



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

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

August 8th, 2020

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List of Recommendations:

1. The QELCCC recommends that the Government continues to focus on the Minister of Health's mandate letter commitment to make home care and palliative care more available across the country; *specifically*, to fund all priorities of the Framework on Palliative Care.
2. The QELCCC recommends allocating \$8.75 million of funding over three years earmarked (or ring fenced) for palliative care research, including grief and bereavement. The QELCCC recommends dedicating \$750,000 of this research funding (\$8.75M) for seed/proof of concept projects.
3. The QELCCC recommends that the Compassionate Care Benefit should include a two-week period for grief and bereavement.

Introduction

The Quality End-of-Life Care Coalition of Canada (QELCCC) is a group of 34 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. 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.

As Canada's population continues to age and more people are living with chronic life limiting illnesses, the number of Canadians dying each year will increase by 40% to 330,000 by 2026; by 2036, Canada will see more than 425,000 deaths a year.¹ These statistics suggest that the need for palliative care in Canada will continue to grow. An integrated approach to palliative care that is multifaceted in nature and includes support to those who are grieving, and bereaving will continue to be an essential component of care for Canadians.

Below are three financial recommendations to the Standing Committee on Finance from the QELCCC, plus one policy priority that is pertinent to the Committee located at the end of the submission.

1. Fund the Framework on Palliative Care in Canada

Steps have been taken by the federal government over the years to develop recommendations to improve palliative care, however there are many gaps that remain to be filled.² In 2018, the Federal Minister of Health, Ginette Petitpas Taylor, tabled the Framework on Palliative Care in Canada.³ The new Framework set out the federal government's plan for improving access to palliative care across Canada. The Minister of Health, as required by the *Framework on Palliative Care in Canada Act*, will report on the state of palliative care in Canada within five years' time to Parliament. The Framework on Palliative Care in Canada² is a policy roadmap that sets out measures to ensure that all Canadians with life-limiting illnesses experience the highest attainable quality of life until the end of life.

¹ Statistics Canada. Population Projections for Canada. 2017. Retrieved from <https://www150.statcan.gc.ca/n1/pub/91-520-x/2010001/aftertoc-aprestdm1-eng.htm>

² 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>



In August 2019, Health Canada released the Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada.³ The Action Plan is a five-year plan that will be coordinated by Health Canada. A list of indicators will be developed to measure the progress of the plan and will identify the actions of the plan that are specific to the federal government.

The QELCCC recommends that the Government continue to focus on the Minister of Health's mandate letter commitment to make home care and palliative care more available across the country; *specifically, to fund all priorities of the Framework, including:*

- Palliative care education and training for health care providers and caregivers
- Measures to support palliative care providers and caregivers
- Research and the collection of data on palliative care
- Measures to facilitate equitable access to palliative care across Canada, with a focus on underserved populations.

COVID-19 is highlighting the need for increased palliative care resources, care and support for Canadians. We also need to acknowledge the need to increase preparedness of the palliative care sector in case of future pandemics. This could be accomplished by ensuring that the priorities of the Framework are attained and offset critical end-of-life care during shifting priorities that have been highlighted during COVID-19. Many Canadian jurisdictions name community palliative care as a priority, however, few Canadians receive palliative care at home in their last year of life.²

2. Invest in hospice palliative care research

Investments in health research are an important part of the Government's activities and response to COVID-19. The QELCCC welcomes the Government's announcements to date, however, we would like to highlight the gaps in palliative care research⁴ and provide suggested recommendations to fill these gaps.

Investments in hospice palliative and end-of-life care research show an average annual investment of \$6.6 million from 2005-2013.⁵ The lowest level of investment was in 2010, following the end of the CIHR Palliative and End-of-Life Care Initiative⁶ in 2009. The funding remains in decline;⁷ relative to other areas of cancer research, palliative and end-of-life care remain an underfunded field—it receives only about 1% of the overall investment in cancer research, despite the fact that almost half of cancer patients eventually die of their disease.⁶

³ Health Canada. Action Plan on Palliative Care: Building on the framework on palliative care in Canada. 2019. 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>

⁴ Quality End-of-Life Care Coalition of Canada. Scoping Review on Gaps in Hospice Palliative Care Research. 2018. Ottawa, Ontario: Quality End-of-Life Care Coalition of Canada.

⁵ Canadian Cancer Research Alliance. Pan-Canadian Framework for Palliative and End-of-Life Care Research. 2017. Retrieved from: https://www.ccrca-acrc.ca/wp-content/uploads/2019/06/PEOLC_Report_2016_EN.pdf

⁶ Canadian Institutes on Health Research. Palliative and End-of-Life Care Initiative: Impact Assessment. 2009. Retrieved from <https://www.yumpu.com/en/document/view/52269479/palliative-and-end-of-life-care-initiative-impact-assessment-report>

⁷ 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.



Specifically, the QELCCC recommends allocating \$8.75 million of funding over three years earmarked (or ring fenced) for palliative care research, including grief and bereavement. A Palliative and End-of-Life Care Initiative⁷ was created in the early 2000s via the Tri-Council agencies Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC) and Social Sciences and Humanities Research Council of Canada (SSHRC). Since the end of the Palliative and End-of-Life Care Initiative, a lack of investment in hospice palliative care research has occurred.^{6,7,8}

Yet, palliative and end-of-life care impact all Canadians. Additionally, the QELCCC recommends dedicating \$750,000 of this research funding (\$8.75M) for seed/proof of concept projects. 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 the \$50,000 level per year for fifteen applications over the three-year duration of the program (five per year) to enable for innovative ideas to be developed, tested and prepared for application to larger funding opportunities (without matching funding). In order to unburden the Tri-Council system, the funding could be administered through the existing structures of the Canadian Frailty Network (CFN) or AGE-WELL.⁸

The QELCCC recommends the creation of a standing governments and stakeholder meeting opportunity (federal, provincial and territorial level) for the sector to advance the discussion and to address the gaps to ensure that the Framework's milestones are achieved in all jurisdictions. This encompasses the need for nation-wide indicators/data.²

3. Make the Compassionate Care Benefit more flexible

With the continuing increase of the seniors' population¹ and caregivers receiving the Compassionate Care Benefit, the QELCCC recommends that the Compassionate Care Benefit should include a two-week period for grief and bereavement. The Compassionate Care Benefit is one of five special benefits of the Employment Insurance system and is currently received by a person when their loved one requires support and care in the final weeks of life. The maximum amount of time currently allotted to the benefit is 26 weeks.

Our recommendation will not cost any additional funds; just amend the benefit to be more flexible to the practical experiences of grief and bereavement. Palliative care does not necessarily end when someone has died. Family members, potential recipients of the Compassionate Care Benefit, may need support as they grieve the loss of a loved one and try to manage numerous strains and stresses. Bereavement programs are often part of the comprehensive care offered as part of hospice palliative care.

By adjusting the Compassionate Care Benefit, more Canadians will have access to the time necessary to heal, minimize economic hardships and take care of some of the more practical business following a loved one's death.



Policy recommendation from the QELCCC: Equitable access to palliative care drugs for Canadians

People living with life-limiting illness, their families and caregivers can face challenges in accessing a number of different types of support, such as access to various provincial and territorial drug plans.⁸ We hope that as discussions on pharma-care evolve at the federal government level, that access to palliative care drugs are a part of this dialogue to ensure that people with life limiting illnesses do not have to face unnecessary hardship as a result of their location.

This submission is supported by the following organizations:

- ALS Societies across Canada
- Canadian AIDS Society
- Canadian Association of Occupational Therapists
- Canadian Association of Psychosocial Oncology (CAPO)
- Canadian Association of Social Workers
- Canadian Breast Cancer Network
- Canadian Cancer Society
- The Canadian Home Care Association
- Canadian Hospice Palliative Care Association (CHPCA)
- Canadian Network of Palliative Care for Children
- Canadian Nurses Association
- Canadian Society of Palliative Care Physicians
- Canadian Society of Respiratory Therapists
- Canadian Virtual Hospice
- Carers Canada
- College of Family Physician of Canada (CFPC)
- HealthCareCAN
- Heart and Stroke Foundation
- Mental Health Commission of Canada
- National Initiative for the Care of the Elderly (NICE)
- Pallium Canada
- Realize
- SE Health

⁸ Canadian Institute for Health Information. Access to Palliative Care in Canada. 2018. Retrieved from <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>