



Palliative Care  
Coalition of Canada  
Coalition canadienne  
pour les soins palliatifs

# **Submission to The Standing Committee on Finance's Pre-Budget Consultations in Advance of the 2024 Budget**

**Palliative Care Coalition of Canada (PCCC)**

**August 4, 2023**

## RECOMMENDATIONS

1. Dedicate \$7 million over three years to develop the required infrastructure for national standards, common datasets, and a pan-Canadian Atlas for palliative care.
2. Invest \$8.75 million over three years earmarked for palliative care research.
3. Continue to invest in achieving the goals of the Framework and Action Plan on Palliative Care in Canada to support healthcare providers and caregivers.

## INTRODUCTION

The [Palliative Care Coalition of Canada \(PCCC\)](#), formerly known as the [Quality End-of-Life Care Coalition of Canada](#) is a group of more than 30 national stakeholder organizations dedicated to improving palliative care for everyone in Canada. The Coalition believes that all people in Canada have the right to equitable access to quality palliative care, which includes grief and bereavement support. To achieve this, there must be a well-funded, sustainable national strategy for palliative care. It is the mission of PCCC to work together in partnership to achieve this goal. PCCC welcomes the opportunity to submit this brief to the Standing Committee on Finance as part of their study for Budget 2024.

Palliative care improves the quality of life, provides comfort and dignity, and alleviates suffering for those living with a serious illness. It also provides support for caregivers caring for individuals living with a serious illness. Palliative care services are critical as Canada's population continues to age and more people are living longer with chronic, serious, and increasingly complex health challenges.

Investing in palliative care can assist the Government of Canada to make progress on its four shared priorities to improve healthcare for people in Canada:

- Palliative care is often delivered by or in collaboration with family health services, particularly in rural and remote areas and in underserved communities. Ensuring family health services are equipped to provide a palliative approach to care would make it easier for them to care for their patients
- Palliative care services can be delivered in all settings and can help patients to stay where they wish to receive care, relieving pressure on healthcare workers and backlogs in acute care settings, as noted by the [Ontario Medical Association](#) and others
- Palliative care services support caregivers and their loved ones with the mental health impacts of facing a serious illness, as well as with grief and bereavement
- Palliative care teams are interdisciplinary and work across various settings and models of care, so they would have the expertise to offer as we modernize our healthcare system

Despite the increased need for palliative care services, challenges persist with the availability and accessibility of these services. In the Canadian Institute for Health Information (CIHI)'s report [Access to Palliative Care in Canada, 2023](#), some improvements have been made since their last report in 2018. However, only 58% of people in Canada who might benefit from palliative care are receiving it before they die. Moreover, it found that location, disease, and age affect who has access to palliative care. Access to these services varies by jurisdiction, care setting, and diagnosis, with some life-limiting illnesses—such as dementia—having worse access than others. It also found that people are still receiving palliative care late in their illness trajectory – half of those identified as needing palliative care were identified 22 days or less before their death – when earlier interventions have been shown to improve quality of life, reduce the use of emergency departments and other acute care, and increase the likelihood people will die in the setting of their choice.

But most troubling of all, the report identified that, even though Canada's [Framework](#) and [Action Plan](#) on Palliative Care in Canada has identified data collection as a priority, CIHI could only access data from three provinces, Ontario, Alberta, and British Columbia, and one territory, Yukon, to write its report. The main reason

is that there is no common Canadian definition or adhered-to standard for palliative care, and no agreed-upon common data sets to track services across the country. Without a shared understanding of what constitutes palliative care and how to track it, we will never be able to get a true picture of the state of palliative care in Canada, particularly in community-based settings such as hospices, or for vulnerable populations, such as pediatric palliative care. If we cannot fully assess what palliative care services people in Canada are receiving, we cannot hope to one day guarantee that everyone in Canada can get the palliative care they have a right to receive, much less the quality palliative care they need or want.

The federal government must report back on its progress in implementing both its Framework and Action Plan on Palliative Care (at the five-year mark) in December 2023. Everyone in Canada has a right to access affordable, culturally safer, and high-quality palliative care, regardless of where they live or in what setting they choose to receive care. PCCC encourages the federal government to learn from its findings in developing this report and to make additional investments in palliative care to make this principle a reality.

## DETAILED RECOMMENDATIONS

### 1. Dedicate \$7 million over three years to develop the required infrastructure for national standards, common data sets, and a pan-Canadian Atlas for palliative care.

As noted above, there is no single reporting source, data repository or mapping of the state of palliative care in Canada. Calls for improved data on palliative care service provision and the identification of gaps to move toward enhanced quality of life for people living with life-limiting illnesses are outlined in the [Framework](#). People across Canada deserve better than the current approach that systemically fails to provide sustainable, creative, and necessary options to ease pain, death, and dying. To do this effectively, a coordinated pan-Canadian effort involving evidence-based tools, a platform to track data, and a pan-Canadian Atlas are needed. Establishing national standards, common datasets, and a pan-Canadian Atlas – a graphical representation and textual description that maps the current state of palliative care service provision across different domains and elements – for palliative care will help define what constitutes quality palliative care in Canada, sensitize providers and people in Canada to palliative care services and when/where they should be offered, and provide a sightline into how palliative care is being delivered across the country, including possible gaps that need to be addressed, particularly for underserved populations and pediatric palliative care. Australia's [Palliative Care Outcomes Collaboration](#) is an example that Canada can consider implementing. PCCC recommends funding the creation of a Pan-Canadian Palliative Care Atlas to map the current state of palliative care service provision across different domains and elements. The Atlas will provide policymakers, administrators, healthcare leaders, educators, and advocates with a baseline assessment to assist in developing and implementing national standards for palliative care across Canada, tracked by the collection of common data sets.

An initial investment of \$7 million will help with the implementation of the projects over three years in a phased approach, building on existing evidence to date, including establishing a database to track data, as well as creating a process for providing information to program leads, provincial and federal funding bodies, and the public to inform care and priorities. Funding for this initiative should be done in collaboration with Health Canada's efforts on the Health Data Strategy as well as its investments to develop new health data indicators.

Increasing the capacity and preparedness of all provinces and territories, and the organizations and providers delivering care in their jurisdictions, to provide consistently high-quality palliative care services and track data on the accessibility and delivery of palliative care will help improve care for everyone in Canada facing serious illnesses.

## **2. Invest \$8.75 million over three years earmarked for palliative care research.**

PCCC recommends that the federal government invests \$8.75 million of funding over three years earmarked for palliative care research (including grief and bereavement) through the Tri-Council.

Palliative care research is identified as a research gap in the [Framework](#) and [Action Plan](#) but has seen an unfortunate decline in funding by [public](#) and [charitable](#) funders alike. The 2021 investment into the work of the Pan-Canadian Palliative Care Research Collaborative (PCPCRC) is highly welcomed, but further commitment is needed, including studying the impact of the COVID-19 pandemic.

Additionally, PCCC recommends that \$750,000 be set aside for a specific call for seed/proof of concept funding at the \$50,000 level per year for fifteen applications over the three-year duration of the investment (five per year) to enable innovative ideas to be developed, tested, and prepared for application to larger funding opportunities, without matching funding.

## **3. Continue to invest in achieving the goals of the Framework and Action Plan on Palliative Care in Canada to support healthcare providers and caregivers**

PCCC welcomed the commitment made by the Government of Canada in Budget 2021 of \$29.8 million over six years to implement the Framework and Action Plan in Canada. Similarly, PCCC supports the government's efforts to address the challenges facing Canada's health workforce, namely the lack of supply of healthcare workers, low retention, and workplace conditions that put additional pressures on workers, all while patient workloads and fear for personal safety are increasing. PCCC feels the Government of Canada, though, is missing an opportunity by considering these separate and distinct initiatives, rather than considering palliative care part of the solution to the challenges in our healthcare systems.

Evidence from Canada, the United States, and the United Kingdom, shows palliative care can significantly reduce the healthcare costs of patients who are dying. Medicare data from the United States shows that 25% of total healthcare costs are spent in the last year of life with approximately 40% (10% of the total Medicare budget) spent in the last four weeks of life. The provision of palliative care enables more efficient and appropriate use of finite healthcare resources by [reducing the costs of caring for people at the end of life](#). It can reduce hospital admissions, length of hospital stays, re-admissions, visits to intensive care units (ICUs), and inappropriate diagnostics or interventions, all of which negatively impact a patient's quality of life and cost the health system significantly more than providing palliative care. A study in Ontario found that shifting the location of care from acute care to home care for just 10% of patients at the end of life could save the healthcare system [\\$9 million annually](#). Palliative care also [improves patient care](#): it is associated with improved patient and caregiver satisfaction, better symptom control, and a greater likelihood of the person dying in the setting of choice.



Therefore, PCCC encourages the Government of Canada to continue investments in palliative care that promote its integration into the healthcare system. This includes supporting interdisciplinary collaboration and team-based care in palliative care through funding and policy initiatives. Similarly, we encourage the Government of Canada, as it develops policies and programs to address our shortage of healthcare workers, to ensure there is sufficient capacity to deliver palliative care according to the [Canadian Interdisciplinary Palliative Care Competency Framework](#) developed by the Canadian Partnership Against Cancer, particularly in settings like home care and hospice.

Furthermore, PCCC encourages the Government of Canada to continue funding for training and education that integrates palliative care competencies and a palliative approach to care into healthcare education at undergraduate, graduate, and professional development and continuing education programs across healthcare sectors and professions, committing resources to the improvement and widespread adoption of current educational and training materials for caregivers, and scaling evidence and competency-based educational solutions to improve access to and quality of palliative care for everyone in Canada. This also includes direct funding towards the adoption of training programs for healthcare professionals, concentrating on cultural competence and inclusive care, to better serve underserved and difficult-to-reach populations.

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