



Fact Sheet: Hospice Palliative Care in Canada

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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.
- Seniors make up the fastest-growing age group. In 2003, an estimated 4.6 million Canadians were 65 years of age or older, a number that is expected to double in the next 25 years. By 2041, about one in four Canadians is expected to be 65 or over.²
- By 2031, the number of older seniors (persons aged 80 years and over) will then account for between 6.1 % and 6.5 % of the total Canadian population.³
- Each year more than 259,000 Canadians die.⁴
- 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.⁵
- 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%).⁶ Hospice palliative care programs and services are beneficial for all of these groups, which total 73% of all Canadian deaths.
- In 2007, 37% of Canadians reported that they have been diagnosed by a physician as having a chronic condition or illness.⁷

- 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.⁸
- Chronic diseases account for 70% of all deaths.⁹
- The CHPCA estimates that each death in Canada affects the immediate well being of an average of five other people, or more than 1.25 million 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.¹⁰

Access to Hospice Palliative Care in Canada

- Only 16% to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services – depending on where they live in Canada.¹¹ Even fewer receive grief and bereavement services.
- When asked, most people have indicated that they would prefer to die at home in the presence of loved ones¹², yet almost 70% of Canadian deaths occur in a hospital. Note: In Quebec, deaths in residential and long-term care centres are included in the “hospital” category.¹³
- 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.¹⁴
- The 2005 Senate Report *Still Not There: Quality End-of-Life Care: A Progress Report*, reported that despite a number of significant advancements at the federal level in palliative and end-of-life care since 2000, significant disparities across Canada remained with respect to access to end-of-life care, quality of care and out-of-pocket costs to the patient.
- The Senate Special Committee on Aging’s final report *Canada’s Aging Population: Seizing the Opportunity*, released in April 2009, made a total of 32 recommendations to the federal government. Among the 32 recommendations, the following related directly to hospice palliative care for seniors:
 - That the federal government apply the gold standard in palliative care developed by the Canadian Hospice Palliative Care Association and the Canadian Home Care Association to veterans, First Nations and Inuit, and federal inmates.
 - That Canadian Institutes of Health Research funding for palliative care be extended beyond 2009.
 - That the federal government create a supplementary transfer program to assist provinces and territories which have an older population in meeting the increased needs of their seniors.
 - That the federal government establish a specific time-limited fund to enable provincial, territorial and federal governmental drug benefit plans to develop a common list of drugs used by seniors; that this list form the basis of a common national formulary to be implemented by all jurisdictions as a benefit list for all Canadian seniors; and that this initial focus on seniors form the basis for a national pharmacare program.
- Canadians living in remote and rural areas, or those living with disabilities, have severely limited access to formal hospice palliative care services.
- Inadequate government support and health care system approach in all its forms 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.¹⁵
- 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.¹⁶
- 75% of all deaths occur in people over 65 years of age.¹⁷
- 75% of deaths today still take place in hospitals and long-term care facilities.¹⁸
- Billing schedules under provincial health plans focus on clinical procedures and discourage physicians from practicing palliative care in the community.
- In December 2006, the Canadian Hospice Palliative Care Association (CHPCA) 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.¹⁹
- In 2004, the federal, provincial and territorial First Ministers made a commitment to provide funding for certain palliative home care services and the CHPCA made a commitment to report on the progress of the jurisdictions.
- Only six of 13 jurisdictions have policies on providing nursing and personal care services 24 hours a day, seven days a week.²⁰
- Among jurisdictions that have appropriate policies and procedures in place to ensure access to services, there is still a cited lack of resources, lack of training and geography (rural areas) that limits their ability to provide adequate palliative home care services to all palliation home care patients.²¹
- Most jurisdictions indicated that they do not track the proportion of people dying at home who have access to nursing care, personal care and respite services – all essential services.²²

Funding for Hospice Palliative Care Programs

- From 2001 to 2006 the federal government funded the Secretariat on Palliative End-of-Life Care (Health Canada) with an annual budget between \$1M and \$1.5 M dollars; however, in 2007 the federal government disbanded the End-of-Life Care Secretariat and stopped work on the national palliative and end-of-life care strategy.
- 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.
- Hospice palliative care programs are still at least 50% funded by charitable donations, and families must bear part of the cost of dying at home, in longer-term care – almost anywhere outside a hospital.²³
- 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.²⁴
- The final report of the Commission on the Future of Health Care in Canada (2002 Romanow Report) recommends the commitment of \$89.3 million annually to the Canadian health care system to address hospice palliative care needs.²⁵

- The cost of doing nothing: If we extrapolate from current Canadian Institute for Health Research (CIHR) funding, we might expect CIHR to keep funding about \$4 million of palliative end-of-life care research per year through open operating grants. However, there is a high risk that a significant portion of the capacity created through this initiative will be lost if no further action is taken.²⁶

Training and Education

- Canada currently has over 200 palliative care physicians who work either full-time or part-time.²⁷
- The Quality End-of-Life Care Coalition of Canada reports that over the next 10 years, professional education will be even more important in a systems-wide approach to hospice palliative and end-of-life care – where Canadians will receive quality care in all care settings where they die.²⁸
- 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 began to offer Hospice Palliative Care Nursing Certification to Canadian nurses.²⁹
- Much of Canada’s end-of-life care is provided by family physicians, many of whom could benefit from training in pain management and other related 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 co-hosted a project, entitled Educating Future Physicians in Palliative and End-of-Life Care, 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 2008.³⁰
- In 2010, the CHPCA, in partnership with the Social Work Competencies on Palliative Education Executive Committee, embarked on a project to integrate competencies for social work practice in hospice palliative care into social work undergraduate and graduate education curricula and continuing education programs. The ultimate goal is to increase the capacity of all social workers delivering psychosocial end-of-life care to patients and families to provide consistent, good quality care at the end-of-life, regardless of location and context of practice.
- The CHPCA offers six learning and resource commons. Available for health professional education, caregiving, advance care planning, pediatrics, aboriginal issues and international issues, the commons were created as repositories for resources relating to palliative and end-of-life care. This allows Canadians to search and share resources related to hospice palliative end-of-life care.³¹
- In 2009, the CHPCA’s Nurses Interest Group reviewed and approved the Canadian Hospice Palliative Care Nursing Standards of Practice. Best read in conjunction with the 2008 Canadian Nurses Association’s hospice palliative care nursing competencies, both documents provide a framework for building professional hospice palliative care nursing practice and will guide discussion and policy development.³²
- The Difficult Pain BET (CIHR NET Grant) developed the world’s first on-line palliative care research methods course; most palliative medicine residency programs across Canada made

the 12-week course mandatory or strongly recommended. The program is being adapted for students.³³

- CARENET (CIHR NET Grant) discovered medical trainees have significant exposure to dying patients, and are often responsible for determining their level of care. As a result, they are suffering significant sadness and fear, or complex emotions such as distress, grief, and guilt. The NET is exploring training and healing tools, working with key leaders in medical curriculum development.³⁴
- Physician communication in end-of-life care is an essential clinical skill, yet many health care professionals struggle with the important discussions that take place at the end of life. Internal medicine residents at five universities across Canada recently participated in surveys designed to assess their knowledge of end-of-life care, particularly their perceived strengths and weaknesses, learning priorities and attitudes towards caring for dying patients. The results of this research could guide curriculum development at medical schools and help improve communication between doctors, patients and families.³⁵
- To help family caregivers provide care and advocate for their loved ones, the CHPCA, in collaboration with The GlaxoSmithKline Foundation, developed the *Living Lessons*[®] *Influencing Change: A Patient and Caregiver Advocacy Guide*, a handbook, as well as other training materials for family caregivers.³⁶

Raising Awareness

“Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”³⁷ Harvey Chochinov

- 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 Canadian Hospice Palliative Care Association (CHPCA) is working to raise awareness of the importance of advance care planning. From 2006 to 2008, the theme for National Hospice Palliative Care Week focused on advance care planning.³⁸
- 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.³⁹

Advance Care Planning

- Advance care planning or ACP is a process whereby a capable (mentally competent) adult engages in a plan for making personal health care decisions in the event that this person becomes incapable (legally incompetent to personally direct) his or her own health care.⁴⁰
- The Canadian Hospice Palliative Care Association has assumed a position of leadership in ACP in Canada and has initiated a five-year project to develop a national framework for ACP in Canada. The key objective of the national framework is to provide a model that can be used to guide all related activity, program development and standards of practice.
- Effective, ongoing communication among the patient, family and health care team is essential to effective ACP.⁴¹
- Successful ACP often begins well in advance of serious illness.⁴²

- In 2003, Ipsos-Reid conducted a poll on behalf of The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, which indicated that 44% of Canadians have spoken to their families regarding their end-of-life care and only 9% of Canadians have spoken to their physicians regarding their end-of-life care.⁴³
- *Challenges and Issues in 2010: The Quality End-of-Life Care Coalition of Canada* states that one of the key challenges over the next ten years will be persuading Canadians that end-of-life care planning is important for everyone, not just those diagnosed with a life-limiting illness, such as cancer.⁴⁴

The Role of Informal and Family Caregivers

“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers.”

Rosalynn Carter, former First Lady

- 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%).⁴⁵ 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%).⁴⁶
- 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.⁴⁷
- Since January 2004, Human Resources and Skills Development Canada has offered 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.⁴⁸
- In June 2006, the Government implemented changes to the Compassionate Care Benefit through the Employment Insurance (EI) program to increase the number of people who can access the benefit. The expanded definition means that EI-eligible workers can claim the Benefit while they are absent from work to provide care to a sibling, grandparent, grandchild, in-law, aunt, uncle, niece, nephew, foster parent, ward, guardian, or a gravely ill person who considers the claimant to be like a family member. The Benefit remains available to those caring for parents, children and spouses. Common-law partners are also eligible to receive the Benefit. This refers to people who have been living in a conjugal relationship for at least a year, and includes same-sex couples.⁴⁹
- A 2009 evaluation of the Compassionate Care Benefit from the perspective of family caregivers confirmed that there are a number of critical barriers to the successful uptake of the benefit, including:
 1. the general lack of awareness regarding the Compassionate Care Benefit existence;
 2. various issues with the application process;
 3. the requirement of a two week unpaid waiting period;
 4. the inadequate amount of time the leave provides; and
 5. the inadequate financial compensation the Compassionate Care Benefit offers.⁵⁰
- As a leading-edge global company, GlaxoSmithKline includes 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.⁵¹

- 70% of family and informal caregivers acknowledge that providing care to a loved one is stressful.⁵²
- 70% of family and informal caregivers indicate that they require time away from the responsibility of caring for a loved one.⁵³
- 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 experience⁵⁴
- Formal support is important, but does not seem to reduce stress.⁵⁵
- 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.⁵⁶
- Current estimates for replacement costs for unpaid care-giving in Canada indicates a significant economic contribution by caregivers; estimates for care provided in 2009 range between 25 to 26 billion dollars.⁵⁷
- In a qualitative study inclusive of caregivers 75 years and older, it was concluded that the higher risk of health issues amongst this older cohort produced more complex care-giving issues. However, it was also found that the caregivers tended to downplay their care-giving situation in an effort to make it more manageable, and consequently were reluctant to access formal services for assistance.⁵⁸
- A meta-analysis of 23 studies comparing the health indicators of caregivers for people with dementia with non-caregivers matched for age and gender found that stress hormones in caregivers were 23% higher, and that their antibody responses were 15% lower than those of non-caregiver. These findings suggest the care-giving may influence the physical health of caregivers.⁵⁹
- The increasing reliance on de-institutionalized care has had a great impact on Canada's 1.5 to 2 million family caregivers, a group that provides hands-on care, spiritual and emotional care, and care coordination worth \$25-26 billion annually, while incurring \$80 million dollars annually in out-of-pocket costs.⁶⁰
- Family caregivers of patients in the advanced stages of cancer experience a high level of psychological distress, which increases significantly as the patient loses autonomy. Health care policies and programs need to be revisited in order to take the reality of these patients and their families into account.⁶¹
- The Senate's Special Committee on Aging's final report *Canada's Aging Population: Seizing the Opportunity* released in April 2009 made the following strong recommendations in support of assistance for caregivers:
 - That the Employment Insurance Act be amended to:
 - eliminate the two-week waiting period before receipt of the compassionate care benefit;
 - increase the compassionate care benefit to 75 (seventy-five) percent of the earnings of workers;
 - increase the length of the benefit from 6 to 13 weeks; and
 - provide access to the benefit during times of medical crisis, and not only during the palliative stages of illness.

- That the federal government work collaboratively with the provinces and territories, policy-makers, stakeholders and family caregivers to establish a National Caregiving Strategy. The Strategy should form part of a larger federal integrated care initiative.

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.⁶²
- On September 21st 2004, the Canadian Institutes for Health Research (CIHR) announced 16.5 million dollars to fund research in hospice palliative care; the funding ended in 2009.⁶³ The CIHR funding 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
 - Improving Communication and Decision-Making
- Following the completion of the above CIHR funding initiative, a report was prepared detailing the initiative's accomplishments, what was learned and where they need to go from here.⁶⁴
- Since the launch of the Institute for Cancer Research, Canada has almost doubled its world share of palliative end-of-life care publications between 2004 and 2009: at 8% it is almost twice Canada's overall world share of health research publications.⁶⁵
- A recent study suggests that patients with life-limiting advanced chronic disease identify that receiving honest information about their condition and having time to prepare for life's end are key aspects of quality end-of-life care. Of the 440 patients studied, only 18% stated that they had discussed their prognosis with a physician. Overall satisfaction with end-of-life care, however, was significantly higher among those patients who had held that discussion. These patients were more willing to discuss preferences regarding cardiopulmonary resuscitation and were also more likely to prefer a home death.⁶⁶
- The CANHELP questionnaire was designed to help researchers, healthcare providers and their patients better understand the satisfaction with end-of-life care and to identify opportunities for improvement. A recent survey of 363 patients and 193 family members from six centers across Canada suggests that improved psychological and spiritual support, better advance care planning, and improved relationships with physicians, including better communication and decision-making, may efficiently improve end-of-life care in Canada. Initially used by researchers to measure end-of-life care satisfaction, the questionnaire is now also available for patients and families as a catalyst for discussions with their doctors and other medical professionals (see www.thecarenet.ca for more information).⁶⁷ (CIHR NET Grant)

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, by 2046, we may need home care for twice as many people proportionally, as we do today.⁶⁸
- 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 or part-time, or being self-employed.⁶⁹
- 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*.⁷⁰
- Current end-of-life care research increasingly suggests that Canadians prefer to die at home or in their home communities (e.g. in long-term care facilities) instead of in hospital settings.⁷¹
- Given that Canada has a rapidly ageing population with the need for palliative home care for people diagnosed with advanced illnesses, provinces must establish standards to assess and decrease wait times for this type of care. If all variables remain the same, in 2046 Canada can expect to have more than 750,000 people receiving home care.⁷²

Quality End-of-Life Care Coalition of Canada (QELCCC)

- The Canadian Hospice Palliative Care Association is the Secretariat of the Quality End-of-Life Care Coalition of Canada (QELCCC), a group of 33 national associations and organizations with an interest in end-of-life care issues.⁷³
- 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*.⁷⁴
- In June of 2005, the QELCCC developed the “Framework for a National Strategy for Palliative and End-of-Life Care” for hospice palliative care needs in Canada.⁷⁵
- The QELCCC Framework includes three distinct models or working groups:⁷⁶
 - Intra-Governmental Consultation & Engagement Working Group
 - Inter Governmental & Stakeholder Consultation and Engagement Working Group
 - Community-Based Working Group
- In May 2008, the QELCCC released *Hospice Palliative Home Care in Canada: A Progress Report*, a report card to provide an overview of the palliative home care services in Canada to determine if jurisdictions are meeting the urgent needs required by these patients.⁷⁷
- The progress report revealed that jurisdictions across Canada have made significant progress in giving more people access to a range of palliative home care services (case management, nursing, personal care, pharmaceuticals), but there is still room for improvement.⁷⁸

- In January 2010, the QELCCC released *Blueprint for Action 2010 to 2020*, which summarizes the QELCCC's priorities for the next 10 years:
 1. Ensure all Canadians have access to high quality hospice palliative end-of-life care;
 2. Provide more support for family caregivers;
 3. Improve the quality and consistency of hospice palliative end-of-life care in Canada; and
 4. Encourage Canadians to discuss and plan for end-of-life.⁷⁹

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About the Canadian Hospice Palliative Care Association

The Canadian Hospice Palliative Care Association (CHPCA) is the national voice for hospice palliative care in Canada. It is a bilingual, national charitable non-profit association whose mission is the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.

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 of research on hospice palliative care;
- advocacy for improved hospice palliative care policy, resource allocation and supports for caregivers.

CHPCA works in close partnership with other national organizations and will continue to move forward with the goal of ensuring that all Canadians, regardless of where they may live, have equal access to quality hospice palliative care services for themselves and their family.

***All Canadians have the right to die with dignity, free of pain, surrounded by their loved ones,
in the setting of their choice.***

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