

Palliative Care Coalition of Canada Coalition canadienne pour les soins palliatifs

Written Submission for the Pre-Budget Consultations in Advance of the Upcoming Federal Budget

By: Palliative Care Coalition of Canada (PCCC)



RECOMMENDATIONS

1. Double the investment made in Budget 2021 of \$29.8 million and extend the funding to the end of 2028-2029 to take the necessary steps to address the remaining gaps identified in Health Canada's Report on the State of Palliative Care in Canada.





INTRODUCTION

The <u>Palliative Care Coalition of Canada (PCCC)</u> is a group of more than 30 national stakeholder organizations dedicated to improving palliative care for everyone in Canada. PCCC believes that all people in Canada have the right to equitable access to quality palliative care, which includes grief and bereavement support. PCCC welcomes the opportunity to submit this brief to the Standing Committee on Finance as part of their study for Budget 2025.

<u>Palliative care</u> is an approach that aims to relieve suffering and improve the quality of life for those living with a 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 a serious illness while supporting their families, caregivers, and loved ones.

While palliative care services can be accessed by anyone no matter their age, it is critical to consider Canada's aging population, who are living longer overall with serious, complex, and chronic health challenges and could greatly benefit from increased access to palliative care (<u>Gillespie</u>, <u>2023</u>). However, challenges persist with the availability and accessibility of these services. In Canada, only an estimated 58% of people who might have benefited from palliative care ended up accessing these services, and of those, approximately half are only identified as needing these services 22 days or less before their death (<u>CIHI</u>, <u>2023</u>). This delay in identification reduces access and delays critical interventions that can improve the quality of life and the likelihood that the person will die in their setting of choice, prioritizing comfort while maintaining dignity.

Palliative care not only improves patient care but also helps reduce costs to the healthcare system and enables the efficient and appropriate use of finite healthcare resources. While many Canadian jurisdictions name "community palliative care" as a priority, 61% of those who receive palliative care still only receive it in hospital (CIHI, 2023) and, according to the limited data we do have, patients admitted to hospital with palliative conditions had stays longer than 2 weeks on average (CIHI, 2023). Research indicates that the early delivery of palliative care typically reduces hospital admissions, long hospital stays, many re-admissions, visits to intensive care units (ICUs), and inappropriate diagnoses and interventions—all of which are costly to the healthcare system and negatively impact a person's quality of life (WHO, 2020). Implementing palliative care in the community and primary care settings can reduce costs and yield a positive return on investment. In the United States, palliative care training for interdisciplinary teams has been shown to save hospitals 9-25% per inpatient stay, while community-based palliative care can save between \$2000-\$4000 per patient per month within the final few months of life (PCLC, n.d.).

To ensure that palliative care reaches those who require it, there needs to be a shift in the awareness and understanding of services for everyone, including providers, caregivers, and patients. There also needs to be an increased understanding of the landscape of palliative care services across Canada.



There is no agreed-upon common data set to track services – this data is crucial. If we cannot fully assess what palliative care people in Canada are receiving, we cannot guarantee that we are fulfilling everyone's right to access palliative care, much less ensuring they get the quality of care they deserve.

Furthermore, the palliative care needs of a population cannot be met by palliative care specialists alone. There is a need to improve access to and the provision of palliative care across many care settings, including primary care. Primary care is often the first point of contact with the healthcare system and, at its most effective, uses a team-based approach whereby healthcare providers with various expertise work collaboratively to support individuals and families. Many people in Canada address their healthcare needs in primary care settings, and a strong primary care system is considered the cornerstone of a high-functioning healthcare system (<u>Starfield et al., 2005</u>).

Healthcare professionals in primary care settings are ideally positioned to identify the need for palliative care and to initiate it early upon identification of a serious chronic or terminal illness, building on existing long-term relationships with patients and continuity of care where it exists. Systematic reviews have found that primary care teams can deliver a palliative approach to care – and it can improve patient and family outcomes (e.g. Shaw et al. 2010). However, Health Canada's own public opinion research also shows that primary care providers report a lack of knowledge, confidence, tools, and practical support to implement this approach in practice. As such, improved access requires building primary-level palliative care capacity via supporting the development of core competencies of healthcare professionals and by providing comprehensive palliative care education programs. As interprofessional primary care teams expand, there is a need for the Government of Canada to make improving palliative care within primary care settings a priority by dedicating funding to palliative care research and education to accelerate the spread and scale-up of programs to ensure that everyone in can access quality palliative care services within the care continuum.

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

- Ensure that family health services are equipped to provide a palliative approach to care for their patients, particularly in rural and remote areas and underserved communities.
- Palliative care services are delivered in all settings to allow patients to stay where they wish to receive care, relieving pressure and backlogs in acute care settings.
- Palliative care services support caregivers and loved ones with the mental health impacts of facing serious illness, as well as grief and bereavement.
- Interdisciplinary palliative care teams that work across various settings and models of care.



THE FRAMEWORK ON PALLIATIVE CARE IN CANADA – FIVE YEARS LATER

In December 2023, the Government of Canada released its <u>Report on the State of Palliative Care in</u> <u>Canada</u>, which outlined the progress made so far in increasing access to palliative care in the five years since the publication of the <u>Framework on Palliative Care in Canada</u>. The report indicated that over the past 5 years, the number of people receiving some form of palliative care has increased, as well as the number of people dying at home with palliative support. Public awareness and uptake of advance care planning have improved, and the greater availability of palliative care education and training for healthcare professionals has enhanced their understanding of the critical importance of timely and high-quality palliative care.

The report also confirmed, however, that age, geographic location, and disease diagnosis remain barriers to accessing palliative care for many people in Canada. Further challenges remain in ensuring that palliative care supports are accessible earlier in the disease trajectory and that people with community supports in place do not die in hospital. While PCCC recognizes and appreciates the investments and positive strides made by the federal government to date, the report underscores the need for continued collective action to ensure that palliative care supports are available and accessible to everyone in Canada. High-quality, affordable, and culturally safe palliative care is the right of every resident of Canadian.

One essential component of improving access to palliative care is to continue to build on the training and education available to healthcare providers. Standardized education across all health disciplines, including grief and bereavement training, will increase providers' capacity to deliver high-quality palliative care.

This education should also be provided to caregivers, who are integral members of the healthcare team supporting each patient. Adequately supporting caregivers will require exploring their needs and capacity as well as a commitment to building greater care capacity within the community. Expanding capacity could be supported using technology to connect specialized palliative care providers and community-based providers. We welcome the government's commitment to a National Caregiving Strategy and hope to participate in the development process.

Another critical measure to support palliative care providers and caregivers is an increased focus on addressing gaps in research (<u>Antonacci et al, 2020</u>) and data collection. Standardized data and increased research capacity are a necessary foundation for successful palliative care delivery in Canada. Outcome measures and precise palliative care indicators are needed, along with economic models and best practices, to further integrate palliative care into home and long-term care.

Equitable access to palliative care across Canada can only be achieved by identifying and addressing barriers experienced by patients and carers. All individuals living with life-limiting illnesses, along with those who support them, deserve a palliative approach to care throughout their journey. This includes



support for pediatric palliative care, which is often not included in the discussion around palliative care beyond the need for data and research.

PCCC encourages the government to take swift action to further develop education and increase support for healthcare providers, including caregivers, to address gaps in research and data, and to ensure that barriers to equity of access are assessed and confronted. These are the next steps to ensure that everyone in Canada can access high-quality palliative care when and where they need it.

RECOMMENDATION

In Budget 2021, the Government of Canada invested \$29.8 million over 6 years in palliative care. Given Health Canada's progress report findings, PCCC recommends that the Government of Canada further invest in implementing the Framework and Action Plan on Palliative Care in Canada. We believe this investment should include:

- \$7 million over three years in new or dedicated money to develop infrastructure for national standards, common data sets, and a <u>pan-Canadian Atlas</u> for palliative care. This initiative addresses the current lack of a centralized reporting source or data repository, which is essential for improving palliative care services and identifying gaps. The Atlas would map the state of palliative care services, aiding in establishing quality standards, raising awareness, and highlighting service delivery gaps, particularly for underserved populations and pediatric care. This effort should be coordinated with Health Canada's Health Data Strategy.
- \$8.75 million over three years in palliative care research, including grief and bereavement, to address gaps in research funding, with special emphasis on the importance of continued and stable commitment to research in this area. We also recommend allocating \$750,000 over multiple years for seed funding to support innovative ideas and proof-of-concept projects.
- Funding to facilitate the integration of palliative care into broader health workforce strategies which can help address challenges like healthcare worker shortages, retention issues, and workplace conditions.
- Continuing efforts to expand awareness, particularly for underserved communities.

While not all of the government's initial investment of \$29.8 million has rolled out yet, we expect the government would need to double that amount and extend the funding to the end of 2028-2029 to take the necessary steps to address the remaining gaps identified in Health Canada's progress report and scale up the successes they have piloted so far.

At this time of transformation in our healthcare systems, investing in ensuring everyone in Canada has access to high-quality, affordable, and culturally safer palliative care from the point of diagnosis with a serious illness, regardless of the setting in which they choose to receive care, will improve outcomes for patients and their loved ones, create efficiencies in our healthcare systems, and help



the government achieve its goals of delivering real results to improve person-centered care for everyone in Canada.

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