



FACT SHEET:  
**HOSPICE  
PALLIATIVE  
CARE IN CANADA**



**Canadian Hospice Palliative Care Association**  
**Association canadienne de soins palliatifs**



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# FACT SHEET: HOSPICE PALLIATIVE CARE IN CANADA



## HOW TO USE THIS DOCUMENT

This document is a collection of current statistics and knowledge of hospice palliative care in Canada. Whether you are receiving care, are a health care professional, a caregiver or are interested in learning more about hospice palliative care in Canada, CHPCA hopes this document is helpful. Please note that this document is not all encompassing, rather it represents a sweeping look at hospice palliative care in Canada. If you conduct research, or have information you'd like to share for next year's fact sheet, please send to [info@chpca.net](mailto:info@chpca.net)

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## Death and dying in 21<sup>st</sup> century Canada

**In Canada, there is approximately one death every two minutes (Statistics Canada, 2019)**

- ▶ While Canadians are living longer, they are not always living better caused by chronic conditions, degenerative diseases or cancer (Canadian Institute for Health Information, 2018)
- ▶ By 2026, the number of deaths in Canada is projected to increase to 330,000, and to 425,000 by 2036 frailty (Government of Canada, 2018)
- ▶ Of the 270,000 Canadians who die each year, 90% die of chronic illness, such as cancer, heart disease, organ failure, dementia or frailty (Government of Canada, 2018)

## Access to Hospice Palliative Care in Canada

**Between 62% and 89% of those who die could benefit from palliative care — including nearly everyone who does not die unexpectedly (CIHI, 2018)**

- ▶ 1 in 6 Canadians (15%) who died in 2016-2017 received publically funded palliative home care in their last year of life (Health Canada, 2018a)
- ▶ 62% of Canadians who received palliative care did so in an acute care hospital in their last month of life (CIHI, 2018)
- ▶ (86%) of Canadians expect the federal government to develop and implement national standards for palliative care (Morrison, 2018)
- ▶ 9-in-10 (89%) Canadians agree that a document outlining the federal government's plan for implementing a palliative care program should be readily available for all Canadians (Morrison, 2018)
- ▶ 85% of the public support for integrating national standards for palliative healthcare services into the Canada Health Act (Morrison, 2018)
- ▶ Few Canadians (15%) have early access to palliative care in the community (CIHI, 2018)
- ▶ Canadians who got palliative care at home were 2.5 times more likely to die there than those who received regular home care (CIHI, 2018)
- ▶ 80% of the time, palliative care was provided during admission was unplanned or through an emergency department (CIHI, 2018)



## Canada's Aging Population

- ▶ Canadians between the ages of 45 and 74 are more likely than younger adults and older seniors to receive palliative care (CIHI, 2018)

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- ▶ By 2036, the average life expectancy at birth for women will be 86.2 years and 82.9 for men (Government of Canada Report on Seniors, 2014)

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- ▶ Approximately 88% of new cancer diagnoses and 95% of cancer deaths occur among Canadians over 50 years of age (Government of Canada, 2018c)

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## Chronic and Life Limiting Illness in Canada

- ▶ By 2030—in less than two decades—seniors will number over 9.5 million and make up 23 percent of Canadians (Government of Canada Report on Seniors, 2014)

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- ▶ The likelihood of being diagnosed with cancer increases with each decade of life, from 29 cases per 100,000 in Canadians less than 30 years of age to more than 2,200 cases per 100,000 among Canadians aged 80 to 89 years (Government of Canada, 2018c)

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- ▶ Canadians with cancer are 3 times more likely to receive palliative care than Canadians with other conditions (CIHI, 2018)

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- ▶ 44% of adults 20+ have at least 1 common chronic diseases like,
  - hypertension (25%),
  - osteoarthritis (14%),
  - mood and/or anxiety disorder (13%),
  - osteoporosis (12%),
  - diabetes (11%),
  - asthma (11%),
  - chronic obstructive pulmonary disease (10%),
  - ischemic heart disease (8%),
  - cancer (8%)
  - and dementia (7%) (Public Health Agency of Canada, 2018)

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## Pediatric Hospice Palliative Care

**21 million children around the world need palliative care, with approximately eight (8) million of them needing specialist palliative care (Connor et al., 2018)**

- ▶ The number of children who received specialized pediatric palliative care in Canada more than quadrupled between 2002 and 2012 (Widger et al., 2016)

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- ▶ 51% of the children who died in 2012 received these services only for the last 30 days of their lives (Widger et al., 2016)

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- ▶ Barriers to receiving pediatric palliative care include uncertain prognosis (55%), family not ready to acknowledge incurable condition (51%), language barriers (47%), and time constraints (47%) (Davies, Sehring et al., 2008)

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## Funding for Hospice Palliative Care Programs

- ▶ The Government of Canada is engaging provinces across Canada with a confirmed investment of \$11 billion over a ten year timeframe. While the original report focuses on two priority areas (home and community care which includes palliative care, and mental health and addiction.

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- ▶ \$1.9 million over three years to the Canadian Hospice Palliative Care Association to help Canadians prepare for their future health care needs, including through public education and awareness, community workshops, and a renewed strategy to promote advance care planning.

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- ▶ \$2 million over three years to the Canadian Virtual Hospice to expand existing virtual services and resources for palliative care and grief support to meet the needs of underserved communities, including families caring for a dying child, Francophones, and LGBTQ2 communities.

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- ▶ \$600,000 over two years to the Canadian Home Care Association to help improve delivery of palliative care at home and communication with patients, families, and caregivers.

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## Potential Cost Savings in Canada's Health Care System

### Canada has higher mean per capita hospital expenditures and the highest proportion of people dying in acute care hospital settings (Bekelman et al., 2016)

- ▶ Admission costs were reduced by 40 per cent when palliative care consultation was received within 48 hours of admission (Canadian Society of Palliative Care Physicians, 2017)

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- ▶ Shifting care from a hospital setting to in-home community-based care resulted in cost savings of \$1,677 per child per month on average—an 11% decrease in spending on a traditionally high-cost population (Gans, Kominski et al., 2012)

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- ▶ Palliative care savings are achieved through various ways, including:
  - Reducing the overall length of hospital stay
  - Moving patients from hospital to home or to hospice facilities, at a lower cost per day than acute care
  - Reducing the number of ICU admissions
  - Reducing unnecessary diagnostic testing
  - Reducing inappropriate disease-targeting interventions (Canadian Society of Palliative Care Physicians, 2017)

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## Raising Awareness

- ▶ National Hospice Palliative Care Week – The first week of May marks National Hospice Palliative Care week. This week is dedicated to celebrate achievements, share knowledge and raise awareness of issues surrounding hospice palliative care in Canada.

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- ▶ World Hospice Palliative Care Week – October 12th 2019 people from around the world who have been impacted by a life-limiting illness -- either personally or by supporting a loved one advocate for policy makers to pay attention to prioritize palliative care policies and services.

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## Research

- ▶ Research gaps exist on the access to palliative care, notably at the community level, where data is lacking on home care, hospice care and residential care (Canadian Institute for Health Information, 2018)
- ▶ 2012–2017: research funding by the CIHR of \$494 million to support research on aging — some of which directly impacts palliative care, e.g. \$14.8 million on research related to palliative care in cancer.
- ▶ Other investments indirectly support palliative care, e.g., the Team Grant in Late Life Issues — a four year grant of \$2.8 million to build research capacity and provide high-quality evidence to inform health and social care professionals and policy makers.

## Settings of Care

### Home Care

**99% of palliative care received at home was provided by family or friends, making it possible for them to stay there (Canadian Institute for Health Information, 2018)**

- ▶ Canadians who got palliative care at home were 2.5 times more likely to die there than those who received regular home care (CIHI, 2018)
- ▶ Residents who received palliative care in their long-term care home were more likely to die there than residents who did not receive palliative care in the last year of life (CIHI, 2018)
- ▶ People who received palliative home care in their last year of life were 2.5 times more likely to die at home than other home care clients (CIHI, 2018)

### Residential Hospices

- ▶ In Canada, there are 88 residential hospices (CIHI, 2018)
- ▶ The majority of hospices require patients to have a life expectancy of 3 months or less to be admitted. (CIHI, 2018)

### Long Term Care

- ▶ Almost 30,000 people died in long-term care facilities in 2016–2017, or 17% of all deaths in those jurisdictions (CIHI, 2018)
- ▶ People who received palliative care in their long-term care residence were less likely to die in hospital than other long-term care residents (CIHI, 2018)
- ▶ Of those who died in 2016–2017 who were long-term care residents in their last year of life,
- ▶ 97% who received palliative care in long-term care died in their residence while 2% died in hospital; and
- ▶ 77% of those without formal palliative care died in their long-term care facility and 18% — or 1 in 5 — died in hospital (CIHI, 2018)
- ▶ Those admitted to long-term care stay for an average of 2 years, and most remain there until the end of life (CIHI, 2018)





## Settings of Care (cont'd)

### Palliative care in hospitals

**When community support is insufficient, many Canadians must rely on hospitals for palliative care. Even though more people (42%) of Canadians – or about 116,000 people – died in acute care hospitals in 2016–2017. At least some patients and their families associated hospital deaths with more distress (CIHI, 2018)**

- ▶ Of people who died in acute care hospitals across Canadian provinces and territories in 2016–2017, 25% received primarily palliative care, which means they were identified as palliative patients for the longest portion of their hospital stay (CIHI, 2018)
- ▶ Many patients (44%) who died in hospital were initially admitted for an acute health problem, but they were later designated as palliative patients (CIHI, 2018)

## The Role of Family and Informal Caregivers (or Carers)

- ▶ More than six million people – 35% of our workforce – provide unpaid, informal care while balancing job responsibilities (Government of Canada, 2015)
- ▶ 80% of care is most often provided by informal caregivers like family, friends and neighbours (Fast, 2009)
- ▶ About 1 in 3 caregivers reported distress (CIHI, 2018)
- ▶ As the time they spend providing care increases, so does the distress they experience (CIHI, 2011)
- ▶ 37% to 40% say that caregiving has had an impact on family relationships, and 48% say it has affected friendships (The Change Foundation, 2018)
- ▶ 7% are caring for children with exceptional needs, such as a disability or chronic (The Change Foundation, 2018)
- ▶ Estimates of the imputed economic contribution of unpaid caregivers for Canada, for 2009, would be \$25-\$26 billion (Hollander et al., 2009)
- ▶ 57% of workplaces try to make concessions to allow their employees to handle caregiving responsibilities; 32% say their workplace doesn't try to accommodate (The Change Foundation, 2018)
- ▶ 15% of caregivers postponed enrolling in an education or training program because of their caregiving duties (The Change Foundation, 2018)

### Long Term Care

- ▶ Young carers are considered between the ages of 16 to 24 (The Change Foundation, 2018)
- ▶ Young carers tend to downplay their role and are less likely to consider themselves a caregiver (The Change Foundation, 2018)
- ▶ One-third feel stressed about many of their responsibilities (The Change Foundation, 2018)
- ▶ One quarter are using personal finances or savings to pay for caregiving expenses (The Change Foundation, 2018)



## Professionals: Training and Education

- ▶ Data from an international survey of primary care physicians shows that Canadian doctors feel less prepared to manage care for palliative patients than do their peers in 10 other countries (CIHI, 2018)

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- ▶ Although 90% of medical curricula have lectures related to palliative care, there is little mentorship and just 12% of students were required to participate in mandatory clinical rotations in palliative care (CIHI, 2018)

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- ▶ Few residents are exposed to hands-on palliative care training – 18% in acute care facilities, 16% in palliative care units within an acute care setting, 18% in cancer centres and 11% in a community or outpatient environment (CIHI, 2018)

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- ▶ There are few faculty positions in Canadian universities to address undergraduate and postgraduate needs for education in palliative care (CIHI 2018)

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## Accessibility Issues

- ▶ While the northern population represents about 6% of the population of Ontario, barriers to providing health care in this area are numerous and include geography, health care system eligibility criteria, limitations of the available workforce, palliative care educational deficits, as well as differences in cultural competencies (Michael SC Conlon et al., 2019)

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- ▶ Among these challenges are system capacity issues, lack of understanding of the benefits of hospice palliative care among health care professionals and the public, geography and demographic diversity of care (CIHI, 2018)

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## Advance Care Planning

### Summary of findings from Canadian Hospice Palliative Care (CHPCA) survey Canadians are thinking about end-of-life care but few have taken action (2019) <sup>1</sup>

- ▶ 80% of people in Canada think it is important to do Advance Care Planning Yet less than 1 in 5 people in Canada have an Advance Care Plan

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- ▶ People in Canada value conversations about their future or personal health care

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- ▶ 93% think it's important to discuss it with family and friends, but only 36% did

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- ▶ 80% think it's important to discuss it with a health care provider, but only 8% did

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- ▶ 66% think it's important to discuss it with a lawyer, but only 7% did

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### *People think conversations should start early*

- ▶ 40% between 35 to 54 years of age

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- ▶ 36% when they are healthy

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- ▶ 28% when they are making their will

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- ▶ 11% when diagnosed with a serious illness

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<sup>1</sup> These observations are based on an online survey of 2,948 Canadians, 18 years of age or older, conducted between February 6th and 25th 2019. Participants were recruited from an online panel and administered a survey online.





## Medical Assistance in Dying (MAiD)

- ▶ As of December 31, 2017, more than 3,700 medically assisted deaths were recorded across the Canada (CIHI, 2018)

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- ▶ 40.5% of assisted deaths occur in hospital (Health Canada, 2018b)

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- ▶ 43.3% in patients home (Health Canada, 2018b)

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- ▶ 16.2% long term care or assisted living facilities (Health Canada, 2018b)

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- ▶ The average age of those who died was 73 years (CIHI, 2018)

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- ▶ Medical assisted deaths were almost equally divided among men (49%) and women (51%) (Health Canada, 2018b)

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- ▶ The proportion hospitalized primarily for palliative care was higher than for other people who died in hospital (25%) (Health Canada, 2018b)

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- ▶ 30% of all people who received assistance in dying at a hospital were identified as having palliative needs prior to their hospital admission (Health Canada, 2018b)

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- ▶ Approximately 14% of requests for medical assistance in dying were unfulfilled because the patient died prior to completion of the assessment process (Health Canada, 2018b)

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# Hospice Palliative Care Reports and Key Documents

The following list of key reports and documents about palliative care in Canada listed in reverse chronological order (2019 to 1995):

## Key Documents

- ▶ [\(2018\) QELCCC Key Messages](#)
- ▶ [\(2015\) The Way Forward](#) - The National Framework: A Roadmap for an Integrated Palliative Approach to Care
- ▶ [\(2010\) QELCCC Blueprint for Action: 2010-2020](#)

## Reports from Health and Professional groups

- ▶ [\(2018\) Access to Palliative Care in Canada](#) - Canadian Institute for Health Information
- ▶ [\(2018\) Medical Assistance in Dying](#) - Canadian Council of Academies
- ▶ [\(2017\) Economics of Palliative Care](#) - Canadian Society of Palliative Care Physicians
- ▶ [\(2016\) Right to Care: Palliative Care for All Canadians](#) - Canadian Cancer Society
- ▶ [\(2016\) Palliative Care Matters Consensus Statement](#) - Palliative Care Matters
- ▶ [\(2016\) How to improve palliative care in Canada](#) - Canadian Society of Palliative Care Physicians

## Reports from the Federal Government

- ▶ [\(2018\) Framework on Palliative Care in Canada](#)
- ▶ [\(2017\) A Common Statement of Principles on Shared Health Priorities](#)
- ▶ [\(2014\) Action for Seniors Report](#)
- ▶ [\(2002\) Building on Values: The Future of Health Care in Canada: Final report of the royal commission on the Future of health care in Canada. Two of the 47 recommendations specifically relate to palliative care](#)



# Hospice Palliative Care Reports and Key Documents (cont'd)

## The Senate of Canada

- ▶ [\(2017\) Framework on Palliative Care in Canada Bill C-277](#)
- ▶ [\(2012\) Time for Transformative Change: A Review of the 2004 Health Accord](#)
- ▶ (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 (6) of the recommendations focused on hospice palliative care.
- ▶ [\(2009\) Canada's Aging Population: Seizing the Opportunity](#). Final report of the special senate committee on Aging
- ▶ [\(2005\) Still Not There. Quality End-of-Life Care: A Progress Report Eight](#) (8) of its 32 recommendations are specifically related to palliative and end-of-life care and caregivers.
- ▶ [\(2002\) The Health of Canadians – The Federal Role: Volume. Six](#) (6) recommendations for reform. Final report of the standing senate committee on social Affairs, science and technology.
- ▶ [\(2000\) 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.](#)
- ▶ [\(1995\) Of Life and Death: Final report of the special senate committee on euthanasia and Assisted suicide.](#)

## The House of Commons

- ▶ [\(2011\) Not to Be Forgotten: Care of Vulnerable Canadians](#). Final report of the ad hoc Parliamentary committee on Palliative and compassionate care.
- ▶ [\(2010\) 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

- ▶ [\(2009\) 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

## **OUR MISSION:** “That all Canadians have access to quality hospice palliative care.”

The CHPCA is the national voice for Hospice Palliative Care in Canada. Advancing and advocating for quality hospice palliative care in Canada, its work includes public policy, public education and awareness. Established in 1991, its volunteer Board of Directors is composed of hospice palliative care workers and volunteers from Canadian provinces and territories as well as members-at-large. 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.

## Hospice Palliative Care Partners in Canada

### **QUALITY END-OF-LIFE CARE COALITION OF CANADA**

The Quality End-of-Life Care Coalition of Canada (QELCCC) is a group of over 35 national organizations dedicated to advocating that “all Canadians have the right to die with dignity, free of pain, surrounded by their loved ones and in a setting of their choice” (QELCCC, 2015). The Coalition believes that to achieve quality end-of-life care for all Canadians there must be a well-funded, sustainable national strategy for hospice palliative care. The QELCCC advocates for the creation of A Canadian Hospice Palliative Care Implementation Collaborate as part of the Framework on Palliative Care in Canada (2018) that will enable a fully engaged strategy with a patient-centric approach to hospice palliative care.

### **Other Partner Organizations and Initiatives**

- Canadian Society of Palliative Care Physicians
- Canadian Virtual Hospice
- Pallium Canada
- Palliative Care Matters

## How to Contact CHPCA

### **MAILING ADDRESS:**

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# Definitions

## HOSPICE PALLIATIVE CARE

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 (ACP)

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)

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

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.
- An 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

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

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

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.



# Definitions (cont'd)

## PAIN AND SYMPTOM MANAGEMENT

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.

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