

# **Submission to The Department of Finance Canada's Pre-Budget Consultations 2022**

**Submitted by the Quality End-of-Life Care Coalition of Canada (QELCCC)**

**February 24, 2022**





## RECOMMENDATIONS

The QELCCC recommends that the federal government:

1. Establish a centralized and national coordination office as suggested by the Framework on Palliative Care in Canada, such as the Office of Palliative Care (OPC), that will:
  - a. Serve as a single focal point and knowledge centre for palliative care at the federal level.
  - b. Coordinate implementation of the federal government's Framework and Action Plan on Palliative Care in Canada.
  - c. Play a leadership role in connecting governments and stakeholders across jurisdictions to promote better access to high-quality care in Canada.
  - d. Work with stakeholders to set a common definition of palliative care and consistent standards for the delivery of palliative care.
2. Earmark new annual funding to create a Palliative Care Collaborative, comprised of federal, provincial, and territorial government representatives, key health stakeholders, and patient groups, to implement the Framework and Action Plan on Palliative Care in Canada. Priorities would include:
  - a. Measures to facilitate equitable access to palliative care for Canadians of all ages across Canada with a closer look at underserved populations.
  - b. Measures to support palliative care providers, including data collection and research.
  - c. Palliative care education and training for health care providers, volunteers, communities, and caregivers.
3. Allocate \$8.75 million of new funding over three years specifically earmarked for palliative and end-of-life care research and knowledge translation, including grief and bereavement care. Of this, dedicate \$750,000 over the three years to seed/proof-of-concept projects, without matching funds.





## INTRODUCTION

The Quality End-of-Life Care Coalition of Canada (QELCCC) is a group of 35 national stakeholder organizations dedicated to improving end-of-life care for all Canadians. The Coalition believes that all Canadians have the right to quality hospice palliative care, which includes grief and bereavement supports. To achieve this, there must be a well-funded, sustainable national strategy for palliative care. It is the mission of the QELCCC to work together in partnership to achieve this goal.

Of the more than 270,000 Canadians who die each year, 90 per cent die of chronic illness such as cancer, heart disease, organ failure, dementia or frailty. Many of these individuals could benefit from hospice palliative care, but access to these services across Canada varies.<sup>1</sup>

As Canada's population ages, the demand for palliative care will increase. Due to advances in medicine, people are living longer with chronic conditions, degenerative diseases or cancer, which means we need both better access to palliative care and different approaches in delivering palliative care than we did mere decades ago. When provided early, palliative care can improve quality of life for individuals by relieving symptoms, enabling a more dignified death, and supporting loved ones through the grief and bereavement process.

The COVID-19 pandemic has further highlighted the importance of access to high-quality palliative care and grief and bereavements supports. Acknowledging this, in Budget 2021, the federal government provided Health Canada with \$29.8 million over six years to improve access to quality palliative care by advancing the government's palliative care strategy and laying a better foundation for coordinated action on long-term and supportive care needs. This is a good start toward ensuring better access to high-quality palliative care in Canada, but it barely scratches the surface in terms of the funding needed to ensure proper awareness, access and delivery of quality palliative care.

To ensure the federal government achieves the palliative care goals it set through the last budget, it is vital that the mechanisms to implement and achieve these objectives are in place and properly funded. To this end, in this submission, the QELCCC has outlined three recommendations that we encourage the federal government to include in Budget 2022 to help Canada move forward in implementing and promoting better palliative care, and ensuring all Canadians have access to high-quality palliative care when and where they need it.

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<sup>1</sup> Health Canada. Framework on Palliative Care in Canada. 2018. Retrieved from <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>.





## DETAILED RECOMMENDATIONS

### Establish a national office to oversee palliative care at the federal level

#### Recommendation

Establish a centralized and national coordination office as suggested by the [Framework on Palliative Care in Canada](#), such as the Office of Palliative Care (OPC), that will:

- a. Serve as a single focal point and knowledge centre for palliative care at the federal level.
- b. Coordinate implementation of the federal government's [Framework](#) and [Action Plan](#) on Palliative Care in Canada.
- c. Play a leadership role in connecting governments and stakeholders across jurisdictions to promote better access to high-quality care in Canada.
- d. Work with stakeholders to set a common definition of palliative care and consistent standards for the delivery of palliative care.

#### Rationale

As identified by the Framework on Palliative Care, given the inter-jurisdictional, cross-sectoral nature of palliative care in Canada, a single focal point and knowledge centre at the federal level is needed to better help connect stakeholders and facilitate implementation of the Framework and Action Plan. The Framework on Palliative Care recommends the creation of the Office of Palliative Care (OPC) to provide high level coordination of activities and serve as the central body overseeing palliative care for the federal government.

According to the Framework on Palliative Care, the OPC should coordinate implementation of the Framework; connect governments and stakeholders and palliative care activities across Canada; serve as a knowledge centre from which best practices can be compiled and shared; align activities and messaging to support public awareness raising across Canada; and work with stakeholders to facilitate consistency of standards in palliative care.

QELCCC recommends that the creation of the OPC is done in consultation with provincial and territorial counterparts as well as key health stakeholders and patient groups to define the OPC's roles and objectives, including those outlined in the Framework, like establishing evidence-based palliative care standards.





## **Create a Palliative Care Collaborative to inform the implementation of the Framework and Action Plan on Palliative Care**

### Recommendation

Earmark new annual funding to create a Palliative Care Collaborative, comprised of federal, provincial and territorial government representatives, key health stakeholders, and patient groups, to implement the [Framework](#) and [Action Plan](#) on Palliative Care in Canada. Priorities would include:

- a. Measures to facilitate equitable access to palliative care for Canadians of all ages across Canada with a closer look at underserved populations.
- b. Measures to support palliative care providers, including data collection and research.
- c. Palliative care education and training for health care providers, volunteers, communities, and caregivers.

### Rationale

The weight of uncertainty placed on patients, underserved groups, health care professionals and the Canadian health care system(s) points to the need for an effective integrated palliative approach to care across all settings. As part of the federal government's Framework and Action Plan on Palliative Care, QELCCC recommends that a Palliative Care Collaborative be established to advise and assist the federal government in implementing the Framework and Action Plan.

The Collaborative would enable a fully engaged strategy with a patient-centric approach to palliative care and would work to implement the Framework nationally, provincially, territorially and in local communities across Canada. This would provide opportunities for communication and collaboration among government and health system stakeholders with palliative-care related portfolios, including diverse Ministries, and work with federal entities to set standards for palliative care services across provinces and territories.

The Collaborative would function as a governance table for federal, provincial, territorial governments with input from NGOs, academia, research institutes, health organizations, and patient groups. The QELCCC recommends new annual funding of \$15 million to support this work.





## Make earmarked investments in hospice palliative and end-of life care research and knowledge translation

### Recommendation

Allocate \$8.75 million of new funding over three years specifically earmarked for palliative and end-of-life care research and knowledge translation, including grief and bereavement care. Of this, dedicate \$750,000 over the three years to seed/proof-of-concept projects, without matching funds.

### Rationale

Palliative and end-of-life care research is identified as a research gap in the [Framework](#) and [Action Plan](#) on Palliative Care. Palliative and end-of-life care research remains an underfunded field and federal investments continue to decline.<sup>2</sup> Taking cancer research as an example, relative to other areas, palliative and end-of-life research receives only about 1% of the overall investment in cancer research, even though almost half of cancer patients eventually die of their disease.<sup>3</sup> According to a 2019 report by the Canadian Cancer Research Alliance, investment in palliative and end-of-life cancer research by all funding sources decreased substantially in the last few decades. Funding through the Canadian Institutes of Health Research's (CIHR), the largest funding source, dropped from \$3.2 million per year in 2005 to \$1.9 million in 2015.<sup>4</sup>

In 2003, recognizing that palliative and end-of-life care were receiving limited attention in the research and health care communities, CIHR launched the Palliative and End-of-Life Care Initiative with an investment of \$16.5 million over six years. Since the Initiative ended in 2009, much of the research capacity and ground gained through the Initiative has been lost.

To help immediately fill the research and knowledge gaps, the QELCCC recommends that the government allocate \$8.75 million over three years earmarked specifically for palliative care research, including grief and bereavement care. A portion of this funding should be allocated to research specific to pediatrics and to populations who have difficulty accessing palliative care. This funding could be administered through the CIHR's Institute on Aging. We also recommend that \$750,000 of this research funding be dedicated to seed/proof-of-concept projects, without matching funds. Proof of research concept projects are projects completed in preparation for an application to larger funding bodies, such as the Tri-Council Agencies. This could be done at a level of \$50,000 per application for five applications each year, covering fifteen applications over the three-year duration of the funding. This would enable innovative ideas to be developed, tested and

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<sup>2</sup> Quality End-of-Life Care Coalition of Canada. Environmental Scan on Palliative Care Research Funding. 2017. Ottawa, Ontario: Quality End-of-Life Care Coalition of Canada.

<sup>3</sup> Canadian Institutes on Health Research. Palliative and End-of-Life Care Initiative: Impact Assessment. 2009. Retrieved from [https://publications.gc.ca/collections/collection\\_2010/irsc-cihr/MR21-145-1-2009-eng.pdf](https://publications.gc.ca/collections/collection_2010/irsc-cihr/MR21-145-1-2009-eng.pdf).

<sup>4</sup> Canadian Cancer Research Alliance. Canada's Research Investment in Palliative and End-of-Life Cancer Care, 2005–2016. 2019. Retrieved from: [https://www.ccrca-acrc.ca/wp-content/uploads/2020/08/PEOLC\\_2016\\_EN.pdf](https://www.ccrca-acrc.ca/wp-content/uploads/2020/08/PEOLC_2016_EN.pdf).





prepared for application to larger funding opportunities. To unburden the Tri-Council system, the funding could be administered through the existing structures of AGE-WELL.

## CONCLUSION

The COVID-19 pandemic has shown the importance of investing in high-quality palliative care and grief and bereavement supports. This includes funding better access to and delivery of palliative care, as well as research and knowledge translation to support better palliative care services and innovations in end-of-life care. To ensure consistent, comprehensive palliative care across Canada, and make sure our country is ready to meet future needs, it is vital that Canada take a national approach and finally move forward in implementing the Framework and Action Plan on Palliative Care in Canada.

### This submission is supported by the following organizations:

- ALS Societies Across Canada
- Canadian Aids Society
- Canadian Association for Spiritual Care
- Canadian Association of Psychosocial Oncology
- Canadian Association of Social Workers
- Canadian Breast Cancer Society
- Canadian Cancer Society
- Canadian Hospice Palliative Care Association
- Canadian Network of Palliative Care for Children
- Canadian Nurses Association
- Canadian Society of Palliative Care Physicians
- Canadian Society of Respiratory Therapists
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- HealthCareCAN
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- Realize
- SE Health
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