### FINANCE PROPOSAL TO THE HOUSE OF COMMONS

# Standing Committee on Finance Pre-budget Consultation 2018 Submission

# Building Palliative Care Capacity Across All Care Providers: Time for a Concerted Drive

On behalf of

#### **Pallium Canada**

A community of clinicians, educators, researchers, carers, administrators, volunteers and citizen leaders working together throughout Canada to build palliative and end-of-life capacity as an integral part of a sustainable health system and caring communities.

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www.pallium.ca

## **Executive summary**

Effectively responding to serious-illness and dying is defining Canadian socio-economic policy today, brought to the attention of all Canadians by the recently passed Medical Assistance in Dying legislation. Fortunately, there are solutions and innovations. The time has come to scale and disseminated these more broadly and rapidly. This requires a sustained and substantive investment that is proportionate to the scale of the need.

Pallium Canada is ready to leverage our successful capacity-building innovations as well as rapid prototyping and testing of promising innovations. This includes: a) a larger and sustained push into shifting the continuum of care towards community-based, home care and integration of palliative care earlier in other settings to facilitate earlier community-care integration (including rural and remote regions); b) mapping out access to palliative care across the country; c) mobilizing the community to participate in providing support, focusing at this stage on life-skills training for community members and caregivers; d) scaling up the integration of Indigenous Peoples perspectives and wisdom into our products and tools; and e) leveraging existing resources and structures to amplify our innovations. Our initiative will involve four specific strategies:

- 1: Caring for Canadians Palliative Care is Everyone's Business
- 2: Strengthening Systems
- 3: Supporting a National Palliative Care Strategy Programs
- 4: Investing in a Sustainable Canadian Health and Social Care System

Pallium Canada would require the Government of Canada to provide funding of \$12 million annually for a period of five years, to build innovative home care, community care and healthcare system capacity, essential to creating preferred, equitable and cost-efficient care for our most vulnerable and support for their families in the face of historically unprecedented demographic, economic and policy changes.

#### **CONTEXT**

A growing number of reports<sup>1 2</sup> including Federal Bill C-14 on Medical Assistance in Dying (MAID), Quebec Bill 52 on Right to Die legislations and Private Member Bill C-277 on Developing a National Framework for Palliative Care, highlight alarming gaps in the availability of palliative care, and call for action. Key to improving access is training more health care providers and carers. If 'Right to Die' is to be accessible to every Canadian, then it is imperative that federal and provincial healthcare systems ensure a palliative care approach is accessible to all – providing balance and a full range of options and choices.

Multi-sectoral government linkages similar to the 2011 federal non-partisan committee united on 'Care of Vulnerable Canadians'<sup>3</sup>. Now more than ever it is imperative to implement those recommendations; again inviting inter-sectoral engagement across Ministries and all jurisdictions of Canada, particularly the Ministry of Health, Veteran Affairs Canada, Ministry of Indigenous and Northern Affairs and the Department of National Defence.

Palliative Care is part of a movement toward fundamental justice and basic human rights for citizens facing the last fragile stage of life.

Not to be Forgotten, Care of Vulnerable Canadians, Parliamentary Committee on Palliative and Compassionate Care, 2011

Consistent with the federal government theme of productive people and productive businesses leading to enhanced growth and prosperity Pallium recognizes the burden and toll currently held by those caring for one another through life's end.

#### **Current Capacity for Palliative Care:**

- In public opinion polling, most Canadians are supportive of palliative care, but are not aware of the choices available to them or where to access services. Most did not have advance care plans to guide their care if they were not able to communicate their wishes in the future
- The Majority of Canadians who have a preference of where they die, would prefer to die in their home (75%)<sup>4</sup>, and 93% believe palliative care services should be available in the setting of their choice
- Approximately 70% of deaths occur in hospital the most costly setting (at \$1100 /day versus \$120/day in the community)<sup>5</sup> most often not the preferred or the most appropriate location
- 40% of terminally ill cancer patients visit the emergency department within the last 2 weeks of life
- 41% of long term care home residents have at least one hospital admission in their last 6 months of life
- At least 25% of the total cost of palliative care is borne by families.<sup>6</sup>

<sup>&</sup>lt;sup>1</sup> Right to Care: Palliative Care for All Canadians, Canadian Cancer Society, 2015

<sup>&</sup>lt;sup>2</sup> Palliative Care, Canadian Medical Association's National Call to Action, 2015

<sup>&</sup>lt;sup>3</sup> Care of Vulnerable Canadians, Parliamentary Committee on Palliative Care Report, 2011

<sup>&</sup>lt;sup>4</sup> CHPCA, What Canadians Say: The Way Forward Survey Report, for The Way Forward initiative, Harris/Decima: 2013

<sup>&</sup>lt;sup>5</sup> Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of- Life Shared-Care Project, published online 16 January 2012Palliat Med

#### WHAT IS NEEDED?

Approximately 270,000 Canadians die every year in Canada<sup>7</sup>; cancer and diseases of the heart, lungs, nervous system, kidneys and liver account for about 64% of these deaths. Almost all of these patients would benefit from a palliative care approach. And this is the tip of the iceberg; hundreds of thousands of patients with these diseases are living across Canada and they too would benefit from a palliative care approach alongside treatments to control their disease. There is a strong and ever-growing body of evidence that shows palliative care, particularly when integrated earlier in the illness, improves patients' quality of life and reduces health care costs without reducing their life expectancy.

If more care providers were trained in palliative care, they would be better prepared to provide care throughout the course of life-threatening illness, and those in their care would be more likely to receive care in the setting of their choice.

It is estimated that only 15 to 30% of Canadians have access to specialized palliative care and most only receive these services within the last days or weeks of life. In addition, family caregivers provide 70% to 80% of care given in Canadian homes and communities, saving taxpayers an estimated \$25 billion dollars per year if these services were remunerated. Few have life skills related to dealing with life threatening illness. Family caregivers face significant physical, emotional and financial stresses in carrying out their tasks. Caregivers need skills development and resources to better carry out this role.

Effectively responding to serious-illness and dying is defining Canadian socio-economic policy today, brought to the attention of all Canadians by the recently passed Medical Assistance in Dying legislation. Fortunately, there are solutions and innovations across Canada. The time has come to scale and disseminated these more broadly and rapidly. This requires a sustained and substantive investment that is proportionate to the scale of the need.

#### WHY PALLIUM CANADA?

Pallium Canada is a not-for-profit, internationally recognized, pan-Canadian organization that has been at the forefront of developing, testing and implementing strategies to increase primary-level palliative care. It takes the approach that palliative care is everyone's business, not just the responsibility of a small number of palliative care specialist physicians and nurses. It has, for example, developed workshops and tools for doctors, nurses, pharmacists, emergency first-responders and other health care professionals that work across different settings - from home and community to long term care and hospitals. Pallium has also begun work with mobilizing Compassionate Communities, building upon its model of the Continuum of Compassionate Care.

<sup>&</sup>lt;sup>6</sup> CHPCA Fact Sheet – Hospice Palliative Care in Canada (2014)

<sup>&</sup>lt;sup>7</sup> Canadian Hospice Palliative Care Assoc. (CHPCA) 2012

 $<sup>^{8}</sup>$  Ibid.

<sup>&</sup>lt;sup>9</sup> Canadian Nurses Association, Health Is where the Home Is, 2014.

The overall goal of Pallium's work is to strengthen Canadians' ability to provide home and community-based palliative care through education and support to healthcare professionals and family/neighbor carers so that every Canadian who requires palliative care will receive it early, effectively and compassionately.

Pallium Canada has a community of 540 trained and certified palliative care clinician educators of different professions across the country delivering courses. This represents a major force that can be further galvanized and mobilized to scale up the work of educating and implementing quality improvement palliative care initiatives across the country.

#### WHAT IS THE PROPOSED SOLUTION?

Given the urgency and the scale of the challenge, we will deploy more rapidly and broadly our successful capacity-building innovations as well as rapid prototyping and testing of promising innovations. This includes: a) a larger and sustained push into shifting the continuum of care towards community-based, home care and integration of palliative care earlier in other settings to facilitate earlier community-care integration (including rural and remote regions); b) mapping out access to palliative care across the country; c) mobilizing the community to participate in providing support, focussing at this stage on life-skills training for community members and caregivers; d) scaling up the integration of Indigenous Peoples perspectives and wisdom into our products and tools; and e) leveraging existing resources and structures to amplify our innovations. Our initiative will involve four specific strategies:

#### 1: Caring for Canadians - Palliative Care is Everyone's Business

This strategy has the potential to transform our society into a skilled, informed and compassionate one respect to end-of-life care. It also has potential for significant economic benefits, with projected savings through access to quality non-hospital palliative care 2012-2036 ranging from \$247 million to over \$2.1billion<sup>10</sup>.

#### **Pallium Solutions:**

Working directly with communities nationwide to co-design and scale up delivery of:

- Learning Essential Approaches to Palliative Care (LEAP) courses
- Innovative online and at-the-bedside educational supports for generalist-level healthcare providers and family carers
- Inclusion of the voices and wisdom of Indigenous perspectives in our courseware.
- Language and culturally respectful LEAP Facilitators, Administrators, Coordinators and Coaches
- Rapid deployment of innovations leveraging existing structures.

<sup>&</sup>lt;sup>10</sup> Health Canada. Canadian Strategy on Palliative and End-of-Life Care, 2007

#### 2: Strengthening Systems

Provincial and Territorial Health Accord priorities for expanded home and community palliative care provision is a critical focus reflected in Pallium's approach. This strategy uses Pallium's experience in stakeholder engagement and collaborative partnerships.

#### **Pallium Solutions:**

- Bring together educators and institutions currently providing aspects of palliative care education from across the learning cycle (undergraduate, postgraduate, continuing professional development) and across professions, sectors and settings
- Mobilize Pallium's diverse network of palliative care professionals, providers and volunteers and explore opportunities for collaboration and consolidation to enhance opportunities and reduce duplication of efforts
- Work with provinces and territories, national palliative care organizations and academic institutions nationwide on strategies and frameworks to integrate palliative care throughout the health care system
- Collaborate between Pallium and Federal and Provincial governments and health ministries to establish provincial hubs to significantly expand training and skills development reach
- Collaborate with Practice-Based Research Networks (PBRNs) Palliative Care Quality
  Improvement Facilitators to undertake Quality Improvement work specifically related to
  palliative care.

#### 3: Supporting a National Palliative Care Strategy

This strategy focuses on supporting the development of a consistent, evidenced-based, good quality palliative care strategy that meets the needs of all Canadians (urban, rural, remote, and culturally respectful, across all settings of care).

#### **Pallium Solutions:**

- Mobilize patients and families, health professionals, educators, researchers, care-providers, health administrators from all three levels of government, Indigenous leaders, health systems experts, economists, industrialists, e-health and communications experts, and social system experts to provide strategic guidance towards a National Palliative Care strategy
- Highlight pragmatic options and solutions that incorporate the strengths of the health care, social and financial sectors as well as varied realities across the provinces and territories, taking into account the country's current and near-future economic situation
- Work with provincial partners to develop the Canadian palliative care atlas (map) with national and provincial report cards; and evidence-based effective delivery models to facilitate and guide improvements.

#### 4: Investing in a Sustainable Canadian Health and Social Care System

This strategy is about shifting the continuum of compassionate care towards community based care and mobilizing engagement on the basis that caring for those with life limiting illness involves sectors beyond health care, including the social, industrial and financial sectors.

#### **Pallium Solutions:**

- Enhance the vitality Canada's communities to support end of life care by catalyzing the concept of Compassionate Communities
- Support carers through LEAP for carers courseware and tools and virtual, just in time, applications
- Actively engage neighbourhood facilitators in community development and support for carers through voluntary engagement.
- Support palliative and home care innovation through targeted funds and strategies, such as Pallium's proposed capacity-building fund<sup>11</sup>.

#### WHAT IS THE ASK?

That the Government of Canada provide funding to Pallium Canada of \$12 million annually for a period of five years, to build innovative home care, community care and healthcare system capacity, essential to creating preferred, equitable and cost-efficient care for our most vulnerable and support for their families in the face of historically unprecedented demographic, economic and policy changes.

 $<sup>^{11}</sup>$  Report of the Standing Committee on Finance, December 2016