



Canadian Cancer Society  
Société canadienne  
du cancer

# Right to Care: Palliative care for all Canadians



# About this report

The Canadian Cancer Society (the Society) is a national, community-based organization of volunteers whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. We are working towards a world where no Canadian fears cancer.

This report highlights the major gaps in care and existing barriers to ensuring all Canadians have access to quality palliative care, when they need it. It outlines the importance of palliative care in healthcare delivery, and in particular, for Canadians dealing with cancer. By doing so, the Society strives to inform our advocacy and information delivery activities as well as those of our partners, such as governments and other organizations, so that we can improve accessibility, affordability and quality of palliative care for all Canadians affected by a life-altering illness.

## Methodology

The information in this report was gathered from relevant academic articles, grey literature and websites from palliative care researchers, research institutes, governments and non-governmental organizations. Though efforts were made to collect all relevant information, this report should not be considered a systematic review of the literature.

The Society also gathered information through discussions with palliative care researchers and practitioners. Some key informants also helped ensure the report's accuracy by reviewing the content. The experts we spoke to are among the country's most accomplished and respected, but they represent just some of the researchers and practitioners dedicated to palliative care across Canada.

## Acknowledgements

We offer a heartfelt thanks to the following experts for their time and expertise in supporting the Society's work in palliative care:

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Quotes from Canadians have been placed throughout this report in order to demonstrate real situations or perspectives that people have on palliative care. Some quotes are taken from discussions with palliative care experts. Several are taken from public consultations organized by the Canadian Cancer Society in Quebec in 2014.

The content and conclusions in this report do not necessarily reflect the opinion of the individuals or organizations listed above.



# Executive summary

This report highlights major gaps in care and the barriers Canadians face when accessing quality palliative care at the time that they need it. It is informed by several reports, academic research articles, websites and discussions with palliative care experts.

With Canada facing a 40% projected increase in new cancer cases over the next 15 years, there is an urgent need to gauge the state of palliative care across the country. The Canadian Cancer Society is adding to the discourse through this up-to-date, national overview of palliative care – where we currently stand, where we need to go and what needs to be done. It presents a comprehensive analysis of the issues at hand that will inform and galvanize our activities and support the work of governments and other stakeholders to improve the accessibility and quality of palliative care for all Canadians affected by a life-altering illness.

Improvements to the palliative care system in Canada are desperately needed. Without clear national standards and accountabilities, individual jurisdictions are left to develop their own policies, programs and guidelines, resulting in inconsistent or inadequate access across the country. In Ontario, for instance, 40% of cancer patients do not receive a palliative assessment in their last year of life. In some regions of Atlantic and Western Canada, administrative data showed that less than half of people who die in a hospital receive palliative care. Remarkably, there are many jurisdictions in the country where we do not even know how many Canadians receive quality palliative care. We lack consistent and ongoing data collection at a systematic level, which leaves us unable to more effectively hold our healthcare systems accountable to make positive changes.

## What do we know about palliative care?

**Palliative care is care that focuses on quality of life of patients and families.**

By focusing on care guided by patients' values and best interests, palliative care leads to better quality of life and satisfaction with care, as well as people getting the most appropriate care for their needs.

**There are gaps in palliative care across the country.** Indicators such as location of death, use of acute care before death and referrals to formal palliative care show that there is significant room for improvement. Many Canadians who require palliative care receive it in acute and emergency care, if they receive it at all. About 45% of cancer patients die in acute care hospitals even though most Canadians prefer to die at home. Not only are acute care settings more costly than dedicated palliative care, they are also not as equipped to provide the most appropriate care to palliative care patients and their families.

**Palliative care can increase the efficient use of our public healthcare dollars, but increased care outside a hospital setting can place undue financial hardship on family caregivers.** Healthcare costs tend to increase substantially in the months and weeks before death, due to increasing frailty and dependence on healthcare services. Administrative data from Ontario show that palliative care delivered in acute care costs about \$1,100 per day, while care in other settings can be much lower. However, moving care outside the hospital setting often places a significant financial burden on family caregivers. Family caregivers carry a substantial portion of the total costs of providing end-of-life care, and an international report grades Canada poorly on the costs of end-of-life care because of the costs to patients and families for palliative care outside hospitals.

**There are a number of barriers affecting the improvement of palliative care in Canada, including:**

- a lack of standards, insufficient data collection and no consensus on what indicators should be used to evaluate palliative care
- insufficient training for healthcare providers
- patients, families and healthcare providers misunderstanding palliative care
- insufficient support for patients and family caregivers
- inadequate funding for palliative care

## **Working together for better palliative care**

All stakeholders, including federal and provincial/territorial governments, professional organizations, researchers, institutions training healthcare workers, healthcare facilities, charities and patient groups, including the Society, must work together to address the barriers to palliative care. We must:

***Guarantee access to quality palliative care to all Canadians*** in federal and provincial/territorial legislation.

***Develop and implement measurable palliative care standards*** to ensure access to quality palliative care. At the same time, a plan for ongoing and consistent data collection should be developed to enable us to understand the state of palliative care, make improvements and hold healthcare decision makers accountable.

***Train healthcare providers*** to ensure we have sufficient palliative care specialists and that all healthcare professionals can provide basic palliative care and know when a referral to formal palliative care is needed.

***Support patients and family caregivers*** by ensuring they have the information and tools needed to engage in advance care planning, undertake being a family caregiver and be knowledgeable about

palliative care. Improvements to income support and job protection can help the millions of Canadians who already provide care to a loved one.

***Provide appropriate funding for palliative care.*** Improving palliative care in all settings – including outside the hospital – should result in more efficient use of healthcare dollars, but there will be upfront costs to facilitate the change. Federal and provincial/territorial governments should work together to establish a financing plan and create a national palliative care transition fund to ensure the changes needed to improve palliative care in Canada can take place.

Quality palliative care provides patients and families with the care they need, when they want, in the setting of their choice. It benefits not only patients and their families but is an efficient use of healthcare dollars that can help create a more sustainable healthcare system. Palliative care is an important component of the continuum of care, and it currently does not receive sufficient attention, funding and resources. We must act now to improve the quality of and access to palliative care.

“ With our aging population, the need for palliative care is ever mounting. Death plays no favourites. We need to face the difficult reality that across the lifespan, many conditions are not curable. But quality of life and providing comfort to patients, irrespective of their age or prognosis, are always critical. The goals of palliative care are to make people comfortable and to get them where they want to be, while they want to be there.  
- Dr Harvey Max Chochinov



# 1. Introduction

“ My father died of cancer last year, and he was lucky to be admitted to hospice. I know my father left in peace without suffering. Having been admitted to the hospital emergency department before hospice, although the staff did its best, the environment, level of attention and quality of interventions were not the same. – Sylvie



Cancer is a disease that touches almost everyone, whether as a patient, caregiver, family member or friend. It wreaks havoc on our bodies, causing a range of physical symptoms, like pain, nausea/vomiting and shortness of breath. Patients and loved ones alike also manage psychological symptoms from dealing with a diagnosis, the practical implications of fighting the disease and the possibility of death. Cancer treatments and medicines can often make these side effects much worse.

Patients and families have come to expect suffering when dealing with advanced cancer and believe that it is normal. While some physical and psychological symptoms may be unavoidable, palliative care can and does relieve and control these symptoms to improve the physical and mental well-being of those dealing with advanced cancer.

The importance of access to quality palliative care is expected to receive increasing attention as federal and provincial/territorial governments address the recent Supreme Court's decision regarding medically assisted dying.<sup>a</sup> Given this larger context, the Society's report takes on particular importance as a tool meant to improve the access to and quality of palliative care for all Canadians.

<sup>a</sup> In February 2015, the Supreme Court of Canada rendered a unanimous decision in the case *Carter v. Canada*, striking down the provisions in the Criminal Code that prohibited physician-assisted dying.

## Canadian Cancer Society

### *Palliative care*

Palliative care focuses on quality of life of patients with progressive, life-altering illness. Palliative care includes expert pain and symptoms management; skilled psychosocial, emotional and spiritual support; and comfortable living conditions with the appropriate level of care – whether at home, in a hospital or any other settings of patients' choice. Palliative care is applicable early in the course of illness, in conjunction with other therapies and uses a multidisciplinary team approach to address the needs of patients and their families. **End-of-life care** is a component of palliative care focusing on specific care needs for someone who is dying.

## World Health Organization

### *Palliative care*

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual.

## Speak Up! National Campaign

### *Advance care planning*

A process of reflection and communication, a time for patients to reflect on their values and wishes and to let others know their future health and personal care preferences in the event that they become incapable of consenting to or refusing treatment or other care. Advance care planning means having discussions with family and friends, especially a substitute decision maker – the person who will speak for a patient when they cannot. It may also include writing down their wishes and may even involve talking with healthcare providers and financial and legal professionals.

Box 1. Important definitions of palliative care

## What is palliative care?

Palliative care is a critical component of the cancer control spectrum and healthcare overall. While curative treatment focuses on ridding the body of disease, palliative care addresses the quality of life of patients and their families throughout their cancer journey. It also includes end-of-life care – care for patients as they approach death. Although palliative care includes end-of-life care, it is more than that. Palliative care can be delivered progressively throughout the course of the disease. The type and intensity of palliative care required varies depending on a patient's needs and can be provided by a family physician, a palliative care specialist or other healthcare provider. Palliative care is guided by a patient's wishes, values and goals of care and is determined and communicated through advance care planning.

Although definitions of palliative care vary, it is consistently defined as care that addresses both physical and non-physical symptoms, can be delivered throughout the course of the disease, involves a team of healthcare providers and supports patients as well as their families.<sup>[1] [2] [3]</sup> It is delivered by specialists as well as non-specialists and in different locations, including hospitals, hospices, long-term care facilities and in homes.<sup>[4]</sup> The definition of key terms used by the Canadian Cancer Society and others are shown in Box 1.

## The growing need for palliative care

Palliative care is not just for the elderly, but for anyone facing a serious illness at any age. Pediatric palliative care in particular involves unique considerations with regards to how the family and patient's needs and values must be managed.

Palliative care was mainly developed for, and is still largely delivered to, patients with advanced cancer. Cancer Care Ontario reports that 80–85% of patients receiving palliative care are patients with cancer, while in Nova Scotia this proportion was reported to be 80–90%.<sup>[5] [6]</sup>

Cancer is the leading cause of death in Canada, accounting for about 30% of all deaths. Despite advances in cancer prevention, early detection and treatment, the number of people diagnosed with cancer is expected to increase dramatically in the years to come as the population grows and ages.<sup>[7]</sup> In 2015, it is estimated that 196,900 new cases of cancer will be diagnosed in Canada and that 78,000 Canadians will die from the disease. By 2030, the number of new cancer cases is expected to be 40% higher (Figure 1).<sup>[7]</sup> This increase in the number of cancer patients will lead to an increase in the number of Canadians requiring palliative care and also in the number of family caregivers.

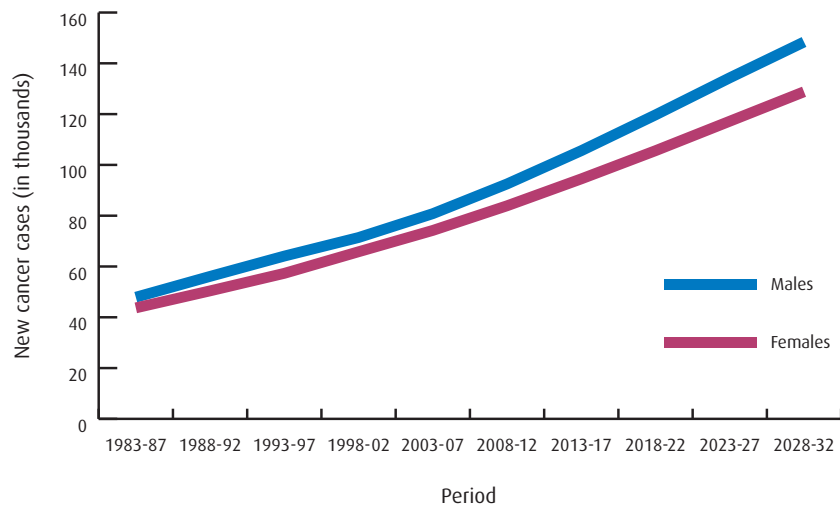


Figure 1. Average annual new cases for all cancers in Canada (in thousands)

## Canada's healthcare system

In Canada, healthcare is a shared jurisdiction. Healthcare delivery is primarily the responsibility of provincial/territorial governments. Under the Canada Health Act, the federal government provides financial support to provinces/territories, but they are also responsible for funding and/or delivering care to certain populations.<sup>b</sup> Given this shared responsibility across jurisdictions, it is not surprising that care, including palliative care, differs significantly across the country.<sup>[8]</sup> While different approaches to care delivery may be needed given Canada's vast and diverse geography and demographics, Canadians should be able to expect that the quality of and access to care will remain consistent.

The Canadian health system is often thought of as being universal and comprehensive, but only hospital services that are medically necessary (as defined by each province/territory) are currently insured under the Canada Health Act. Additional care and services may be paid for in whole or in part by provincial policies, private insurers or by patients and families themselves. This complex and piecemeal funding is particularly problematic for palliative care, which often can and should be delivered outside a hospital setting.

<sup>b</sup> First Nations and Inuit Communities, the incarcerated and members of the Royal Canadian Mounted Police and Canadian military.



## 2. Benefits of quality palliative care

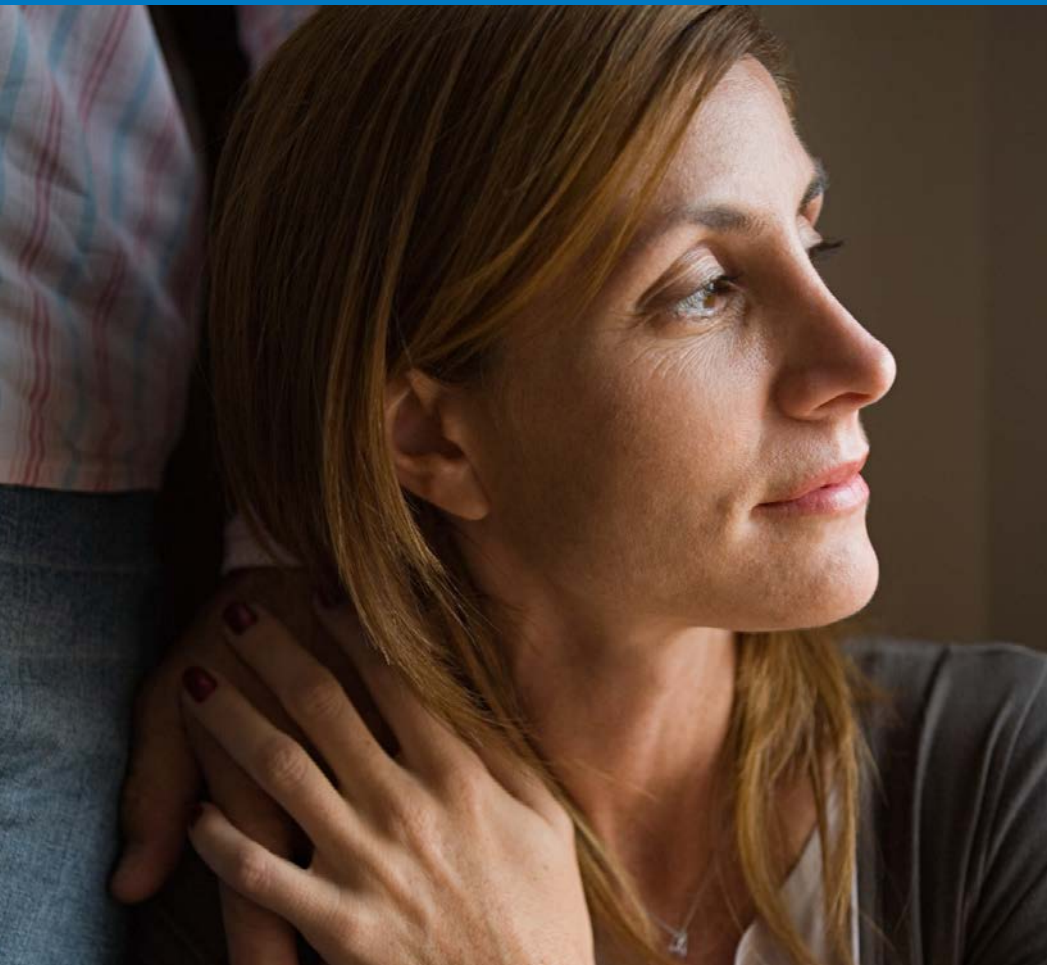
“ Making the end humane: it helps show the importance of those who have left us. And undoubtedly, it helps those who remain. – Jenny

Palliative care is essential. It improves the quality of life of patients and family caregivers and reduces suffering. It has been shown repeatedly to have a significant and positive impact for patients and family caregivers. The research literature shows that the benefits of palliative care include improved pain and symptom management, reduced hospital admissions and stays, and better patient and caregiver satisfaction.<sup>[9] [10] [11]</sup>

### Palliative care when you need it

Palliative care should be available throughout the cancer journey, including while patients are still receiving treatment. Clinical trials, including one in Canada, have shown that palliative care interventions delivered while a patient is still receiving treatment leads to better quality of life, improved symptom control and increased satisfaction of care.<sup>[12] [13]</sup> A pivotal study on early palliative care found that metastatic lung cancer patients who received palliative care integrated with standard oncologic care not only had better quality of life and fewer depressive symptoms, but also had a longer median survival than patients who received standard oncologic care alone.<sup>[14]</sup>

Palliative care can and should be provided progressively for patients throughout the course of the disease. This is a strongly held view among the experts who contributed to this report, as well as by leading healthcare organizations such as the Canadian Medical Association (CMA)<sup>[2]</sup>, the Canadian Society for Palliative Care Physicians (CSPCP)<sup>[15]</sup>, the World Health Organization (WHO)<sup>[11]</sup>, the Institute of Medicine (IOM)<sup>[3]</sup> and the American Society of Clinical Oncology (ASCO)<sup>[16]</sup>.





In Canada, policy makers increasingly recognize the need for earlier palliative care. Figures 2 and 3 show two examples of Canadian models of palliative care that include the introduction of palliative care early in the course of the disease and show the intensity of palliative care increasing as the disease progresses.<sup>[17] [18]</sup>

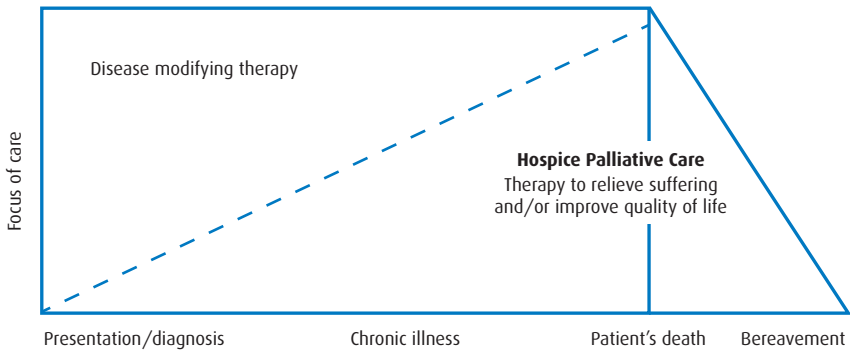


Figure 2. CHPCA Hospice Palliative Care Model

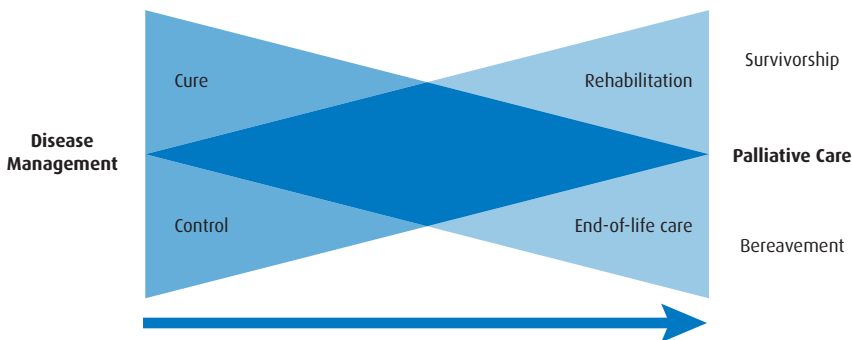


Figure 3. Bow-tie model of palliative care

## Advance care planning

Advance care planning is an ongoing process of reflection, learning, discussing and recording decisions about one's care needs (see Box 1).<sup>[19]</sup> Advance care planning leads to people thinking about what kind of care they may or may not want if their disease progresses, their values (for example, what is important to them to be able to do as their disease progresses?), choosing who will make medical decisions for them if they are unable and making a record of these decisions. A number of studies have confirmed the positive impact of advance care planning, including improved quality of end-of-life care, care more in line with a patient's preferences and increased use of community care, like hospices and home care.<sup>[20] [21] [22]</sup>



### 3. Assessing palliative care in Canada

#### Glenn's story: an example of end-of-life in rural Ontario.

In spring 2014, Glenn was feeling unwell and after several tests, discovered what was likely to be cancer on his liver. Since his healthcare facility wasn't able to run the additional tests that he needed, Glenn spent the next several weeks travelling to a larger hospital an hour away from his hometown. All the while, Glenn and his wife Rita didn't have a firm diagnosis for his condition.

During this time, Glenn's condition began to rapidly decline. His family struggled to understand what was happening and what they could do to help. Discussing end-of-life care at this point was difficult without a firm diagnosis. His pain symptoms began to worsen. Glenn had already been prescribed painkillers, and his doctor prescribed stronger pain medication when pressed by Glenn's family members.

After 3 weeks, Glenn finally received his diagnosis of advanced liver cancer that had also metastasized to his lymph glands and brain. Glenn's doctor scheduled him to see an oncologist at the nearest cancer centre 5 hours away. Little was discussed about end-of-life counselling.

Travelling to see the oncologist was very difficult for Glenn. After a long appointment with the oncologist, he was offered radiation treatment. Glenn chose to receive treatment, but after 2 sessions he became too sick and was admitted to emergency.

At this point, Glenn's family decided to have him flown home. His town did not have a hospice center, so he was taken to the only palliative care bed at his local hospital. Glenn and his family felt that he could die with dignity there, and it would lessen the responsibility of making home care arrangements. The palliative care nurses worked diligently to manage his pain symptoms as the unit did not have the equipment for self-administration of drugs. Glenn passed away 2 days later surrounded by family.

Box 2. Glenn's story

Gaps in palliative care have been documented in numerous Senate reports over the past two decades.<sup>[23] [24]</sup> Each of these reports has shown an urgent need for better palliative care and made a number of recommendations on how to improve the state of palliative care in Canada. The more recent 2010 Senate report found persisting gaps in palliative care, resulting in "Canadians dying in needless pain."<sup>[25]</sup>

#### Indicators of palliative care

Measuring the quality of palliative care services in Canada is challenging. Surveillance data on palliative care are sparse and inconsistently collected, leaving major gaps in our knowledge.<sup>[26]</sup> Moreover, since palliative care includes many different types of care and can be provided in many different locations under the control of multiple jurisdictions, it can be difficult to even know what information is important to collect.

Results from indicators should be interpreted with caution – they all have their limitations and each provides piecemeal information on palliative care.

Regardless, indicators provide valuable information on the state of palliative care in Canada and the following are a few key indicators that should be considered when assessing the state of palliative care.

#### Location of care and of death

Place of death is often used as a measure of access to palliative care. However, there is a disconnect between what people want and what is happening. While patient surveys show that seriously ill people often want to die at home, about 45%<sup>c</sup> of all cancer deaths in Canada occur in acute care hospitals.<sup>[27]</sup> For individuals who die in hospital, a substantial proportion of deaths do not occur in palliative care units. Instead, they occur in units that may not have comprehensive palliative support focusing on a patient's quality of life and are often more costly than palliative care units (for example,

<sup>c</sup> Between 39% and 69% depending on the province.

emergency departments and intensive care).<sup>[28]</sup> The gap between preference and actual place of death has been attributed to inadequate support of community-based care.<sup>[29] [30] [31]</sup> However, place of death does not take into account patients who received most of their care in the community or at home but spent only their final moments in a hospital.

A better indicator of palliative care is location of care. Palliative care should be available to patients in a variety of settings, including the home, hospital, hospice or other setting, depending on what is most appropriate for a patient's care needs and preferences. Some patients can have their care managed at home or in the community. Others who have more serious care needs may need to be in a hospice or in a hospital palliative care unit. A patient's care needs and preferences can also change as the disease progresses. The availability of home care is widely variable. In 2003, 71% of Canadians in Nova Scotia had access to some level of home care in the last 6 months of life.<sup>[32]</sup>

Based on 2010 Ontario data, the median time before death in which a cancer patient was referred to home care was 76 days. However, the range of wait times in local health integration networks ranged from 52 to 225 days before death.<sup>[33]</sup>

### **Use of healthcare services near death**

The number of cancer patients receiving aggressive and/or curative treatment care close to the time of death can be indicators of inappropriate care. If a patient's primary care needs are palliative, then they would likely receive the best care in palliative care units, rather than acute care services.

A 2013 Canadian study found that 22% of cancer patients admitted to acute care could have had their care needs addressed solely by palliative care and that 34% of cancer patients who primarily needed palliative care had stays in hospital of more than 14 days.<sup>[27]</sup> In 2010, about 42% of cancer patients in Ontario were admitted to the emergency department in the last 2 weeks of life.<sup>[33]</sup> These results point to areas that need improvement in delivering end-of-life care.

With better palliative care, fewer patients would be admitted to emergency room and acute care. And patients overall would be spending less time in the hospital.<sup>d</sup> This may be harder to achieve in some regions than others. A report examining the end of life in Western Canada found that people from smaller, rural areas typically spent more time in hospitals in their last year of life compared to larger, urban centres.<sup>[34]</sup>

### **Identification of palliative care needs**

While oncologists may refer their patients to specialized palliative care, many of them do so late in the disease course and some not until the last days of life.<sup>[35]</sup> In Ontario, about 40% of cancer patients do not receive a palliative assessment in the last year of life.<sup>[33]</sup> For Western Canada (i.e., British Columbia, Alberta, Saskatchewan and Manitoba), data from 2003–2004 deaths show that only about 13–16% of people received hospital palliative care during their last hospitalization.<sup>[34]</sup> A similar report in the Atlantic provinces (i.e., Newfoundland and Labrador, New Brunswick, Nova Scotia and Prince Edward Island) examining only patients who died in acute care, found that about 59% received palliative care during their last hospitalization, although this rate was as low as 13% in PEI.<sup>[36]</sup> A more recent study from Nova Scotia showed that about 40% of study subjects<sup>e</sup> were enrolled in a palliative care program prior to their death.<sup>[37]</sup>

In addition to formal palliative care, it is important to know how many and which kind of healthcare providers who are not specialized in palliative care are able to provide a basic level of palliative care or at least are able to identify palliative care needs. At the time of writing, information on this indicator is not systematically collected in Canada.

<sup>d</sup> A study in Ontario showed that as the number of patients using home care increases, there was not a corresponding decrease in the use of nursing and personal support workers, hospital admissions and emergency department visits.<sup>[63]</sup> This suggests that it is important not only to measure the quantity of use of different healthcare settings near death, but that it is also crucial to evaluate the quality of care that patients receive.

<sup>e</sup> This study excluded people who died suddenly, or who had a cause of death other than from a terminal illness, organ failure or frailty.

## Nationwide inequalities

Provinces and territories vary greatly in the level of planning they have done for palliative care, as well as the level of funding and other resources they have devoted to palliative care.

Many provinces have developed, to some degree, a strategy or framework for palliative care.<sup>f</sup> However, these plans vary in comprehensiveness and ability to evaluate availability, accessibility and quality of palliative care. Several provinces and territories also have policies and programs to support palliative care like drug coverage policies, home care and emergency health services programs.<sup>g</sup> Only Quebec has passed legislation that guarantees end-of-life care for those with a terminal illness.<sup>h</sup>

Even with the development of palliative care policies in some provinces/territories, there is little publically available data evaluating how well systems are funded and delivering palliative care. Without widespread consensus on definitions, indicators to measure and standards to aim for, Canada lacks the basic knowledge needed for sustained improvement in palliative care.

<sup>f</sup> As of March 2015, a scan done by Society staff found palliative and/or end-of-life strategies, either contained within a cancer control strategy or as an independent strategy, in Newfoundland, New Brunswick, Nova Scotia, Quebec, Ontario, Manitoba, Alberta and British Columbia.

<sup>g</sup> Nova Scotia, Manitoba, Saskatchewan, Alberta and British Columbia have drug coverage plans specific to palliative care. Other provinces/territories have broader drug plans that may cover drugs used for palliative care. All provinces and territories have some level of a formal home care program. Nova Scotia and PEI paramedics provide emergency community palliative support in homes.

<sup>h</sup> *An Act Respecting the End of Life*. The act comes into force December 2015.

## 4. Costs associated with palliative care

“ My mother was a caregiver for my father for a year and a half. Apart from their 2 daughters occasionally, she received no help at home. After my father died, she needed 2 years to recover, she was so exhausted. – Martine





## Costs within the healthcare system

Most of the analyses on the costs of palliative care are limited to the weeks or months prior to death. Healthcare costs increase dramatically as patients approach death due to the increasingly frailty and care needs of a patient. In 2001–2002, the total monthly public cost per cancer patient 6 months before death was just over \$2,000, the cost 4 months before death increased to just over \$4,000 and at 1 month before death it was \$12,000 (Figure 4).<sup>[38]</sup>

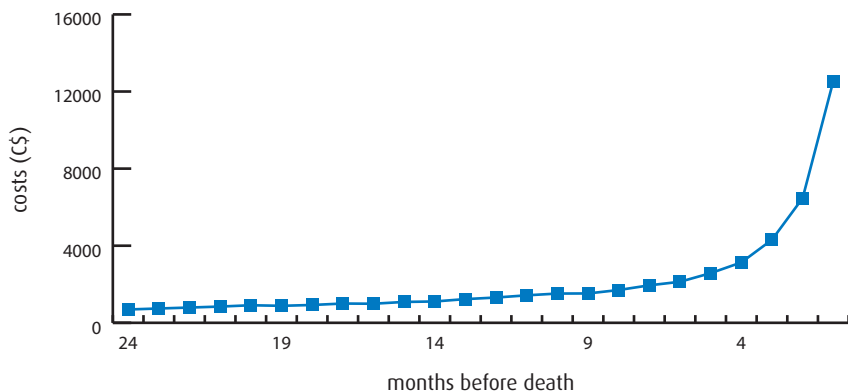


Figure 4. Trend in average total public cost per person during the 2 years prior to death from cancer, Canada 2001–2002

When quality palliative care is available for people in their communities and homes, patients are less likely to be in emergency departments, intensive care units and acute care<sup>[29] [39]</sup> – which are usually more costly than palliative care and not designed for patients whose primary needs are palliative. According to the 2014 Ontario Auditor General’s report, costs<sup>i</sup> of palliative care during the last month of life are \$1,100 per day in an acute-care hospital versus \$770 per day in a palliative care unit in hospital, \$460 per day in a hospice bed and under \$100 per day in the home.<sup>[40]</sup> This year, an estimated 78,000 Canadians will die from cancer and about 45% of these patients will die in acute care.<sup>[7] [27]</sup> Many of these patients could receive more appropriate care in other settings, resulting in not only better care for patients but also better use of healthcare dollars.

<sup>i</sup> The costs included were all public healthcare costs of the institutions included in audit, excluding drug costs.

## Costs outside the system

In addition to direct public costs, palliative care incurs substantial costs outside the public system that must be considered. Insufficient funding for, access to and support – including respite and education – for palliative care in community and home settings adds another burden to Canadians who provide care for their loved ones. One of the most expensive components of palliative care at the end of life is the cost of unpaid family caregiver time.<sup>[41] [42]</sup>

A study from Ontario showed that for home-based palliative care, unpaid caregiving costs made up 77% of total palliative care expenses.<sup>[41]</sup> This is in addition to other financial costs to family caregivers such as purchasing equipment or other resources to provide care, travel expenses, medications and other expenses. There were more than 8.1 million informal caregivers in Canada in 2012<sup>[43]</sup>, and the overall financial costs incurred by these caregivers, in addition to the mental and emotional stress of caring for a loved one, are substantial. Analyses of the number of hours spent and type of work done by family caregivers estimate that the economic contributions of family caregivers in Canada was in the range of \$25–26 billion in 2009.<sup>[44]</sup>



<sup>j</sup> Unpaid caregiving time includes times devoted by family or friends to caregivers, time lost from the paid labour market and lost leisure time.

## 5. Palliative care gaps and barriers to improvement

“ I volunteer in palliative and can tell you the beds are always full. It breaks my heart when they have to move patients out who do not die ‘on schedule’. We must humanize healthcare so that people feel like people instead of numbers. – Celine



There are a number of current gaps and barriers that inhibit palliative care access and availability in Canada.

### Lack of common standards or frameworks

A number of documents have been developed on guiding principles or models for palliative care in Canada, yet there is a lack of tangible nationwide, evidence-based, integrated care standards and guidelines to ensure delivery of quality care. There is no consensus on the number of palliative care beds, palliative care specialists and other healthcare providers that should be available to adequately support the Canadian population. But this type of planning is possible and has been done in some provinces. Alberta, for example, completed capacity-planning work in 2013 and has set a benchmark of 7.7 hospice beds per 100,000 inhabitants.<sup>[45]</sup> In Quebec, this ratio was established in a 2007–2008 report at 10 palliative care beds per 100,000 inhabitants.<sup>[46]</sup>

Moreover, there is a lack of validated frameworks or policies to guide healthcare providers in the delivery of palliative care, including tools to help identify which patients can benefit from palliative care. Some provincial agencies are making progress in this area. Cancer Care Ontario launched an initiative in 2008 that aims to screen all patients with cancer for symptoms using common assessment tools.<sup>[47]</sup> The agency is also piloting an initiative used widely in the United Kingdom, where healthcare providers simply ask themselves: “Would you be surprised if this patient died within 1 year?” to help guide their palliative care needs.<sup>[40]</sup>

These are only a few examples that show the potential of developing standard tools of practice across large jurisdictions.

## Insufficient and inconsistent data collection

There are serious gaps in knowledge of the current state of palliative care across Canada. Some key reports, including several published by the Canadian Institute for Health Information (CIHI), give a snapshot of palliative care, but these are limited to select indicators of palliative care and only to a specific period of time.<sup>[27] [34] [36]</sup> Available data on palliative care is also incomplete because of inconsistent data collection and a lack of common definitions. Some quality indicators for palliative care have been developed in academic literature<sup>[48] [49]</sup>, but jurisdictions use different indicators to collect data. This is a problem given that the value of performance indicators lies in enabling comparisons between jurisdictions to identify consistencies and differences.

Some jurisdictions are already collecting data in a consistent and ongoing manner to evaluate palliative care programs. The Edmonton Zone Palliative Care Program has released annual reports about their program since 1999, which includes indicators such as number of hospice admissions, number of people who died waiting for hospice, average waiting time for hospice and number of hospice beds.<sup>[50]</sup> In Ontario, the Cancer Quality Council of Ontario reports on end-of-life measures including house calls in the last weeks of life, percentage of patients who had no palliative care assessment in the last week of life, location of death and use of acute and emergency services prior to death.<sup>[33]</sup>

These efforts, however, are confined to certain provinces or regions. Without nationwide leadership, best practices in data collection will not become standard practice across the country.

## Insufficient education for healthcare providers

“ Every primary care physician should be able to do palliative care, have an understanding of the basics of care provision and access to palliative care specialist services. – Dr Robin Fainsinger

The Canadian Society for Palliative Care Physicians (CSPCP) reported that in 2011, the majority of Canadian medical schools had fewer than 10 hours of palliative care in their curriculum.<sup>[51]</sup> More recently, a survey of physicians who practice palliative care in Canada found that for many respondents, palliative care was not their primary area of focus and that over half of those did not have formal training in palliative medicine.<sup>[4]</sup> A number of the experts consulted for this report stressed that palliative care education for healthcare providers is insufficient for specialists and non-specialists alike. They emphasized that not nearly enough palliative care specialists are being trained to cover the anticipated level of attrition in the field due to retirement expected over the next 10 years or to meet the increasing needs of our aging and growing population.

Course curricula have been developed for palliative care by organizations such as Pallium and the CSPCP. Leadership is needed from universities and governments alike to ensure curricula are implemented across all medical, nursing, pharmacy and allied health schools in Canada. Furthermore, this education should be inter-professional due to the team-based nature of effective quality palliative care delivery.

A lack of national standards and common definitions makes it difficult to know who is providing palliative care and what specific qualifications they possess. The fact that palliative care only recently became recognized as a specialty, that physicians with different backgrounds can practice palliative care and that the number of hours devoted to palliative care by physicians varies widely, makes it even more difficult to assess the number of trained palliative care physicians.<sup>[52]</sup>



## Misunderstanding of palliative care

“ People have fears that things are going to get worse with palliative care. But in fact, care is often better, quality of life is better and there’s evidence of that. – Dr Gary Rodin

Misconceptions still exist about palliative care. Most patients, families and physicians associate palliative care with “giving up”. As a result, patients and families may not want to talk about it and physicians may be reluctant to refer patients to palliative care. Physicians who lack adequate knowledge or skills believe that palliative care is only for persons in their last days of life, and they do not want to cause the patients to lose hope.<sup>[53]</sup>

There are many initiatives to promote knowledge of palliative care and advance care planning in Canada. National campaigns such as *Speak Up!*, *The Way Forward* and *Choosing Wisely Canada* promote awareness of palliative care and provide tools for advance care planning for physicians, patients and families alike.<sup>[19] [54] [55]</sup> Resources like the Canadian Virtual Hospice provide a wealth of information for patients and caregivers.<sup>[56]</sup> Alberta has its *Goals of Care* designation – a process where healthcare providers consult with patients and record their care preferences on Alberta Health Service forms.<sup>[57]</sup> Despite these initiatives, too few Canadians are engaging in advance care planning, with an estimated 20% of Canadians completing an advance care plan and about 47% designating a substitute decision maker.<sup>[58]</sup> A study on elderly patients at risk of dying in the next 6 months found that, although 73% had named a surrogate decision maker for healthcare, only 48% of patients questioned had completed an advance care plan.<sup>[59]</sup>

### Carolyn and Paul’s story: an example of good end-of-life care in different settings

When Carolyn was diagnosed with advanced lung cancer, she and her husband, Paul, agreed that she would stay at home for as long as possible.

Over time, they made changes to the home, adding a hospital bed to the master bedroom, a bench for the bath and an extension for the toilet so that Paul could lift and lower her more easily. Home care nurses visited regularly to help bathe Carolyn and give Paul a break from caregiving.

For Paul, the biggest challenge was his bad back. He had trouble lifting Carolyn out of bed. At the suggestion of their oncologists, Carolyn and Paul looked into a small hospice nearby. They liked its homelike feel – the beautiful gardens, the large living room, a kitchen and sunroom for everyone to share and 6 private bedrooms.

“Every one of the bedrooms had a view outside. There was a birdfeeder on every window and a huge covered patio in the back,” Paul remembers. “All the meals were cooked there. It really had all the comforts of home. And you were allowed to bring anything from home that would make you feel more comfortable.”

Carolyn had an interview and went on a waiting list before a space became available. When the phone call came, they were both ready for it. “Carolyn was happy about it because we had lots of information. And she knew that I was struggling to keep her at home.”

During her 6 weeks in the hospice, a team of specially trained nurses, social workers and volunteers attended to her every need. “They looked after her so well, and they provided all the care that I wasn’t able to give her,” says Paul.

Paul and Carolyn were comfortable with their decision – they felt that they’d made the right choice. Carolyn could die with dignity here.

Box 3. Carolyn and Paul’s story



## Insufficient support for caregivers

As people turn to palliative care at home or in the community, there is an increasing burden on family caregivers.

Patients and families carry a large portion of the financial burden of palliative care (see Section 4). The federal government has recently improved the Employment Insurance (EI) Compassionate Care Benefits program, which will provide income support up to 26 weeks to employees who need to take time off from work to provide care for a loved one.<sup>k</sup> All provinces/territories have legislated for unpaid job-protected compassionate care leave for up to 8 weeks, with the exception of Quebec, which has legislated compassionate care leave for up to 12 weeks.

However, in an international report ranking the affordability of end-of-life care, Canada ranked relatively poorly – 27th on a global comparison of 40 countries, with a score of 4.2/10.<sup>l</sup> The report concludes that while hospitalization is 100% funded by the government, home care is still a considerable financial burden for people. This suggests that current policies such as federal and provincial/territorial compassionate care policies are not meeting the needs of Canadians.

## Inadequate investment in palliative care

Insufficient funding in palliative care is a common cause of the system's gaps and barriers. While some organizations are making progress in developing frameworks of care and medical curricula, many palliative care experts consulted for this report identified a clear need for increased support from governments to implement these projects. Some researchers also noted that palliative care receives much less in research funding compared to other areas of healthcare research.

<sup>k</sup> In the 2015 federal budget, the government announced plans to extend the compassionate care benefit from 6 weeks to 6 months, allowing people to take care of a gravely ill loved one who has a significant risk of dying. The changes are set to take place on January 3, 2016.

<sup>l</sup> The Economist Intelligence Unit Report's evaluation examined the availability of public funding of end-of-life care, the financial burden to patients for available end-of-life care services and the average payment by patient for end-of-life care service per week.

## 6. What needs to be done?

“ After waiting for 18 hours in the hospital emergency room for a bed, my mother was exhausted and cold. The image of her lying on an emergency room trolley covered with her coat after being told she had an untreatable cancer will never leave me. – Susan



As the projected number of deaths from chronic disease grows, so will the need for access to palliative care. Palliative care leads to better patient outcomes and results in better use of healthcare dollars. It is an important component of the continuum of care that does not receive sufficient attention, funding and resources. Now is the time to act. We must improve the quality and accessibility of palliative care for those who need it.

**Guaranteed access** to palliative care should be embedded in federal and provincial healthcare legislation as part of larger cancer control and chronic disease control strategies. Quality palliative care is an essential part of healthcare, and governments must guarantee that all Canadians have affordable access to it.

**Minimum standards of palliative care** should be developed and implemented to support planning for palliative care delivery. These should be measurable standards, such as number of palliative care and hospice beds, and number of palliative care healthcare professionals that are needed per 100,000 Canadians. This work can be expanded from work already done in some jurisdictions. Federal and provincial/territorial governments must work collaboratively to establish consistent standards to avoid further increasing inequalities in care. With the existence of several national and provincial palliative care networks, such as the Quality End-of-life Care Coalition of Canada and Canadian Partnership Against Cancer's (CPAC) network on palliative and end-of-life care, leading experts and key stakeholders are already being brought together. These are opportunities to collaboratively develop and implement nationwide standards.

In order to measure performance against established standards, common practices in data collection and evaluation of palliative care services should be developed and implemented. This requires establishing a common set of indicators to allow for meaningful comparisons of palliative care across jurisdictions and over time. Data on palliative care should be routinely reported by a national agency to encourage accountability and ongoing capacity. There

are best practices in monitoring and evaluation that could be expanded across the country.

**Education for physicians and other healthcare workers is essential** in order to ensure a sufficient number of trained healthcare providers can meet the needs of the population. All healthcare professionals should have basic training in palliative care and should know when to refer a patient to a palliative care specialist. At the same time, the number of palliative care specialists must be increased. The need for more healthcare providers and specialized palliative care physicians is supported by the results of the recent National Palliative Medicine Survey conducted by several healthcare professional and research organizations<sup>m</sup>, as well as a recent call to action published by the Canadian Medical Association.<sup>[4][61]</sup>

Medical and other health professional curricula and residency programs must ensure that sufficient hours are devoted to palliative care. Continuing education courses on palliative care should be developed, or existing courses should be expanded across jurisdictions. Education on palliative care must be informed and developed with input from palliative care specialists.

**Better support for patients and families** is needed to ensure they understand that palliative care is active and competent care that provides symptom relief and improves quality of life. It is not “giving up” or something to be feared. Encouraging and promoting advance care planning should be standard practice.

In addition, support for family caregivers must be improved to ensure that palliative care provided outside of a hospital setting does not result in significant financial impact. As a start, provincial/territorial compassionate care leave should be improved

<sup>m</sup> Canadian Society for Palliative Care Physicians, Canadian Medical Association, Royal College of Physicians and Surgeons of Canada, College of Family Physicians of Canada, and the Technology Evaluation in the Elderly Network.

to complement the recent improvement of EI Compassionate Care Benefit. While the federal legislation provides up to 26 weeks of job protection, most provincial and territorial legislations provide only 8 weeks of job protection.

Financial support could also be implemented or improved. Quebec has a refundable caregiver tax credit, and Nova Scotia offers caregivers a small caregiver benefit. However, both of these programs could be improved and implemented in all provinces and territories. At the federal level, the family caregiver tax credit could be made refundable.

There are also a number of work policies that employers can develop and implement to support their employees who need to take time off to provide care and support for a critically ill family member.<sup>[62]</sup>

***Palliative care funding*** must be increased in order to meet the expected increase in incidence of cancer and other chronic diseases, as well as the aging population. The recommendations in this report and others must be accompanied by adequate funding for the human resources and healthcare infrastructure required to improve access to and quality of palliative care for all Canadians. There also needs to be increased investment in palliative care research to continue developing and evaluating effective practices.

Palliative care will result in the better use of our healthcare dollars by reducing demands on costly care and tailoring care to better meet patients' needs and circumstances. However, upfront investments will be required. In order to ensure adequate funding for meaningful improvements, a transition fund developed collaboratively by federal and provincial/territorial governments should be established.

## Working together for change

The Canadian Cancer Society provides information and support to Canadians dealing with cancer, funds research on all aspects of cancer including quality of life and advocates for better health and social policies at all levels of governments. Ensuring that availability and accessibility to quality palliative care across the country is inherent to the Society's mission.

Fortunately, we are not working alone. Many organizations are already working hard on the issues mentioned in this report, either individually or collaboratively in existing networks. Collaboration across regions, sectors and professions is crucial to ensure consistency and continuity in delivering quality palliative care across the country.

Patients and families face numerous challenges when dealing with advanced cancer. Access to quality palliative care should not be another one, especially in a healthcare system that is applauded for having universal coverage for medically necessary healthcare services. This is not just a question of how Canadians die – it is a question of how well we will live, right up until the end. In that regard we can do better, and together we must act now to create positive change.





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