



Access to Palliative  
Care in Canada  
2023



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Please note that the analyses and conclusions in this report do not necessarily reflect the opinions of the individuals mentioned above.

## About this report

Canadians are living longer and, as we do, the number of people living with life-limiting illnesses, such as cancer or kidney disease, is growing. These factors increase the demand for palliative care, which focuses on relieving suffering and improving the quality of life of patients and their loved ones during life-limiting illness. Supporting and improving access to palliative care is a goal of Canada's health systems.

In 2018, the Government of Canada released its *Framework on Palliative Care in Canada*, establishing the goals and priorities for palliative care services.<sup>1</sup> One of these goals was to improve equitable access to palliative care. That same year, the Canadian Institute for Health Information (CIHI) published *Access to Palliative Care in Canada*, describing palliative care services across the country.<sup>2</sup> This report builds on our 2018 report and measures progress toward the goal of increasing Canadians' access to palliative care services. Specifically, we look at

- Whether more Canadians are accessing palliative care;
- Who isn't getting the palliative care they need; and
- Where gaps exist and what opportunities there are to improve.

Our main findings are as follows:

- More people are receiving some form of palliative care compared with 5 years ago.
- More people are dying at home with palliative support compared with 5 years ago.
- Some people experience greater barriers to accessing palliative care because of their age, where they live or their disease diagnosis.
- Things have improved in the last 5 years but there are still signs of poor-quality palliative care, including people not getting palliative care until just before they die, and people dying in hospital even when they have community supports such as long-term care or home care.

Changes are needed to better assess Canadians' access to quality palliative care. These changes include better understanding who is receiving what care, better identifying those who face barriers to access, and tracking data that will tell us more about how we're doing, including how well patients' symptoms are controlled, the level of stress patients and caregivers feel, and how satisfied they are with palliative care.

# The caregiver perspective

The World Health Organization states that timely access to palliative care improves quality of life for patients and their families.<sup>3</sup> In 2022, CIHI spoke with a small group of family caregivers from across Canada about their recent experiences with palliative care services for a loved one. They told us that high-quality palliative care

- Honours the beliefs and preferences of the patient and their family;
- Is discussed early with the patient and family so they can make plans and benefit sooner;
- Takes a team-based approach by including the patient and family as integrated members of the team;
- Ensures that patients and families are always given comprehensive information on the options available for palliative care; and
- Provides the resources needed to let patients die in their preferred setting with support for them and their families at the end of life.

Patients involved in the development of this report say there's reason for concern in Canada about uneven access to and gaps in the delivery of care. As well, much of the responsibility for advocating for palliative care falls on the patient and their caregivers at the same time as caregivers have reported a lack of information on services and resources available to them. Decisions on when a patient should start receiving palliative care, what will change when they do and what the difference is between palliative and end-of-life care are also unclear to caregivers. In addition, the information CIHI has does not necessarily reflect the patient's experience. For example, the data can tell us whether the patient is in a palliative state but does not provide details about that care (see Appendix B for data sources).



## Caregivers who shared their stories with us

**Paul** was a caregiver for his wife Suzanne, who was diagnosed with breast cancer. In the 4 years between her diagnosis and her death, the cancer spread to the bone and put pressure on her brain, causing seizures. Most of her care was provided by Paul at home with little home care support. They made multiple trips to hospital for her symptoms before she eventually died in hospice after a 2-day stay. Paul and his wife lived in an urban area in Ontario.

**Amy** was a caregiver for her mother, who had dementia and chronic obstructive pulmonary disease (COPD). Amy lived with her mother while she cared for her and had the support of home care and a palliative care team. Amy and her mother made many trips to the emergency department for hydration and pain management. Amy was with her mother when she died at home, 2 months after her mother started receiving palliative care. Amy and her mother lived in a rural area in Ontario.

## Introduction

Canadians are living longer and, as we do, the number of people living with life-limiting illnesses, such as cancer or kidney disease, is growing. These factors increase the demand for palliative care, which focuses on relieving suffering and improving the quality of life of patients and their loved ones during life-limiting illness. Supporting and improving access to palliative care is a goal of Canada's health systems.

Palliative care can include a variety of services focused on managing symptoms, reducing pain, and providing psychological, social, emotional, spiritual and practical support. Developed in the mid-1970s as a medical specialty serving patients with cancer, the concept has expanded to include people living with any life-limiting illness, as well as their families.<sup>1</sup>

Many provincial and national surveys have found that given the choice, most Canadians would prefer to die at home. To do that comfortably and safely, most will require palliative care in their homes. CIHI data shows that where patients get palliative care impacts where they will die; those who want to die at home are more likely to do so if that's where they received their palliative care.





## Spotlight: Shared Health Priorities indicator — Death at Home or in Community

Measuring the percentage of Canadians who die at home or in the community, rather than in hospital, provides an indication of whether Canadians are getting access to community-based services. Data shows that slightly more than half of Canadians die at home or in the community (54.5%) rather than in hospital.<sup>ii, 4</sup>

However, not everyone wants to die at home, as it can put considerable stress on patients and their families. There is evidence that many people who are severely ill tend to favour institutional care, such as a hospital, when they get closer to death.<sup>5</sup> This decision may partly reflect a forced, rather than willing, choice when people come to understand what supports they can expect in different settings. In the article “Where would Canadians prefer to die?”<sup>5</sup> Laura Funk and colleagues discuss several studies that gave reasons people shift to wanting to die in an institution. These reasons include worry over whether they’ll be safe at home, concern about whether their symptoms can be managed and a desire to protect their loved ones from the demands and stress of caring for them as they die. When asked how they would feel about dying at home in situations where they had less family or professional support and more severe symptoms, people “expressed greater preference for care on a palliative care unit or hospice.”<sup>5 (p. 7)</sup>



## What caregivers told us

I told her I would try to keep her at home. That’s what she wanted. But I didn’t. I wasn’t able to give that level of care. At the hospital, they said “you can’t give her what she needs, she can’t go home.”

— Paul, Caregiver

As hard as it was to have her pass at home, emotionally, it also was nice to know that we were able to follow through on her wishes [to die at home].

— Amy, Caregiver

ii. This excludes deaths from external causes such as poisonings, assaults, self-harm and transport accidents, because these individuals would have had limited choice in where they spent their last days, or end-of-life services may not have been appropriate.



## Spotlight: Survey on hospice care in Canada

Hospice services, particularly residential care, play an important role in palliative and end-of-life care. When people have greater needs than can be managed at home, a hospice offers an alternative to dying in hospital. Residential hospices are an alternative to receiving end-of-life care in hospitals but are not plentiful in any of the provinces or territories.

In partnership with the Canadian Hospice Palliative Care Association, CIHI surveyed community hospice operators and service providers across the country, including those who offer residential, non-residential, auxiliary or outpatient services virtually or at home.<sup>iii</sup> Respondents were asked about the palliative care services these organizations provide across Canada.

- On average, residential hospice programs reported having 12 beds per site and serving 203 patients per year. Around half (49%) reported they were “always” or “usually” operating at full capacity.
- Wait times for hospice care were usually 1 week or less (72%), and the typical length of stay in most residential hospices (67%) ranged from 1 to 4 weeks.
- Wait times for non-residential hospice programs varied by service; companionship programs and bereavement support had the highest proportion of wait times longer than 30 days.
- Care in the organizations was provided by regulated medical professionals and allied health staff, non-medical staff, volunteers and non-medical providers. According to respondents, residential programs had higher levels of regulated medical and allied health professionals (44% and 26%, respectively) when compared with non-residential programs (12% and 18%, respectively). Non-residential programs reported a higher reliance on volunteers in their operations (69% compared with 29% in residential programs).

There is considerable variation in how hospice beds are organized. In Alberta, hospice care involves beds that are located in less resource-intensive units in hospitals (included in acute care numbers in this study). Other provinces may opt to have hospice beds closer to where patients are, such as local long-term care homes or rehabilitation facilities. Both Ontario and Quebec report that they have increased their hospice and publicly funded community palliative care beds, with more additions planned.<sup>6, 7</sup>

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iii. A total of 88 respondents, representing 102 community hospice programs, completed the online survey in March 2022. Answers were based on the previous 12 months (March 2021 to March 2022). Respondents were from areas across Canada, but the majority were from Ontario (53%) and British Columbia (25%). More detailed information is available upon request.

Palliative care should ideally start close to when a patient is diagnosed with a life-limiting illness. In reality, most people meet the criteria for palliative care only in the final days or weeks of life. It is at this point that they are identified as a palliative patient. This means that most of what is reported as palliative care using the data CIHI collects is actually end-of-life care. See Appendix A for the definitions of care used in this report.



## What caregivers told us

It's like the wall between active treatment and palliative care is deep in the culture of the system.

— Paul, Caregiver

Right now, they are very strict as to whether a person needs palliative care. My mother needed to be bedbound, unable to do any activity or normal care before she qualified.

— Amy, Caregiver

There are clear benefits to avoiding care in hospital at the end of life for both patients and health care systems. Research shows that people who die in hospital are more likely to get treatments designed to save lives, but these treatments can be painful, cause unnecessary stress for patients and their loved ones, and use scarce health care resources.<sup>8,9</sup> As well, hospitals may not provide the care people expect as they get closer to death. Patients may receive minimal attention, with more emphasis on physical needs and less on their emotional and psychosocial needs.<sup>10</sup>



## What caregivers told us

She was being hydrated in the emergency department, then I went home to feed the kids, and when I went to the bed where she was admitted she wasn't being hydrated anymore. The nurse said [it was] because the doctor — who we had never met, or met my wife — said no, it wasn't indicated. I didn't understand that that's what happens. There was no discussion, we weren't prepared.

— Paul, Caregiver

This report, *Access to Palliative Care in Canada, 2023*, is intended to look at whether more Canadians are accessing palliative care, who isn't getting the palliative care they need and where gaps still exist. The picture we present is incomplete for a number of reasons:

- Guidelines for palliative care from many organizations focus on principles for quality palliative care.<sup>11</sup> They do not provide a standard of what services should be offered. Without this standard, it is difficult to evaluate how well health systems are performing with respect to access and quality.
- Our information comes from several data sources (see Appendix B). These data sources capture information on services and medical outcomes, leaving gaps in what we know. For example, when a patient is identified as palliative in hospital, there is little information on the quality of the palliative care they receive or the ease of access.
- Palliative care is a provincial and territorial responsibility, and services can be delivered in a number of different settings. This makes cross-country comparisons difficult.<sup>1</sup> For example, Alberta provides palliative or end-of-life care in specialized, less resource-intensive units within hospitals. Other jurisdictions provide the same care in other types of health care facilities or in the community, such as long-term care homes or hospices.
- When they are surveyed, Canadians generally report that they would prefer to die at home, but every individual case is different. The data does not include the patient's preferred place of dying.



## Spotlight: Medical assistance in dying

Since MAID was legalized in Canada in 2016, its use has steadily increased (to 3.3% of all deaths in the country in 2021, an increase of 32.4% from 2020). A patient can request MAID only once they have been informed of all options to relieve suffering, including palliative care. The majority of people who chose assisted death also received palliative care (80.7%).

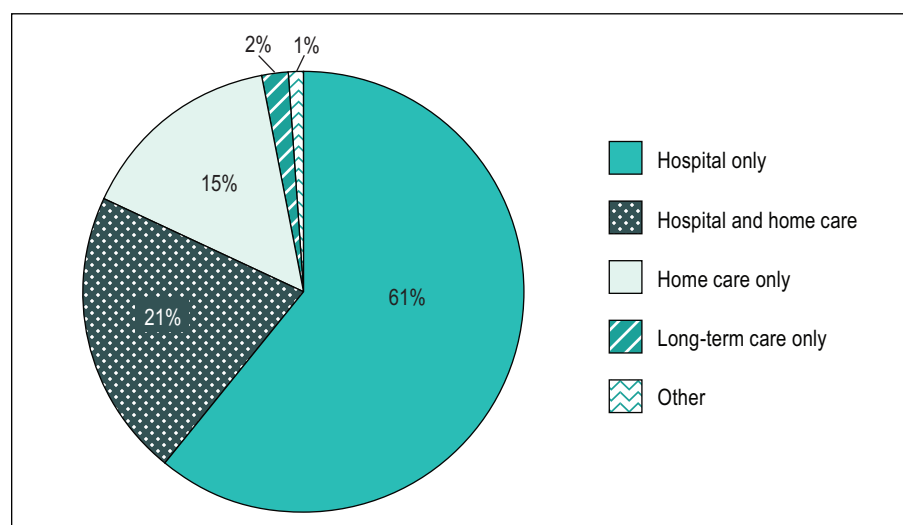
- People who chose MAID typically had a cancer diagnosis (65.6%), cardiovascular condition (18.7%), chronic respiratory condition (12.4%) or neurological condition (12.4%).
- Between 2021 and 2020, a higher proportion of MAID recipients died at home (44.2% and 35.1%, respectively).
- Only 28% of primary care physicians report feeling well-prepared to care for patients who ask for MAID, an increase from 17% in 2019.

## Who is receiving palliative care?

In the last years and months of life, the complexity of health concerns increases, and many Canadians will receive care from different providers and in different settings. This report examines patients in jurisdictions where there is information for a broad range of care settings such as hospitals, publicly provided home care and long-term care.<sup>iv</sup>

In 2021–2022, 58% of those who died (89,000 people) were described in CIHI's data as palliative and received some form of palliative care. This finding is an increase from the 52% reported in 2016–2017 (see Table D1 in Appendix D for a detailed comparison). Among those who received some form of palliative care, 61% had palliative care in hospital only, while 36% received palliative home care (see Figure 1).

**Figure 1** Patients identified as palliative, by care setting



### Notes

Includes deaths in Ontario, Alberta, British Columbia and Yukon only.

"Hospital" refers to acute care, subacute care, emergency department care and complex continuing care.

"Other" includes a combination of long-term care, home care and acute care.

### Sources

Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2020–2021 to 2021–2022, Canadian Institute for Health Information.

iv. The jurisdictions for which we have full information on inpatient, home care and long-term care are Ontario, Alberta, British Columbia and Yukon. Deaths captured reflect those who died in hospital or died while in home care or long-term care, which is estimated to be 80% of all deaths in these 4 jurisdictions. See Appendix C for details on the methodology.

Not everyone receives palliative care early enough. Across the country, decisions to begin palliative or end-of-life care are made by checking the patient's condition against a checklist, such as the Palliative Performance Scale.<sup>12</sup> However, many patients do not meet the criteria to qualify for care until they are at the end of their lives. Currently, half of patients die within 22 days of being identified as palliative regardless of where they received their care. Half of patients receiving care in hospital lived only 11 days or fewer once identified as palliative. Patients receiving palliative home care were identified earlier and lived longer — half died within 119 days of being identified as a palliative patient.



## What caregivers told us

If I hadn't pushed for palliative care, I don't know if she actually would have received it. But then, once I recognized that she was getting worse, I noticed a big decline fairly quickly and pushed [for palliative care] at that point.

— Amy, Caregiver

The suffering that was induced by not having adequate palliative consultation or care for Suzanne was mostly psychological rather than physical. When we finally got to talk to someone, it wasn't happy information, but it was information. You can begin to adjust and be part of the planning.

— Paul, Caregiver

# Who isn't receiving the palliative care they need?

Palliative care should be accessible to all Canadians regardless of their age, their sex or gender, the expected path of their illness, their community, their socio-economic status or their culture. Our analysis shows, however, that this isn't the case.

## Location

There was some variation in access to palliative care among the jurisdictions we examined. Among people who died in 2021–2022, 59% of those who died in Ontario received palliative care compared with 57% in Alberta, 52% in British Columbia and 50% in Yukon (see Table D2 in Appendix D for a detailed comparison).

Patients living in urban and rural/remote<sup>v</sup> settings were identified as palliative at similar rates overall (59% versus 58%) and were able to access home care similarly (21% versus 22%) in 2021–2022. However, palliative patients living in rural areas were more likely to be hospitalized primarily for palliative care compared with those living in urban areas (36% and 29%, respectively) and were also more likely to die in hospital than those in urban areas (29% and 23%, respectively). A recent study highlights that rural areas are in most need of improvements in community supports such as respite care and in-home support for family caregivers.<sup>13</sup>

## Disease and age

Patients with cancer have better access to palliative care than those with other conditions. In 2021–2022, of the common diseases we looked at, patients with cancer were the most likely to be identified as palliative (77%), while patients with dementia were the least likely to receive palliative care in the last year of life (39%). It is possible that this variation is a result of how predictable a disease is; for example, cancer is well understood and has a relatively predictable progression, which makes the decision of when to start palliative or end-of-life care more clear-cut.

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v. Neighbourhood income and place of residence were derived from Statistics Canada's Postal Code Conversion File Plus (PCCF+). This data excludes missing values for place of residence and neighbourhood income quintile.

Age also impacts access to palliative care. In 2021–2022, younger seniors — age 65 to 84 at time of death — were the group most likely to receive palliative care, followed by those age 19 to 64. Canadians age 85 and older who died were less likely to receive palliative care than younger people.

## Other barriers

Some people experience greater barriers in accessing palliative care. These inequalities in accessing palliative care cannot be fully examined, as CIHI data does not include comprehensive information on some patient characteristics such as race, religion and language,<sup>vi</sup> which research has shown determine an individual's access to palliative care.<sup>14–16</sup>

Canadian research on ethnic background and palliative care suggests that people of colour and recent immigrants may have poor access. One recent study<sup>14</sup> looked at patterns of palliative hospital visits and found that country of birth and racial or ethnic group were factors in where patients went for care and their length of stay. Specifically, those “born abroad were more likely to die in hospital and less likely to be discharged to PCU [palliative care unit] than those born in Canada.”<sup>14</sup> (p. 5)

Palliative care programs founded on First Nations values and beliefs around death are being developed across Canada. In creating palliative care programs that align with First Nations culture, Mary Lou Kelley and colleagues note that “While social, cultural and spiritual support is available in First Nations communities, people lack access to PC [palliative care] programs, especially pain and symptom management.”<sup>17</sup> (p. S53) They further note that “Consequently, First Nations people frequently leave their communities to access service that is geographically distant and often culturally unsafe due to differences in language, values, beliefs and expectations.”<sup>17</sup> (p. S53)

People experiencing homelessness also face barriers to receiving palliative care. Previous studies report that issues such as unstable housing and a lack of social supports can make it more difficult to get palliative care.<sup>18</sup> In 2021–2022, 51 people were admitted to hospital who were experiencing homelessness and receiving palliative care. Once in hospital, they were more likely to have a longer stay in hospital as well as to wait longer to be discharged to an alternate level of care (ALC) setting than the typical hospital patient receiving palliative care (see Table 1). This finding indicates that there are barriers in accessing support for people experiencing homelessness.

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vi. CIHI's policy on the release and disclosure of Indigenous-identifiable data aims to ensure appropriate access to, and use of, any information that identifies, or could be used to identify, Indigenous individuals or communities. The policy requires that any release of Indigenous-identifiable data at CIHI be accompanied by approvals from appropriate Indigenous authorities (i.e., First Nations, Inuit and/or Métis governments, communities and/or organizations).



## Definition: Alternate level of care

The term “ALC” describes patients who occupy a hospital bed but do not require the intensity of services provided in that care setting.<sup>19</sup> Typically, patients who stay for more than 1 ALC day are waiting for admission to another facility or care service. Higher levels of ALC can indicate that there are limited resources for those patients where or when they are needed. When talking about palliative care, this could mean patients are waiting for a hospice bed or for home supports to be put in place.

**Table 1** ALC days among patients hospitalized for palliative care

Type of patient	Total hospitalizations for palliative care	Percentage of hospitalizations with more than 1 ALC day	Median length of ALC stay* (days)
General patient population	29,741	8.6%	10
Patients experiencing homelessness	45	27%	22.5

### Notes

\* Among hospitalizations with more than 1 ALC day.  
Includes acute care and subacute care. Excludes Quebec.

### Source

Discharge Abstract Database, 2021–2022, Canadian Institute for Health Information.



## What experts told us

There aren't a lot of options at the end of life for people who have unstable housing, and it's not unusual to hear about people dying in places like cars or parks. There are also challenges accessing pain medications because of people's stigmas and biases around drug use. As a society we should care for our people, especially at the end of their lives.

— Dr. Kelli Stajduhar, Professor and Tier 1 Canada Research Chair in Palliative Approaches to Care in Aging and Community Health, School of Nursing and Institute on Aging and Lifelong Health, University of Victoria

# Where are Canadians receiving palliative care?

In the following sections, we take a closer look at the care received by patients in the settings where they received their palliative care.

## Home care

Canadians would prefer to die at home with support, and more are doing so.<sup>4</sup> In 2021–2022, 13% of those who died did so at home supported by palliative home care. This finding is a substantial increase from the 7% we reported in 2016–2017 (see Table D1 in Appendix D for a detailed comparison).



## What caregivers told us

The quality of life of patients receiving palliative home care can be improved by having family and friends around them, especially at the end of life. Caregivers highlighted that a sense of community was very important at the end of life, and some people receiving palliative care in a health care facility are sent far from their family or community and lack this connection.<sup>4</sup>

Having palliative home care connects palliative patients with a broader range of services than is available in acute care. These services can include everything from pain and symptom management to support for family caregivers, and they enable patients and caregivers to be more involved in the decision-making about their care. Access to home care also has an impact on how patients interact with hospitals: in 2021–2022, patients supported by palliative home care spent fewer days on average in hospital in the last year of their lives compared with those who received palliative care only in hospital (18 days versus 28 days, respectively). As well, only 11% of people receiving palliative home care had life-saving interventions, compared with 26% among people not getting palliative home care.

For patients admitted to hospital, some interventions are performed regardless of whether they are receiving home care, such as computed tomography (CT) scans and blood transfusions. However, 2 invasive hospital procedures — putting people on ventilators to breathe and inserting a central venous catheter to deliver drugs or other fluids or to draw blood — ranked among the top 5 interventions for patients who received palliative care in hospital only (see Table D5 in Appendix D). Neither procedure is generally accepted as appropriate care for a patient with a life-limiting illness at the end of life.



## What experts told us

CT scans are often done to try to explain the symptoms patients are experiencing. This more often occurs when patients are admitted to hospital. Typically, the more palliative care is involved, the less CT scans are done. Central lines are often put in for ease of access. They can also be used to provide nutrition — both of these, however, go against the goals of care in a palliative care approach.

— Dr. Peter Tanuseputro, Family Physician and Clinician Investigator, Division of Palliative Care, Department of Medicine, University of Ottawa

Dying at home requires home care supports that are not always available, such as timely access to medications or to specialized equipment and supplies. In 2021–2022, almost 1 in 4 patients with palliative home care were transferred to hospital at the very end of life. Almost half (45%) were admitted for the main purpose of receiving palliative care. This finding suggests that these patients could no longer be supported at home and expected to die in the hospital, even though their intention may have been to die at home.



## What caregivers told us

I went online to see what was available to people with home care, and what she was getting was not close to what they were saying was available. I was told that was what they were aiming to give, but nobody gets that.

— Amy, Caregiver

## Long-term care

Long-term care facilities are both institutions and people's homes. Residents generally need support to manage most aspects of daily life, but the level of specialized medical care they require varies. Long-term care homes have access to nursing care and medical support around the clock, so residents should be able to die in place if that is what they or their family members prefer. That does not always happen.

Given that residents in long-term care homes typically have long-lasting, complex illnesses, defining when palliative care should begin can be challenging and may not be accurately captured in the data. In 2021–2022, 34% of residents identified as having less than 6 months

to live (by definition, could benefit from palliative care) were recorded as having received palliative care, an increase from 22% in 2016–2017. In addition, 3 times as many residents who died in long-term care homes in 2021–2022 were reported to have received palliative care in their last year of life compared with 2016–2017 (19% versus 6%).

Across Canada in 2021–2022, 6,100 residents of long-term care homes were transferred to hospital and died there. The reason for admission for 28% of those residents was to receive palliative care. Of those admitted (outside of Quebec), 7% spent time in ALC, with most (70%) waiting for care in another facility. In some cases, residents who stayed in hospital for more than 30 days may have lost their place in long-term care and needed to wait for another bed, while others may have been waiting for a bed in a hospice.

## Hospital care

Hospitals can provide a supportive function for those receiving palliative care in the community. Data from across Canada shows that more than two-thirds of those admitted to hospital and identified as palliative were admitted *with* palliative care (roughly 100,000 hospitalizations in 2021–2022). This means that, although these patients were palliative, they were admitted for a condition that could be treated and they were expected to be discharged home again. The data shows patients admitted to hospital *with* palliative conditions had stays longer than 2 weeks on average, and during that time 59% had an intervention, 22% stayed in the intensive care unit and 33% were discharged to home or hospice (see tables D3 and D4 in Appendix D).

Although the current emphasis is on shifting palliative care to the community, there are times when hospital-based palliative care is the more appropriate, or only, choice.

Roughly 44,000 patients were admitted to hospital in 2021–2022 *for* palliative or end-of-life care. These admissions could have been planned or resulted from a lack of access to the care they needed in the community. The data we collect does not contain the information needed to differentiate patients who prefer to die in hospital from those who do so because they have no good alternative. Patients admitted to hospital *for* palliative care had average stays of 12 days, but most stayed 1 week or less. Although not all of these hospitalizations ended in death, these stays reflect care needs at the end of life, as well as an opportunity to provide this care in the community by funding more intensive palliative home care or increasing the number of hospice beds.

## Emergency departments

The decision to go to an emergency department is made when a person is in crisis or has no other place to receive care. For patients who are palliative and their caregivers, a visit to the emergency department can indicate a lack of access to quality palliative care at home and in the community. This gap is particularly important for patients who are palliative,

as once they are seen in the emergency department they are often admitted to hospital, and once admitted it can become difficult for them to be discharged back to their home or community.



## What caregivers told us

When Suzanne had a seizure, we had no idea if this is something that was going to happen, so we called an ambulance and she was admitted to hospital.

— Paul, Caregiver

Of the patients who went to the emergency department for palliative care, 66% were admitted to hospital. These admissions were largely unplanned, and more than 1 in 4 of these people died within 24 hours. The top 4 reasons palliative care patients were admitted to hospital were shortness of breath, weakness, abdominal pain and altered level of consciousness.



## What experts told us

In P.E.I., through our Paramedics Providing Palliative Care at Home Program, we found that improving education of paramedics in treating palliative emergencies has tremendous benefit to patients and their families and helped them to stay at home. Prior to this program, almost all emergency calls in P.E.I. involving patients with palliative care plans ended in hospital transports. Now, paramedics are able to assess patients and *treat* symptoms in the patient's home. This process has consistently avoided transfer to the ER for approximately one-third of calls.

— Dr. Mireille Lecours, Provincial Palliative Care Medical Consultant, Health PEI

For many of those admitted to hospital, there is an indication they wanted to be discharged but were unable to leave, mainly because they were waiting for a bed outside of the hospital. Since 2016–2017, there has been some improvement in the amount of time palliative care patients spend waiting to be discharged — in 2021–2022, 8.6% of patients receiving palliative care spent 2 or more days waiting to be discharged, compared with 9.5% in 2016–2017.<sup>vii</sup> Fewer patients (46%) whose main reason for hospitalization was palliative care died waiting for admission elsewhere, down from 47% in 2016–2017.

vii. ALC results exclude Quebec.

## Moving forward

Since our first report on palliative care in Canada 5 years ago, CIHI has modernized and expanded our data collection, with a focus on expanding home care data and improving data standards. This has helped to expand reporting of palliative care in this report.

For example, due to improved home care data coverage, we could examine patients across care settings in more jurisdictions (Ontario, Alberta, B.C. and Yukon). As well, due to changes in coding guidelines in Quebec, we were able to include all provinces and territories in our acute care analysis (both *with* and *for* palliative care).

To do a more thorough job assessing access to, and quality of, palliative care in Canada, the following improvements in data collection are needed:

- Define an appropriate set of standard palliative care services, particularly for palliative home care, to ensure people receive consistent care across the country.
- Gather more complete data on characteristics of patients, particularly those more likely to face barriers to care.
- Assess the quality of care and report on outcomes that better reflect what patients and caregivers are experiencing. These aspects include symptom management, patient and family stress and satisfaction, reduction in unnecessary tests and treatments, and cost effectiveness in palliative care by place of delivery: home, hospice, long-term care, day programs and acute care.

Without being able to measure those aspects of palliative care, we remain limited in our ability to determine whether Canadians have access to effective palliative care. That said, our analysis shows that more people are receiving some form of palliative care than they were 5 years ago, and more people are dying at home with palliative care support. Indicators or analyses in this report suggest several areas where palliative care needs to be improved:

- People come to emergency departments because their caregivers don't have the required support to provide the palliative care they need at home.
- People die in hospital waiting for palliative care in the community.
- People die in hospital even when community supports like home care or long-term care are in place.

Discussing end-of-life plans can be difficult, though our evidence shows that most people are comfortable doing it — in 2022, most Canadian primary care physicians (94%) reported having end-of-life conversations with patients. At the same time, 67% of Canadian seniors reported discussing with family, friends and health care professionals the treatment they want if they can't make decisions for themselves.<sup>20</sup>

However, only 40% of primary care physicians reported feeling prepared to care for patients with palliative care needs — this is similar to the proportion reported in 2019 (39%). Feeling prepared could reflect having both the resources (such as enough time to spend with patients and support from other health providers) and the ability and/or training.

The design, management and governance of palliative care services in each province and territory can vary greatly. The last report from Health Canada on this topic highlighted many differences in how provinces and territories deliver palliative care:<sup>1</sup> few have centralized care, many are unaware of how many palliative care beds are available, and care is not consistently delivered between hospitals, long-term care homes and other facilities, as well as at home.

Perhaps most importantly for patients and caregivers, health data on palliative care should help target areas where barriers to access, in particular early access, still exist. Better information will help to identify the challenges patients and providers experience.



## What caregivers told us

My wife's referral for palliative care was rejected because she was receiving radiation to reduce her lesion. The receptionist just told me she's receiving active care so she doesn't qualify and there was nothing more she could do. When we went back to the oncologist's office, there was just nothing more anyone would do.

— Paul, Caregiver

# Appendices

## Appendix A: Key definitions

**Table A1** Key definitions

Concept	Definition
<b>complex continuing care</b>	Ongoing hospital-based professional services provided to individuals with complex health needs who may not be ready to be discharged from hospital but who no longer need acute care services. These patients may be in a hospital or long-term care home. <sup>21</sup>
<b>end-of-life care</b>	Care that occurs in the last part of a person's life, usually in the last days, weeks or months. <sup>22</sup>
<b>home care</b>	Care delivered in the community in private homes and residential settings, as well as in hospitals and ambulatory clinics. Home care programs deliver a wide range of health and home support services, including end-of-life care. <sup>23</sup>
<b>hospice care</b>	Care that focuses on the comfort and quality of life of a person with a serious illness who is approaching the end of life. Includes comfort care and support for the family; however, attempts to cure the person's illness are stopped. <sup>24</sup>
<b>long-term care</b>	A variety of services designed to meet a person's health or personal care needs during a short or long period of time. <sup>25</sup>
<b>long-term care home</b>	A facility that provides living accommodation for persons who require on-site delivery of 24-hour, 7-day-a-week supervised care, including professional health services, personal care, and services such as meals, laundry and housekeeping. <sup>26</sup>
<b>palliative care</b>	An approach to care that aims to reduce suffering and improve the quality of life of persons living with life-limiting illness. <sup>1</sup>



## Appendix B: Data sources

At CIHI, separate databases have been developed to measure particular settings in health care systems. These databases have different structures, scopes and purposes, and these differences affect how palliative care is, and is not, captured in each setting. These are the main sources of data used in this report:

- **Hospitalization data** comes from the Discharge Abstract Database–Hospital Morbidity Database (DAD-HMDB) and the National Ambulatory Care Reporting System (NACRS). A patient in the acute care databases (DAD-HMDB) has a palliative care diagnosis when they are admitted *for* palliative care or for a reversible condition *with* palliative care as a secondary condition. In ambulatory care (emergency), there is no distinction. There is no detailed information on the care they received or what their preferences are (i.e., whether they prefer to die at home or have any advance directives).
- **Home care data** comes from the Home Care Reporting System (HCRS) and Integrated interRAI Reporting System (IRRS; Ontario home care data only). This data covers patients receiving home care. Patients in this database are categorized by the type of care they are receiving. For those patients receiving end-of-life care at home with the goal of providing comfort and quality of life, there is a criterion to meet before this type of care can be delivered (i.e., the patient has a well-documented deteriorating disease course and is expected to live less than 6 months).
- **Long-term care data** comes from the Continuing Care Reporting System (CCRS) and covers residents whose physicians have prescribed palliative care as a treatment plan. This database contains little information on the treatments provided outside of major medical treatments.

While hospitalization data is collected across Canada, home care and long-term care data is widely collected only in Ontario, Alberta, British Columbia and Yukon (see Appendix C).

## Appendix C: Methodology

### Data overview

- The following CIHI databases were used to identify both deaths and palliative care provided in Ontario, Alberta, British Columbia and Yukon: DAD-HMDB (acute care hospitalizations, including subacute care in Alberta), HCRS (home care), IRRS (Ontario home care only) and CCRS (long-term care and complex continuing care). It is for only these 4 jurisdictions that we can follow patients across data settings.
- The acute care analyses include all provinces and territories and are based on the DAD-HMDB. Any patient movement in and out of acute care is determined by transfer in/out information on the patient chart and information collected at discharge.
- The emergency department analyses include 2 provinces (Ontario and Alberta) and are based on NACRS.

### Inclusion and exclusion criteria

- The cohort for the pathway approach consists of all deaths identified in home care, long-term care, complex continuing care and acute care (including subacute and emergency departments) in 2021–2022. Patients are identified as palliative if there are indications of palliative care in any of those care settings in the last year of life (using data from 2021–2022 and 2020–2021).
- The analysis of acute care consists of all hospital discharges in 2021–2022 where there is an indication of palliative care. There is no requirement that the hospitalization ends in death, and patients may appear more than once (except for specific analyses involving death).
- The methodologies for identifying both deaths and palliative care are unchanged from CIHI's 2018 report on access to palliative care,<sup>2</sup> with the following exceptions:
  - The pathway approach now includes Ontario, Alberta, British Columbia and Yukon.
  - Home care data is unavailable from Calgary Zone and British Columbia's Northern Health Region.
  - A small number of long-term care facilities in Alberta's Edmonton Zone and North Zone (around 6% of long-term care facilities in Alberta) did not submit data for 2021–2022.
  - Due to changes in coding guidelines in Quebec, we are now able to include all provinces and territories in the acute care analysis for both admissions *for* and *with* palliative care. Note that Quebec does not submit data identifying patients treated by palliative care providers, but this should have little impact on comparability (in the rest of Canada, only 3% of patients identified as palliative in acute care under our methodology are identified only through service provider codes).
- For detailed information on the methodology for this report, contact us at [healthreports@cihi.ca](mailto:healthreports@cihi.ca).

## Data coverage and gaps

- Across care settings, there is no consensus on what receiving palliative care means and what services this should include. This lack of consensus makes comparable measurement in all settings across Canada challenging. As such, being flagged as palliative under this methodology doesn't guarantee that a patient actually received quality palliative care.
- For information on coverage and interprovincial comparability, please refer to the limitations described in Table A1 of CIHI's 2018 report on access to palliative care,<sup>2</sup> subject to the modifications described above.

## Appendix D: Supplementary data

**Table D1** Palliative care by setting, 2021–2022 compared with 2016–2017

Measure	Ontario and Alberta, 2016–2017	Ontario and Alberta, 2021–2022	Ontario, Alberta, British Columbia and Yukon, 2021–2022
Deaths captured in data collected by CIHI	106,045	126,984	153,524
Identified as palliative in any setting	52%	59% ↑	58% ↑
Identified as palliative in acute care only	32%	32% —	35% ↑
Identified as palliative in home care	15%	24% ↑	21% ↑
Died at home with palliative home care	7%	16% ↑	13% ↑

**Sources**

Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017 and 2020–2021 to 2021–2022, Canadian Institute for Health Information.

**Table D2** Total decedents and proportion receiving palliative care service in the last year of life, by province and territory, 2021–2022

Measure	Ontario	Alberta	British Columbia	Yukon
Deaths in 2021–2022	105,763	21,221	26,302	238
Identified as palliative in any setting	59%	57%	52%	50%
Identified as palliative in home care	26%	14%	6%	14%
Died at home with palliative home care	18%	6%	2%	5%

**Note**

Includes deaths in Ontario, Alberta, British Columbia and Yukon only.

**Sources**

Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2020–2021 to 2021–2022, Canadian Institute for Health Information.

**Table D3** Comparison of types of palliative admission to hospital

Measure	Admissions <i>with</i> palliative care	Admissions <i>for</i> palliative care
<b>Patients in 2021–2022</b>	103,033	44,034
<b>Length of stay in hospital (average number of days)</b>	17	12
<b>Had an intervention</b>	59%	26%
<b>Of those who had an intervention:</b>		
Had only diagnostic interventions	18%	24%
Had only non-diagnostic interventions	43%	51%
Had both diagnostic and non-diagnostic interventions	39%	25%
<b>Had a COVID-19 diagnosis</b>	9%	4%
<b>Stayed in ICU</b>	22%	4%
<b>Had palliative care specialist on record</b>	13%	13%
<b>Died in hospital</b>	56%	71%
Among those who died in hospital, percentage who died within 24 hours	7%	16%
<b>Discharged home*</b>	23%	12%
<b>Discharged to other residential setting†</b>	10%	10%

**Notes**

\* "Home" is a private home, with or without support.

† "Other residential setting" includes long-term care and most hospice settings.

ICU: Intensive care unit.

Includes admissions for acute and subacute care.

**Source**

Discharge Abstract Database–Hospital Morbidity Database, 2021–2022, Canadian Institute for Health Information.

**Table D4** Most common interventions in palliative care hospitalizations  
(first 5 CCI characters)

Top 10 interventions for patients admitted <i>for</i> palliative care	Number
Transfusion, circulatory system (1LZ19)	3,385
Pharmacotherapy, total body (1ZZ35)	2,109
Assessment, total body (for MAID) (2ZZ02)	1,305
Implantation of internal device, vena cava (central venous catheter) (1IS53)	1,289
Drainage, abdominal cavity (1OT52)	1,066
CT, head (3ER20)	969
Drainage, pleura (1GV52)	956
Ventilation, respiratory system (1GZ31)	812
CT, abdominal cavity (3OT20)	811
CT, brain (3AN20)	787
<b>Top 10 interventions for patients admitted <i>with</i> palliative care</b>	
Top 10 interventions for patients admitted <i>with</i> palliative care	Number
Transfusion, circulatory system (1LZ19)	23,073
Implantation of internal device, vena cava (central venous catheter) (1IS53)	18,379
Ventilation, respiratory system (1GZ31)	14,214
Pharmacotherapy, total body (1ZZ35)	11,621
CT, head (3ER20)	8,438
CT, abdominal cavity (3OT20)	8,364
CT, brain (3AN20)	7,239
Drainage, pleura (1GV52)	5,978
Inspection, small intestine (2NK70)	5,650
Drainage, abdominal cavity (1OT52)	5,420

**Notes**CCI: *Canadian Classification of Health Interventions*.

Includes all admissions to the hospital (acute care and subacute care).

**Source**

Discharge Abstract Database–Hospital Morbidity Database, 2021–2022, Canadian Institute for Health Information.

**Table D5** Most common interventions (first 5 CCI characters) for patients receiving palliative care at home versus in other sectors

Patients with palliative care in home care	Number
Transfusion, circulatory system (1LZ19)	3,318
Pharmacotherapy, total body (1ZZ35)	2,675
CT, abdominal cavity (3OT20)	2,276
CT, head (3ER20)	1,849
CT, total body (3ZZ20)	1,532
Implantation of internal device (central venous catheter) (1IS53)	1,414
CT, brain (3AN20)	1,376
CT, thoracic cavity not elsewhere classified (3GY20)	1,211
Drainage, abdominal cavity (1OT52)	1,186
Drainage, pleura (1GV52)	1,084
<b>Patients with palliative care in other sectors</b>	
	<b>Number</b>
Transfusion, circulatory system (1LZ19)	12,035
Implantation of internal device (central venous catheter) (1IS53)	11,801
Ventilation, respiratory system (1GZ31)	9,681
Pharmacotherapy, total body (1ZZ35)	6,640
CT, head (3ER20)	6,440
CT, brain (3AN20)	5,758
CT, abdominal cavity (3OT20)	5,462
CT, total body (3ZZ20)	3,237
Dialysis, urinary system not elsewhere classified (1PZ21)	3,184
Drainage, pleura (1GV52)	3,078

**Notes**

CCI: *Canadian Classification of Health Interventions*.

Includes all admissions to the hospital (acute care and subacute care) for decedents in Ontario, Alberta, British Columbia and Yukon.

“Other sectors” includes acute care, subacute care, long-term care and emergency departments.

**Source**

Discharge Abstract Database–Hospital Morbidity Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2020–2021 to 2021–2022, Canadian Institute for Health Information.

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