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers;
- development of national norms of practice for hospice palliative care in Canada;
- support for research regarding issues related to hospice palliative care;
- Advocacy for improved hospice palliative care policy, resource allocation and supports for professional, informal and family caregivers.

Definition of Hospice Palliative Care

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- Cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

The Right of Every Canadian

The CHPCA is the secretariat for the Quality End-of-Life Care Coalition of Canada (QELCCC), a network of 30 national organizations, who support the belief 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 believes that achieving quality end-of-life care for all Canadians requires a well-funded, sustainable national approach to palliative and end-of-life care.

The Need for Hospice Palliative Care

More than 259,000 Canadians will die in 2007². Statistics Canada has projected that the rate of deaths in Canada will increase by the year 2020 to more than 330,000 deaths per year – a 33% increase from 2004 rates³. These figures are highly illustrative of the growing need for hospice palliative care programs and services for all Canadians.

For senior Canadians, hospice palliative care programs and services are especially vital. Considerable evidence exists that older people suffer unnecessarily, due to widespread under-assessment and under-treatment of their problems, as well as lack of access to hospice palliative care.⁴ For example, more than half of all cancers strike people age 65 or older, with over two-thirds of all cancer deaths in the same age group⁵. Yet, it has been found that the largest risk factor for inadequate pain relief in cancer is being over the age of 70⁶.

By 2026, approximately 20% of the population will be over 65⁷. Among Canadians aged 65 and older, about 80 percent have one chronic disease, and of those, about 70 percent suffer from two or more chronic diseases⁸. There is also a higher incidence of complicating factors in the elderly, including the prevalence of arthritis (limiting function), negative social and economic factors, and a lack of advance care planning. Seniors are therefore more likely to have highly complex problems and disabilities, necessitating packages of care that require partnership and collaboration between different groups and across many settings.

The 2000 Senate Report *Quality End-of-Life Care: The Right of Every Canadian* reported that approximately 15% of Canadians who require hospice palliative care services have access to these specialized services. While some improvements have been made, such as the creation of regional hospice palliative care programs, significant deficiencies in hospice palliative care access still exist.

The CHPCA 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. These effects may include disruptions to living arrangements, loss of income, grief and other psychological issues, including depression and anxiety or increased rates of physical illness in elderly spouses. Because quality hospice palliative care addresses the physical, psychological, social, spiritual and practical issues of both patient and family, providing a solid support for those affected by a loved one's approaching or recent death, it can reduce the incidence of further health problems. An investment in hospice palliative care for one patient pays dividends in protecting the health of those in their circle of family and close friends.

Key Points

Access ♦ Education ♦ Training ♦ Research ♦ Awareness ♦ Informal Caregiver Role

Access

Most Canadians with life-threatening illnesses would prefer to die at home surrounded by family and friends, yet about 75% of deaths in Canada still occur in hospital or long-term facilities⁹. Elderly patients in long-term and continuing care facilities generally have limited access to hospice palliative care services.

Due to the disparity in population distribution, as well as inequities in health care across the country, access to hospice palliative care is inconsistent between population groups. For example, Canadians living in remote and rural areas, have severely limited access to hospice palliative care services, compared to their counterparts in urban centres. Those living with disabilities also do not benefit from the same level of access as those who are more able-bodied.

In 2004, in the *10-Year Plan to Strengthen Health Care*, governments recognized the need for hospice palliative care services in the home. In that plan, the federal, provincial and territorial First Ministers made a commitment to “provide first dollar coverage by 2006 for certain home care services ... [including] case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life¹⁰. It is important to note that the federal government is responsible for provision of health care services to Aboriginal Canadians.

To support provincial and territorial government efforts in attaining these goals, the CHPCA and the Canadian Home Care Association subsequently published *The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home*.¹¹ To date, however, it appears that federal, provincial and territorial preparation and implementation of the *10-Year Plan to Strengthen Health Care* is moving slowly, although the CHPCA is hopeful that some marked improvements will be apparent when it completes its update report in early 2008.

Education for Future Physicians

In 2004, the Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC)¹² project was launched, as a joint project of the Association of Faculties of Medicine of Canada and the CHPCA with funding from Health Canada. Its goal is to address the crucial need for appropriate education and training for all health professionals who are involved in providing palliative and end-of-life care, through consensus-building activities.

EFPPEC has successfully brought education in palliative and end-of-life care to all undergraduate medical students and clinical postgraduate trainees at Canada’s 17 medical schools, so they will graduate with competencies in these areas by the year 2008. EFPPEC is seeking a project extension to incorporate other future health care providers.

Training for and Capacity Building for Current Health Care Providers

Since 2001, the Pallium Project¹³ has used two, one-time Government of Canada investments equalling \$4.57 million to increase access, enhance quality and build capacity for hospice palliative care by intentionally using known innovation and knowledge transfer practices. The Pallium Project has linked, supported and enabled a diverse range of collaborators at the local, provincial/territorial and national levels and across health delivery, academic, government and voluntary sectors. For every \$1 invested by the federal government, at least \$3 in total hospice palliative care capacity-building has been leveraged from some provincial/territorial and sectoral partners.

As the only funded national palliative care initiative under the recently completed \$800 million Primary Health Care Transition Fund, Pallium worked with several hundred collaborators in Canada's 13 provinces and territories to implement Pallium Project (Phase II). Local champions contributed to 72 sub-projects, initiatives and strategic capacity-building activities (one example is Learning Essential Approaches to Palliative and End-of-Life Care (LEAP) Training Programs, weekend training courses held across Canada). As a result, common, standards-based professional development curriculum is now being used throughout Canada, as well as a robust set of practice tools to help front-line generalist practitioners and those responsible for planning community-based, hospice palliative care services.

Canada is still in its earliest days of working across the provinces, territories and with federal service delivery providers to implement a shared care model of quality care for the dying. This model enables people to live well until death in their homes or other local community settings. It enables generalist, primary-care practitioners to practice compassionately and competently. It enables the comparatively few Canadian palliative care clinical specialists and researchers to maximize effective use of their scarce time and resources. It moves towards bringing families and the voluntary sector into the fold as full and equal partners in quality end-of-life care. It supports family as the unit of care, helping mitigate known family health risk factors of chronic and mental illness which often manifest during decline, dying and death.

Research

There is an acute need for research into more effective pain and symptom management, psychosocial aspects of hospice palliative care, and effective methods of delivering hospice palliative care services and programs within the health care system. Yet, hospice palliative care research has traditionally been poorly funded. A sustained hospice palliative care research plan is required to ensure a coordinated approach to this issue.

On September 21, 2004, the Canadian Institutes for Health Research (CIHR) announced \$16.5M to fund research in hospice palliative care. The CIHR funding has allowed for a rich diversity of research topics in hospice palliative care including: Palliative and End-of-Life Transitions, Family Caregiving, Tackling Difficult Pain, Cancer-Associated Cachexia and Anorexia, Vulnerable Populations, and Improving Communication and Decision-Making. Unfortunately, the funding will expire in 2009 – less than two years away – and no new commitment has been made.

Awareness

Many Canadians are not aware of the concept of hospice palliative care, or of the programs and services that may be available to them. The CHPCA and hospice palliative care programs and services throughout Canada continue to work to increase the level of awareness through several initiatives.

National Hospice Palliative Care Week is held annually in early May, and is geared to the Canadian public. The past two years have focused on the issue of Advance Care Planning, the process in which patients and their health care professional(s) discuss a patient's wishes about their health care choices at the end-of-life. The focus of the Week in 2008 will continue to be Advance Care Planning, as there remains much confusion among Canadians regarding the different terminologies as well as the medical, ethical and legal issues associated with them, such as Advance Care Directives, Do Not Resuscitate (DNR) orders and right to refuse treatment.

National Hike for Hospice Palliative Care is held each year in conjunction with the Week to increase awareness of hospice palliative care generally, as well as local hospice palliative care programs and

services specifically, and to provide local hospice palliative care programs and services with a fundraising event.

For those in the community of practice, the CHPCA provides the means to share information. In May 2007, Calgary Health Region and Fraser Health, along with the CHPCA and the Health Quality Council of Alberta, collaboratively presented the Inaugural Canadian Symposium on Advance Care Planning. As well, the CHPCA maintains several national listserves for specialized communities of practice, such as researchers, nurses, paediatric health care providers and volunteers.

Informal Caregiver Issues

Approximately 36% of informal caregivers¹⁴ (including those providing hospice palliative care) in the community are over the age of 70¹⁵, making caregiving a crucial issue for seniors. Informal caregivers who are offering palliative and end-of-life care require ongoing training and support to ensure not only quality care for the patient, but also for the caregivers themselves.

Informal caregivers are being asked to take on a larger burden of care, including an economic burden. The main role of informal caregivers used to be that of providing companionship and emotional comfort to the dying loved one. However, due to changes in the health care system, informal caregivers are now providing a significant amount of personal care and, in some settings, medical care. They are being asked to provide this care at a time when they are also dealing with their own sense of impending loss and grief, and when their main focus is on being with the dying person and providing emotional support through the process of dying¹⁶.

The Compassionate Care Benefit was introduced in 2004 as a support for family caregivers, and is an important step in meeting the financial support needs of many patients and their family caregivers. However, as it is an Employment Insurance-based benefit, it does not provide all of the support necessary to family caregivers, nor does it reach all Canadian family caregivers, especially seniors. In the case of seniors, what they need most could be access to respite care, bereavement support, or financial assistance for extra medical costs incurred when caring for a loved one in their home.

Recommendations

National Leadership ♦ Access ♦ Education ♦ Training ♦ Research ♦ Awareness ♦ Informal Caregiver Support

National Leadership

- 1) A crucial leadership role exists for the federal government to guide and oversee activities so that quality end-of-life care services are integrated into the health care system, are coordinated with other health services, are comprehensive in nature and effectively use health care dollars. A Federal/ Provincial/ Territorial/ Community (FPTC) Accord or Declaration on end-of-life care would pave the way for the creation of a consistent minimum standard of nationally available hospice palliative care. A funded national hospice palliative care partnership would provide the leadership, vision, standards, best practices and awareness necessary for ensuring the provision of quality end-of-life care to all Canadians.
- 2) The “silo” effect of current national strategies – chronic disease, cancer, heart health, diabetes, Aboriginal – must be counter-balanced with a broadly-based strategy for hospice palliative care, as the one area of commonality among them all.

- 3) Hospice palliative care issues extend far beyond the arena of health care, cross-cutting many government departments including Health, Public Health, Privy Council, Human Resource/Social Development, Revenue, Aboriginal Affairs, International Development and many more. As such, it warrants national leadership.

Access

- 4) Hospice palliative care must exist as an integrated, comprehensive and coordinated service within a funded home and community-based health care delivery system. Effective care reaches into hospitals, patient's homes, nursing homes and residential care homes within the community. The CHPCA envisions a scenario where tertiary, or specialist, care programs and teams would be present in areas where the population warrants and supports it. Existing primary and secondary care clinicians in all settings would be trained in basic hospice palliative care, and tertiary care programs and teams would then serve as a resource to primary care clinicians when necessary.

Education

- 5) In the short- to medium-term, there is a need and opportunity for continued pan-Canadian leadership to enable continuous education of health care professionals as well as other shared, investment-based capacity-building. Continued innovation and well-designed coordination are predictable critical success factors against an emerging back drop characterized by: extreme short staffing throughout health care delivery systems, a voluntary sector under strain, and families spread across the country who are experiencing unprecedented economic and social pressures.

Training

- 6) There is a need for continuing interdisciplinary training at the clinical level, including volunteers.

Research

- 7) There is a need to disseminate and encourage knowledge translation of currently funded CIHR projects on hospice palliative care.
- 8) The CIHR funding program in this important area must be continued past the current funding limit of 2009.

Awareness

- 9) The public must be better-informed about hospice palliative and end-of-life care programs and services. Awareness of Advance Care Planning must continue to grow in order to open and continue the dialogue on dying and death in order to better serve all Canadians.

Informal Caregiver Support

- 10) Dying makes no distinction among socio-economic strata or employment status; consequently, caregivers are from all realms of Canada's population. The limited supports available to Canadian caregivers must be expanded to include a roster of programs and services that address multiple caregiver issues including:
 - Expansion of the Compassionate Care Benefit to allow for more Canadians to qualify outside the current Employment Insurance restrictions.
 - Extension of the current length of the Compassionate Care Benefit to a minimum of 13 weeks.
 - Creation of a national respite program, so that caregivers are able to get the physical and emotional rest that they need to care for their loved one, as well as safeguard their own health.

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- ¹ Senator Sharon Carstairs (Chair) and Senator Wilbert Joseph Keon (Deputy Chair), *Special Senate Committee on Aging Interim Report: Embracing the Challenge of Aging*, (Ottawa, 2007), 22.
- ² Population Projections for Canada, Provinces and Territories – 2000-2026, Statistics Canada, Catalogue #91-520, 110.
- ³ Population Projections for Canada, Provinces and Territories – 2000-2026, Statistics Canada, Catalogue #91-520, 124.
- ⁴ Elizabeth Davies and Irene J Higginson, eds., *Better Palliative Care for Older People*, (Copenhagen: World Health Organization, 2004), 6.
- ⁵ Shabbir M.H. Alibhai, MD, MSc, FRCP(C), “Further Reflections on Cancer, Old Age, and the Meaning of Life”, *Geriatrics & Aging*, Volume 10, Number 5, May 2007, 277.
- ⁶ Charles S. Cleeland et al., “Pain and Its Treatment in Outpatients with Metastatic Cancer”, *New England Journal of Medicine*, Volume 330, Number 9, March 1994, 592-596.
- ⁷ Senator Sharon Carstairs, *Still Not There, Quality End-of-Life Care: A Progress Report*, (Ottawa, 2005), 1.
- ⁸ Ontario Health Quality Council, *2007 Report on Ontario’s Health System*, (Ontario, 2007), 77.
- ⁹ *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*, (Ottawa, 2000), <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm>. Accessed June 12, 2007.
- ¹⁰ *10-Year Plan to Strengthen Health Care*, (Government of Canada, 2004), [http://www.hc-sc.gc.ca/hcs-sss/delivery-prestation/fptcollab/2004-fmm-rpm/index_e.html]. Accessed June 12, 2007.
- ¹¹ Canadian Hospice Palliative Care Association, *The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home*, (Ottawa, 2006).
- ¹² The EFPPEC web site may be viewed at <http://www.efppec.ca/>. Accessed June 12, 2007.
- ¹³ The Pallium Project web site may be viewed at <http://www.palliumca/>. Accessed June 12, 2007.
- ¹⁴ *Informal Caregivers* are family members, loved ones, or friends and neighbours who provide support or care for the dying family member, loved one, or friend. *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* (CHPCA, 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.”
- ¹⁵ Canadian Coalition for Seniors Mental Health website: <http://www.ccsmh.ca/en/caregivers.cfm>. Accessed June 12, 2007.
- ¹⁶ Canadian Hospice Palliative Care Association, *Voice in Health Policy - The Role of Informal Caregivers in Hospice Palliative and End-of-Life Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges*, (Ottawa, April 2004), 6.