Palliative Care
Coalition of Canada
Coalition canadienne
des soins palliatifs

Blueprint for Action

2025–2030

Contents

Palliative Care Coalition of Canada (PCCC) Blueprint for Action 2025–2030

Nine of every 10 Canadians who die each year – almost 300,000 people in 2023 – have a serious illness, such as cancer, heart disease, organ failure, dementia or frailty.[1] Thanks to early detection and advances in treatment, many will live years and even decades with their illness. Over that time, they want to lead full active lives. They want a say in their care: to understand the benefits and risks of different treatments and services and to choose the ones that are right for them.

The palliative approach to care gives individuals and their loved ones a stronger voice in their care. It is also a highly effective way to meet a person's and chosen family's full range of needs – physical, psychosocial and spiritual – throughout the process of aging or living with serious illness. It integrates key aspects of palliative care[2] into the care provided by primary care, home care, long-term care and other health and social service providers (see box).

A palliative approach to care encourages open communication about the person's illness. It reinforces their autonomy and right to be involved in making their own care decisions. It actively supports family members, friends and neighbours who care for the person (i.e. caregivers). It enriches both the health and the quality of life for the person, their loved ones and caregivers. It also provides comfort and support with grief and bereavement.[3]

A palliative approach to care makes key aspects of palliative care available to people who are aging or living with serious illness. It includes:

- providing person-centred care that focuses on quality of life
- communicating openly with the person and loved ones about the illness from diagnosis (i.e. early in the disease trajectory)
- involving the person and their loved ones in care planning (i.e. assessing needs, setting goals of care, discussing treatment options, planning for possible deteriorations in health)
- optimizing comfort and relieving/preventing suffering
- working from a place of cultural safety and humility – which means understanding how a person's culture may affect their attitudes towards illness and death as well as their experiences with health and social service systems (e.g. racism, discrimination)
- helping the person and their loved ones deal with feelings of loss, grief and bereavement they may experience at any stage of aging or serious illness
- encouraging and supporting self-care for everyone involved in the person's care (i.e. health care providers, caregivers, volunteers)

The Way Forward National Framework, 2013, Quality End-of-Life Care Coalition of Canada.

https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care/professionals-providing-care.html#s2

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[1] Statistics Canada. Deaths 2023.

[2] Palliative care is an approach that aims to relieve suffering and improve the quality of life for those living with serious illness and their loved ones. It addresses the specific physical, psychological, social, spiritual, and practical issues associated with life-limiting illnesses, and related expectations, needs, hopes, and fears. This care provides comfort and dignity to someone experiencing serious illness while supporting their families, caregivers, and loved ones. World Health Organization.

[3] The Way Forward National Framework, 2013, *Quality End-of-Life Care Coalition of Canada.*

The palliative approach to care does not just benefit people who are aging or living with serious illness and their families. It also helps the health care system. It reduces hospital admissions, long hospital stays, readmissions, visits to intensive care units and inappropriate diagnoses and interventions – all of which are costly for the system and hurt the patient's quality of life.[4]

While many Canadian jurisdictions have made a community-based palliative approach to care a priority, only 58% of Canadians who could benefit from these services are able to access them. Of those:

- half are only identified as needing these services in the last three weeks of their lives
- 68% are only able to receive these services in hospital, where the focus is on end-of-life care rather than the potential to live well for months or years with frailty or serious illness.[5]

The 30+ organizations that make up the Palliative Care Coalition of Canada (PCCC) are committed to working collectively and autonomously with government, health and social service systems and providers, and individuals and their families and caregivers to ensure everyone in Canada who is aging or living with serious illness has access to a palliative approach to care.

About the Palliative Care Coalition of Canada

The PCCC – formerly known as the Quality End-of-Life Care Coalition of Canada (QELCCC) – was established in December 2000. That same year, it began work on its first Blueprint for Action. That Blueprint has been revisited and revised twice: in 2009 and 2020.

Over the past 24 years, members of the PCCC have worked collaboratively with government and health system partners to first, improve access to palliative care for those nearing the end of life; second – based on research on the broader benefits – improve access to a palliative approach to care for people who are aging or living with serious illness.

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[4] Fact Sheet: Palliative Care, 2020, World Health Organization.

[5] Access to Palliative Care in Canada, 2023, Canadian Institute for Health Information.

Progress to Date

The PCCC’s efforts have resulted in several new initiatives and gains:

- In 2013, *The Way Forward* (developed by the Palliative Care Coalition of Canada in collaboration with the Canadian Hospice Palliative Care Association and Health Canada), set out a national framework for a palliative approach to care.
- In 2016, Employment and Social Development Canada extended the maximum duration of compassionate care benefits from six weeks to 26 weeks and, a year later, expanded their definition to make people who are “like a family member” eligible for all caregiving benefits.
- In 2018, Health Canada issued the *Framework on Palliative Care in Canada* (2018).
- Since 2018, the Canadian Institutes of Health Research have invested in 259 palliative care research grants and awards.
- In 2019, Health Canada released its *Action Plan on Palliative Care*.
- In its 2021 budget, the Government of Canada allocated $29.8 million over six years to advance its palliative care strategy and lay the foundation for coordinated action to improve access to quality palliative care.
- In 2021, Health Canada, the Canadian Partnership Against Cancer and other partners published the *Canadian Interdisciplinary Palliative Care Competency Framework*, which set a national standard for professional education in palliative care, and provides a curriculum that educators can use in six health and social service disciplines that provide care for people who are aging or living with serious illness.
- In 2021, Pallium Canada and partners launched a five-year national community of practice initiative to support ongoing training for providers caring for people with serious illnesses.
- In 2021, the House of Commons and the Senate unanimously passed Bill C-220: *An Act to amend the Canada Labour Code*, giving all workers covered under that code up to 10 days off work following the death of an immediate family member (bereavement leave).

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2013	**2016**	**2018**	**2019**	**2021**

In December 2023, the Government of Canada released its ***Report on the State of Palliative Care in Canada***, which highlighted the progress made in improving access to palliative care including:

- more people receiving some form of palliative care and more being able to die at home with palliative support
- greater public awareness of the benefits of a palliative approach to care
- more Canadians engaged in advance care planning and talking to their loved ones about their care wishes
- more health and social service providers receiving education and training in the palliative approach to care
- more health and social service providers aware of the critical importance of timely access to a palliative approach to care for people who are aging or living with serious illness
- more funding for research to continually improve the palliative approach to care.

Between 2019 and 2021, the number of Canadians who talked to a family member about their care wishes almost doubled: from one in three (36%) to nearly two in three (59%).

Canadian Hospice Palliative Care Association, 2021, as quoted in the report.

Progress has been made. However, the *Report on the State of Palliative Care in Canada* also confirmed that there are still serious gaps. Many people in Canada continue to face barriers to accessing a palliative approach to care due to age, geographic location, disease diagnosis, race/ethnicity, unstable housing and other factors. Most are not able to access these services early enough in their disease trajectory to receive the full benefits.

The PCCC appreciates the investments that the government has made over the past two decades in encouraging a palliative approach to care. However, it also recognizes that the goals of the Blueprint for Action have not yet been achieved. There is still an urgent need for collective action to ensure that everyone in Canada who is aging or living with serious illness has access to a palliative approach to care and to high-quality, affordable, culturally safer palliative care services.

Priorities 2025–2030

Over the next five years, the PCCC will support efforts to address the following four priorities – thereby ensuring more people in Canada have access to a palliative approach to care:

#1. Engaged, Informed Public

The palliative approach to care for people who are aging or living with serious illness will not be a priority in our health and social service systems until it is a priority for everyone in Canada. With the aging of our population, more and more people will experience frailty or serious illness, and more will become caregivers. The type and quality of care that people receive at these times in their lives will depend on their ability and willingness to plan for illness and death while still enjoying life.

In 2023, Health Canada launched a four-year public education campaign designed to improve understanding of a palliative approach to care. Members of the PCCC are working with Health Canada to extend the campaign's reach and maximize its impact.

Desired Outcomes

- More people in Canada are engaged in advance care planning.
- More people in Canada have conversations about their health needs and wishes as they age or when they are living with serious illness.
- More people in Canada are aware of the benefits of a palliative approach to care and seek it these services when needed.
- Members of vulnerable, underserved populations and their loved ones are aware of palliative services and able to access them.

Over the next five years, the PCCC will use its networks and resources to:

Raise public awareness of:

- the benefits of a palliative approach to care
- the importance of communicating with health and social service providers, family members, friends and caregivers about their wishes for their health care (i.e. advance care planning)
- the critical support caregivers[6] provide for individuals who are aging or living with serious illness
- the resources and services available to support people who are aging or living with serious illness as well as their caregivers and those experiencing grief and bereavement
- the unique needs of infants, children and young adults living with serious illness as well as their loved ones, and the services available to support them (regardless of their medical complexity)
- the unique needs of populations that are underserved in terms of accessing a palliative approach to care, such as immigrants and refugees, rural, remote and Indigenous communities, 2SLGBTQ+ communities, incarcerated individuals and ex-offenders, people living with disabilities, people living in long-term care homes, and people experiencing poverty and homelessness.[7]

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[6] Family members, friends and neighbours who provide care.

[7] *The Way Forward National Framework: A roadmap for an integrated palliative approach to care*, 2015, The Way Forward initiative, Canadian Hospice Palliative Care Association.

Advocate with governments to:

- launch targeted education and awareness campaigns to:
  - encourage conversations about a palliative approach to care, advance care planning, goals of care, illness, death and dying, and support for grief and bereavement among vulnerable, underserved populations who face barriers accessing palliative care
  - raise awareness of resources available for individuals, families and caregivers.

#2. Skilled, Supported Care Providers

To give more people in Canada access to high-quality, culturally safer palliative approaches to care, our health system needs a wide range of people – health and social service providers, caregivers and volunteers – who have the knowledge, skills and competencies to provide that kind of care. It also needs the capacity to train and support those providers and caregivers.

As noted on page 4, curriculum and programs are now in place to help health and social service providers in six disciplines – both those in practice and those entering practice – develop the competencies they need. Less has been done to support caregivers. According to the 2023 *Report on the State of Palliative Care in Canada*, more than eight million family and friend caregivers are providing care at home for someone who is seriously ill. Most of them feel unprepared and overwhelmed. About one in three report distress: 35% in 2018–19 and 37% in 2021–22.[8] They are also concerned about inequitable access to care, lack of information about resources and services, and the pressure to advocate for improvements in palliative care.

Desired Outcomes

- The health and social service system recognizes the value and benefits of a palliative approach to care for people who are aging or living with serious illness.
- Palliative care competencies are an integral part of undergraduate or entry-to-practice training for all new health and social service providers.
- More health and social service providers currently in practice have acquired palliative care competencies and are able to demonstrate them in their work.
- Caregivers feel more supported in their roles and less isolated.
- People who are aging or living with serious illness and their families feel more confident about the care they receive.

To increase the number of health and social service providers and caregivers who have the skills and support to provide a palliative approach to care, the PCCC will:

Support advocacy with health and social service provider training programs to:

- Provide **undergraduate and entry-to-practice level programs** for all health and social service providers so they develop the competencies they need to integrate a palliative approach to care into their practice
- Increase the number of **health and social service providers currently in practice in all settings of care who are trained in the palliative approach to care**, ensuring more people in Canada have earlier access to effective, compassionate, and comprehensive palliative care services
- Increase **the number of healthcare professionals with advanced palliative care training** who can train, mentor and support other interdisciplinary teams of health and social service professionals, provide care for individuals with complex needs, and lead the education, research and quality improvement efforts that will drive progress and advances in the field.

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[8] Access to Palliative Care in Canada, 2023, Canadian Institute for Health Information.

Work with bodies that **set and enforce the entry to practice and educational accreditation standards** to:

- Ensure entry to practice standards and training programs for health and social service professions **include the competencies necessary to provide high-quality palliative care**
- Ensure that all health and social service providers entering practice in Canada, including internationally trained providers, have the knowledge and skills to provide a **culturally safer palliative approach to care**
- Promote **continuing professional development** in a palliative approach to care across all health and social professional associations and colleges, and support the accreditation of these initiatives
- Encourage all health and social service organizations to **adopt and implement nationally accepted standards for a palliative approach to care**.

Advocate and work with health and social service systems to:

- **Educate all leaders, administrators and policymakers** about the growing need for skills in the palliative approach to care in all **health and social service workforce planning**
- **Change culture and shift attitudes within health and social service systems**:
    - **Make a palliative approach to care an integral part of all health and social services** for people aging or living with serious illness
    - **Coach and mentor managers** so they can confidently support health and social service providers, caregivers and volunteers in providing a palliative approach to care
    - Ensure health and social service providers have **better access to practical information, tools, education and supports** needed to provide quality care and reduce feelings of isolation, including:
        - complementary care services
        - technology (such as AI, remote monitoring, virtual reality) and online supports
        - clinical tools and standards
        - medication guidelines and protocols
    - Help health and social service providers, caregivers and volunteers integrate **self-care practices** into their work routines and overcome their own fears and biases related to loss, dying and death[9]
    - **Reduce stigma** in the workplace related to caregiving, death, dying and grieving.

Support efforts to develop and implement a national strategy for caregivers and volunteers:

- Help caregivers and volunteers provide better care, feel **more supported, and reduce feelings of stress and isolation**
- Provide **better access to information, training and tools –** including online supports
- **Educate and mobilize communities**, including faith groups and volunteer organizations, to support people living with serious illness and their caregivers.

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[9] *The Way Forward National Framework: A roadmap for an integrated palliative approach to care*, 2015, The Way Forward initiative, Canadian Hospice Palliative Care Association.

#3. Knowledge to Improve Quality of Care and Life

To support the system-wide implementation of a palliative approach to care, we need stronger evidence and a more robust data infrastructure. The 2020 report, *Gaps in Hospice and Palliative Care Research: A Scoping Review of the North American Literature*, identified the urgent need for:

- new knowledge to improve health equity, inclusion, and cultural safety in a palliative approach to care
- evidence to inform the development of supports for caregivers
- a more consistent way to collect data on the experiences of people receiving care as they age or live with serious illness.

Desired Outcomes

Evidence is used to inform the ongoing development of a palliative approach to care, including mental health policies and programs to support caregivers.

Comprehensive, high-quality data are readily available and used to drive policy and improve care.

More people who are aging or living with serious illness and their families:

- have equitable access to evidence-based, culturally safer, inclusive care that meets their diverse needs.
- enjoy better quality of care and life.

The importance of this research was echoed in the CIHR Institute on Aging's strategic research priorities for 2023–2028.

Evidence and new knowledge gathered through research or data analyses must be widely shared and used to improve both care and quality of life for people aging or living with serious illness and their families.

To promote an evidence-based palliative approach to care, the PCCC will:

Support advocacy with research funding agencies:

- Encourage a range of **funding opportunities for interdisciplinary health and social system research –** including seed funding for research teams, grants to demonstrate proof-of-concept and resources to bring innovative solutions and models of care to scale and encourage their uptake
- Champion the inclusion of **palliative care experts in funding review processes** (e.g. Canadian Institutes of Health Research's (CIHR) College of Reviewers)
- Highlight the need for research that **fills current critical gaps in knowledge**
  - **Health Equity –** Identify systemic barriers and disparities in access to palliative care, particularly for underserved regions and populations such as Indigenous communities, racialized groups, 2SLGBTQ+ individuals, prisoners and children.
  - **Culturally Safer Care –** Explore how cultural values and overlapping identities (e.g. race, gender, socioeconomic status) influence care preferences and access. Use the findings to inform culturally safer palliative care.
  - **Healthy Providers and Systems –** Develop insights into the role of primary care providers, clinical specialists and all other health and social service providers in a palliative approach to care, and assess the impact of training and professional development on patient outcomes and health and social service system performance.

  - **Mental Health of Caregivers –** Understand the psychological, emotional and social impacts of caregiving, focusing on high-stress subgroups of caregivers, including those caring for children and individuals with serious complex conditions. Use the findings to develop tailored mental health interventions and policies that enhance caregiver well-being.

Work with researchers and health and social service systems to gather better data to inform a palliative approach to care:

- Establish **standardized definitions, data collection protocols and performance indicators**
- Develop a **national Atlas of Palliative Care** that captures diverse experiences, allows meaningful analyses and comparisons, and supports evidence-based policies and practices.

Partner with health and social service stakeholders to share and mobilize new knowledge:

- Actively promote **evidence-based best practices** and the consistent implementation of a palliative approach to care across jurisdictions, sectors, settings and service providers.

#4. Equitable Access to High Quality Palliative Care for All

Everyone in Canada who is aging or living with serious illness and their loved ones should be able to access culturally safer palliative care – including support with grief and bereavement – regardless of their age, diagnosis or the setting where they choose to receive care. But that is not currently the case. Only about 58% of Canadians currently have access to palliative care – most only within the last three weeks of their lives and in hospital – and even fewer receive culturally safer care.

Desired Outcomes

People who are aging or living with serious illness have access to flexible models of care that meet their diverse needs.

More people in Canada have access to culturally safer palliative approach to care that reflects their values, needs and preferences.

More people who are aging or living with serious illness – including members of vulnerable or underserved communities – enjoy better quality of health and life.

The COVID-19 pandemic helped start conversations about the kind of care people want to receive when faced with aging or serious illness. It also helped health and social systems make better use of technology to deliver services remotely. However, fundamental systemic barriers still limit access to a palliative approach to care, including a lack of awareness of its benefits, shortage of skilled providers, lack of system capacity, geography and social determinants of health. The barriers are highest for culturally diverse and underserved populations.

To provide more equitable access to high quality culturally safer palliative care, the PCCC will:

Support advocacy with health and social service systems to:

- Adopt and scale up **flexible service delivery options and models of a palliative approach to care –** ones that make effective use of interdisciplinary teams of health and social service providers and all available resources – for both adults and children as well as members of vulnerable and underserved populations
- Ensure people moving from one setting, province/territory or system[10] to another continue to receive uninterrupted high-quality care.

Advocate with government to:

- Ensure palliative care frameworks and action plans stress the importance of **appropriate, equitable, culturally safer care** that meets the needs of individuals and their caregivers and takes into account their age, culture, race, faith, sexual orientation, gender identity, disability and social determinants of health (e.g. income, housing)
- Address the growing need for palliative care skills in all **health workforce planning, recruitment, and retention** initiatives
- Provide appropriate **resources and supports for Indigenous communities** so their members receive a palliative approach to care that reflects their preferences and cultural practices
- Ensure all mental health initiatives include **comprehensive grief and bereavement supports** for patients, their caregivers, and their health and social service providers. Tailor those supports to meet the needs of diverse and underserved communities.
- Provide consistent, nationwide access to **essential palliative care medications**, including ensuring those medications can be accessed and administered at the required times, even outside regular office or clinic hours.

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[10] Access to Palliative Care in Canada, 2023, Canadian Institute for Health Information.

Special Thanks

Special thanks to the team who facilitated the development of the Blueprint for Action 2025–2030:

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