



Fact Sheet: Hospice Palliative Care in Canada

At some time, in some way, we must all face the end of life. And most of us share a common hope – that when death comes to us or to a loved one, it will be peaceful and free of pain. We hope to face death surrounded by those we love, feeling safe, comfortable and cared for.¹

The Demand for Hospice Palliative Care in Canada

- Canada's population is aging. As a result, the Canadian Hospice Palliative Care Association (CHPCA) estimates that over the next 40 years demand for hospice palliative care services will continue to increase.
- Each year more than 259,000 Canadians die.²
- The leading causes of death in Canada are: diseases of the circulatory system (about 35%), neoplasms (tumours or cancers) (about 28%) and diseases of the respiratory system (about 10%).³ Hospice palliative care programs and services are beneficial for all of these groups, which total 73% of all Canadian deaths.
- In 2004, Statistics Canada projected that the rate of deaths in Canada will increase by 33% by the year 2020 to more than 330,000 deaths per year.⁴
- In 2007, 37% of Canadians reported that they have been diagnosed by a physician as having a chronic condition or illness.⁵
- 1 in 3 Ontarians lives with one or more chronic diseases. Of those, almost 4 of 5 over the age of 65 have one chronic disease, and of those, about 70% suffer from two or more.⁶
- Chronic diseases account for 70% of all deaths.⁷
- 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.
- Hospice palliative care programs allow patients to gain more control over their lives, manage pain and symptoms more effectively, and provides support to family and informal caregivers.⁸

Access to Hospice Palliative Care in Canada

- 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.⁹
- Canadians living in remote and rural areas, or those living with disabilities, have severely limited access to hospice palliative care services.
- When asked, most people have indicated that they would prefer to die at home in the presence of loved ones¹⁰, yet almost 60% of Canadian deaths occur in a hospital.¹¹
- As a result of health care restructuring, the number of institutionally-based palliative care beds has been cut and care has devolved to community-based agencies.
- Government funding of community-based hospice palliative care has not increased proportionately, leaving a significant gap in the health care system.

- Inadequate government support for hospice palliative care programs results in a significant additional burden on family and informal caregivers.
- A 2004 Ipsos-Reid survey reported that on average, Canadians estimate that 54 hours per week would be needed to take care of a dying loved one in their homes.¹²
- Based on the estimate of 54 hours per week required to care for a dying loved one, 64% of those polled indicated that they could not devote the estimated number of hours per week given their current schedule.¹³
- 75% of deaths today still take place in hospitals and long-term care facilities.¹⁴
- Billing schedules under provincial health plans focus on clinical procedures and discourage physicians from practicing palliative care in the community.
- In June of 2005, the Quality End-of-Life Care Coalition of Canada (QELCCC) developed a “Framework for a National Strategy for Palliative and End-of-Life Care” for hospice palliative care needs in Canada.¹⁵
- The QELCCC Framework includes three distinct models or working groups:¹⁶
 - Intra-Governmental Consultation & Engagement Working Group
 - Inter Governmental & Stakeholder Consultation and Engagement Working Group
 - Community-Based Working Group
- The QELCCC Framework also addresses the following key areas:¹⁷
 - Research
 - Policy Development & Best Practices
 - Knowledge Transfer
 - Knowledge Translation & Dissemination
- In December 2006, the Canadian Hospice Palliative Care Association and the Canadian Home Care Association published *The Pan-Canadian Gold Standards for Palliative Home Care: Toward Equitable Access to High Quality Palliative and End-of-Life Care at Home*. This document identifies the gold standard level of care and a consistent approach across the country for hospice palliative care services at home in the following areas: Case Management, Personal Care, Nursing Care and Palliative-Specific Pharmaceuticals.¹⁸

Training and Education

- Canada currently has just over 200 palliative care physicians who work either full-time or part-time.¹⁹
- Canada’s schools of nursing are moving forward with plans to offer formal hospice palliative care training and education as part of their curriculum.
- In April 2004, the Canadian Nurses Association (CNA) began to offer Hospice Palliative Care Nursing Certification to Canadian nurses.²⁰
- Much of Canada’s end-of-life care is provided by family physicians, many of whom lack adequate training in pain management and other required skills.
- Hospice palliative care training and education is equally under-funded for other disciplines engaged in hospice palliative care, including nurses, social workers, psychologists, and spiritual counselors
- The CHPCA, in partnership with the Association of Faculties of Medicine of Canada (AFMC) co-hosted a project, entitled Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC), which worked with all 17 medical schools in Canada. Its purpose was

to integrate hospice palliative care education into the core medical curriculum by its completion in March 2008.²¹

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.
- Traditionally hospice palliative care research has been poorly funded. A sustained hospice palliative care research strategy is required to ensure a coordinated approach to this issue.²²
- In 1999, the Canadian Hospice Palliative Care Association (CHPCA) produced the *Canadian Agenda for Research in Palliative Care*. Recommendations included the need to build research capacity in Canada by establishing more fellowships in hospice palliative care for researchers in the early stages of their careers.²³
- On September 21st 2004, the Canadian Institutes for Health Research (CIHR) announced 16.5M dollars to fund research in hospice palliative care.²⁴ The CIHR funding allows 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
 - Improving Communication and Decision-Making

The Role of Informal and Family Caregivers

- In 2007, 23% of Canadians said that they had cared for a family member or close friend with a serious health problem in the last 12 months. Adverse effects on this group of people included: using personal savings to survive (41%) and missing one or more month of work (22%).²⁵ In 2006, of the 26% of Canadians who said that they had cared for a family member or close friend with a serious health problem in the previous 12 months, other adverse effects reported were: negative effect on mental health (41%) and negative effect on physical health (38%).²⁶
- With the devolution of care to the community and the home, families are facing an increased burden to care for loved ones with little formal support.²⁷
- As a leading-edge global company, GlaxoSmithKline has included in their employee benefit package the option of up to 13 weeks paid leave to employees who require time away from work to care for a dying family member.²⁸
- 70% of family and informal caregivers acknowledge that providing care to a loved one is stressful.²⁹
- 70% of family and informal caregivers indicate that they require time away from the responsibility of caring for a loved one.³⁰
- Whether or not the family or informal caregiver has a choice in taking on the role of caregiver is a significant factor in the degree of stress and disruption they experience³¹
- Formal support is important, but does not seem to reduce stress.³²
- Family and informal caregivers providing hospice palliative care at home are undertaking a wider range of tasks in an environment where they typically have less support from

professional caregivers. Tasks assigned to family and informal caregivers may include: psychological, social and spiritual care; personal care; medical care, including administration of medications and injections; homemaking services; and advocacy and care-coordination.³³

- In January 2004 Human Resources and Skills Development Canada (HRSDC) began offering the Compassionate Care Benefit through the Employment Insurance program. The benefit provides 8 weeks leave (6 weeks paid) to eligible Canadians to care for a dying loved one.³⁴

The Role of Home Care

- The delivery of formal home care generally relies on public funding. Unfortunately there has been an increase in the demand for home care services without an increase in funding of these programs.
- A lack of funding of home care programs affects the need for trained volunteers and family and informal caregivers.
- There is a shortage of home care workers in urban, rural and remote areas.
- In 2003 the Home Care Sector Study Corporation published a report entitled Canadian Home Care Human Resources Study that has projected that if all variables remain the same, in 2046 Canada can expect to have more than 750,000 Canadians receiving home care. When factoring in changes in the age distribution of the population, by 2046 Canada may have an additional 700,000 people using home care. This means that if we had the population distribution today which we will have in 2046 we may need to care for twice as many people with home care as we do today.³⁵
- The Canadian Home Care Human Resources Study indicates that 65% of family and informal caregivers are under 50 years of age with 64% of them working full time, part-time or self-employed.³⁶
- Emerging pan-Canadian health trends indicate that effective home care can contribute to lower long-term costs for the health care system, therefore these costs should fall under the parameters of the *Canada Health Act*.³⁷

Funding for Hospice Palliative Care Programs

- Generally hospice palliative care programs rely disproportionately on charitable giving; a majority of the cost of programs is provided by private donors, restricting the size, scope and access to programs.
- Currently only a small number of provinces have designated hospice palliative care as a core service under their provincial health plans. In the remaining provinces, hospice palliative care may be included in provincial home care budgets or other health service budgets, leaving the funding vulnerable to budget reductions.
- The final report of the Commission on the Future of Health Care in Canada recommends the commitment of \$89.3 million annually to the Canadian Health Care System to address hospice palliative care needs.³⁸

Raising Awareness

- Public awareness programs are critically important in helping Canadians face end-of-life issues and raising the awareness of the current gaps in service.

- The CHPCA is the Secretariat of the Quality End-of-Life Care Coalition of Canada (QELCCC), a group of 30 national associations and organizations with an interest in end-of-life care issues.³⁹
- The QELCCC supports the full implementation of the recommendations identified in the June 2000 Senate report entitled *Quality End-of-Life Care: the Right of Every Canadian*.⁴⁰
- The GlaxoSmithKline Foundation in partnership with the CHPCA have created the ***Living Lessons***[®] initiative, a public awareness and social marketing campaign designed to provide tools and resources to patients, family members, caregivers, volunteers and health care providers.⁴¹

Secretariat on Palliative and End-of-Life Care (Health Canada)⁴²

- From 2001 to 2006 the federal government funded the Secretariat on Palliative and End-of-Life Care (Health Canada) with an annual budget between \$1M and \$1.5M dollars.
- The Secretariat was charged with the development and implementation of a National Strategy for Palliative and End-of-Life Care in Canada.
- The Secretariat focused on the following three areas:
 - Community
 - Inter-Departmental (at the Federal level)
 - Federal/Provincial/Territorial
- The Secretariat created five Working Groups and a Coordinating Committee to oversee the development and implementation of the National Strategy.
- The five Working Groups included:
 - Research
 - Surveillance
 - Public Information and Awareness
 - Professional Education
 - Best Practices and Quality Care
- The 2006-2007 budget for the Secretariat on Palliative and End-of-Life Care (Health Canada) was \$470,000, down from almost 1.2M in 2005-2006.
- In March 2007, the Secretariat disbanded the Working Groups and the Coordinating Committee.
- In April 2007, the Secretariat entered into an evaluation and analysis phase and will report to the Minister of Health when their analysis is complete.

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