



### FACT SHEET: HOSPICE PALLIATIVE CARE IN CANADA

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

#### CONTENTS

- An Overview: Access to Hospice Palliative Care in Canada ..... 2
- Demand for Hospice Palliative Care in Canada ..... 3
  - Canada’s Aging Population ..... 3
  - Chronic and Life-Limiting Illness in Canada ..... 3
  - Pediatric Hospice Palliative Care ..... 4
- Funding for Hospice Palliative Care Programs ..... 4
  - Potential Cost Savings in Canada’s Health Care System ..... 5
- Raising Awareness ..... 5
- Research ..... 6
- Settings of Care: ..... 6
  - Home Care ..... 6
  - The Role of Family and Informal Caregivers (or Carers) ..... 7
  - Residential Hospices ..... 9
  - Long Term Care ..... 9
- Professionals: Training and Education ..... 10
- Other Issues: ..... 11
  - Advance Care Planning ..... 11
  - Medical Assistance in Dying (MAiD) ..... 11
  - Bill C-277: An Act providing for the Development of a Framework on Palliative Care in Canada ..... 12
- Hospice Palliative Care Partners in Canada ..... 12
  - Quality End-of-Life Care Coalition of Canada (QELCCC) ..... 12
  - Other Partner Organizations and Initiatives ..... 13
- Definitions ..... 14
- Hospice Palliative Care Reports (1995-2017) ..... 16
  - Key Documents ..... 16
  - Reports from Health and Professional Groups ..... 16
  - Reports from the Federal Government ..... 16
- About the Canadian Hospice Palliative Care Association ..... 18
- How to Contact CHPCA ..... 18
- References ..... 19

## AN OVERVIEW: ACCESS TO HOSPICE PALLIATIVE CARE IN CANADA

*The topic of end-of-life is on people's minds. Three-quarters of Canadians (74%) report having thought about end-of-life. <sup>2</sup> Support for hospice palliative care is almost unanimous, with the vast majority of Canadians (96%) being supportive, including 66% who are very supportive.<sup>3</sup>*

- 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.<sup>4</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>5</sup>
- The Economist's Intelligence Unit ranks Canada as eleventh (falling two spots since 2010) in an international 'Quality of Death' index released in 2015. Sponsored by Singapore-based The Lien Foundation, the 'Quality of Death' index measures current hospice and palliative care environments across 80 countries in terms of the quality and availability of end-of-life care.<sup>6</sup>
- In Western Canada, when asked, most people have indicated that they would prefer to die at home in the presence of loved ones<sup>7</sup>, yet almost 70% of Canadian deaths occur in a hospital.<sup>8</sup>
- 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 or symptom-free (27%) or that there were some issues relating to pain and symptom management (24%).<sup>9</sup>
- 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.<sup>10</sup>
- 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>11</sup>
- 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.<sup>12</sup>
- As of February 2012, all provinces now have some form of palliative drug coverage for home care patients.<sup>13</sup>
- Only 6 of 13 jurisdictions have policies on providing nursing and personal care services 24 hours a day, seven days a week.<sup>14</sup>
- 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.<sup>15</sup>

## DEMAND FOR HOSPICE PALLIATIVE CARE IN CANADA

- In 2016, more than 269,000 Canadians died.<sup>16</sup> Projections also show Canada will have far more very elderly people. In 2016, there were roughly 1.5 million people aged 80 or over.<sup>17</sup> It is projected to increase to 3.3 million by 2036.<sup>18</sup>
- 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.<sup>19</sup>
- 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.<sup>20</sup>
- 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.<sup>21</sup>
- 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.<sup>22</sup>

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## CANADA'S AGING POPULATION

- 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.<sup>23</sup>
- 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.<sup>24</sup>
- The first Baby Boomers turned 65 in 2011. In 10 years, they will be entering their 80s, with younger Boomers filling out the ranks of those 60 to 70.<sup>25</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>26</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>27</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.

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## CHRONIC AND LIFE-LIMITING ILLNESS IN CANADA

- Chronic diseases account for 70% of all deaths.<sup>28</sup>
- Over 3 in 10 Canadians (32%) personally suffer from a chronic illness while 4 in 10 (39%) have a sufferer in their immediate family. When taken together, 6 in 10 Canadians (57%) either personally suffer from a chronic illness or have a sufferer in their immediate family.<sup>29</sup>
- Many disease-specific organizations have developed information and tools for Canadians. Some of these include:
  - [Canadian Cancer Society](#)
  - [Heart and Stroke Foundation](#)
  - [Alzheimer Society Canada](#)
  - [Kidney Foundation](#)

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## PEDIATRIC HOSPICE PALLIATIVE CARE

- In Canada, in a geographical area with 250,000 people and a child population of about 50,000, about 50 children are likely to have a life threatening condition and, at any given time, about half of those children will need hospice palliative care. Each year, about 5 will die from a life-threatening illness.<sup>30</sup>
- Although the number of childhood deaths each year may seem small, the emotional, social and financial impact is extraordinary. A child's death is a painful, sorrowful loss for parents, siblings, extended family members, teachers, health care caregivers, volunteers and others. During the dying journey, children and their families suffer from reduced quality of life, loss of family income, inconsistency in the availability and quality of hospice palliative care, and the lack of true choices about where the child dies (75% to 80% of deaths among children in Canada occur in hospital intensive care units which may not be the first choice for children and families).<sup>31</sup>
- The practice of hospice palliative care, which began in the 1970s, is designed to enhance choice, relieve suffering, and ensure the best quality of care during living, dying and grieving. Until recently, hospice palliative care had focused predominantly on the needs of adults who are dying, and the needs of children have been overlooked. This is changing. Groups such as Children's International Palliative Projects and Services (ChIPPS) and the Canadian Hospice Palliative Care Association Pediatric Interest Group [Canadian Network of Palliative Care for Children (CNPCC)] have brought together leaders in the field to share ideas and advance the field of pediatric hospice palliative care. They have worked to adapt the Canadian Hospice Palliative national principles and norms of practice for pediatric care.<sup>32</sup>

## FUNDING FOR HOSPICE PALLIATIVE CARE PROGRAMS

- Canadian families frequently shoulder 25% of the total cost of palliative care due to costs associated with home based services<sup>33</sup> such as nursing and personal care services.
- As Health is a provincial responsibility, funding varies from province to province.
- 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.<sup>34</sup>
- In 2016, the Federal Government announced it would provide an additional \$5 billion in funding over 10 years to several targeted initiatives, including Home Care, from which funding for palliative care would be drawn, but not until health accord agreements between the federal government and individual provinces had been negotiated. All negotiations had been concluded in the spring of 2017, however details on how the funding would be provided, reporting mechanisms from the provinces and other accountability measures have not yet been announced as individual bilateral agreements with each province were still being negotiated as of summer 2017.<sup>35</sup>
- 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.<sup>36</sup>
- There are no direct costs for patients in residential hospices.
- 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.<sup>37</sup>
- 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.<sup>38</sup>
- From 2001 to 2006, the federal government funded the Secretariat on Palliative End-of-Life Care (Health Canada) with an annual budget between \$1 million and \$1.5 million 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 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.<sup>39</sup>
- 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.<sup>40</sup>

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## POTENTIAL COST SAVINGS IN CANADA'S HEALTH CARE SYSTEM

- Depending on the estimate, expanding access to quality palliative care would have saved between \$40 million and \$345.5 million between 2003 and 2011 in the province of Ontario alone. Projected savings from 2012 to 2036 range between just under \$247 million to just over \$2.1 billion, again depending on the estimate scenario.<sup>41</sup>

## 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."*<sup>42</sup> – Dr. Harvey Chochinov

- The CHPCA hosts **National Hospice Palliative Care Week** during the first week of May each year. Themes are often drawn from the World Hospice Palliative Care Day theme.<sup>43</sup> But in 2017, HPC Week theme was: "Hospice Palliative Care is about Living Well. Right to the End." More information is available at [www.chpca.net/week](http://www.chpca.net/week).
- The CHPCA also highlights **National Carer Day** on the second Tuesday in April. It is an awareness campaign bringing attention to the work of family and informal or unpaid caregivers (or Carers). This awareness campaign was launched in 2012 in partnership with We Care Home Health Services<sup>44</sup> and is now spearheaded by [Carers Canada](http://Carers Canada). More information is available at [www.carerscanada.ca/awareness-2/%20-%20national-carer-day](http://www.carerscanada.ca/awareness-2/%20-%20national-carer-day)
- Every year on April 16, CHPCA celebrates **Advance Care Planning Day** in Canada through its [Advance Care Planning in Canada](http://Advance Care Planning in Canada) project. CHPCA brings national attention to the issue of ACP with a different theme each year, and provides free resources to the public and organizations to promote the issue. More information is available at [www.advancecareplanning.ca](http://www.advancecareplanning.ca)
- **World Hospice Palliative Care Day** is organized by the [Worldwide Palliative Care Alliance](http://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.<sup>45</sup> More information is available at [www.thewhpca.org/world-hospice-and-palliative-care-day](http://www.thewhpca.org/world-hospice-and-palliative-care-day)
- In the fall of 2017, CHPCA will launch **National Bereavement Day** to be held annually on the third Tuesday in November. This day will bring attention to bereavement issues, which form an important part of Hospice Palliative Care. For more information, visit [chpca.net/news-and-events-bereavementday](http://chpca.net/news-and-events-bereavementday).
- The GlaxoSmithKline Foundation (GSK), in partnership with the CHPCA, have created the **Living Lessons**<sup>®</sup> initiative, a public awareness and social marketing campaign designed to provide tools and resources to patients, family members, caregivers, volunteers and health care providers. More information is available at [www.eolcaregiver.com/living-lessons.aspx](http://www.eolcaregiver.com/living-lessons.aspx)

## RESEARCH

- Released in April 2017, “Investing in Canada’s Future: Strengthening the Foundation of Canadian Research” (more commonly known as the Naylor Report) has highlighted a number of deficiencies in the funding of health research in Canada, which has affected palliative and end of life research across the country. The report can be accessed here: [www.sciencereview.ca/eic/site/059.nsf/eng/home](http://www.sciencereview.ca/eic/site/059.nsf/eng/home)
- Since the launch of the Canadian Institutes for Health Research (CIHR) 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.<sup>46</sup>
- Findings published in *The New England Journal of Medicine* shed 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 were not only happier, more mobile and in less pain as the end neared – but they also lived on average nearly three months longer.<sup>47</sup>
- A 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.<sup>48</sup>
- 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.<sup>49</sup>

## SETTINGS OF CARE:

### 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%).<sup>50</sup>*

- 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.<sup>51</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>52</sup>
- If the death occurs in the home, Canadians (90%) are more likely to say that the setting matched the family member’s preference. 7 in 10 (69%) of those whose family member died in a hospital believe the same.<sup>53</sup>
- 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*.<sup>54</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>55</sup>

- A recent study showed that most seniors (93%) in Canada live at home and want to stay there as long as possible.<sup>56</sup>
- In 2016, the Canadian Home Care Association (CHCA), the Canadian Nurses Association (CNA) and the College of Family Physicians of Canada (CFPC) worked together to create the Better Home Care: A National Action Plan, with the goal of recommending ways to enhance home care and respond to the changing health needs of Canadians as well as embrace advances in health technology. The Action Plan suggests ways to make home care 1) more available and accessible 2) achieve better health outcomes and quality of care and 3) Improve the experiences of individuals receiving health care and support. The plan can be downloaded at: <http://www.thehomecareplan.ca><sup>57</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>58</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>59</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>60</sup>
- 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. In addition, hospice palliative care services and treatment can lead to better outcomes, such as improvement of symptoms and reduced caregiver burden, while reducing costs.<sup>61</sup>

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## THE ROLE OF FAMILY AND INFORMAL CAREGIVERS (OR CARERS)

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*“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 of the United States*

- 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>62</sup>
- The average number of hours per week that Canadians expect for caring for a dying family member is 54.4.<sup>63</sup>
- Expectations of commitment have increased. More Canadians in 2013 expected that proper care would require two or more days of commitment each week (73%) compared to 10 years ago (59%).<sup>64</sup>
- 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.<sup>65</sup>
- 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%).<sup>66</sup>
- In 2016, 16% of Canadians said that they had cared for a family member or close friend with a serious health problem in the last 12 months, and 33% of them were caring for other family members like children simultaneously. Adverse effects on this group of people included: using personal savings to survive (40%) and missing one month or more of work (20%).<sup>67</sup>
- While these caregivers are most likely to rely on the doctor for care of their loved one, less than half say the support and information they need is often available, and only one fifth say it is always available.<sup>68</sup>



- 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%).<sup>69</sup>
- In 2007, 2.7 million Canadian family caregivers over the age of 45 were helping seniors with long-term health conditions.<sup>70</sup>
- Many leading-edge global companies such as GSK and Innovative Medicines Canada 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.<sup>71</sup>
- In 2016, CHPCA launched the Canadian Compassionate Companies program. The Canadian Hospice Palliative Care Association and its Champion's Council will award the designation of a CCC if your company meets at least three out of five of the following criteria:
  1. Your company has a HR policy that lays out a Companionate Care Leave Benefit (CCLB) endorsing the job protected family medical Employment Insurance benefit currently at 26 weeks.
  2. Your employees' jobs are protected while they are off on the CCLB program.
  3. Compassionate Care leave could provide employees with income top-up of benefits over and above the job protected family medical EI benefits leave offered through the provinces and the Federal EI program.
  4. Your company has a caregiver accommodation policy that allows for support and flexibility within economic reason.
  5. Your company will promote Advance Care Planning (ACP) using resources and tools at [www.advancecareplanning.ca](http://www.advancecareplanning.ca) or create their own materials.<sup>72</sup>
- 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 experience.<sup>73</sup>
- 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.<sup>74</sup>
- 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.<sup>75</sup>
- 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 to 26 billion annually, while incurring \$80 million dollars annually in out-of-pocket costs.<sup>76</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>77</sup>
- 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.<sup>78</sup>
- 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.<sup>79</sup>
- 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.<sup>80</sup>
- 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%.<sup>81</sup>



- 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%.<sup>82</sup>
- 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.<sup>83</sup>
- 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.<sup>84</sup>
- 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.<sup>85</sup>
- In late 2013, the CHPCA re-launched 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. It is available for order at <http://market-marche.chpca.net/>.

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## RESIDENTIAL HOSPICES

- Currently, there are 88 residential hospices in Canada (as of August 2017).
- Hospices provide end-of-life services to patients suffering from all illnesses, not just cancer.
- Hospices have residents of a variety of ages, not just the elderly, and can include children, although there are also pediatric hospices who care only for children and adolescents with life-limiting or terminal illnesses.
- In Canada, both terms "palliative care" and "hospice care" are used to refer to the same thing - this specific approach to care. However, some people use hospice care to describe care that is offered in the community rather than in hospitals or other settings of care. In the U.S., they are viewed differently: both palliative care and hospice care provide comfort. But palliative care can begin at diagnosis, and at the same time as treatment. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness.<sup>86</sup>
- A residential hospice differs from palliative care programs in other settings in that patients come to live at the hospice where their full end-of-life needs are met including pain and symptom management, nutrition, additional therapeutic services, and support for family or loved ones both during the illness, and after death, in the case of the latter.
- There is no cost to a person living in a residential hospice.
- Support services are provided to the family members of patients in a hospice both during the illness, and after their death.
- How to find a Hospice : <http://www.chpca.net/family-caregivers/directory-of-services.aspx>

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## LONG TERM CARE

- Long-term care facilities or Residential care is one setting of care in which hospice palliative care is administered.
- As of 2013, there were 1334 facilities with 147,926 beds in Canada
- 82.7% of the residents are over 75 years old
- Of those facilities, homes spend \$10,290,102,000 in expenses which includes palliative care expenditures
- About 66% of the total spending is on salaries
- The facilities employed the equivalent of 126,979 full time employees

## PROFESSIONALS: TRAINING AND EDUCATION

*Hospice palliative care is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.<sup>87</sup>*

- A revised edition of the CHPCA National Norms of Practice was launched in late 2013 and is available at [www.chpca.net/norms](http://www.chpca.net/norms).
- **Physicians:** In the 2014 National Palliative Medicine Survey, 183 physicians identified themselves as family physicians with a focused practice in palliative care or specialists/subspecialists in palliative medicine. These physicians worked an average of over 35 hours/week in palliative medicine. 931 respondents indicated that they provide palliative care consultations on a limited basis, averaging 7 hours per week. This is an important fact as we work to establish the size and nature of the workforce that will be required to meet the growing palliative care needs of Canadians.<sup>88</sup>
- In early 2014, the Royal College of Physicians and Surgeons granted palliative care sub-specialty status.<sup>89</sup>
- **Nurses:** As of February 2017, there are 1338 Canadian Nurses Association (CNA)-certified Hospice Palliative Care Nurses in Canada.<sup>90</sup>
- 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.<sup>91</sup>
- **Social Workers:** 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 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.<sup>92</sup>
- The Quality End-of-Life Care Coalition of Canada (QELCCC) 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>93</sup>
- 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.<sup>94</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**® *Influencing Change: A Patient and Caregiver Advocacy Guide*, a handbook, as well as other training materials for family caregivers and professionals.<sup>95</sup>
- CHPCA also distributes copies of the widely renowned "A Caregivers Guide: A Handbook about End-of-Life Care" via its online [Marketplace](#).

## OTHER ISSUES:

### 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.<sup>96</sup>*

- 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.advancecareplanning.ca](http://www.advancecareplanning.ca).
- Effective, ongoing communication among the patient, family and health care team is essential to effective ACP.<sup>97</sup>
- Successful ACP often begins well in advance of serious illness.<sup>98</sup>
- 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.<sup>99</sup>
- 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 ill and unable to communicate. Only 9% had ever spoken to a healthcare provider about their wishes for care.<sup>100</sup>
- When asked about the importance of discussing end-of-life care with different types of individuals, 6 in 10 Canadians surveyed (61%) say that having the discussion is extremely important with at least one individual.<sup>101</sup>
- The majority of Canadians (52%) indicate that the advance care planning process should begin when a person is healthy, yet only 13% have an advance care plan prepared.<sup>102</sup>
- Three-quarters of Canadians would turn to their family physician (73%), for more information on hospice palliative care services.<sup>103</sup>
- *Challenges and Issues in 2010: The Quality End-of-Life Care Coalition of Canada* states that one of the key challenges over the next 10 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.<sup>104</sup>

### MEDICAL ASSISTANCE IN DYING (MAID)

- Bill C-14, called An Act to amend the Criminal Code and to make related amendments to other Acts (or Medical Assistance in Dying) was tabled on April 14, 2016 in response to the Supreme Court of Canada *Carter vs Canada* decision of February 6, 2015. On June 16, it passed into law and in the following months, Provincial Medical Regulators provided guidelines for their members while provincial governments moved to introduce or pass legislation to implement the new law. It is up to individual facilities – including residential hospices – to decide if they wish to allow MAID to be performed on site at all, and whether to be directly involved in providing the service or allowing outside organizations to perform the service on site. More information about MAID is available on the government of Canada website: [healthycanadians.gc.ca](http://healthycanadians.gc.ca) under "Health system and services", "Health services", "End-of-Life Care".
- CHPCA created a Q&A Guide for Health Care professionals and hospice volunteers to navigate conversations from patients and their families about MAiD. It is available for download by [clicking here](#) .

- The general public strongly supports all scenarios to help those reaching the end of their life. While MAiD receives less support than options which help to support and comfort those dying and their families, 70% of the public express support for MAiD, with 55% supporting this option strongly.<sup>105</sup>
- Among health care providers, MAiD does receive support from the majority, however this support is not as strong as what is seen by the general public, nor is it as strong as other end-of-life care options: Roughly 90% support enhanced pain management, home care and hospice care, but there is less support for medically assisted death, particularly among doctors, of whom only 58% show any support.<sup>106</sup>

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#### BILL C-277: AN ACT PROVIDING FOR THE DEVELOPMENT OF A FRAMEWORK ON PALLIATIVE CARE IN CANADA

- In 2016, Member of Parliament Marilyn Gladu introduced a private member's bill (PMB) in the House of Commons, calling on the federal government to develop a palliative care framework. The text of the bill (C-277) can be viewed by [clicking here](#).
- Bill C-277 was studied by the House of Commons Standing Committee on Health (HESA), who heard witness testimony in March 2017, including CHPCA. Following some minor amendments, it was then passed by the House of Commons and sent to the Senate for review. Report 8 from HESA and testimony from witnesses can be viewed by [clicking here](#).
- Legislative progress on the legislation can be viewed by [clicking here](#).

#### HOSPICE PALLIATIVE CARE PARTNERS IN CANADA

*While CHPCA is the National voice for hospice palliative care in Canada, there are number of partner organizations with whom we work hand in hand to further the goal of access to quality hospice palliative care in Canada.*

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#### 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 39 national associations and organizations with an interest in end-of-life care issues.<sup>107</sup>
- 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.<sup>108</sup>
- The Way Forward Initiative project was led by the QELCCC and managed by the CHPCA from 2011-2014. Over three years, the initiative developed a framework for the integration of the palliative approach to care.<sup>109</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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#### 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 was led by the CHPCA under the guidance of the Quality End-of-life Care Coalition of Canada (QELCCC).
- *The Way Forward* conducted a poll through Harris/Decima, which was released in December 2013. For the full report, please visit [www.hpcintegration.ca](http://www.hpcintegration.ca)

- There are also six other discussion documents available on *The Way Forward* initiative all of which are available at [www.hpcintegration.ca](http://www.hpcintegration.ca):
  - 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 three 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
  - The Way Forward: Impact and Lessons Learned

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#### OTHER PARTNER ORGANIZATIONS AND INITIATIVES

- [Canadian Society of Palliative Care Physicians](#)
- [Canadian Virtual Hospice](#)
- [Pallium Canada](#)
- [Palliative Care Matters](#)

## DEFINITIONS<sup>110</sup>

### HOSPICE PALLIATIVE CARE

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Care that aims to relieve suffering and improve the quality of life.

\*A more detailed definition taken from *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Revised and Condensed Edition: 2013* is available here: <http://www.chpca.net/about-us.aspx>

### ADVANCE CARE PLANNING

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A process people can use to: think about their values and what is important to them with regard to their health care choices; explore medical information that is relevant to their health; communicate their wishes and values to their loved ones, substitute decision-maker and health care team; and record their health care choices and decisions in the event they can no longer speak for themselves. The process may involve discussions with their health care providers and people who are significant in their lives. Advance care planning may result in the creation of an advance directive or “living will”, which is a person’s formal or informal instructions about their future care and choice of treatment options.

### CAREGIVER (OR CARER)

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Anyone who provides care. Formal caregivers are members of an organization and accountable to defined norms and professional standards of practice. They may be professionals, support workers, or volunteers. They are sometimes called “providers.” Family caregivers are not members of an organization. They are family members and other significant people (as identified by the care recipient) who provide unpaid care and assistance to individuals living with a debilitating physical, mental or cognitive condition. Family caregivers usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards or practice.

### ILLNESS

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Absence of wellness due to disease, other conditions, or aging.

- An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening.
- A chronic illness is likely to persist for months to years. If it progresses, it may become life threatening.
- An advanced illness is likely to be progressive and life threatening.
- A life-limiting illness is one that affects health and quality of life, and can lead to death in the near future.
- A life-threatening illness is likely to cause death in the immediate future.

### CHRONIC DISEASE

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A chronic disease is one that may develop slowly, last a long time, be incurable, and be progressive and/or life-limiting. Examples of life-limiting chronic diseases include cardiovascular disease, chronic kidney disease, congestive heart failure, diabetes, dementia, emphysema, multiple sclerosis, amyotrophic lateral sclerosis and some forms of cancer. The disease and its treatment may cause symptoms such as fatigue, pain and sleep problems; they can also limit people’s activities, cause them psychological distress and have a negative effect on their quality of life. A chronic disease can’t be cured but its symptoms can be managed.

## INTERDISCIPLINARY, MULTIDISCIPLINARY OR INTERPROFESSIONAL TEAM

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Caregivers with different training and skills who work together to develop a team and implement a person's plan of care. Membership varies depending on the services required to address the person's and family's identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers, psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

## SETTING OF CARE

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The location where care is provided. Settings of care may include the person's home, primary care setting (e.g., a doctor's office, nursing station, community clinic), an acute, chronic, or long-term care facility, a hospice or palliative care unit, a jail, a homeless shelter.

## PAIN AND SYMPTOM MANAGEMENT

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Pain and other symptoms that cause discomfort (e.g., shortness of breath, fatigue, changes in mood or functional ability, psychosocial or spiritual distress) can be caused by underlying diseases. They can also be caused by the treatments for those diseases, the side effects of treatments and the process of aging. The integrated palliative approach to care focuses on helping people manage pain and other symptoms as a way to reduce discomfort and improve quality of life. Many different techniques can be used to manage symptoms, including medication, exercise (physiotherapy), breathing, meditation, the use of heat and cold, biofeedback processes, diet, repositioning, counselling and psychosocial and spiritual support.



## HOSPICE PALLIATIVE CARE REPORTS (1995-2017)

The following list of key reports and documents about palliative care in Canada listed in reverse chronological order (2017 back to 1995):

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### KEY DOCUMENTS

- (March 2015) The Way Forward - [The National Framework: A Roadmap for an Integrated Palliative Approach to Care](#)
- (2010) [QELCCC Blueprint for Action: 2010-2020](#)

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### REPORTS FROM HEALTH AND PROFESSIONAL GROUPS

- (2017) [Economics of Palliative Care](#) - CSPCP
- (2016) [Right to Care: Palliative Care for All Canadians](#) – Canadian Cancer Society
- (2016) [Palliative Care Matters Consensus Statement](#) - Palliative Care Matters
- (November 2016) [How to improve palliative care in Canada](#) - Canadian Society of Palliative Care Physicians

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### REPORTS FROM THE FEDERAL GOVERNMENT

- (November 2002) [Building on Values: The Future of Health Care in Canada: Final report of the royal commission on the Future of health care in Canada](#). Author: Roy J. Romanow, QC, Commissioner. *Two of the 47 recommendations specifically relate to palliative care*

### THE SENATE OF CANADA

- (March 2012) [Time for Transformative Change: A Review of the 2004 Health Accord Final report of the standing senate committee on social Affairs, science and technology](#).
- (January of 2011) the standing senate committee on social Affairs, science and technology was charged with examining and reporting on the progress in implementing the 2004, 10-Year Plan to Strengthen Health Care. This report was more generally about the reform of the 2004 health Accord and tabled 46 recommendations based on 13 hearings and one roundtable discussion. Six of the recommendations focused on hospice palliative care.
- (April 2009) [Canada's Aging Population: Seizing the Opportunity](#). Final report of the special senate committee on Aging. Author: the Honourable Sharon Carstairs, PC., Chair. Made 17 recommendations.
- (June 2005 ) [Still Not There. Quality End-of-Life Care: A Progress Report](#). Author: The honourable Sharon Carstairs, PC. - 8 of its 32 recommendations are specifically related to palliative and end-of-life care and caregivers.
- (October 2002) [The Health of Canadians – The Federal Role: Volume six: recommendations for reform](#). Final report of the standing senate committee on social Affairs, science and technology.
- (June 2000 ) [Quality End-of-Life Care: The Right of Every Canadian](#): Final report of the subcommittee to update of life and death of the standing senate committee on social Affairs, science and technology.
- (June 1995 ) [Of Life and Death: Final report of the special senate committee on euthanasia and Assisted suicide](#).

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### THE HOUSE OF COMMONS

- (November 2011) [Not to Be Forgotten: Care of Vulnerable Canadians](#). Final report of the ad hoc Parliamentary committee on Palliative and compassionate care.

- (June 2010 ) [Raising the Bar: A Roadmap for the Future of Palliative Care in Canada](#). All party committee of Members of the Senate of Canada and House of Commons. Eleven of the 14 recommendations concern palliative care and support for caregivers.

#### HEALTH CANADA:

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- (2009) [The 'How-To' Guide to Hospice Palliative Care Twinning Projects](#)
- (2008) [Implementation Guide to Advance Care Planning in Canada: A Case Study of Two Health Authorities](#)
- (2007) [Canadian Strategy on Palliative and End-of-Life Care: Final Report](#)
- (2006) [Advance Care Planning: The Glossary Project: Final Report](#)
- (2006) [Hospice Palliative Care: Public Awareness Raising Framework](#)
- (2005) [Canadian Strategy on Palliative and End-of-Life Care: Progress Report of the Coordinating Committee: December 2002 to March 2004](#)
- (2005) [The information needs of informal caregivers involved in providing support to a critically ill loved one](#)
- (2002) [National Action Planning Workshop on End-of-Life Care](#)

## ABOUT THE CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION

*"THAT ALL CANADIANS HAVE ACCESS TO QUALITY END-OF-LIFE CARE."*

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.

## HOW TO CONTACT CHPCA

### MAILING ADDRESS

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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](mailto:info@chpca.net)

### WEBSITE

<http://www.chpca.net>

### SOCIAL MEDIA

Facebook: <https://www.facebook.com/CanadianHospicePalliativeCare>

Twitter: <https://twitter.com/CanadianHPCAssn>

Instagram: <https://www.instagram.com/cdnhpcassn/>

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