



Fact Sheet: Hospice Palliative Care in Canada

| | |
|--|----|
| Access to Hospice Palliative Care in Canada..... | 1 |
| Demand for Hospice Palliative Care in Canada | 2 |
| Funding for Hospice Palliative Care Programs | 3 |
| The Way Forward: An Integrated Palliative Approach to Care | 4 |
| Advance Care Planning..... | 5 |
| Raising Awareness..... | 5 |
| Research | 6 |
| Role of Family and Informal Caregivers | 6 |
| Role of Home Care | 8 |
| Training and Education | 9 |
| Quality End-of-Life Care Coalition of Canada (QELCCC) | 10 |
| About the Canadian Hospice Palliative Care Association..... | 11 |
| References | 12 |

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.
- The topic of end-of-life is on people’s minds. Three-quarters of Canadians (74%) report having thought about end-of-life.³
- Support for hospice palliative care is almost unanimous, with the vast majority of Canadians (96%) being supportive, including 66% who are very supportive.⁴
- Almost half of Canadians (47%) say hospice palliative care is available to all those at the end of their life regardless of their illness. Only 19% say it is available to those dying of life threatening illnesses. However, one-third of Canadians (34%) are not sure to whom hospice palliative care services are available.⁵
- The vast majority of Canadians believe that hospice palliative care has a positive impact. The following are statements about hospice palliative care that see a large majority of Canadians either agreeing or strongly agreeing. They feel that it:
 - Greatly reduces the stress and burden placed on the family (93%);
 - Should involve all care providers (94%);
 - Improves quality of life for patients (94%);
 - Should be provided in the patient’s setting of choice (93%);
 - Should be integrated for all people with chronic, life-limiting conditions (90%);

- Helps a patient manage their choices along the way (93%); and
 - Should be available early in the course of a disease (87%).⁶
- Canadian families frequently shoulder 25% of the total cost of palliative care due to costs associated with home based services⁷ 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.⁸
- When asked, most people have indicated that they would prefer to die at home in the presence of loved ones⁹, yet almost 70% of Canadian deaths occur in a hospital.¹⁰
- Half of Canadians (50%) feel that their family member's death involved some pain, but that it was managed well. The remaining groups feel that the family member's death was either pain and symptom free (27%) or that there were some issues relating to pain and symptom management (24%).¹¹
- 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.¹²
- 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.¹³
- 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.
- 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.¹⁴
- As of February 2012, all provinces now have some form of palliative drug coverage for home care patients.¹⁵
- Only six of 13 jurisdictions have policies on providing nursing and personal care services 24 hours a day, seven days a week.¹⁶
- 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.¹⁷

Demand for Hospice Palliative Care in Canada

- 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 2009.¹⁸
- Over three in ten Canadians (32%) personally suffer from a chronic illness while four in ten (39%) have a sufferer in their immediate family. When taken together, six in ten

Canadians (57%) either personally suffer from a chronic illness or have a sufferer in their immediate family.¹⁹

- 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.²⁰
- The first Baby Boomers turned 65 in 2011. In less than 15 years they will be entering their 80s, with younger Boomers filling out the ranks of those 60 to 70.²¹
- In 2010, more than 252,000 Canadians died.²² 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 2036.²³
- Chronic diseases account for 70% of all deaths.²⁴
- 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.²⁵
- The cost of dying in Canada ranges from as low as \$10,000 for a sudden death to between \$30,000 and \$40,000 for someone with a terminal disease such as cancer or chronic obstructive pulmonary disease. It is estimated that, compared to usual acute care, hospital-based hospice palliative care may save the health care system approximately \$7,000 to \$8,000 per patient.²⁶
- In a Saskatchewan study, the average monthly per person cost to the health care system increased from \$1,373 12 months before death to \$7,030 for the last 30 days; when user fees were included, the average costs were \$1,641 and \$7,420 respectively. ²⁷
- Hospital-based palliative care reduces the cost of end-of-life care by 50% or more, primarily by reducing the number of ICU admissions, diagnostic testing, interventional procedures and overall hospital length of stay.²⁸
- The 2011 Census indicates that 92.1% of Canadians 65 years and over lived in private homes: alone, with others, or as part of a couple.²⁹
- 74% of seniors (age 65 years and older) and 48% of older adults (age 45 to 64 years) reported having one or more chronic conditions. And 24% of seniors reported having three or more chronic conditions.³⁰
- Canadian Institutes of Health Research's Institute of Aging report that Alzheimer's disease and other related dementias affect about 8% of seniors 65 and over, increasing to a third of seniors (or more) among those 85 and over.³¹

Funding for Hospice Palliative Care Programs

- Residential 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 long-term care – almost anywhere outside a hospital.³²
- The majority of Canadians (73%) feel that the provincial governments place too little priority on this end-of-life care, including over one-third (35%) who feel that it is far too little.³³
- 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.³⁴

- The Canadian Institute for Health Information notes that per capita healthcare costs rise from \$9,264 for a person younger than one year old to \$12,050 for those aged 75-79 and upwards to \$20,113 for those 80 and older.³⁵
- Depending on the estimate, expanding access to quality palliative care would have saved between \$40 and \$345.5 million between 2003 and 2011 in the province of Ontario Alone. Projected savings from 2012 to 2036 range from just under \$247 million to just over \$2.1 billion, again depending on the estimate scenario.³⁶
- Just over 3.1 million Canadians were estimated to have provided informal care to home care recipients in 2007, totalling over 1.5 billion hours.³⁷
- CIHI reports that 45% of provincial and territorial health expenditures in 2009 were directed to seniors, even though that group accounted for only 14% of the population.³⁸
- 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.

The Way Forward: An Integrated Palliative Approach to Care

- In 2011, the federal government made a one time commitment of \$3 million to fund the study and framework creation 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.
- There are six other discussion documents available on The Way Forward initiative:
 - *The Palliative Approach: Improving Care for Canadians with Life-limiting Illnesses* by Jean Bacon
 - *Integrating a Palliative Approach into the Management of Chronic, Life-Threatening Diseases: Who, How and When?* By Jean Bacon
 - *Cost-Effectiveness of Palliative Care: A Review of the Literature* by Corinne Hodgson
 - *Innovative Models of Integrated Hospice Palliative Care* by Janet Dunbrack
 - *Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care* by Marg McAlister
 - *Synthesis of Recommendations from National Reports on Hospice Palliative Care* by Michelle MacDonald
- The initiative has also produced the following two documents:
 - *The Way Forward National Framework: A Roadmap for the Integrated Palliative Approach to Care* by Jean Bacon
 - *Palliative Care in the Community: An environmental scan of frameworks and indicators* by Dale McMurchy and Monica Aggarwal
- All of these documents are available at www.hpcintegration.ca
- The Way Forward also conducted a poll through Harris/Decima which was released in January 2014. For the full report, please visit www.hpcintegration.ca.

Advance Care Planning

- Advance care planning (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.³⁹
- Effective, ongoing communication among the patient, family and health care team is essential to effective ACP.⁴⁰
- Successful ACP often begins well in advance of serious illness.⁴¹
- 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.⁴²
- 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.⁴³
- When asked about the importance of discussing end-of-life care with different types of individuals, six in ten Canadians surveyed (61%) say that having the discussion is extremely important with at least one individual.⁴⁴
- The majority of Canadians (52%) indicate that the advance care planning process should begin when a person is healthy, yet Only a 13% have an advance care plan prepared.⁴⁵
- Three-quarters of Canadians would turn to their family physician (73%), for more information on hospice palliative care services.⁴⁶
- *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.⁴⁷
- A March 2012 Ipsos-Reid poll found that 86% of Canadians have not heard of advance care planning and that less than half have had a discussion with a family member or friend about healthcare treatments if they were ill and unable to communicate⁴⁸.
- The CHPCA has developed the *Speak Up: Start the Conversation About End-of-Life Care* campaign to raise awareness and educate Canadians on Advance Care Planning. More information can be found at www.advancereplanning.ca.

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.”⁴⁹ Harvey Chochinov

- The CHPCA hosts National Hospice Palliative Care Week the first week of May each year. Traditionally, themes are drawn from the World Hospice Palliative Care Day theme⁵⁰.

- 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 Services⁵¹.
- 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. It is the second Saturday of October.⁵²
- 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.⁵³

Research

- 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.⁵⁴
- Findings published in The New England Journal of Medicine shed 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.⁵⁵
- 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.⁵⁶
- 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.⁵⁷

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 provides 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.⁵⁸
- The average number of hours per week that Canadians expect for caring for a dying family member is 54.4.⁵⁹
- In 2013, expectations of commitment have increased. More Canadians this year expect that proper care will require two or more days of commitment each week (73%) compared to 10 years ago (59%).⁶⁰
- When asked whether they feel they could devote that much time to caring for a dying loved one, the majority of Canadians (65%) indicate that they would not be able to.⁶¹
- 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%).⁶²
- 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%).⁶³ 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%).⁶⁴
- In 2007, 2.7 million Canadian family caregivers over the age of 45 were helping seniors with long-term health conditions.⁶⁵
- Many leading-edge global companies such as GlaxoSmithKline and Rx&D now include in their employee benefit package the option of paid leave to employees who require time away from work to care for a dying family member.⁶⁶
- 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 experience⁶⁷
- 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.⁶⁸
- Current estimates for replacement costs for unpaid caregiving in Canada indicates a significant economic contribution by caregivers; estimates for care provided in 2009 range between 25 to 26 billion dollars.⁶⁹
- 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.⁷⁰
- In 2012, the federal government announced that parental caregivers of critically ill children under the age of 18 can claim up to 35 weeks within a year under the Federal Employment Insurance Program (EI). The benefits were made available as of January 2013.⁷¹

- 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 5.⁷²
- In 2012, about 8.1 million individuals, or 28% of Canadians aged 15 years and older, provided care to a family member or friend with a long-term health condition, disability or aging needs.⁷³
- New data from the 2012 Statistics Canada's General Social Survey showed that women represented the slight majority of caregivers at 54%. The survey also found that caregiving responsibilities most often fell to those aged 45 to 64, with 44% of caregivers in this age category.⁷⁴
- Ailing parents were the most common recipients of care, with 39% of caregivers looking after the needs of their own parents and another 9% doing so for their parents-in-law. The least common were spouses, at 8%, and children, at 5%.⁷⁵
- For the first time, Statistics Canada looked at the types of health conditions requiring care. Age-related needs topped the list, with 28% of caregivers providing care for these needs. Cancer was next at 11%, followed by cardio-vascular disease at 9%, and mental illness at 7%.⁷⁶
- Over one-quarter (28%) of caregivers, or 2.2 million individuals, could be considered "sandwiched" between caregiving and raising children. Most of them were women between the ages 35 and 44, and were helping their parents or parents-in law, while also having at least one child under 18 living at home.⁷⁷
- Those caring for their child and spouse received the most financial support from governments. In 2012, 30% of caregivers of children received government financial assistance, compared with 14% of caregivers of spouses and 5% of caregivers of parents.⁷⁸
- 52% of caregivers of children, 42% of caregivers of spouses and 28% of caregivers of parents said that they would have liked more help than they received, financial or otherwise.⁷⁹
- In late 2013, the CHPCA will re-launch a newly revised version of the popular *A Caregiver's Guide* with the support of The Military and Hospitaller Order of Saint Lazarus of Jerusalem.

Role of Home Care

- According to a 2014 Harris/Decima survey, those Canadians that have a preference of where they die, the majority would prefer to die in their home (75%).⁸⁰
- 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. By 2046, we may need home care for twice as many people proportionally, as we do today.⁸¹
- 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.⁸²

- If the death occurs in the home, Canadians (90%) are more likely to say that the setting matched the family member's preference. Seven in ten (69%) of those whose family member died in a hospital believe the same.⁸³
- 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*.⁸⁴
- 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.⁸⁵
- A recent study showed that most seniors (93%) in Canada live at home and want to stay there as long as possible.⁸⁶
- 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.⁸⁷
- A Canadian report estimated that it costs approximately \$4,700 per client to provide palliative care in the home – or about one-quarter of the \$19,000 for acute care.⁸⁸
- The home and community care workforce – largely nurses and home support workers – will need to adapt to growing demand. Integrated teams that connect primary, home, and community care will be essential to support frail seniors with complex care needs.⁸⁹
- Ontario found that between 20 and 50% of people on waiting lists for residential long-term care could age safely and cost-effectively at home if some basic services were accessible. And hospice palliative care services and treatment can lead to better outcomes, such as improvement of symptoms and reduced caregiver burden, while reducing costs.⁹⁰

Training and Education

- Canada currently has over 250 palliative care physicians who work either full-time or part-time.⁹¹
- A revised edition of the CHPCA *National Norms of Practice* was launched in late 2013 and is available at www.chpca.net/norms.
- In early 2014, the Royal College of Physicians and Surgeons granted palliative care subspecialty status⁹².
- In 2014, funding was provided to the Pallium Foundation of Canada for an initiative called, *Building the Future of Palliative Care Together*, which aims to strengthen the community of clinicians, caregivers, educators, administrators, volunteers, citizens and other partners. Through this program the Pallium Foundation will equip more front-line healthcare providers with the skills and knowledge they need to care for people with life-threatening conditions.⁹³
- 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.⁹⁴

- 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.
- 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. They will be reviewing and revising this document in late 2013.⁹⁵
- 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.⁹⁶
- 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 and professionals.⁹⁷

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 37 national associations and organizations with an interest in end-of-life care issues.⁹⁸
- 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.⁹⁹
- The Way Forward Initiative project is led by the QELCCC and managed by the CHPCA. Over the next three years, the initiative will develop a framework for the integration of the palliative approach to care.¹⁰⁰
- More information on the Coalition including reports, achievements and membership can be found at www.qelccc.ca.

**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.

"That all Canadians have access to quality end-of-life care."

References

- ¹ *Living Lessons*® (2001) The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association.
- ² Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada*. Ottawa: CIHI.
- ³ Ibid. 21
- ⁴ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 46
- ⁵ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 43
- ⁶ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 47
- ⁷ Costs associated with resource utilization during the palliative phase of care: a Canadian perspective, *Palliative Medicine*, Dec 2009.
- ⁸ <http://www.lifebeforedeath.com/qualityofdeath/index.shtml>
- ⁹ Canadian Institute for Health Information. (2007). *Health Care Use at the End of Life in Western Canada*. Ottawa: CIHI. p. 22.
- ¹⁰ 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)
- ¹¹ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 16
- ¹² Barbara L, Carole T., Dudgeon D. (2010) Why do patients with cancer visit the emergency department near end of life? *CMAJ*. March 15.
- ¹³ 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.
- ¹⁴ Ipsos-Reid Survey. Hospice Palliative Care Study: Final Report, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, January 2004, p.31.
- ¹⁵ Press release: "Palliative Home Care Patients Eligible for Free Drug Coverage," February 15, 2012. <http://gov.ns.ca/news/details.asp?id=20120215004>
- ¹⁶ 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.
- ¹⁷ Ibid.
- ¹⁸ 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>
- ¹⁹ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). P.8
- ²⁰ 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>.
- ²¹ Statistics Canada. (2012). Annual demographics estimates, Canada, provinces and territories. Ottawa: Minister of Industry. P. 39 retrieved from <http://www.statcan.gc.ca/pub/91-215-x/91-215-x2012000-eng.pdf>
- ²² 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> >
- ²³ 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>
- ²⁴ Rachlis, Michael. Presentation to the Local Health Integration Networks (LHIN) Education Session, Toronto, Ontario, April 6, 2006
- ²⁵ *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."
- ²⁶ Hodgson, Corinne. *Cost-effectiveness of Palliative Care: A Review of the Literature* (2012). Ottawa, ON: CHPCA. P.3.
- ²⁷ Hollander, J.M., Guiping, L., Chappell, N.L. (2009). Who cares and how much? *Healthcare Quarterly*, 12(2), 42-49.
- ²⁸ Hodgson, Corinne. *Cost-effectiveness of Palliative Care: A Review of the Literature* (2012). Ottawa, ON: CHPCA. P.11.
- ²⁹ Milan, Anne, Nora Bohnert, Sandrine Levasseu, and Francois Page. (2011). *Living Arrangements of Seniors*. Ottawa : Statistics Canada. P. 1.

-
- ³⁰ Canadian Institute for Health Information. (2011) What is the Impact of Multiple Chronic Conditions? Ottawa: Canadian Institute of Health Information. P 6.
- ³¹ Canadian Institutes of Health Research (2011). Cognitive Impairment in Aging Partnership: A strategic initiative of the CIHR Institute of Aging. www.cihr-irsc.gc.ca/e/26988.html
- ³² Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010, p.9.
- ³³ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 49
- ³⁴ 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.
- ³⁵ Canadian Institute for Health Information. (2012) National Health Expenditure Trends, 1975 to 2012. See *Highlights*, p. xiv. Retrieved from <https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1952>
- ³⁶ Institute of Marriage and Family Canada. (2013). Why Canada needs more palliative care. P. 1. Retrieved from <http://www.imfcanada.org/issues/why-canada-needs-more-palliative-care>
- ³⁷ Hermus Greg, Carole Stonebridge, Louis Theriault, and Fares Bounajm. (2012). Home and Community Care in Canada: An economic footprint. Ottawa: The Conference Board of Canada. P ii.
- ³⁸ Canadian Institute for Health Information. *Portraits of Home Care in Canada*. Ottawa: Canadian Institute for Health Information, 2010. P. 1
- ³⁹ "Educating Future Physicians in Palliative and End-of-Life Care" (2007). *Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Material*.
- ⁴⁰ Advance Care Planning in Canada. Environmental Scan. June 2009. http://www.chpca.net/projects/advance_care_planning/advance_care_planning_index.html
- ⁴¹ Advance Care Planning in Canada. Environmental Scan. June 2009. http://www.chpca.net/projects/advance_care_planning/advance_care_planning_index.html
- ⁴² Official results have yet to be published. Please go to www.advancecareplanning.ca for more information.
- ⁴³ Ibid.
- ⁴⁴ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 29
- ⁴⁵ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 33, 35
- ⁴⁶ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 44
- ⁴⁷ Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010, p.17.
- ⁴⁸ Ipsos Healthcare – The Healthcare Research Specialists, Canadian Hospice Palliative Care Association. Advance Care Planning Poll. March 2012. Page 7
- ⁴⁹ 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
- ⁵⁰ www.chpca.net/week
- ⁵¹ www.chpca.net/caregiverday
- ⁵² Website: <http://www.worldday.org/about/#What-is>
- ⁵³ Website: <http://www.living-lessons.org>
- ⁵⁴ Canadian Institutes of Health Research. (2009). Impacts of the Palliative and End-of-Life Care Initiative 2003-2009. Ottawa, ON. October.
- ⁵⁵ 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.
- ⁵⁶ Daren K Heyland, Diane E Allan, Graeme Rocker, Peter Dodek, Deb Pichora, Amiram Gafni, Canadian Researchers at the End-of-Life Network (CARENET)
- ⁵⁷ Canadian Institutes of Health Research. Impacts of the Palliative and End-of-Life Care Initiative 2003-2009. Ottawa, ON. October 2009, p. 36
- ⁵⁸ Canadian Caregiver Coalition. (2009). Statement on Caregiver Language, www.ccc-ccan.ca.
- ⁵⁹ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 18
- ⁶⁰ Ibid. 18
- ⁶¹ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 19

-
- ⁶² 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.
- ⁶³ 10th Annual Health Care in Canada Survey: A national survey of health care providers, managers, and the public, 2007, <http://www.hcic-sssc.ca>
- ⁶⁴ Health Care in Canada Survey 2006: A national survey of health care providers, managers, and the public, 2006, <http://www.hcic-sssc.ca>
- ⁶⁵ Cranswick, K. & Dosman, D. (2008). *Eldercare: What we know today*. Ottawa, ON: Statistics Canada.
- ⁶⁶ Website: <http://www.gsk.ca/>
- ⁶⁷ Website: <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiver-interven/det-anal-eng.php#a1>
- ⁶⁸ 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
- ⁶⁹ Hollander, J.M., Guiping, L., Chappell, N.L. (2009). Who cares and how much? *Healthcare Quarterly*, 12(2), 42-49.
- ⁷⁰ Hollander, M.J., Liu, G., Chappell, 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.
- ⁷¹ Website: <http://www.serviccanada.gc.ca/eng/ei/publications/ccbdifficulttimes.shtml>
- ⁷² Website: www.chpca.net/caregiverday
- ⁷³ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁷⁴ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁷⁵ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁷⁶ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁷⁷ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁷⁸ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁷⁹ Statistics Canada. (2013) Study: Caregivers in Canada, 2012. Component of Statistics Canada catalogue no. 11-001-X. Accessed from <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>.
- ⁸⁰ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). 22
- ⁸¹ 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>
- ⁸² Website: www.cacc-acssc.com/english/pdf/homecareresources/highlights-final.pdf
- ⁸³ Ibid. 13
- ⁸⁴ 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>
- ⁸⁵ Bacon, J. (2008) *Hospice Palliative Home Care in Canada: A Progress Report*. Ottawa: Quality End-of-Life Care Coalition of Canada.
- ⁸⁶ Canadian Institute for Health Information. (2011). *Health Care in Canada, 2011: A focus on seniors and aging*. Ottawa, ON: CIHI.
- ⁸⁷ Health Council of Canada. Seniors in need, caregivers in distress. April 2012 http://www.healthcouncilcanada.ca/tree/HCC_HomeCare_FA.pdf
- ⁸⁸ The Ontario Association of Community Care Access Centres (OACCAC), The Ontario Federation of Community Mental Health and Addiction Programs (OFCMHAP) & The Ontario Hospital Association (OHA). Ideas and Opportunities for Bending the Health Care Cost Curve. Advice for the Government of Ontario, April 2010. 2010
- ⁸⁹ Conference Board of Canada. (2013). Future Care for Canadian Seniors – Why it Matters. 6.
- ⁹⁰ Jean Bacon (2012). The Palliative Approach: Improving Care for Canadians with Life-limiting Illnesses. Canadian Hospice Palliative Care Association. P. 10.
- ⁹¹ Website: <http://www.cspcp.ca/english/index.php/>
- ⁹² Sullivan, Patrick. "Specialty status granted to palliative care MDs." Canadian Medical Association – Health care advocacy, clinical knowledge and CME. Last modified January 31, 2014. <http://www.cma.ca/specialtystatusgrantedtopalliativecaremds>.
- ⁹³ For more information please visit <http://www.pallium.ca/>
- ⁹⁴ Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. Ottawa, ON. January 2010, p.11.

⁹⁵ 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

⁹⁶ Ibid.

⁹⁷ Website: www.market-marche.chpca.net

⁹⁸ Website: <http://www.chpca.net/qelccc.htm>

⁹⁹ Quality End-of-Life Care Coalition of Canada. *Blueprint for Action 2010 to 2020*. Ottawa, ON. January 2010.

¹⁰⁰ Website: www.hpcintegration.ca