THE FRAMEWORK ON PALLIATIVE CARE IN CANADA— FIVE YEARS LATER

A REPORT ON THE STATE OF PALLIATIVE CARE IN CANADA

Health Canada Santé Canada

Health Canada is the federal department responsible for helping the people of Canada maintain and improve their health. Health Canada is committed to improving the lives of all of Canada's people and to making this country's population among the healthiest in the world as measured by longevity, lifestyle and effective use of the public health care system.

Également disponible en français sous le titre :
Cadre sur les soins palliatifs au Canada – Cinq ans plus tard. Un rapport sur l'état des soins palliatifs au Canada.

To obtain additional information, please contact:

Health Canada
Address Locator 0900C2
Ottawa, ON K1A 0K9
Tel.: 613-957-2991
Toll free: 1-866-225-0709
Fax: 613-941-5366
TTY: 1-800-465-7735
E-mail: publications-publications@hc-sc.gc.ca

Publication date: December 2023

Cat.: H22-4/16-2023E-PDF
ISBN: 978-0-660-68417-8
Pub.: 230507

TABLE OF CONTENTS

1. Minister's Message

In Canada, given the choice, most people with serious illness prefer to spend the end of their lives at home or in a home-like setting in their community. Many Canadians find it difficult to plan for that time and to discuss serious illness, death, dying and end-of-life care with their loved ones and health care providers. Being proactive and compassionate about these topics is critical to the well-being of people living with serious illness and their families and loved ones.

As Minister of Health, I am pleased to present Health Canada's 2023 *Report on the State of Palliative Care in Canada*. Since the release of the Framework on Palliative Care in Canada in 2018, there have been collective efforts to advance palliative care awareness, access to training, supports for caregivers and providers, and to stimulate research and improve data collection on palliative care. And I am especially encouraged to report that, since 2018, we have moved closer to our collective vision for palliative care in Canada. This progress is the result of collective and collaborative efforts by governments, organizations and individuals over the last five years.

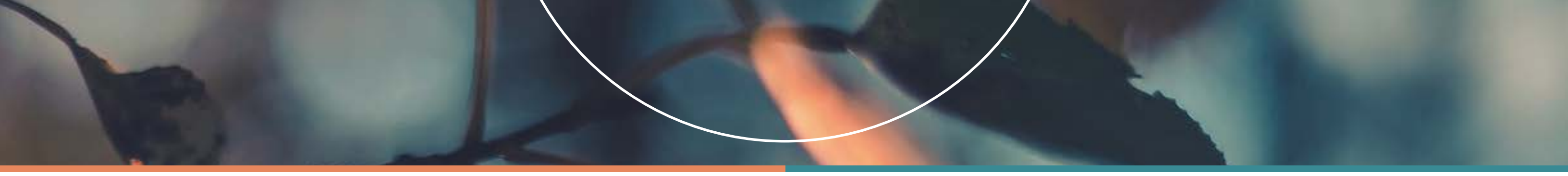
More Canadians are engaging in Advance Care Planning, sharing their wishes for their future care with their care teams and those closest to them. More Canadians are receiving palliative care at home compared to five years ago. When a person cannot be at home, they have more access to hospices than they did five years ago. More health care providers, at all levels, are trained in palliative care and how to have those difficult but necessary conversations. There are more resources available for all of us, to help support us as we care for our loved ones at the end of life and find our way through grief related to their loss.

But there is still more work to do. Persistent gaps remain in equitable access to services for some, based on their age, where they live or other factors. In many cases, palliative care is received very late in a person's illness. While research capacity is increasing and data improvements are being made, consistent measurement remains a challenge.

The Government of Canada will continue to use the Framework as a guide for our future, making strategic investments through the remaining years of the Action Plan on Palliative Care, and working with other governments, First Nations, Inuit and Métis Partners, experts and stakeholders, to see its vision through.

Thank you to all who have contributed to the improvements in palliative care. Together, we are moving toward our vision of Canadians having the best possible quality of life right to the end of life.

The Honourable Mark Holland, P.C., M.P.
Minister of Health



2. Introduction

2.1. FRAMEWORK ON PALLIATIVE CARE

The Government of Canada passed a bill on December 12, 2017 (Parliament of Canada, 2017) providing for the Minister of Health to create a framework on palliative care. The Act states that the Minister must:

- develop a framework that supports improved access to palliative care across Canada;
- consult provinces, territories and palliative care providers to make the framework; and
- report on the state of palliative care in Canada by December 4, 2023.

The Minister of Health tabled the Framework on Palliative Care in Canada in Parliament on December 4, 2018. The Framework was developed through broad consultation as a consensus, strategic policy document. It offers a guideline for all palliative care stakeholders to work toward the shared vision of "all Canadians with serious illness living well until the end of life".

2.2. PROGRESS REPORT

The Framework outlined a shared vision of success to be achieved through changes in palliative care policies and programming. Since the release of the Framework in 2018, more Canadians are accessing palliative care and more care is provided in the community (Canadian Institute for Health Information, 2023a). In its 2023 report, Access to Palliative Care in Canada, the Canadian Institute for Health Information notes that 58% of Canadians who died in 2021–2022 received palliative care. This is an increase from 52% in 2016–2017 (Canadian Institute for Health Information, 2023a).

More people are dying at home with palliative support compared to five years ago. Among those who received some form of palliative care, 61% had palliative care in hospital only, while 36% had palliative home care. In 2021-2022, 13% of Canadians died at home with palliative care – an increase from 7% in 2016-2017. This data reflects improvements in meeting Canadians' wishes to remain at home as long as possible. When people receive palliative home care, they have their needs identified earlier and they may live longer (Canadian Institute for Health Information, 2023a).

When receiving care at home is no longer possible or desired, a hospice setting can provide a home-like environment for palliative care. Since 2018, there has been an increase in the availability of hospice settings for Canadians and their families. According to the Canadian Cancer Society's recent report[1] (Canadian Cancer Society, 2023), the number of residential hospice beds is increasing across provinces and territories. In a 2017 survey, there were 88 residential hospices in Canada. As of May 2022, there were 142 sites with 1,530 beds. The majority of these are in Ontario, Quebec and British Columbia (Canadian Cancer Society, 2023).

Provinces and territories are collaborating with a range of partners to expand residential hospice services. For example:

- Yukon's first hospice, Wind River Hospice House (co-located in Whistle Bend Care Home), which is funded and operated by Yukon Government, opened in 2020.
- Saskatchewan's first stand-alone hospice facility opened in Saskatoon in 2021 and a second site opened in 2023 in Prince Albert.

---

[1] This report was prepared by the Canadian Cancer Society's Don Green Palliative Care Advocacy Team.

- In New Brunswick, there are three residential hospices located in Fredericton, Moncton and Saint John providing palliative and end-of-life care services in community settings. A fourth residential hospice is set to open in Miramichi in the fall of 2023 through an innovative partnership with the province's Extra-Mural Program home health care services.

Despite improvements in the last five years, there are still gaps in care. Some people do not get palliative care until just before they die. Others die in hospital even when community supports, such as home care, may be available. The Canadian Institute for Health Information reports that some people experience greater barriers to accessing palliative care because of their age, where they live, or their diagnosis (Canadian Institute for Health Information, 2023a). Specifically designed palliative care initiatives can address these known barriers to meet the needs of underserved populations.

People who may not have resources and supports or whose "home" may not be safe face additional barriers in accessing palliative care. This includes people who lack adequate shelter or who may not have family or friend care providers. The barriers experienced by those without family or friend care providers underscore the importance of supporting and spreading community-based programs, such as compassionate communities.[2] The compassionate community approach recognizes that it is everyone's responsibility to care for each other. Similarly, achieving the vision of the Framework – that all Canadians with serious illness live well until the end of life – will be possible only through the combined efforts of governments, stakeholders, health care providers, caregivers, and communities.

This progress report takes stock of the landscape of palliative care in Canada and proposes recommendations on next steps for continued action. In the following sections, actions of governments, organizations and the many palliative care stakeholders reflect the collective action taken toward the common goals described in the Framework's Blueprint (Appendix A).

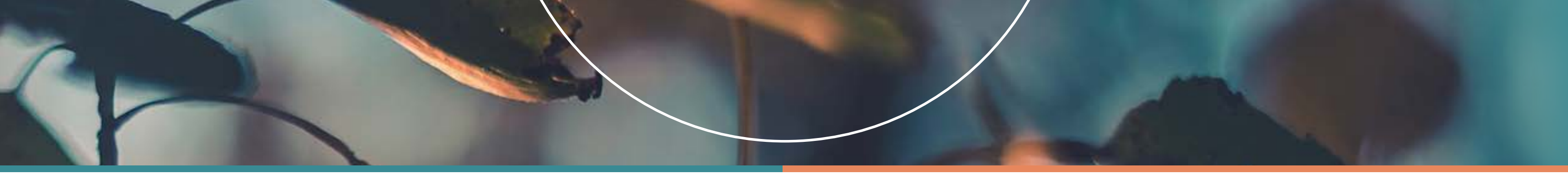
TABLE 1. SUMMARY OF CURRENT PROGRESS AND FUTURE ACTION IN FRAMEWORK PRIORITY AREAS

PRIORITY AREA	HIGHLIGHTS OF CURRENT PROGRESS	ACTIONS MOVING FORWARD
Palliative care training and education	• New professional development and education resources are helping providers become better prepared to support people with serious illness. • A minimum standard of competencies is helping frontline providers from multiple disciplines provide a palliative approach to care. • Communities of practice are building local capacity to provide a palliative approach to care for patients and their families.	• Increase palliative care education, experiences and mentorship for health provider students. • Include the Canadian competency framework in more education programs and employment standards. • Continue to support education focused on improved communication skills.

---

[2] Compassionate Communities are emerging in Canada as a response to the experience of living with serious illness, dying and grieving. Through actively caring for people in difficult times, the Compassionate Communities movement (Kellehear, 1999) is committed to improving community members' lives. Compassionate Communities also raise awareness of health, well-being, and end-of-life issues. They support not only the person who is ill, but also caregivers and loved ones.

PRIORITY AREA	HIGHLIGHTS OF CURRENT PROGRESS	ACTIONS MOVING FORWARD
Measures to support palliative care providers and caregivers	• Advance Care Planning is increasing, including for underserved populations. • New awareness initiatives on palliative care and grief literacy are underway. • Compassionate care benefits have been expanded. • More palliative care and grief supports for patients and caregivers close to home are available.	• Support the growth of compassionate communities. • Continue to promote improved care in the community, including home-based palliative care. • Develop new resources to help patients and caregivers understand the illness and what comes next.
Research and the collection of data on palliative care	• Research capacity is increasing and new large-scale research collaborations to support researchers are underway. • To improve delivery and increase access to home-based palliative care, initiatives to train primary care teams in the provision of home-based palliative care are being assessed on a national scale. • New initiatives to improve data standardization and measurement of patient outcomes are beginning.	• Include more diverse populations, illnesses and care providers in research, and measure equitable access to care. • Build research capacity through expanded research networks. • Move towards data standardization across jurisdictions. This includes common indicators and better data about palliative care delivery, patients' and families' outcomes and experiences.
Measures to facilitate equitable access to palliative care across Canada	• New strategies and initiatives are working to improve access for diverse populations. • New resources are being developed to support communities seeking to improve access to palliative care for the homeless and vulnerably housed. • Innovative models of care delivery that include paramedics are underway. • Engagement and funding for First Nations, Inuit and Métis-led initiatives are underway.	• Spread and scale models of care that address the needs of persons living with homelessness or who are vulnerably housed. • Create and share resources and supports that address the specific needs of underserved populations (e.g., children and youth and people living with illness other than cancer). • Continue engagement with First Nations, Inuit and Métis communities. • Spread and scale innovative models that improve access for underserved populations, including community-led initiatives for First Nations, Inuit and Métis Peoples.



3. Supporting Palliative Care

The federal, provincial and territorial governments share responsibility for health care. The federal government provides financial support to the provinces and territories. The responsibility for administration and delivery of health care services, including palliative care, falls primarily under provincial and territorial jurisdiction.

The Common Statement of Principles on Shared Health Priorities outlines common priorities for action for the federal government and the provinces and territories. This includes improving access to palliative and end-of-life care at home or in hospices.

The Federal Budget 2017 invested $6 billion over ten years in federal funding to support these common priorities. Bilateral agreements between the federal government and provincial and territorial governments (2017–2022) described how the first five years of funding would be used. Once these agreements expired, new one-year agreements (2022–2023) were put in place; together, these agreements deliver on the first six years of the 10-year funding. The remaining four years of funding for home and community care, including palliative care, will be integrated into new Aging with Dignity bilateral agreements (currently being negotiated) as part of the Federal “Working Together to Improve Care for Canadians” plan.

While there is no indicator specific to measuring progress on access to palliative care, the Common Statement of Principles has an indicator on “place of death” in order to better understand the setting in which Canadians are spending their end of life. This indicator showed that, in 2020, 55% of Canadians died at home or in the community (meaning outside of hospitals and acute care facilities). However, this indicator is not broken down to distinguish those who may have received palliative care.

Data from the Canadian Institute for Health Information, Statistics Canada and researchers are improving our understanding of palliative care data related to access and quality.

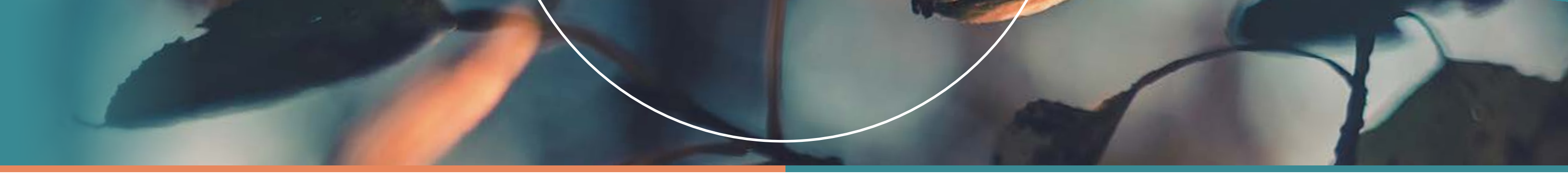
Complementary to the 2017 agreements with provinces and territories, in 2019 Health Canada released a multi-year Action Plan on Palliative Care to tackle issues identified during the Framework’s development. Federal investments of $24 million from 2019 to 2021 supported implementation of the Action Plan. Budget 2021 provided an additional $29.8 million over a six-year period (starting in 2021-2022) for Health Canada to continue to implement the Action Plan. This funding extends beyond the timeline of this report, allowing for a longer-term focus on the Framework’s collective vision for palliative care.

As of 2023, 12 out of 13 provinces and territories have a published palliative care framework or actions to improve palliative care specific to their jurisdictions (Appendix B).

National, regional and local organizations are also working to improve access to palliative care. Many of these organizations represent people with serious illness, their caregivers, family (or chosen family), friends, and those who provide palliative care or a palliative approach to care.[3] Some organizations’ innovative palliative care initiatives are highlighted throughout the remainder of this report.

---

[3] A palliative approach to care (sometimes called “primary- or generalist-level palliative care”) includes the core elements of palliative care. This care can be provided by non-specialists, such as primary care providers, social workers, spiritual care providers, personal support workers, volunteers, caregivers, and other community members. Most people with serious illness can benefit from this kind of care from the time of diagnosis and throughout their illness (even while undergoing treatments meant to cure). If symptoms or needs become complex, primary care providers can refer the patient to a palliative care specialist or team for more comprehensive care (often referred to as “specialist-level palliative care”) (Government of Canada, 2023b).



4. Reporting on Progress toward the Framework's Vision

The medium-term goals in the Framework envisioned for palliative care in Canada align with the timeline of this report. They include:

- increased awareness of palliative care, and greater uptake of advance care planning;
- access to training, education, and tools for palliative care providers to allow them to meet the goals of patients and families;
- access to supports for caregivers and providers;
- research undertaken and applied, and improved data collection and reporting to align with policy goals; and,
- mechanisms to facilitate consistent, equitable access to palliative care for all who could benefit.

4.1. PALLIATIVE CARE TRAINING AND EDUCATION

One goal of the Framework was that all health care providers (regulated or not) would have core skills to provide a palliative approach to care, supported by specialists as needed. Over the last five years, Canada has made progress in improving access to training, education, and tools for palliative care providers. This helps providers to meet the goals of patients and families.

- Health Canada has invested just under $18.5 million in training, resources and supports for providers and caregivers.
- The 12 provinces and territories that participated in a recent survey reported having focused on workforce education in palliative care (Canadian Cancer Society, 2023).
- Half (52%) of respondents to a 2021 survey led by a recent Canada Research Chair in Palliative and End of Life Care (Pesut et al., 2022) felt the availability of health care professionals trained in palliative care had improved since 2016. Respondents cited the importance of shifting to virtual learning, resulting in more effective and timely education.

Project ECHO™ is a five-year national community of practice initiative, funded by Health Canada, to support continuous professional development for health care providers who care for patients with serious illness. Led by Pallium Canada and partners from across Canada, the project builds local capacity to provide palliative care for patients and their families. Since its launch in March 2021, Pallium and its Hub Partners have delivered over 250 learning sessions, with over 13,000 learner encounters and over 15,500 recording views.

In 2021, Health Canada, the Canadian Partnership Against Cancer and other partners developed the Canadian Interdisciplinary Palliative Care Competency Framework. The goal of this Competency Framework was to set a common standard for the knowledge and skills that nurses, physicians, social workers, personal support workers, volunteers, and spiritual care practitioners need in order to provide palliative care. The Competency Framework leveraged existing provincial frameworks to develop a minimum standard of competency across the country. It also includes domains to address care for First Nations, Inuit and Métis Peoples. The Framework will include additional disciplines in the future.

The Canadian Interdisciplinary Palliative Care Competency Framework In Action

The following projects are just a few examples of how the use of common competencies are improving care through initiatives supported by a range of governments and partners.

The **Canadian Home Care Association** is implementing a Health Canada-funded project to help home care organizations enhance the competencies of their frontline providers. This project will help to deliver a compassionate, emotionally responsive approach to care for patients in their homes.

The **Yukon Palliative Care Education Flowcharts for Health Care Providers and Caregivers** was released in 2022. Embedded within these flowcharts are the Canadian Interdisciplinary Palliative Care Competency Framework's self-assessments for each discipline. These flowcharts help service providers map areas for professional development and then identify educational resources to close those gaps in their knowledge and skills.

Recently, the **British Columbia Centre for Palliative Care** developed and implemented palliative care education initiatives, guided by both the provincial and Canadian competency frameworks. Their Serious Illness Conversation training is a nationally recognized, evidence-based education and capacity-building program. The program supports health care providers to initiate and conduct conversations with people who are seriously ill and their family members or loved ones. Conversations can focus on people's wishes, fears, goals and priorities for care.

Pallium has developed tools to put the Competency Framework into action. In 2021 alone, 7,982 learners engaged in the "Learning Essential Approaches to Palliative Care" course and Pallium hosted 313 learning sessions. Evaluations of these courses and their impact shows a marked change in the knowledge, attitudes and comfort level of health care workers delivering palliative care.

The **Canadian Society of Palliative Care Physicians** is developing modules to help physicians prepare for the Subspecialty in Palliative Medicine examination. This multi-year (2022-2025), Health Canada-funded project with a national scope will develop 11 new accredited online study modules and update five existing modules. Physicians can use the 16 modules for self-study as part of their requirement to participate in continuing professional development. Non-specialists can also take part in this self-study. This project will help to create a consistent level of palliative care practice across Canada. In its first year, 87% of participants reported enhanced knowledge. Eighty-eight percent had a better understanding and awareness of various medications, treatments, and practices. Eighty-three percent of participants felt more confident in their exam preparation.

> **"I will always think now of whether a person with a life-limiting illness might benefit from a palliative approach to care. I will be a better advocate for them."**
>
> *— Learning Essential Approaches to Palliative Care: Personal Support Worker Learner*

4.2. MEASURES TO SUPPORT PALLIATIVE CARE PROVIDERS AND CAREGIVERS

Governments and partners who contributed to the development of the Framework imagined a future with better awareness and understanding of palliative care, increased uptake of Advance Care Planning, and better supports for caregivers and providers.

An important first step to access palliative care services is being aware of palliative care and how it can help. Engaging in Advance Care Planning allows people time to reflect on their wishes and values. It also helps other people understand the care they would want in the future if they were unable to speak for themselves.

Since the launch of the Framework, more Canadians are engaging in Advance Care Planning and there is growing recognition that this is helpful for their families. In a recent poll, 93% of Canadians said it was important to talk to family members about their care wishes. Between 2019 and 2021, the number of Canadians who talked to a family member almost doubled: from one in three (36%) to nearly two in three (59%) (Canadian Hospice Palliative Care Association, 2021).

- Since 2018-2019, Health Canada has invested $8.3 million to raise awareness of palliative care for care providers and for caregivers.

Examples of some of the promising awareness initiatives launched since 2022 are outlined in the box that follows. Building on this existing work and leveraging the expertise and perspectives of multiple stakeholders, in 2022-23, Health Canada launched its multi-year public education campaign. The campaign addresses myths that act as barriers to accessing palliative care. The campaign also aims to increase grief literacy and improved understanding and awareness of a palliative approach to care. The main audiences are the public and non-palliative specialist providers. Health Canada and the Canadian Cancer Society are working together on elements of the campaign to extend its reach and maximize its impact. As part of this work, Health Canada commissioned a public opinion survey in 2022. This survey measured current views on palliative care and grief.

Before the campaign started, 58% of respondents indicated they were somewhat to very familiar with palliative care. Forty-five percent agreed or strongly agreed that they would know where, when, and how to seek help with their grief. Please visit the Understanding Canadians' views on palliative care survey report for more baseline public opinion results on Canadians' views on palliative care and grief.

Health Canada plans to commission a follow-up survey at the end of the campaign in 2026–27. The follow-up survey will signal whether people's understanding of palliative care and grief has improved since 2022. It can also help identify areas where more work will be needed to address knowledge barriers to accessing care.

National Efforts to Improve Palliative Care Awareness In Action

The **Canadian Hospice Palliative Care Association** works to increase public awareness of palliative care, best practices, and current research. They do this through campaigns, conferences, educational webinars, and knowledge translation initiatives such as **National Hospice Palliative Care Week**.

The **Canadian Cancer Society** launched an **awareness campaign in January 2023 called About Life**. The goal of the campaign was to show what palliative care has given to the people (and their loved ones) who have received it. The intent is to demonstrate why everyone in Canada needs access to palliative care. People nationwide viewed the advertisements and videos more than 10 million times. The Canadian Cancer Society won a Polaris Award (silver medal) for the "Best Campaign Created for a Non-Governmental Organization Dealing with Issues Related to Health".

More than 8 million family and friend caregivers in Canada are providing care in the home to someone who is seriously ill. Sharing their lived experience, patients and caregiver advisors informed the development of the Canadian Institute for Health Information's 2023 report (Canadian Institute for Health Information, 2023a). These patient and caregiver advisors expressed concern about inequitable access to care, lack of information about services and resources, and the pressure to advocate for improvements in palliative care.

Most caregivers will feel unprepared and overwhelmed at some point. About one in three caregivers reports distress (35% in 2018-2019 and 37% in 2021-2022) (Canadian Institute for Health Information, 2023b). A number of programs exist to support caregivers, including support to take a period of leave from work, access to online resources (including grief and bereavement supports), and access to volunteer navigation programs.

Employment and Social Development Canada also offers leave and job security for working people who are supporting individuals with serious illness through three types of Employment Insurance benefits:

- family caregiver benefit for a critically ill or injured child under 18 (up to 35 weeks);
- family caregiver benefit for critically ill or injured adults (up to 15 weeks); and,
- compassionate care benefits (up to 26 weeks for a person of any age who requires end-of-life care).

- On January 3, 2016, the maximum duration of compassionate care benefits was extended from 6 weeks to 26 weeks.
- In December 2017, Employment and Social Development Canada expanded the definition of "family member" to include people who are "like a family member" for all caregiving benefits. This expanded definition offers more flexible options for those providing care for a loved one.

Spotlight on Compassionate Community Initiatives and Supports for Caregivers

In 2023, more than 223 Compassionate Community Initiatives were in place across Canada (Pallium Canada, British Columbia Centre for Palliative Care, and Hospice Palliative Care Ontario, 2023).

The Compassionate Communities movement in British Columbia, supported by the **British Columbia Centre for Palliative Care** and the British Columbia Compassionate Communities – Framework for Action, includes seed grants to community-based organizations. The movement offers training, toolkits, and coaching. This movement helps to equip staff and volunteers with necessary skills and resources to provide psychosocial, practical, and spiritual support closer to people's homes.

In Alberta, **Covenant Health's Palliative Institute** launched Compassionate Alberta to increase the public's awareness of palliative care and advance care planning, to help Albertans have conversations about living and dying well and plan appropriately for the future.

Statistics Canada has partnered with Health Canada and the Canadian Institute for Health Information to add questions about Compassionate Communities to the Canadian Social Survey Cycle 12. These questions will ask respondents about their involvement with their community. It will also ask whether people would be willing to give or receive help in their community if they had a serious illness. Results will be publicly available in spring 2024 and will be used to help develop programs and policies that support the spread of successful compassionate community initiatives across Canada.

For the over 9 million people grieving a COVID-19 related loss (Canadian Grief Alliance, 2023), and the millions more grieving other losses, where they live, time and cost can make accessing support difficult. To enable all Canadians to access the help they need, with support from Health Canada and others, Canadian Virtual Hospice developed a suite of free, online, bilingual grief resources, available 24 hours a day, seven days a week, from the comfort of people's homes.

These resources include:

- **MyGrief.ca | MonDeuil.ca (for grieving adults)**
- **YouthGrief.ca | DeuilDesAdos.ca (for grieving youth)**
- **KidsGrief.ca | DeuilDesEnfants.ca (for parents, guardians, and educators supporting grieving children)**

> **"I sent a link to the MyGrief.ca modules to my mom. My dad died in the fall, and she has been struggling. She did the anticipatory grief [modules] and was excited that she now realized how she and my dad had been grieving all the losses over the past nine months. It completely opened her eyes to the experience and gave a name for it.... (I) just wanted to say thanks to Canadian Virtual Hospice for the work you do and the fabulous resources you have created. They truly make a difference for people."**
>
> — *Canadian Virtual Hospice user*

Advance Care Planning and Grief Support In Action

The **Canadian Hospice Palliative Care Association** spearheads the Advance Care Planning Canada initiative, collaborating widely to provide public education and a library of resources. In 2023, the Canadian Hospice Palliative Care Association began a Health Canada-funded project to make these resources more accessible to people with disabilities.

Nova Scotia's work on Advance Care Planning included implementing a standardized provincial form and process. These actions help to support discussions on Goals of Care between patients (or their substitute decision-maker) and health care providers. To support identification for patients' Goals of Care, Nova Scotia also added electronic flags to patient charts.

The Quebec Palliative Care Action Plan includes a priority on enhancing health care providers' skills to engage in Advance Care Planning conversations, and more public awareness on the importance of Advance Care Planning.

The **Public Health Agency of Canada's Dementia Community Investment Program** provided funding of almost $700,000 over two years (2020-2021 to 2021-2022) to the British Columbia Centre for Palliative Care to better support people living with dementia. Their work on Advance Care Planning focuses on people in early stages of dementia, those at higher risk for dementia, and their family/friend caregivers.

The **Advancing Grief Literacy in Canada: First Steps Action Plan** project led by the Canadian Virtual Hospice (on behalf of the Canadian Grief Alliance) launched in fall 2023. Health Canada has invested $1 million in this project, which aims to help those who are grieving:

- better understand their experiences and respond to their grief;
- feel supported by the people in their life; and,
- know how to access services.

The project includes a series of accessible online resources, learning opportunities, and a national awareness campaign.

4.3. RESEARCH AND THE COLLECTION OF DATA ON PALLIATIVE CARE

A measure of success in the Framework is a future where stakeholders use innovations and technology to ensure palliative care supports and services are available to those who need them. Consistent data across care settings and providers is important to measure outcomes as well as experiences of people with serious illness and their families.

The Framework identified a need to support data systems and research which provide the evidence base for improvements in palliative care. Over the past five years, there has been significant progress in both the areas of research and data collection.

- Health Canada has invested $3.7 million since 2021 to improve palliative care research and data collection.
- The Canadian Institutes of Health Research invested more than $30 million in palliative care research between 2018-2019 and 2022-2023, mostly through the Institutes of Aging, Cancer Research, and Health Services and Policy Research. In 2022-2023 alone, the Canadian Institutes of Health Research invested approximately $6.8 million in palliative care research, led by 49 researchers, through 60 grants and awards.

Since 2018, the Canadian Institutes of Health Research has supported 215 researchers across 259 palliative care grants and awards. These investments have continued to generate evidence aimed at improving care for people with serious illness. A summary of some promising health care services and patient- and family-oriented research the Canadian Institutes of Health Research has funded are provided in the following box.

Canadian Institutes of Health Research Funded Research Projects

Improving Early Access to Palliative Care: With funding from the Canadian Institutes of Health Research, a team led by Drs. Hsien-Yeang Seow and Ahmed Jakda from McMaster University, and Frederick Burge from Dalhousie University, is evaluating the Community Access to PAlliative Care via Interprofessional Teams Intervention (CAPACITI). This intervention trains primary care teams in the provision of home-based palliative care. Based on previous pilot work, the team is currently assessing the performance of the program on a national scale. The intervention has potential to improve delivery and increase access to home-based palliative care for patients across Canada.

Improving Palliative Care Data: Lakehead University is leading a research collaboration funded by Health Canada, leveraging InterRAI[4] assessment data. This research will study the experiences of people underserved by palliative care, such as:

- minority language groups;
- adults 85 years and older;
- people living with dementia;
- people living with mental illness;
- people in rural and remote settings; and,
- people with intellectual and developmental disabilities.

Lakehead University will use linked, pan-Canadian, population-level, longitudinal data from multiple health care settings. An assessment-based "flag" will be developed to identify those who could benefit from a palliative approach to care. They will create a palliative care assessment tool to promote consistent data collection. Data analyses will improve understanding of needs, experiences, and outcomes.

---

[4] InterRAI instruments are evidence-based, standardized, and validated tools used for patient assessment across different care settings.

Supporting New Researchers: Because palliative care is a small field, it can be difficult for researchers to launch a successful career in this area. This career path can be facilitated via networks of researchers. Health Canada is providing $2.9 million (2021/2022 to 2025/2026) to the Pan-Canadian Palliative Care Research Collaborative. This project fosters mentorship and mutual support. There are over 100 researchers and partners engaged in 25 active research programs. The seed funding and other capacity building activities from this collaboration have laid the groundwork for researchers' success. This is reflected in over $5 million of contributions and grant funding from major funders, such as the Canadian Institutes of Health Research. Data standardization is one priority area, and the work will help build more consistent ways of measuring improvements in palliative care.

In 2018, the Canadian Institute for Health Information published its baseline report on *Access to Palliative Care in Canada* (Canadian Institute for Health Information, 2018) and updated the report in 2023 (Canadian Institute for Health Information, 2023a). The good news is that the 2023 data reflects some improvements to home care reporting and overall access to palliative care. However, data are needed to better measure access to care and experiences across settings in all provinces and territories, as well as who was not able to access palliative care. Data leaders such as Statistics Canada and the Canadian Institute for Health Information are collaborating to improve their palliative care datasets. This work will shed light on the diversity of the Canadian population while identifying who has more challenges accessing care, ultimately informing changes in policy and practice.

While **Statistics Canada** collects and reports on key population indicators such as vital statistics (including numbers and causes of death), it has not previously focused on palliative and end-of-life care. Budget 2021 provided Statistics Canada with $41.3 million over six years, and $7.7 million ongoing, starting in 2021-22, to launch a new initiative called Health Care Access, Experiences, and Related Outcomes, to improve data on supportive care, primary care, and medications across all health care settings. Since Health Canada expressed the need for more data on people's experiences with palliative care, this project will include a one-time open-link survey of people with serious illness or their caregivers who may have accessed palliative care. The invitation to participate will be circulated through websites, social media, and stakeholders' networks in all provinces and territories. In this "open-link" approach, people self-select to participate. Survey results will be available in spring 2025.

4.4. MEASURES TO FACILITATE EQUITABLE ACCESS TO PALLIATIVE CARE ACROSS CANADA

The Framework envisioned consistent, equitable access to palliative care for all who could benefit from it. Improving equity in access to palliative care is a priority for all palliative care stakeholders. Canada has made improvements over the past five years in this area.

- Provinces and territories are developing a range of strategies for improving access to palliative care for diverse populations, including rural and remote communities, people with illnesses other than cancer, and particular cultural and linguistic communities (Canadian Cancer Society, 2023).
- Health Canada has invested $4.9 million to date to facilitate equitable access to palliative care, including investments for Indigenous communities.
- Three 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%) (Canadian Institute for Health Information, 2023a).

However, there is still work to do to meet the needs of diverse populations and to improve access to palliative care. In 2023, the Canadian Institute for Health Information (Canadian Institute for Health Information, 2023a) reported that:

- patients with cancer continue to have better access to palliative care than those with other conditions;
- people with dementia are among the least likely to access palliative care services, compared with people with cancer (39% versus 77%);
- Canadians aged 85 and older are less likely to receive palliative care than younger people;
- in 2021-2022, only 34% of residents in long-term care who had less than six months to live received palliative care; and,
- people experiencing homelessness, new Canadians, and people of colour face additional barriers to accessing palliative care.

Supporting Equitable Access to Palliative Care

The Equity in Approaches to Palliative Care collaborative (**University of Victoria**) developed resources to support communities interested in improving access to palliative care for equity seeking populations. This expertise is informing a federally funded improvement partnership led by Healthcare Excellence Canada, working with the Canadian Partnership Against Cancer, called Improving Equity in Access to Palliative Care. Over four years, up to 20 communities will improve palliative care for people experiencing homelessness or who are vulnerably housed.

Paramedics and Palliative Care: Bringing Vital Services to Canadians was a five-year partnership between Healthcare Excellence Canada and Canadian Partnership Against Cancer. Innovative models of care in Alberta, Nova Scotia and Prince Edward Island inspired this initiative. More than 7,500 paramedics received training and supports in six additional provinces, allowing care for people closer to their homes and communities. Of the approximate 7,000 9-1-1 palliative care calls, 53% were able to receive care at home instead of at the emergency department. Paramedics improved presenting health complaints 87% of the time. Over 92% of surveyed patients and families were satisfied with the care received by paramedics. The model saves health care costs and provides patients, families and caregivers with better access to palliative care 24 hours a day, seven days a week, in the community.

> **"To keep people out of emergency and to keep them at home is amazing … this program has been the link that has been a gap in our service."**
>
> *— Community Palliative Care Team,*
> *Newfoundland and Labrador*

Canadian research also shows that only 18% of children who died and who might have benefited from specialized pediatric palliative care actually received it. Among those children who did get palliative care, 25% received it for less than eight days before they died (Widger et al., 2016).

Understanding patient characteristics, through projects like the Lakehead University research collaboration, will help to support the development of culturally safe and respectful care models. The remaining years of the Action Plan will continue to focus on these issues with a view to more people having access to palliative care, including children.

Together with First Nations, Inuit and Métis organizations, Health Canada is developing policy frameworks to reflect the distinct end-of-life care needs of First Nations, Inuit and Métis Peoples.[5] The Frameworks will be informed by Indigenous-led engagement on palliative and end-of-life care, by parallel engagements happening through other government departments, and by existing published resources.[6]

To date, Health Canada has engaged with 21 First Nations, Inuit and Métis organizations, including representation organizations for non-status/off-reserve and urban Indigenous people. Seventeen of these organizations identified palliative care as a priority and are collaborating with Health Canada in this regard.

Other government departments and organizations are also actively working to advance access to palliative care for First Nations, Inuit and Métis communities. Indigenous Services Canada's First Nations and Inuit Home and Community Care program is a co-designed program that provides funding, or directly provides services, for First Nations on reserve and Inuit.

Budget 2017 provided $8.5 million in ongoing funding for recipients of the First Nations and Inuit Home and Community Care program to deliver palliative and end-of-life care.

The intent of these services is to supplement provincial and territorial services, including primary health care. Some region-specific initiatives have been funded through Budget 2017 funding. These include:

- training front-line providers;
- implementing hospice-like spaces;
- implementing Indigenous Transition Facilitators (discharge planners) to help navigate access to specialized care following being in the hospital; and,
- developing an end-of-life care fund.

Ten out of 13 provinces/territories also noted work is underway in improving access to culturally sensitive palliative care for First Nations, Inuit and Métis communities (Canadian Cancer Society, 2023). Appendix B highlights additional work underway.

First Nations, Inuit and Métis leaders, organizations and governments are working to advance First Nations, Inuit and Métis palliative and end-of-life care.

---

[5] A Peoples-specific approach will be taken, developing unique Frameworks that reflect the voices of First Nations, Inuit, Métis, non-status/off-reserve Indigenous people, urban Indigenous people, and Intersectional Peoples. The Frameworks will also honour distinct goals and recommendations pertaining to palliative and end-of-life care.

[6] For example: the Canadian Partnership Against Cancer's *Beginning the Journey into the Spirit World: First Nations, Inuit and Métis Approaches to Palliative and End-of-Life Care in Canada*. This document was informed by discussions with First Nations, Inuit and Métis Elders and Knowledge Carriers, and community health professionals and researchers with expertise in palliative care. It identifies factors that influence approaches to palliative care in these communities. The document also identifies promising practices and Indigenous-led solutions (Canadian Partnership Against Cancer, 2022).

First Nations, Inuit and Métis Palliative and End-of-Life Care

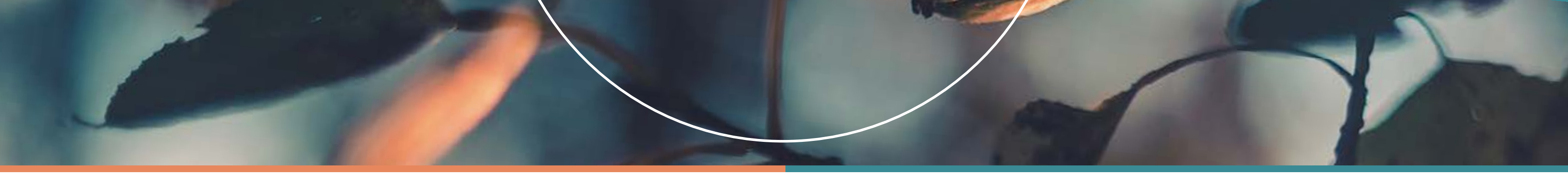
The **Six Nations of the Grand River Territory, Ontario**, is an innovative palliative care program model based on Indigenous culture and community values. It supports people to die at home if they choose. This program has a Palliative Shared Care Outreach Team that includes a First Nations physician, nurse, and social worker. It includes education and mentorship for health care providers, as well as traditional teachings to support clients and staff. Program outcomes include increased deaths at home compared to deaths in hospital or in hospice (Fruch, Monture, Prince, & Kelley, 2016).

The **Centre for Education and Research on Aging and Health at Lakehead University** developed the "Palliative Care for Front-line Workers in Indigenous Communities" curriculum in 2009 (Prince, 2022). This curriculum was created given the need for culturally relevant palliative care education in First Nations, Inuit and Métis communities. Lakehead University created this curriculum with Indigenous communities, Elders, Knowledge Carriers and health care providers. The curriculum recognizes the diversity of First Nations, Inuit and Métis communities' experiences, knowledge, and cultural teachings regarding death and dying. It also uses Indigenous wholistic[7] teaching concepts combined with the palliative approach to care.

Funding from **Indigenous Services Canada** since 2017 has made it possible to support increased palliative and end-of-life care services in First Nations communities in Quebec. This includes such initiatives as rooms reserved for palliative care in certain care facilities. Despite these advancements, there is more work needed to increase funding, training, equipment and to extend service delivery hours (First Nations of Quebec and Labrador Health and Social Services Commission, 2023).

---

[7] The spelling of the term "wholistic" is preferred as it acknowledges the whole person and reflects the need for balance and harmony among the spiritual, emotional, mental and physical aspects of self.



5. Next Steps

This report highlights the progress and momentum made in palliative care over the past five years. All governments and partners working in palliative care in Canada should continue efforts to sustain the gains to date, continue to address gaps, and maintain progress towards achieving the long-term goals envisioned in the Framework (Appendix A). For its part, Health Canada will continue to invest strategically the funding provided by Budget 2021 in support of the priorities outlined in the Action Plan. Collectively, the following recommendations for next steps may help further the work towards our common vision for all Canadians with serious illness to experience the highest attainable quality of life until the end of life.

So that Canadians and caregivers understand and plan for palliative care and develop advance care plans, all governments and partners could:

- continue to destigmatize palliative care so people can benefit sooner in their illness journey;
- ensure more equitable access to grief and bereavement supports;
- sustain efforts to raise awareness and encourage advance care plans;
- support compassionate communities; and,
- tailor and disseminate patient and caregiver tools and resources to better support individual needs.

Even with efforts to raise awareness and encourage advance care plans, culture shifts take time. Current palliative care and grief awareness campaigns (including Health Canada's six-year campaign) and other educational resources will help more people understand palliative care and how to access it. Ongoing conversation and collaboration with governments and partners will be important in these efforts, especially as it relates to how to best grow the Compassionate Communities movement in Canada.

To ensure all providers have increased capacity to deliver quality care, and caregivers have appropriate supports to perform their roles, all governments and partners could:

- continue to advance leading practices in education and training, including mentorship and experiences for health provider students, improving cultural competencies and improving communication skills;
- continue to expand processes and mechanisms to support navigation of available care and resources;
- continue to increase the use of the Canadian Competency Framework as the national standard for education and employment for all health care providers;
- work with Indigenous peoples to develop and disseminate cultural competency guidelines;
- collaborate with organizations to develop and share competency training so that the needs of underserved populations are met; and,
- implement best practice models that integrate palliative care education for interdisciplinary teams.

Ongoing work to support health care provider and caregiver training and add new disciplines to the Competency Framework is underway. Stakeholders are developing a range of projects to implement the Competency Framework to support both education and clinical practice. This will also help position providers to feel better prepared and offer supports to help Canadians with serious illness.

In order that research, data collection, and best practices are implemented to inform and support policy decisions and the provision of palliative care, all governments and partners could:

- build on current expertise to continue developing capacity in all aspects of palliative care research;
- build data capacity including implementing standardized person- and family-reported outcomes measures;
- develop and adopt precise palliative care indicators; and,
- further our understanding of approaches to palliative care in home and long-term care.

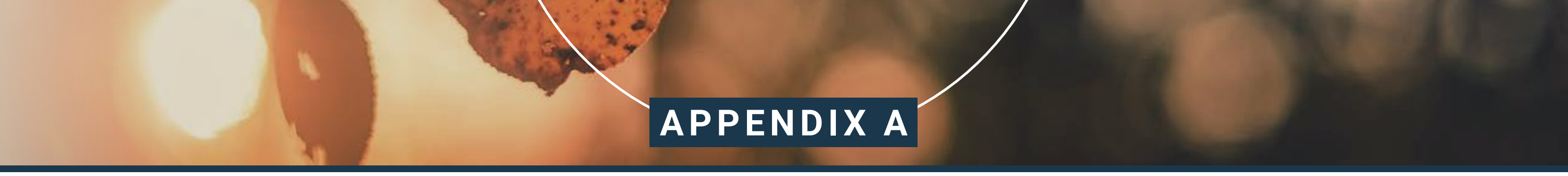
Collaborative work between governments and partners should continue to consider efforts to advance collecting and using comparable data to measure improvements in access to and quality of palliative care. Research networks, such as the one Health Canada has helped launch, are providing and will continue providing mentorship, collaboration, and economies of scale that build research capacity for the future in Canada. The new generation of researchers in this network has been successful in applying for funding from the Canadian Institutes of Health Research to address gaps for underserved populations. These projects include palliative care for people who are vulnerably housed, as well as for frail elderly with neurological conditions, such as Alzheimer's Disease or multiple sclerosis, and will help to inform future improvements in palliative care.

So that the care goals of all people with serious illness and their caregivers are supported, and they benefit from a palliative approach to care, all governments and partners could:

- use a lens of cultural sensitivity and age-appropriateness, and to continue to look for ways to integrate palliative care across care settings;
- focus on inclusive palliative care policies, programs and services to reduce barriers to access;
- continue to engage with First Nations, Inuit and Métis people and to support community-led initiatives to address the needs they identify;
- invest in scaling and spreading innovative models of care, particularly for Indigenous Peoples and other underserved populations (for example, seriously ill children and their families and for those experiencing illnesses other than cancer); and,
- develop palliative care policies, programs, and services that are inclusive and considerate of all ages, sex and gender, and cultural diversity.

A continued focus on spreading and scaling innovative care models will help improve access for people who have not been well supported by traditional models of care.

Moving forward, there are many opportunities to continue to address the palliative care needs of people living with serious illness, their families (or chosen families), and their communities. Provincial, territorial and federal governments, non-governmental organizations and communities could continue to prioritize palliative care improvements. Health Canada will continue looking to support innovative projects to improve access, coordinate knowledge exchange opportunities and the sharing of promising practices in palliative care so that we may continue to learn and improve together. Collaborative action by governments at all levels, non-governmental organizations and communities on the longer-term goals of the Framework will help further our progress to close the gaps in access to quality palliative care in the years to come.



APPENDIX A

Blueprint for the Framework

GUIDING PRINCIPLES:

Palliative Care is Person- and Family-Centred – Death, Dying, Grief and Bereavement are Part of Life – Caregivers are Both Providers and Recipients of Care – Palliative Care is Integrated and Holistic – Access to Palliative Care is Equitable – Palliative Care Recognizes and Values the Diversity of Canada and its Peoples – Palliative Care Services are Valued, Understood, and Adequately Resourced – Palliative Care is High Quality and Evidence-Based – Palliative Care Improves Quality of Life – Palliative Care is a Shared Responsibility

VISION: All Canadians with life-limiting illness live well until the end of life

LONG TERM GOALS 5–10 YEARS

Canadians and caregivers understand and plan for palliative care, and develop Advance Care Plans	All providers have increased capacity to deliver quality care, and caregivers have appropriate supports to perform their roles	All Canadians and caregivers have consistent access to an integrated palliative approach to care	Research, data collection and best practices support and inform policy decisions and government directions about palliative care	Governments, stakeholders, caregivers and communities cooperate to help achieve the goals of Canadians during the entire period of care

MEDIUM TERM GOALS 2–5 YEARS

There is an increased awareness of palliative care, and greater understanding and uptake of advance care planning and advance care directives	Palliative care providers have access to training, education, and tools to meet the goals of individuals and their caregivers	Caregivers and providers are aware of and can access supports to meet the goals of the individual and their caregivers	Mechanisms to facilitate consistent access are advanced, and barriers are addressed	Research is undertaken, applied, and promoted, and data collection activities are planned and reported to align with policy goals	Action aligned with the framework is taken at multiple levels (governments, stakeholders, caregivers, and communities) to improve palliative care and achieve the goals of individuals with life-limiting illness

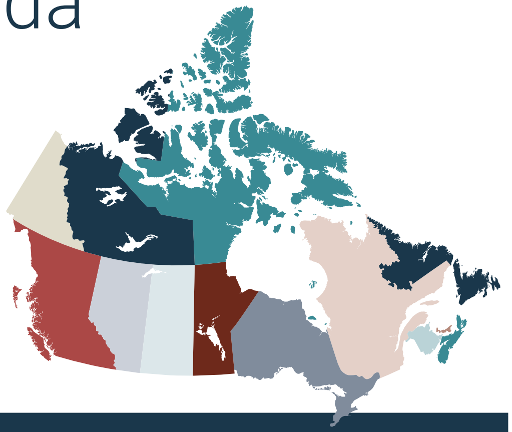
SHORT TERM GOALS

The range of wishes and needs of people with life-limiting illnesses are identified	Training and education needs are identified for health care providers and caregivers	Supports required for palliative care providers and caregivers are identified	Best practices and barriers to consistent access to palliative care are identified	Existing research and data collection gaps are identified	A common framework is developed to guide action and improve access to palliative care in Canada

PALLIATIVE CARE: An approach to care that improves the quality of life of people (adults and children) who are facing problems associated with life-limiting illness, and their families. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Health Canada. (2018). Framework on Palliative Care in Canada. Retrieved from https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html

Provincial and Territorial Efforts across Canada



The following information on provincial and territorial initiatives is from text provided either directly to Health Canada or through the Canadian Cancer Society's 2023 Report on Hospice Palliative Care Across Canada: A review of federal, provincial, territorial and community actions (the latter is identified with an asterisk) (Canadian Cancer Society, 2023).

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
British Columbia*	• A provincial palliative care strategy has been in place since 2013. • The British Columbia Centre for Palliative Care provides resources to the public and supports health care professional education around advance care planning and serious illness conversations. » Advance Care Planning conversations are encouraged across all settings (primary care, home care, hospital, long-term care, retirement homes, community). » A palliative care incentive payment compensates family physicians to undertake and document a care plan for patients who have six months of remaining life expectancy. • Training and skills development are provided through government funding and other organizations. » Focus continues to emphasize a palliative approach to care early in the care trajectory, from all members of the interdisciplinary care team. » Care coordination is supported through virtual monitoring, paramedic outreach, palliative outreach teams, and after-hours palliative nursing service. • Local and regional resources are in place to provide services for marginalized or vulnerable populations, including Indigenous communities.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Alberta	• Since 2019, $20 million has been invested in over 30 initiatives related to palliative care. In 2021, the government engaged with key stakeholders and Albertans to identify what is working well and where gaps remain in optimizing services and supports. The Advancing Palliative and End-of-Life Care in Alberta final report was released in November 2021. Alberta continues to implement its recommendations. • Alberta Health Services is partnering with Pallium Canada to scale and spread province-wide standardized palliative care education through Pallium's Learning Essential Approaches to Palliative Care program. This program caters to the learning needs of many disciplines and practice settings and will enable: » An additional 40 Learning trained facilitators; » Up to 2,000 trained health care providers per year; and, » Up to 10,000 health care aides trained in Learning Essential Approaches to Palliative Care Personal Support Worker. • Select content, including Learning Essential Approaches to Palliative Care Paramedic and an Indigenous Cultural Safety module, will be adapted to the Alberta context. • The Alberta Hospice Palliative Care Association initiated two programs to address the needs of caregivers and those living with a life-limiting illness. 1) The Living Every Season Program is an interactive social support program for adults living with a life-limiting illness. 2) You're Not Alone—Grief Connection is a program that matches grieving adults with trained volunteers who have experienced personal loss and a comparable grief experience. • Covenant Health's Palliative Institute launched Compassionate Alberta, a website aimed at increasing the public's awareness of palliative care and advance care planning. Information, resources, and educational tools have been adapted to reflect the Alberta context. They are being distributed through multiple channels such as: Pallium's Palliative Care ECHO Project, government programming, and building capacity within communities and workplaces via the Compassionate Communities movement. • The University of Calgary is leading the Canadian Atlas of Palliative Care – Alberta Edition, which maps the current state of palliative care services available in Alberta, allowing for provincial and national comparisons. This work will also highlight service provision for priority populations, such as pediatrics, clients experiencing frailty, dementia, or non-cancer diagnoses, caregivers, people encountering structural barriers to access, newcomers, and those living in rural and remote communities. • The Government of Alberta is funding four First Nations to build community capacity to provide culturally appropriate palliative and end-of-life care, education and supports for community members. Funding is also supporting research to identify how culturally appropriate wise practices affect palliative and end-of-life care for Indigenous populations across Alberta.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Saskatchewan	• Saskatchewan's first stand-alone hospice facility opened in Saskatoon in 2021. In August 2023, the second, newly constructed stand-alone hospice facility opened in Prince Albert. Government provides operational funding for both facilities. • Palliative care clients who continue to reside in the community (and whose care consists primarily of managing symptoms such as pain, nausea and stress) can be nominated by their physician for full coverage of benefit drugs under the Saskatchewan Prescription Drug Plan. Individuals designated as end-stage palliative are eligible to receive coverage for the full cost of approved oxygen and corresponding equipment prescribed by a physician. • The Saskatchewan Health Authority's Home Care Program provides primary home care services such as assessment, care coordination, nursing and personal care services based on assessed need to palliative care clients without charge. This may include: » Required dietary supplements/meal replacements and accompanying supplies; » All required dressing and urinary catheter supplies; » Ambulatory infusion pumps, intravenous, and hypodermoclysis equipment and supplies; and, » Incontinence briefs and pads (with some exceptions). • The Saskatchewan Health Authority currently operates 29 designated palliative care beds in health facilities throughout the province. More than 300 "flex" beds in Long-Term Care facilities can be used for palliative care. Clients assessed as acute care management of palliative symptoms or end-stage do not pay a monthly resident charge. • Palliative care training for a range of health care providers across the province began in February 2018 and continues. The Saskatchewan Health Authority has trained over 1,800 employees and physicians in the various Learning Essential Approaches to Palliative Care modules and Victoria Hospice learning opportunities. • An additional nine palliative care physician positions and 7.5 palliative care coordinators have been hired across the Saskatchewan Health Authority, providing enhanced support to palliative clients across the province beginning in 2019.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Manitoba	• Manitoba has established Provincial Clinical Teams for Cancer and Palliative Care and a Provincial Palliative Care Clinical Work Group. These teams enhance equitable and accessible palliative care throughout the province. The involvement of Provincial Clinical Team members and other champions across the province in advancing the palliative care agenda signifies a commitment to improving end-of-life care. Their efforts contribute to fostering innovation and driving progress in regional and provincial palliative care services. The Provincial Clinical Teams are partnering with the Canadian Partnership Against Cancer and Healthcare Excellence Canada for best practices, and in some cases, pilot funding. • Paramedics Providing Palliative Care Project: This project is pilot-funded by Canadian Partnership Against Cancer. It is an initiative where paramedics provide direct support to patients in their homes for symptom management. This model increases the reach of palliative care and offers care options for patients who prefer to receive treatment in their homes. This project was successfully implemented in one region. There are opportunities to scale and spread the learnings from this project to other health regions. • The Improving Equity in Access to Palliative Care Project will develop and implement a plan to improve palliative care for individuals experiencing vulnerable housing or homelessness in one of Manitoba's health regions. The project will also create pathways, programming, and resources for staff involved in caring for individuals who require palliative care. Once completed, the learnings will be analyzed to determine whether it is feasible to implement in other health regions throughout Manitoba. The advisory council for this project includes people with lived experience, Indigenous Partners, shelter sector partners and a Healthcare Excellence Canada coach. • The Models of Care Project is in its early stages and seeks to support the engagement and exploration of the palliative care needs in Dakota Ojibway Tribal Council communities. The project seeks to identify and address gaps in service with the action and evaluation plans promoting holistic healing focused on the spiritual, mental and emotional aspects of health. • Manitoba's palliative care efforts reflect a positive trend toward honouring patient preferences, with more people receiving care at home and choosing to die there. By focusing on home-based care, primary care integration, and equitable access, Manitoba aims to improve the quality of life for patients and their families.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Ontario	• The *Compassionate Care Act* (the "Act", December 2020) requires Ontario's Minister of Health to develop a provincial framework designed to support improved access to palliative care. The Act further requires the Minister to table reports in the Legislative Assembly on the status of palliative care in Ontario one year after the Act comes into force, and three years after the initial report is tabled. » In 2021, Ontario engaged with partners within the palliative care sector to develop a provincial framework. On December 8, 2021, the *Ontario Provincial Framework for Palliative Care* was tabled in the Legislative Assembly of Ontario. The Framework was included in a broader report on the current state of palliative care in the province. The Framework will help Ontario identify key priorities for strengthening palliative and end-of-life care. This includes how it will benefit from the Ontario Health Team model for better integrated care. The implementation strategy will support the Framework's seven building blocks: • Leadership and Accountability • Funding • Provider Education and Mentorship • Integrated Care • Person and Family-Centred Care • Evidence and Data • Public Awareness » Ontario is working with health system partners, including the Ontario Palliative Care Network, on the implementation of the Framework. • As a key step in implementation, Ontario is investing over $53.8 million over the 2023-24 and 2024-25 fiscal years to support and sustain existing hospice providers across the province. This investment will contribute to an operational funding increase of 45% for all approved hospice beds in Ontario, plus an additional increase for hospice beds in small facilities for the next two years. Residential hospices play an important role in Ontario's health system by diverting end-of-life patients from avoidable acute care hospital admissions to be closer to their communities, in a compassionate and home-like setting.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Quebec[*8]	• The Quebec Palliative Care Action Plan includes a priority on enhancing health care providers' skills to engage in Advance Care Planning conversations, and increasing public awareness on the importance of Advance Care Planning. • The Action Plan includes a priority focus on improving access to palliative care for children and adolescents. It also notes a priority to address equitable access for patients with chronic diseases and neurodegenerative disorders, as they have a harder time accessing palliative care compared to patients with cancer. • Other areas of focus include: » support for the implementation of the integrated palliative care approach, using a three-step process of early identification, assessment, coordinated care plan; » improved skills development and communication, including more tools to support health care providers in the provision of quality palliative care, and enhanced competence and confidence by health care professionals; » early identification of individuals who will benefit from palliative and end-of-life care » defined criteria for accessing palliative care based on the needs of the patient and their caregivers, and not only based on medical prognosis; » introduction of early identification of caregiver exhaustion; » a priority to provide support to family or friend caregivers, including consultation with the caregiver and caregiver satisfaction; » indicators identified and reported publicly on the government's public dashboard; and, » regional teams that will be set up to improve access to palliative care for all residents.

---

[8] Information for Quebec was gathered through an online search of publicly available information about palliative care. The Government of Quebec declined to participate in the Canadian Cancer Society survey (Canadian Cancer Society, 2023).

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
New Brunswick*	• In New Brunswick, the provincial Palliative Care Strategy supports the development and standardization of palliative and end-of-life care across the province in all care settings based on a person-centered approach. • The Government of New Brunswick funds training for health care providers working in hospitals and nursing homes, as well as in extra-mural and home support services. • Fee-for-service enhancements are in place for physicians who provide palliative care. • Paramedics providing palliative care at home is an initiative that enhances the knowledge and skills of paramedics to provide care in the home rather than an automatic transfer to the hospital. They collaborate with Extra-Mural Program home health care providers in helping to respect patients' wishes to remain at home. • An end-of-life client care model (combining hospice day programs, outreach programs, access to trained palliative support services for both hospice and extra-mural program patients at home, and respite care services) continues. • Development of palliative care indicators is ongoing. • The Framework identifies the need for equitable access to palliative care across the whole province.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Nova Scotia*	• Nova Scotia has implemented a standardized provincial form and process to support Goals of Care discussions between patients or Substitute Decision Makers and their health care providers. This will support advance care planning and person-centred care by integrating patient values and goals into decisions about their health care and treatment. » To support the identification of Goals of Care, and appropriate levels of medical intervention designations across care settings, electronic flags will be added to patient charts on relevant clinical applications. » This standardized documentation process will enhance and promote communication about Goals of Care decisions within and across health care settings. » A Goals of Care policy is in development. Advance Care Plan and Goals of Care forms, guides, and education tools exist. • Work has begun on a provincial palliative care practice support program for health care providers and volunteers. • Development and implementation of a grief and bereavement model. • Educational resources for health care providers, patients and families have been and are being developed. Additional public awareness is needed. • A palliative care competencies framework was developed in 2017 to support the implementation of the Integrated Palliative Care Strategy. This recognizes the interprofessional nature of palliative care, tailoring and creating educational programs to facilitate the attainment of the competencies. • Education and training are available for health care providers. For example: » Learning Essential Approaches to Palliative Care training has been provided to clinical and leadership staff across Nova Scotia Health, as well as to instructors of Professional Nurses and Continuing Care Assistants, by specialist Palliative Care Providers/educators to enhance knowledge translation. » Development of the Nova Scotia Health Palliative Care education guide (for health care providers), which is accessible on the organization's website. • Quality improvement indicators are being established. • Provincial palliative care strategic priorities have been established. The strategy includes a need to enhance palliative care teams and access in areas of high need. It also identifies the need for partnerships and linkages among care providers, building interprofessional teams that use a lens of inclusion, cultural competency, and safety.

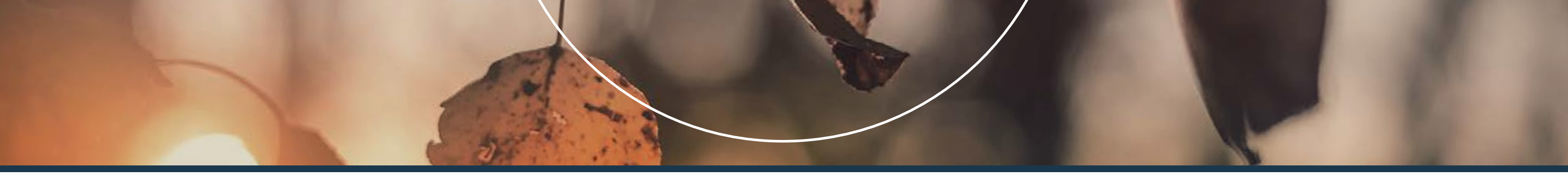
PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Prince Edward Island*	• Information about Advance Care Planning is provided to clients. There is a provincial Goals of Care form, used by some facilities. Standardizing and e-charting will help get more facilities on board. • While Advance Care Planning discussions are happening, more could be done, especially in primary care. • Home care is being delivered by an integrated palliative care team (not contracted out) under one umbrella, which enhances collaboration, consistency and standardization. • The paramedics providing palliative care at home program is for individuals who experience an unexpected event at home, after hours. There is no fee for these after-hours services for patients registered in the Provincial Integrated Palliative Care Program. » The Provincial Integrated Palliative Care Program is available to all residents across the province and is accessible to First Nations Communities. It can be challenging for individuals who do not have access to primary care since a connection to a physician is required for the Provincial Integrated Palliative Care Program. However, this does not prevent an individual from receiving a palliative approach to care from Home Care services. • Learning Essential Approaches to Palliative Care training for health care providers builds competencies, skills, and confidence in providing palliative care. • Standardized assessments are used, such as the Palliative Performance Scale and Edmonton Symptom Assessment System. However, there is a desire to benchmark by having a Canadian Institute for Health Information-supported interRAI-Home Care with the supplement of the palliative care assessment. • A provincial palliative care quality team is looking at adapting the Canadian competency framework. • Use of various platforms that do not integrate may create gaps in knowledge across the care continuum. Moving from a paper-based to an electronic health record would be preferred. Most of the system is electronic with the rollout of the provincial Telus Electronic Medical Record. However, it is not integrated with the systems used by home care and acute care. Work to create a “repository” to share critical information is underway, but the timeline for completion is unknown. The lack of integration of multiple electronic systems across the health system makes sharing of client information difficult.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Newfoundland and Labrador*	• Resource materials are available to the public, including a toolkit for completing an Advance Care Plan. » Policies exist in the provincial health authority (Newfoundland and Labrador Health Services) that require discussion and development of Advance Care Plans with patients and clients. » While the adoption of Advance Care Plans has somewhat improved, more awareness for the public and training for health care providers would support an increase in uptake. • Eastern Urban Zone has a Paramedics Providing Palliative Care Program that provides palliative care in the home. This has successfully led to reductions in hospital admissions. It is currently only available in the St. John's area. Planning is underway for expansion to Eastern Rural Zone. The program is commencing soon in the Western Zone. • Eastern Zone has recently been accepted to participate in a 9-month project with the Canadian Home Care Association's eiCOMPASS Project – SPRINT Implementation Collaborative. The goal is to support local teams to build their capacity and skills to provide high quality, home-based palliative care. • Eastern Zone is completing a needs assessment for people experiencing homelessness or vulnerable housing who could benefit from palliative approaches to care through collaboration with the health care team and local community partners. • Clinical staff in Newfoundland and Labrador Health Services have access to palliative and end-of-life care training (Learning Essential Approaches to Palliative Care training). Expansion of access to this training is facilitated through engagement with Pallium Canada for the delivery of modules targeting home/personal support workers in home care and personal care homes, and personal care attendants working in long-term care homes. • Provincial implementation of a new Central Medical Dispatch Centre is planned for June 2024. This will allow palliative care patients who are registered with Central Medical Dispatch Centre access to call a trained dispatcher to determine suitability for community paramedicine versus a more urgent response by ambulance. • Newfoundland and Labrador Health Services has palliative care resources to provide to patients and clients, such as the Palliative Care Resources Guide created by Eastern Zone. Eastern Zone has a provincial palliative care patient navigator, a first point of contact for clients and clinicians. There is a provincial on-call palliative care physician available for health care professionals. • Newfoundland and Labrador Health Services reports monthly to the Department of Health and Community Services on end-of-life data (for example, number of deaths, location). • Newfoundland and Labrador Health Services has resources for Indigenous populations. These include Aboriginal Patient Navigators, in addition to Non-Insured Health Benefits Navigators. The Aboriginal Patient Navigators Program provides support and assistance for Indigenous patients and their families who travel to St. John's for medical appointments. The Navigators serve to bridge the gap between Indigenous patients and their respective health care professionals.

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Yukon[*]	• The *Development of Palliative Care Education Flowcharts for Health Care Providers and Caregivers* (2022) includes embedding the Canadian Interdisciplinary Palliative Care Competency Framework's self-assessment by discipline. • Initiation and ongoing sustainment of a quarterly palliative care educational newsletter aimed at multidisciplinary health care providers across Yukon began in 2022 and is ongoing. • There is annual facilitation of palliative care specific educational opportunities (such as Life and Death Matters). There has been increased engagement of rural registered and non-registered providers through the use of distance technology (2022 to ongoing). • Public access is available to electronic self-paced education modules related to palliative care (including clinical assessment tools, advance care planning, care of the caregiver) through YGLearn (2022 to ongoing). • Ongoing government-funded access is available for all Yukoners (regardless of employer or work status) to Pallium Canada's Learning Essential Approaches to Palliative Care: Fundamentals online and Learning Essential Approaches to Palliative Care: Personal Support Worker (2020 to ongoing). • Yukon's first hospice, Wind River Hospice House, is funded and operated by Yukon Government and co-located in Whistle Bend Care Home. It opened in 2020. A 2-year evaluation of Wind River Hospice House was completed, using the Quadruple Aim framework to assess areas of success and improvement (2023). • Initiation and ongoing sustainment of Embedding a Palliative Approach to care within the long-term care homes is happening throughout Yukon (2020 to ongoing). • Initiation began in 2021 for the Rural End of Life Funding Program to support clients and families using a self-managed care approach for end-of-life care in rural Yukon communities (ongoing). This program is actively undergoing evaluation to improve efficiencies and the client experience. • Yukon Government provides ongoing funding for Hospice Yukon Society for the following deliverables: » to provide a coordinated, community-based bereavement support program based on the standards established by the Canadian Hospice Palliative Care Association for the terminally ill and their loved ones; » to increase public awareness of Hospice Services; and, » to provide educational resources to communities to foster healthy attitudes towards death, dying, and bereavement. • There is increased outreach to rural Yukon communities and First Nations governments, who deliver community-based care, to support increased palliative care and bereavement at a community level (2023).

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Northwest Territories*	• A strategy exists to encourage Advance Care Planning discussions in all settings: primary care, home care, hospital, and long-term care. However, these conversations are not occurring often enough. » Ongoing education of health care professionals about how to have Advance Care Planning discussions are needed. To address this need, the territory has created policies within primary care and continuing care (home and community care and long-term care) to improve awareness and implementation of Advance Care Planning. • Training and skills development programs are offered and supported by government funding. • Home care provides palliative and end-of-life care in a person's home in every region across the Northwest Territories. The health care providers are usually community health nurses, licensed practical nurses or home care nurses. • End-of-life care is supported in the home, long-term care facility or hospital. This care can include consultation with physician specialists at Stanton Territorial Hospital, palliative medicine specialists from Alberta (when palliative or end-of-life care becomes complex), and specialized grief and therapeutic supports from within the Northwest Territories or Alberta. • There are no indicators or quality measures in place due to gaps in data collection in the Northwest Territories. However, in the future, with the implementation of InterRAI home care and InterRAI long-term care assessments, data will be available. • The Department committed to developing and implementing a Continuing Care Services Action Plan (2017/18–2021/22). The plan supports seniors and elders in the Northwest Territories to age in place for home and community care, palliative care, and long-term care. The goal is to reduce gaps and barriers and provide equitable access to safe, culturally respectful programs and services that respond to community wellness needs. • In 2019, the Department conducted a home and community care review to support aging in place with dignity. The final report included 22 recommendations that are focused on providing consistent, effective client-centred services. The review will continue to advance the actions identified in the Continuing Care Services Action Plan and will include activities to support culturally safe palliative care. • The Department has aligned the palliative approach to the care service delivery model with the guiding principles and recommendations in Caring for Our People and Our Elders: Our Communities. • Supporting elders to live in their homes for as long as possible is a goal identified in the Priorities of the 19th Legislative Assembly (Government of the Northwest Territories, 2019).

PROVINCE/ TERRITORY	SAMPLE EFFORTS IN PALLIATIVE CARE
Nunavut[*]	• Advance Care Planning is often discussed through home care visits. • Education and training are available for health care providers funded by the government (for example, Pallium's Learning Essential Approaches to Palliative Care programs). • There has been progress on the development of home and community care indicators related to access and palliative care.



Bibliography

Antonacci, R., Barrie, C., Baxter, S., Chaffey, S., Chary, S., Grassau, P., Klinger, C. A. 2020. Gaps in Hospice and Palliative Care Research: A scoping review of the North American literature. J Aging Res, 3921245. doi:10.1155/2020/3921245

Canadian Cancer Society. (2023). *2023 Report on hospice palliative care across Canada: A review of federal, provincial, territorial and community actions*. Canadian Cancer Society. Toronto, ON.

Canadian Grief Alliance. (2023). Retrieved from https://www.canadiangriefalliance.ca/

Canadian Hospice Palliative Care Association. (2021). Canadians and Advance Care Planning. A Snapshot of Current Trends. Summer 2021. Retrieved from https://www.advancecareplanning.ca/wp-content/uploads/2021/08/ACP_2021Poll_Summary_EN_FINAL.pdf

Canadian Institute for Health Information. (2018). Access to Palliative Care in Canada. Retrieved from https://secure.cihi.ca/free_products/access-palliative-care-2018-en-web.pdf

Canadian Institute for Health Information. (2023a). Access to Palliative Care in Canada. Retrieved from https://www.cihi.ca/sites/default/files/document/access-to-palliative-care-in-canada-2023-report-en.pdf

Canadian Institute for Health Information. (2023b). Caregiver Distress. Retrieved from https://yourhealthsystem.cihi.ca/hsp/inbrief?lang=en#!/themes/001/access

Canadian Partnership Against Cancer. (2022). *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada*. Canadian Partnership Against Cancer. Toronto, ON.

First Nations of Quebec and Labrador Health and Social Services Commission. (2023). Toward a continuum of long-term person-centred care and services: Final Report – First Nations in Quebec. Retrieved from https://cssspnql.com/en/produit/toward-a-continuum-of-long-term-person-centred-care-and-services-final-report-first-nations-in-quebec/

Fruch, V., Monture, L., Prince, H., & Kelley, M. L. (2016). Coming home to die: Six Nations of the Grand River Territory develops community-based palliative care. International Journal of Indigenous Health, 11, 1: 50-74.

Government of Canada. Reports: Employment Insurance (EI) – Monitoring and Assessment reports. Retrieved from https://www.canada.ca/en/employment-social-development/programs/ei/ei-list/reports.html#Monitoring

Government of Canada. (2021). Budget 2021: A Resilient and Inclusive Recovery. Retrieved from https://www.budget.canada.ca/2021/report-rapport/p3-en.html#

Government of Canada. (2022). Health Care Policy and Strategies Program. Retrieved from https://www.canada.ca/en/health-canada/programs/health-care-policy-strategies-program.html

Government of Canada. (2023a). Indigenous health care in Canada. Retrieved from https://www.sac-isc.gc.ca/eng/1626810177053/1626810219482#

Government of Canada. (2023b). Palliative Care: Overview. Retrieved from https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html

Government of the Northwest Territories. (2019). Mandate of the Government of the Northwest Territories 2019–2023. Retrieved from https://www.eia.gov.nt.ca/sites/eia/files/mandate2019-english-pages-web.pdf

Health Canada. (2019). Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada Retrieved from https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/action-plan-palliative-care/action-plan-palliative-care-eng.pdf

Kellehear, A. Health promoting palliative care: developing a social model for practice. 1999. Mortality, 4,1:,75–82.

Pallium Canada, British Columbia Centre for Palliative Care, & Hospice Palliative Care Ontario. (2023). *Evaluation Guide for Compassionate Communities. Canada*.

Parliament of Canada. (2017). An Act providing for the development of a framework on palliative care in Canada. First Session, Forty-second Parliament, 64-65-66 Elizabeth II, 2015–2016–2017, December 12, 2017. Retrieved from https://www.parl.ca/DocumentViewer/en/42-1/bill/C-277/royal-assent

Pesut, B., Thorne, S., Huisken, A., Wright, D. K., Chambaere, K., Tishelman, C., & Ghosh, S. 2022. Is progress being made on Canada's palliative care framework and action plan? A survey of stakeholder perspectives. BMC Palliat Care, 21(1): 182. doi:10.1186/s12904-022-01074-4

Prince, H. (2022). *Walking alongside Indigenous Peoples who are seriously ill: education for community caregivers*. Centre for Education and Research on Aging & Health, Lakehead University. Thunder Bay, ON.

Widger, K., Davies, D., Rapoport, A., Vadeboncoeur, C., Liben, S., Sarpal, A., Stenkes, S., Cyr, C., Daoust, L., Gregoire, M.C., Roberston, M., Hodgson-Viden, H., Laflamme, J., & Siden, H. 2016. Pediatric palliative care in Canada in 2012: a cross-sectional descriptive study. CMAJ Open, 4(4): E562-E568. doi:10.9778/cmajo.20160054