



Fact Sheet: Hospice Palliative Care in Canada

Table of Contents

Table of Contents.....	1
Access to Hospice Palliative Care in Canada.....	1
Demand for Hospice Palliative Care in Canada.....	3
Federal Recommendations and Legislation on Hospice Palliative Care in Canada.....	3
Funding for Hospice Palliative Care Programs.....	5
Advance Care Planning.....	6
Raising Awareness.....	6
Research.....	7
Role of Family and Informal Caregivers.....	8
Role of Home Care.....	9
Training and Education.....	10
Quality End-of-Life Care Coalition of Canada (QELCCC).....	11
About the Canadian Hospice Palliative Care Association.....	12
References.....	13

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

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.² Even fewer receive grief and bereavement services.
- Canadian families frequently shoulder 25% of the total cost of palliative care due to costs associated with home based services³ such as nursing and personal care services.
- The Economist’s Intelligence Unit ranks Canada as ninth in an international ‘Quality of Death’ index released July 14th, 2010. Commissioned by Singapore based The Lien Foundation, the ‘Quality of Death’ index measures current hospice and palliative care environments across 40 countries in terms of the quality and availability of end-of-life care. Although Canada scored within the top ten countries examined, we are still unable to provide valuable hospice palliative care services to over 70% of those dying within Canada.⁴
- When asked, most people have indicated that they would prefer to die at home in the presence of loved ones⁵, 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.⁶

- According to an Ontario study, 84% of people who died of cancer between 2002 and 2005 visited the emergency department in the last six months of life and 40% visited emergency in the last two weeks.⁷
- According to a Manitoba study, 41% of long-term care/nursing home residents were hospitalized at least once in the six months before their deaths.⁸
- The Canadian Cancer Society's *Canadian Cancer Statistics 2010 – Special Topic: End-of-Life Care*, released in May 2010 reported that Canada has a patchwork approach to providing care at the end of life.⁹
- 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.¹⁰
- 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.
- 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 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.¹¹
- 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.¹²
- A 2004 research study revealed that 75% of all deaths occur in people over 65 years of age.¹³
- A 2000 research study discovered that 75% of deaths today still take place in hospitals and long-term care facilities.¹⁴
- 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.¹⁵
- 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.
- In February 2012, Nova Scotia became the last province to implement a Palliative Home Care Drug Coverage Program. All provinces now have some form of palliative drug coverage for home care patients.¹⁶
- Only six of 13 jurisdictions have policies on providing nursing and personal care services 24 hours a day, seven days a week.¹⁷
- 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.¹⁸

- 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.¹⁹

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.
- 90% of Canadians who die can benefit from hospice palliative care.²⁰
- Seniors make up the fastest-growing age group. It is estimated that seniors could account for between 23% and 25% of the total population by 2036, nearly double the 13.9% in 2009.²¹
- In 2009, Canada had 4.7 million persons aged 65 years or over, twice the number recorded in 1981. According to all the projection scenarios, the growth of this group would accelerate in the coming years. It is projected that by 2061, there will be between 11.9 million and 15.0 million persons aged 65 years or older.²²
- In 2010, more than 252,000 Canadians died.²³ Projections also show Canada will have far more very elderly people. In 2009, there were roughly 1.3 million people aged 80 or over. It is projected to increase to 3.3 million by 2036.²⁴
- 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%).²⁵ 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.²⁶
- 41% of Canadian seniors are dealing with two or more select chronic conditions.²⁷
- Chronic diseases account for 70% of all deaths.²⁸
- 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 caregivers.²⁹

Federal Recommendations and Legislation on Hospice Palliative Care in Canada

- 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.

- The Parliamentary Committee on Palliative and Compassionate Care's report *Not to Be Forgotten: Care of Vulnerable Canadians* (November 2011) released 14 recommendations of which 11 had direct concern for palliative care and support for caregivers. Key recommendations include
 - The re-establishment of the Palliative Care Secretariat to develop a National Palliative and End-of-Life Strategy to collaborate on national standards, dissemination of research and coordinated support.
 - The development and implementation of a National Pain Strategy by federal, provincial, and territorial governments as well as NGO stakeholders to provide a unified approach in the delivery of pain control methods
 - The federal government establish a refundable tax credit for family caregivers, to help families, with the high costs of care giving. As well as set up a Canada Pension credit for family caregivers, so that those who are long term unpaid caregivers receive annual pension credit worth half their average salary from the years leading up to full time unpaid care giving.³⁰
- In March 2012, the Standing Senate Committee on Social Affairs, Science and Technology published their report: *A Time for Transformative Change: A Review of the 2004 Health Accord*. The following recommendations were made in reference to hospice palliative care:
 - That where necessary, jurisdictions expand their public pharmaceutical coverage to drugs and supplies utilized by home-care recipients. (Rec. #14)
 - That the federal government work with the provinces and territories to increase access to palliative care as part of end-of-life health services in a broad range of settings, including residential hospices.
 - That the federal, provincial, and territorial governments develop and implement a strategy for continuing care in Canada, which would integrate home-, facility-based long-term, respite and palliative-care services fully within health-care systems. The strategy would establish clear targets and indicators in relation to access, quality and integration of these services and would require governments to report regularly to Canadians on results.
 - That the federal government work with provincial and territorial governments to develop a pan-Canadian Homecare Strategy, which would include a focus on reducing the burdens faced by informal caregivers.
 - That Health Canada, taking the lead, work with provinces and territories to create and implement an awareness campaign for Canadians about the importance of planning end-of-life care.
 - That the federal government work with provincial, territorial governments and other relevant stakeholders to develop indicators to measure the quality and consistency of home care, end-of-life care, and other continuing-care services across the country.³¹
- 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.³²

- 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.³³
- A 2009 evaluation of the Compassionate Care Benefit from the perspective of family or informal 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.³⁴
- 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.

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.³⁵
- 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.³⁶

- 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.³⁷
- In 2011, the federal government made a one time commitment of \$3 million to fund the study and framework implementation of community-integrative models of hospice palliative care. This initiative is being led by the CHPCA under the guidance of the Quality End-of-life Care Coalition of Canada.

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.³⁸
- The CHPCA 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.³⁹
- Successful ACP often begins well in advance of serious illness.⁴⁰
- The 2012 ACCEPT Study was a prospective audit of current practice related to advance care planning (ACP) in hospitalized patients at high-risk for dying, as well as their families. About 60% of patients reported that they had a written advance directive/living will or some other written document. This varied widely from site to site – with a high of 100% at one site and a low of 20% at another.⁴¹
- A March 2012 Ipsos-Reid poll found that 86% of Canadians have not heard of advance care planning, and that less than half had a discussion with a family member or friend about healthcare treatments if they were will and unable to communicate. Only 9% had ever spoken to a healthcare provider about their wishes for care.⁴²
- *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.⁴³

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.”⁴⁴ 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 CHPCA hosts a National Hospice Palliative Care Week the first week of May each year, with themes being drawn from the World Hospice Palliative Care Day.
- The CHPCA also has a newly launched awareness campaign for family and informal caregivers every April 5. This awareness campaign was launched in 2012 in partnership with We Care Home Health Services.

- The World Hospice Palliative Care Day is organized by the Worldwide Palliative Care Alliance and aims to share their vision to increase the availability of hospice and palliative care throughout the world by creating opportunities to speak out about the issues, raise awareness and understanding of the needs – medical, social, practical, spiritual – of people living with a life limiting illness and their families, and to raise funds to support and develop hospice and palliative care services around the world.⁴⁵
- 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.⁴⁶

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.
- 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.⁴⁷
- Findings published in The New England Journal of Medicine sheds a new light on the effects of end-of-life care. Doctors have found that patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis not only were happier, more mobile and in less pain as the end neared – but they also lived nearly three months longer.⁴⁸
- 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.⁴⁹
- 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).⁵⁰ (CIHR NET Grant)
- 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.⁵¹

Role of Family and Informal 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

- A caregiver is an individual who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions. The term is sometimes qualified with family caregiver, informal caregiver, or unpaid caregiver to differentiate from providers and other health care professionals who provide care.⁵²
- Based on a study in Ontario, palliative care clients were cared for primarily by their spouses or partners (57%) or their children or children-in-law (29%).⁵³
- 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%).⁵⁴ 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%).⁵⁵
- In 2007, 2.7 million Canadian family caregivers over the age of 45 were helping seniors with long-term health conditions.⁵⁶
- 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.⁵⁷
- Most caregivers found caring for loved ones manageable and rewarding. However, more than one in four (22%) showed signs of distress, including anger, depression, being overwhelmed and unable to continue providing care. Caregivers of 12% of Ontario palliative home-care clients exhibited more than one sign of distress.⁵⁸
- Longer hours of informal care and the health status of palliative home-care clients led to significant caregiver distress. Those who provided 18–35 hours of care had high levels of distress. Interestingly, as care topped 36 hours, caregivers learned to manage better. The dying person’s health status—health decline, depressive symptoms and cognitive impairment—also added to caregiver distress. As the health of the loved ones deteriorated and/or depressive symptoms escalated, caregiver distress increased. A mild/moderate decline in cognition of palliative home-care clients was stressful for caregivers. Over time, they learned to cope better.⁵⁹
- 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.⁶⁰
- A 2002 study showed that 70% of family caregivers acknowledge that providing care to a loved one is stressful, and 70% of family caregivers indicate that they require time away from the responsibility of caring for a loved one.⁶¹
- 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 experience⁶²
- Formal support is important, but does not seem to reduce stress.⁶³

- 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.⁶⁴
- 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.⁶⁵
- 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.⁶⁶
- The increasing reliance on de-institutionalized care has had a great impact on Canada's 1.5 to 2 million 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.⁶⁷
- That the federal government works 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.
- In 2012, the CHPCA in partnership with We Care Home Health Services started an awareness campaign for family and informal caregivers on National Caregiver Day, April 5. For more information please go to www.chpca.net.

Role of Home Care

- A lack of funding of home care programs affects the need for trained volunteers and family 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 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
- A recent study showed that most seniors (93%) in Canada live at home and want to stay there as long as possible.⁷²

- According to the 2012 report: *Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?* released by the Health Council of Canada, home care costs in the last six months of life are roughly double what are required for all other home care recipients.⁷³

Training and Education

- Canada currently has over 200 palliative care physicians who work either full-time or part-time.⁷⁴
- 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.⁷⁵
- 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.⁷⁶
- 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 2008.⁷⁷
- In 2010, the Social Work Competencies on Palliative Education Executive Committee in partnership with the CHPCA, 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, paediatrics, 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.⁷⁸
- 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.⁷⁹
- 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.⁸⁰

- 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.⁸¹
- 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.⁸²
- 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.⁸³

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 34 national associations and organizations with an interest in end-of-life care issues.⁸⁴
- 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*.⁸⁵
- 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.⁸⁶
- The QELCCC Framework includes three distinct models or working groups:⁸⁷
 - 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.⁸⁸
- 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.⁸⁹
- 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.⁹⁰

**Canadian Hospice Palliative Care Association
Annex D, Saint-Vincent Hospital
60 Cambridge Street North
Ottawa, ON K1R 7A5**

Telephone: 613-241-3663 or 1-800-668-2785

E-mail: info@chpca.net <http://www.chpca.net>

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.

References

- ¹ *Living Lessons*[®] - The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association (2001).
- ² Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada* (Ottawa: CIHI, 2007).
- ³ Costs associated with resource utilization during the palliative phase of care: a Canadian perspective, *Palliative Medicine*, Dec 2009.
- ⁴ <http://www.lifebeforedeath.com/qualityofdeath/index.shtml>
- ⁵ Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada* (Ottawa: CIHI, 2007), p. 22.
- ⁶ Statistics Canada. *Table 102-0509 - Deaths in hospital and elsewhere, Canada, provinces and territories, annual*, CANSIM (database). <http://cansim2.statcan.gc.ca/cgi-win/cnsmcgi.pgm> (accessed: March 18, 2010)
- ⁷ Barbara L, Carole T, Dudgeon D. (2010) Why do patients with cancer visit the emergency department near end of life? *CMAJ*. March 15.
- ⁸ Seow H, Barbera L, Howell D, Dy SM. (2010). Using More End-of-Life Homecare Services is Associated with Using Fewer Acute Care Services: A Population- Based Cohort Study. *Medical Care* Vol. 48, No. 2. February.
- ⁹ The Canadian Cancer Society's *Canadian Cancer Statistics 2010 – Special Topic: End-of-Life Care*, released in May 2010 reported that Canada has a patchwork approach to providing care at the end of life.
- ¹⁰ Website: <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm>
- ¹¹ Ipsos-Reid Survey. Hospice Palliative Care Study: Final Report, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, January 2004, p.30.
- ¹² Ipsos-Reid Survey. Hospice Palliative Care Study: Final Report, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, January 2004, p.31.
- ¹³ 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>
- ¹⁴ 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>
- ¹⁵ Website: <http://www.chpca.net/> or <http://www.cha.ca/>
- ¹⁶ Press release: "Palliative Home Care Patients Eligible for Free Drug Coverage," February 15, 2012. <http://gov.ns.ca/news/details.asp?id=20120215004>
- ¹⁷ Quality End-of-Life Care Coalition of Canada. Hospice Palliative Home Care in Canada: A Progress Report. Ottawa, ON. Quality End-of-Life Care Coalition of Canada: 2008.
- ¹⁸ Ibid.
- ¹⁹ Ibid.
- ²⁰ Carstairs, The Honourable Sharon. Raising the Bar: A Roadmap for the Future of Palliative Care in Canada. June 2010.
- ²¹ Population Projections for Canada, Provinces and Territories – 2009-2036, Statistics Canada, Catalogue 91-520-XIE. <http://www.statcan.gc.ca/daily-quotidien/100526/dq100526b-eng.htm>
- ²² Population Projections for Canada, Provinces and Territories – 2009-2036, Statistics Canada. October 2010. <http://www.statcan.gc.ca/pub/91-520-x/2010001/part-partie3-eng.htm>.
- ²³ Population Estimates and Projections: Deaths, estimates, by province and territory. Statistics Canada, CANSIM, table 051-0004 and Catalogue no. 91-215-X. 28 Sept 2011. < <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/demo07a-eng.htm> >
- ²⁴ Population Projections for Canada, Provinces and Territories – 2009-2036, Statistics Canada, Catalogue 91-520-XIE. <http://www.statcan.gc.ca/daily-quotidien/100526/dq100526b-eng.htm>
- ²⁵ Deaths, 2003. Statistics Canada, 2005. Catalogue no. 84F0211XIE,
- ²⁶ 10th Annual Health Care in Canada Survey: A national survey of health care providers, managers and the public, 2007, <http://www.hcic-sssc.ca>.
- ²⁷ Canadian Institute for Health Information. (2011). *Health Care in Canada, 2011: A focus on seniors and aging*. Ottawa, ON: CIHI.
- ²⁸ Rachlis, Michael. Presentation to the Local Health Integration Networks (LHIN) Education Session, Toronto, Ontario, April 6, 2006
- ²⁹ *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."
- ³⁰ Albrecht, Harold, Joseph Comartin and Frank Valeriotte. Not to Be Forgotten: Care of Vulnerable Canadians. Final Report of the ad hoc Parliamentary Committee on Palliative and Compassionate Care. November 2011. House of Commons Canada.)
- ³¹ Ogilvie, The Honourable Kelvin Kenneth. *Time for Transformation Change: A Review of the 2004 Health Accord*. Final Report of the Standing Senate Committee on Social Affairs, Science. March 2012. Senate of Canada.
- ³² Website: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
- ³³ Website: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
- ³⁴ Williams A., Crooks V., Giesbrecht M., Dykeman S. (2009). Evaluating Canada's Compassionate Care Benefit: From the Perspective of Family Caregivers.
- ³⁵ Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010, p.9.
- ³⁶ Quality End-of-Life Care Coalition of Canada. Hospice palliative home Care in Canada: A Progress Report. Ottawa, ON. Quality End-of-Life Care Coalition of Canada: 2008.

-
- 37 Website: http://www.hc-sc.gc.ca/english/pdf/romanow/pdfs/HCC_Final_Report.pdf
- 38 “Educating Future Physicians in Palliative and End-of-Life Care” (2007). *Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Material*.
- 39 Advance Care Planning in Canada. Environmental Scan. June 2009.
http://www.chpca.net/projects/advance_care_planning/advance_care_planning_index.html
- 40 Advance Care Planning in Canada. Environmental Scan. June 2009.
http://www.chpca.net/projects/advance_care_planning/advance_care_planning_index.html
- 41 Official results have yet to be published. Please go to www.advancecareplanning.ca for more information.
- 42 Ibid.
- 43 Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010, p.17.
- 44 Harvey Chochinov, testimony before the Subcommittee to Update “Of Life and Death” of the Standing Senate Committee on Social Affairs, Science and Technology, February 28, 2000
- 45 Website: <http://www.worldday.org/about/#What-is>
- 46 Website: <http://www.living-lessons.org>
- 47 Canadian Institutes of Health Research. Impacts of the Palliative and End-of-Life Care Initiative 2003-2009. Ottawa, ON. October 2009.
- 48 Temel Jennifer et al., Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *The New England Journal of Medicine*. Vol. 363:733-742. August 2010.
- 49 Daren K Heyland, Diane E Allan, Graeme Rocker, Peter Dodek, Deb Pichora, Amiram Gafni, Canadian Researchers at the End-of-Life Network (CARENET)
- 50 Heyland DK, Frank C, Tranmer J, Paul N, Pichora D, Jiang X, Day A, for the Canadian Researchers at the End of Life Network (CARENET). Satisfaction with end of life care: A longitudinal study of patients and their family caregivers in the last months of life. *J Palliat Care* 2009 (in press). *Key words: end-of-life care, palliative care, satisfaction with care, outcomes research*
- 51 Canadian Institutes of Health Research. Impacts of the Palliative and End-of-Life Care Initiative 2003-2009. Ottawa, ON. October 2009, p. 36
- 52 Canadian Caregiver Coalition, 2009, Statement on Caregiver Language, www.ccc-ccan.ca.
- 53 The Change Foundation, 2011, *Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions*, www.changefoundation.ca/news.html#informalseniorcare.
- 54 10th Annual Health Care in Canada Survey: A national survey of health care providers, managers, and the public, 2007, <http://www.hcic-sssc.ca>
- 55 Health Care in Canada Survey 2006: A national survey of health care providers, managers, and the public, 2006, <http://www.hcic-sssc.ca>
- 56 Cranswick, K. & Dosman, D. (2008). *Eldercare: What we know today*. Ottawa, ON: Statistics Canada.
- 57 Voice in Health Policy: The Role of Informal Caregivers in Hospice Palliative Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges, CHPCA, August 2004.
- 58 The Change Foundation, 2011, *Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions*, www.changefoundation.ca/news.html#informalseniorcare
- 59 The Change Foundation, 2011, *Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions*, www.changefoundation.ca/news.html#informalseniorcare
- 60 Website: <http://www.gsk.ca/>
- 61 Website: <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal-eng.php#a1>
- 62 Website: <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal-eng.php#a1>
- 63 Website: <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal-eng.php#a1>
- 64 Voice in Health Policy: The Role of Informal Caregivers in Hospice Palliative Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges, CHPCA, August 2004, p. 9
- 65 Hollander, J.M., Guiping, L., Chappell, N.L. (2009). Who cares and how much? *Healthcare Quarterly*, 12(2), 42-49.
- 66 McGarry, J., & Arthur, A. (2001). Informal caring in late life: A qualitative study of the experiences of older carers. *Journal of Advanced Nursing*, 33(2), 181-189.
- 67 Hollander, M.J, Liu, G., Chappel, N.L. (2009). Who cares and how much? The imputed economic contribution to the Canadian health care system of middle aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42-59.
- 68 Canadian Home Care Human Resources Study – Technical Report, The Home Care Sector Study Corporation, 2003, p. 35.
<http://www.cdnhomecare.ca/content.php?doc=33>
- 69 Website: www.cacc-acssc.com/english/pdf/homecareresources/highlights-final.pdf
- 70 The Health of Canadians – The Federal Role – Interim Report, Volume Four – Issues and Options, The Standing Senate Committee on Social Affairs, Science and Technology, September 2001. Website: <http://www.parl.gc.ca/37/1/parlbus/commbus/senate/com-e/soci-e/rep-e/repintsep01-e.htm>
- 71 Bacon, J. (2008) *Hospice Palliative Home Care in Canada: A Progress Report*. Ottawa: Quality End-of-Life Care Coalition of Canada.
- 72 Canadian Institute for Health Information. (2011). *Health Care in Canada, 2011: A focus on seniors and aging*. Ottawa, ON: CIHI.
- 73 Health Council of Canada. Seniors in need, caregivers in distress. April 2012
http://www.healthcouncilcanada.ca/tree/HCC_HomeCare_FA.pdf
- 74 Website: <http://www.cspep.ca/english/index.php/>
- 75 Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010, p.11.
- 76 Website: <http://www.cna-nurses.ca/>
- 77 Website: <http://www.afmc.ca/efppec/pages/main.html>
- 78 Website: <http://www.peol-sp.ca/splash.php>
- 79 Canadian Hospice Palliative Care Association Nursing Standards Committee. (2009). *Canadian hospice palliative care nursing standards of practice*. Retrieved March 22 2010. from http://www.chpca.net/interest_groups/nurses_ig.html

-
- ⁸⁰ Canadian Institutes of Health Research. Impacts of the Palliative and End-of-Life Care Initiative 2003-2009. Ottawa, ON. October 2009, p. 30.
- ⁸¹ Ibid.
- ⁸² Schroder C, Heyland D, Jiang X, Rocker G, Dodek P, for the Canadian Researchers at the End of Life Network (CARENET). Educating medical residents in end-of-life care: Results of a national survey. *J Palliat Med* 2009;12(5):459-470. *Key words: education, end-of-life care*
- ⁸³ Website: www.market-marche.chpca.net
- ⁸⁴ Website: <http://www.chpca.net/qelccc.htm>
- ⁸⁵ 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>
- ⁸⁶ Website: <http://www.qelccc.ca>
- ⁸⁷ Website: <http://www.chpca.net/qelccc.htm>
- ⁸⁸ Quality End-of-Life Care Coalition of Canada. Hospice palliative home Care in Canada: A Progress Report. Ottawa, ON. Quality End-of-Life Care Coalition of Canada: 2008.
- ⁸⁹ Quality End-of-Life Care Coalition of Canada. Hospice palliative home Care in Canada: A Progress Report. Ottawa, ON. Quality End-of-Life Care Coalition of Canada: 2008.
- ⁹⁰ Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010.