



## Hospice Palliative Care in Canada: A Snap Shot

*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.<sup>i</sup>*

### THE BIG PICTURE

Hospice palliative care aims to relieve suffering, while improving the quality of living and dying.

Toward the end of life, most people will experience a serious progressive illness such as heart disease, cancer or breathing disorders<sup>ii</sup> and with Canada's aging population, this is going to become more common. People diagnosed with a life-limiting illness will likely live with it for many years, and experience pain, discomfort, and other symptoms related both to the condition itself and its treatment.<sup>iii</sup>

#### ***Hospice palliative care matters to Canadians***

Support for hospice palliative care is almost unanimous, with 96 per cent of Canadians being supportive, including 66 per cent who are very supportive.<sup>iv</sup>

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%).<sup>v</sup>

#### ***There's a need for hospice palliative care.***

- 50 per cent of Canadians feel that their family member's death involved some pain, but that it was managed well.<sup>vi</sup>
- 27 per cent of Canadians feel that their family member's death was either pain or symptom free or that there were some issues relating to pain and symptom management (24 per cent).<sup>vii</sup>

### DEMAND ... we're getting older.

- Seniors make up the fastest-growing age group in Canada. It is estimated that seniors could account for between 23 per cent and 25 per cent of the total population by 2036, nearly double the 13.9 per cent of 2009.<sup>viii</sup>
- Projections 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.<sup>ix</sup>



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- 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.<sup>x</sup>
- 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.<sup>xi</sup>

### ... we're getting sicker.

- Over three in ten Canadians (32 per cent) personally suffer from a chronic illness while four in ten (39 per cent) have a sufferer in their immediate family. When taken together, six in ten Canadians (57 per cent) either personally suffer from a chronic illness or have a sufferer in their immediate family.<sup>xii</sup>
- In 2010, more than 252,000 Canadians died.<sup>xiii</sup>
- 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.<sup>xiv</sup>
- 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.<sup>xv</sup>

### BENEFITS ... to people, to the system

- Hospice palliative care programs allow patients to gain more control over their lives, manage pain and symptoms more effectively, and they provide support to family caregivers.<sup>xvi</sup>
- Findings published in The New England Journal of Medicine shed 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.<sup>xvii</sup>
- 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 per cent 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.<sup>xviii</sup>
- The cost of dying in Canada ranges from \$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. Compared to usual acute care, hospital-based hospice palliative care may save the health care system approximately \$7,000 to \$8,000 per patient.<sup>xix</sup>
- Hospital-based palliative care reduces the cost of end-of-life care by 50 per cent or more, primarily by reducing the number of ICU admissions, diagnostic testing, interventional procedures and overall hospital length of stay.<sup>xx</sup>
- Caring for terminally ill patients in an acute-care hospital is more than double the cost of providing care in a hospice bed, and over 10 times more than providing at-home care.<sup>xxi</sup>



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- In particular, the cost of providing palliative care in the last month of a patient's life averages about:
  - \$1,100 per day in an acute-care hospital bed;
  - \$630 to \$770 per day in a bed in a palliative-care unit (at the two hospitals in the Ontario study that tracked this information in a comparable way);
  - \$460 per day in a hospice bed; and
  - under \$100 per day where at-home care is provided.<sup>xxii</sup>
- The average stay in a residential hospice in Ontario is 18 days at a total cost of \$8280.<sup>xxiii</sup>

### ACCESS ... an overview

- There is strong and growing evidence that access to hospice palliative care combined with treatment, leads to an improvement in symptoms, better quality of life, higher patient satisfaction and overall better outcomes for individuals and their family caregivers.<sup>xxiv</sup>
- Having access to hospice palliative care means there is less of a burden on caregivers, more appropriate referral to, and use of, hospice services and less use of intensive care.<sup>xxv</sup>
- The Economist's Intelligence Unit ranked Canada ninth in an international 'Quality of Death' index released July 14th, 2010. Commissioned by the Singapore-based Lien Foundation, the index measured hospice and palliative care environments across 40 countries for 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 more than 70 per cent of those dying within Canada.<sup>xxvi</sup>
- Among jurisdictions that have appropriate policies and procedures in place to ensure access to services, there is still a lack of resources and lack of training, and geography (rural areas) limiting jurisdictions' ability to provide adequate palliative home care services to home care patients.<sup>xxvii</sup>

### ACCESS ... by the numbers

Canadians' perceptions:

- 47 per cent of Canadians say hospice palliative care is available to all at the end-of-life regardless of their illness.
- 19 per cent say it is available to those dying of life threatening illnesses.
- 34 per cent of Canadians are not sure to whom hospice palliative care services are available.<sup>xxviii</sup>

The reality:

- Only 16 per cent to 30 per cent of Canadians who die have access to or receive specialist hospice palliative and end-of-life care services. It all depends on where they live in Canada.<sup>xxix</sup> Even fewer receive grief and bereavement services.
- Most people would prefer to die at home surrounded by their loved ones<sup>xxx</sup> yet almost 70 per cent of Canadians die in a hospital.<sup>xxxi</sup>
- Only six of 13 jurisdictions have policies on providing nursing and personal care services 24 hours a day, seven days a week.<sup>xxxii</sup>

There is a cost:



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- 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.<sup>xxxiii</sup>
- Canadian families frequently shoulder 25 per cent of the total cost of palliative care due to costs associated with home based services<sup>xxxiv</sup> such as nursing and personal care services.
- As of February 2012, all provinces now have some form of palliative drug coverage for home care patients.<sup>xxxv</sup>
- 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.<sup>xxxvi</sup>

### FUNDING

- Residential hospice palliative care programs are still at least 50 per cent funded by charitable donations.<sup>xxxvii</sup>
- Families must bear part of the cost of dying at home, in long-term care – almost anywhere outside a hospital.<sup>xxxviii</sup>
- Just over 3.1 million Canadians were estimated to have provided informal home care in 2007, totalling over 1.5 billion hours.<sup>xxxix</sup>
- The Canadian Institute for Health Information (CIHI) 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.<sup>xl</sup>
- CIHI reports that 45 per cent of provincial and territorial health expenditures in 2009 were directed to seniors, even though that group accounted for only 14 per cent of the population.<sup>xli</sup>

### ROLE OF FAMILY AND CAREGIVERS

- 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.<sup>xlii</sup>
- As of 2013, Canadians expect that proper care will require two or more days of commitment each week (73 per cent) as compared to 10 years ago (59 per cent).<sup>xliii</sup>
- Based on an Ontario study, palliative care clients were cared for primarily by their spouses or partners (57 per cent) or their children or children-in-law (29 per cent).<sup>xliv</sup>
- In 2007, 2.7 million Canadian family caregivers over the age of 45 were helping seniors with long-term health conditions.<sup>xlv</sup>
- Whether or not the family or informal caregiver has a choice in taking on that role is a significant factor in the degree of stress and disruption they experience.<sup>xlvi</sup>
- Many leading-edge global companies such as GlaxoSmithKline and Rx&D now include, in their employee benefit packages, the option of paid leave to those who require time away from work to care for a dying family member.<sup>xlvii</sup>



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- 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.<sup>xlvi</sup>
- The increasing reliance on de-institutionalized (or home) 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.<sup>xlix</sup>
- 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.<sup>i</sup>
- In 2012, about 8.1 million individuals, or 28 per cent 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.<sup>ii</sup>
- The 2012 Statistics Canada General Social Survey showed that women represented the slight majority of caregivers at 54 per cent. The survey also found that caregiving responsibilities most often fell to those aged 45 to 64, with 44 per cent of caregivers in this age category.<sup>iii</sup>
- Ailing parents were the most common recipients of care, with 39 per cent of caregivers looking after the needs of their own parents and another 9 per cent doing so for their parents-in-law. The least common were spouses, at 8 per cent, and children, at 5 per cent.<sup>iiii</sup>
- 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.<sup>lv</sup>
- Statistics Canada looked at the types of health conditions requiring care. Age-related needs topped the list, with 28 per cent of caregivers providing care for these needs. Cancer was next at 11 per cent, followed by cardio-vascular disease at 9 per cent, and mental illness at 7 per cent.<sup>lv</sup>
- Over one-quarter (28 per cent) 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.<sup>lvi</sup>
- Those caring for their child and spouse received the most financial support from governments. In 2012, 30 per cent of caregivers of children received government financial assistance, compared with 14 per cent of caregivers of spouses and 5 per cent of caregivers of parents.<sup>lvii</sup>
- 52 per cent of caregivers of children, 42 per cent of caregivers of spouses and 28 per cent of caregivers of parents said that they would have liked more help than they received, financial or otherwise.<sup>lviii</sup>

### HOME CARE

- According to a 2014 Harris/Decima survey, of those Canadians with a preference for where they die, the majority would prefer to die at home (75 per cent).<sup>lix</sup>
- If the death occurs in the home, Canadians (90 per cent) are more likely to say that the setting matched the family member's preference. Seven in ten (69 per cent) of those whose family member died in a hospital believe the same.<sup>lx</sup>
- 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.<sup>lxi</sup>



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- A recent study showed that most seniors (93 per cent) in Canada live at home and want to stay there as long as possible.<sup>lxii</sup>
- 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.<sup>lxiii</sup>
- 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.<sup>lxiv</sup>
- 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.<sup>lxv</sup>
- Ontario found that between 20 and 50 per cent 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.<sup>lxvi</sup>

### TRAINING AND EDUCATION

- Canada currently has over 250 palliative care physicians who work either full-time or part-time.<sup>lxvii</sup>
- In early 2014, the Royal College of Physicians and Surgeons of Canada granted palliative care sub-specialty status.<sup>lxviii</sup>
- 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 equips more front-line healthcare providers with the skills and knowledge they need to care for people with life-threatening conditions.<sup>lxix</sup>
- 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.<sup>lxx</sup>
- 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.
- 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, and / 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.<sup>lxxi</sup>
- To help family caregivers provide care and advocate for their loved ones, the CHPCA, in collaboration with The GlaxoSmithKline Foundation, developed the Living Lessons<sup>®</sup> Influencing Change: A Patient and Caregiver Advocacy Guide, a handbook, as well as other training materials for family caregivers and professionals.<sup>lxxii</sup>

### ADVANCE CARE PLANNING



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- Advance care planning is a process whereby a capable (mentally competent) adult creates a plan for making personal health care decisions in the event that they become incapable (legally incompetent to personally direct) his or her own health care.<sup>lxxiii</sup>
- Effective, ongoing communication among the patient, family and health care team is essential to effective advance care planning.<sup>lxxiv</sup>
- Successful advance care planning often begins well in advance of serious illness.<sup>lxxv</sup>
- The 2012 ACCEPT Study examined current practice related to advance care planning in hospitalized patients at high-risk for dying, as well as their families. About 60 per cent 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 per cent at one site and a low of 20 per cent at another.<sup>lxxvi</sup>
- A March 2012 Ipsos-Reid poll found that 86 per cent of Canadians had not heard of advance care planning, and that less than half had had a discussion with a family member or friend about healthcare treatments if they were unable to communicate. Only 9 per cent had ever spoken to a healthcare provider about their wishes for care.<sup>lxxvii</sup>
- When asked about the importance of discussing end-of-life care with different types of individuals, six in ten Canadians surveyed (61 per cent) say that having the discussion, with at least one person, is extremely important.<sup>lxxviii</sup>

### 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 per cent it is almost twice Canada's overall world share of health research publications.<sup>lxxix</sup>

### ORGANIZATIONS THAT CAN HELP

- 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.
- 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 (*The Way Forward*). This initiative is being led by the CHPCA under the guidance of the Quality End-of-life Care Coalition of Canada. There are six 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](http://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](http://www.hpcintegration.ca).
- **CHPCA**
  - 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.
- **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.<sup>lxxx</sup>
  - In January 2010, the QELCCC released Blueprint for Action 2010 to 2020, which summarizes the QELCCC's priorities for the next 10 years:
    - Ensure all Canadians have access to high quality hospice palliative end-of-life care;
    - Provide more support for family caregivers;
    - Improve the quality and consistency of hospice palliative end-of-life care in Canada; and
    - Encourage Canadians to discuss and plan for end-of-life.<sup>lxxxi</sup>
- More information on the Coalition including reports, achievements and membership can be found at [www.qelccc.ca](http://www.qelccc.ca).

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<sup>i</sup> *Living Lessons*® (2001) The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association.

<sup>ii</sup> Murray SA, Kendall M, Boyd K, et al. Illness Trajectories and Palliative Care. *BMJ*. 2005 Apr 30; 330(7498): 1007-11



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- <sup>vi</sup> Ibid
- <sup>vii</sup> Ibid
- <sup>viii</sup> 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>
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- <sup>xvi</sup> *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."
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- <sup>xxi</sup> Office of the Auditor General of Ontario, 2014 Annual Report, Section 3.08 Palliative Care
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## LET'S TALK ABOUT HOSPICE PALLIATIVE CARE

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<sup>lxxvi</sup> Official results have yet to be published. Please go to [www.advancecareplanning.ca](http://www.advancecareplanning.ca) for more information.

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<sup>lxxviii</sup> 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).

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