

# PROPOSAL TO THE HOUSE OF COMMONS

Standing Committee on Finance
Pre-budget Consultation 2017 Submission

# Palliative Care Education for All Care Providers

Mobilizing Our Compassionate Communities

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On behalf of

## The Pallium Foundation of Canada

A community of clinicians, carers, educators, academics, 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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## Why this proposal is critically important

### George's Story: The true story that inspired Pallium Canada (Pallium) and its vision and mission.

In the mid 1990's, a middle-aged Canadian man with advanced cancer saw a family physician in a small rural Manitoba town. It was the third physician he had visited. He was experiencing severe pain and no one had been able to help. He knew he was terminally ill, was not afraid of dying, but was fearful of suffering in whatever time he had remaining. Unfortunately, the physician, like the other doctors had never received any palliative care education. He informed George that he would not be able to increase his dose of morphine and there was nothing more he could do. George was devastated. Unbeknownst to the physician, the dose was too low and further increases would have been safe and effective. George took his wife by the hand and, as he left the clinic, turned and said: "I hope one day doctors like you can better look after people like me".

Regrettably, scenes like this still play out across Canada. We are not equipped with sufficient palliative and end-of-life care; only 16 to 30% of Canadians have access to palliative care. More alarming, by 2026 the number of Canadians dying will increase by 40 % to 330,000.¹ However, these numbers do not represent two very important sectors with major potential to increase access to palliative care.

- Healthcare providers who are not palliative care specialists (family physicians, nurses, pharmacists, social
  workers and paramedics working in home and community care)
- Carers including family members (young and old) and community

A growing number of reports<sup>2 3</sup> and the recently approved Bill C-14 on Medical Assistance in Dying (MAID) calls for action to improve palliative care, including education of health care professionals and carers. If MAID 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 access, balance and a full range of options and choices.

Tens of thousands of health care professionals who are not specialists in palliative care are involved caring for persons with advanced illnesses. Often at the forefront of diagnosing illnesses, initiating treatments and providing care across illness journeys. They often work in primary care, internal medicine, geriatrics, oncology, nephrology, paramedics or long-term care, and want the best for their patients. In many cases they do not have basic palliative care skills.

Equally important, approximately 25% of Canadians have cared for a family member or close friend with a serious health problem in the last year. These contributions relieve governments of substantial public costs to an estimated \$25 billion dollars if replaced by paid workers. Few have life skills related to dealing with life threatening illness. Fewer understand palliative care and many unfortunately associate it only with dying.

Neighbourhoods, schools and companies provide important opportunities to support life's trials. Being present to a friend or colleague, knowing what to do and say, where to suggest resources, how to meet critical and often unspoken needs, meals, visits or respite, example compassionate care.

These approaches have potential to transform our society into a skilled, informed and compassionate one with respect to end-of-life care. Importantly, they also have potential for significant economic benefits<sup>5</sup>, with projected savings through access to quality non-hospital palliative care 2012-2036 ranging from \$247 million to over \$2.1billion.<sup>6</sup> "Palliative Care is not only the best model for caring for vulnerable and dying Canadians; it also embodies truths that could be transformative of our whole healthcare culture."<sup>7</sup>

<sup>&</sup>lt;sup>1</sup> Health Canada. Canadian Strategy on Palliative and End-of-Life Care. 2007

<sup>&</sup>lt;sup>2</sup> Right to Care: Palliative Care for All Canadians, Canadian Cancer Society, 2015

<sup>&</sup>lt;sup>3</sup> Palliative Care, Canadian Medical Association's National Call to Action, 2015

<sup>&</sup>lt;sup>4</sup> Hollander, J. M., Liu, G., & Chappell, N. (2009). Who cares and how much. *Healthcare Quarterly*, 12(2), 42-49.

<sup>&</sup>lt;sup>5</sup> Health Canada. Canadian Strategy on Palliative and End-of-Life Care. 2007

<sup>&</sup>lt;sup>6</sup> Cardus Health Report, 2015

<sup>&</sup>lt;sup>7</sup> The Parliamentary Committee on Palliative and Compassionate Care, 2011

### Issue: Every Canadian who requires palliative care should receive it early, effectively and compassionately

Pallium has identified four pillars; education, health and social system integration, sustainability and compassionate communities as essential to improved palliative care.

### Essential #1: Canadians need better access to a palliative care approach

**Pallium Solutions** will scale up Learning Essential Approaches to Palliative Care (LEAP) courses; produce innovative online and at-the-bedside educational supports for generalist-level healthcare providers; train, certify and support LEAP Facilitators, Administrators, Coordinators, Coaches and Mentors; and develop regional educational hubs with enhanced access to technology through the Pallium Portal.

### Essential #2: Family and Community Carers need to be recognized, supported and trained

**Pallium Solutions** will develop, disseminate and support LEAP Carers; build 'just-in-time' Care Essentials education with linkages to community resources; and engage community networks supporting Carers.

# Essential #3: Palliative care needs to be consistent, evidence based, of good quality and meet the needs of all Canadians

**Pallium Solutions** will mobilize Pallium's diverse network of palliative care professionals, providers and volunteers; promote Quality Improvement Toolkits; create the palliative care atlas (map) with national report cards; promote evidence-based effective delivery models; incorporate the voices and wisdom of Indigenous perspectives, and ensure needs of all Canadians are met through educating on cultural sensitivities.

## Essential #4: Palliative care needs to be reallocated beyond palliative care specialists to the larger community

**Pallium Solutions** will create palliative care awareness and skills training; contribute to Compassionate Communities; and support "Speak Up" Advanced Care Planning.

### **PALLIUM Funding ASK to Increase Palliative Care across Canada**

That the Government of Canada establish a Pallium Canada Capacity-Building Fund of at least \$11 million annually for a period of at least 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.

### Pallium is well positioned to do this work

Pallium has a proven track record since 2001 as a responsible steward of precious public funding. The *Building the Future* of *Palliative Care Together* initiative in the 2013 Economic Action Plan has enabled Pallium to:

- ✓ Standardize competency-based training and build community capacity by educating over 8,000 front-line healthcare providers while solidifying local interprofessional healthcare teams across rural, remote and urban settings including Indigenous serving communities.
- ✓ Equip over 1,200 First Responders across Nova Scotia and PEI, positively transforming First Responders' scope of practice from an 'assess and transfer' service to preferred, cost-effective care in the home.
- ✓ Train over 500 teachers through Pallium's LEAP Facilitator program.
- ✓ Build strategic partnerships to extend care support (e.g. Cancer Care Ontario, L'Appui pour les proches aidants des ainés, BC Centre for Palliative Care, Six Nations).
- Create a team of expert leaders, change agents, champions, care providers, academic organizations and institutions necessary to mobilize this work.

✓ Achieve International regard as a leader in palliative care education. Collaborating with Ireland, Portugal, Japan, Caribbean, South Africa, Israel, Australia, and New Zealand to contextualize and implement Pallium's training and products (no other country has developed a pan-national program at Pallium's scale).

Pallium is the sole pan-Canadian not-for-profit organization providing interprofessional palliative care education to improve the quality of palliative care across Canada. Pallium develops setting-based interprofessional (Physicians, Nurses, Pharmacists, Social Workers, First Responders, and Care Aides) and informal carer (family, friend, neighbour, coworker and volunteer) education, resources, and clinical decision-support tools to *build community capacity so that every Canadian who requires palliative care will receive it early, effectively and compassionately* (Pallium Vision 2020).

Pallium is well positioned to leverage its past successes and current infrastructure renewal to provide national leadership through its collaborative pan-Canadian network and partnerships to mobilize positive systemic change. With appropriate funding Pallium is ready to scale up its impressive work to date, and with key partners, to realize Vision 2020:

### Canadians receive better access to a palliative care approach.

- 1. Pallium's competency and evidence based, best practice Learning Essential Approaches to Palliative Care (LEAP) courses are scaled up to equip thousands of Canadian healthcare professionals across home, community and institutional care settings with skills and tools to provide a palliative care approach.
- 2. Innovative online and at-the-bedside educational supports for generalist-level healthcare providers expand LEAP courses, Pallium Palliative Pocketbook and eBook, Pallium Resource App, doodles and snippets.
- 3. LEAP Facilitators, Administrators, Coordinators, Coaches and Mentors are expanded, trained and certified to build and support community based palliative care capacity.
- 4. **Regional hubs are created** with dedicated personnel supporting LEAP plus additional palliative care educational events across care settings to ensure access in every province and territory of Canada.
- 5. **The next generation Pallium Portal increases access through technology,** organizing and tracking LEAP activity; providing powerful analysis of the impact of training on improved care practice; facilitator and coach/mentor quality improvement experience; access, barriers and gaps.

### Carers are recognized, supported and trained

- 1. **LEAP for Carers is developed and broadly disseminated** recognizing the major impact on the ability of family, friends and neighbours to care at home and in community.
- 2. **Learning Palliative Care Essentials in 'just-in-time' formats** provide links to community resources, increasing carers and community's ability to sustain important caregiving activities.
- 3. **Community support associations and networks can identify and support carers** through knowledge, skills and confidence building.

### Palliative care is consistent, evidence based, of good quality and meet the needs of all Canadians

- 1. **Quality Improvement Toolkits for setting-specific health service providers are utilized across** home care, family medicine, paramedic, and long-term care, nursing homes, emergency, and hospital settings.
- 2. Pallium's diverse network of committed palliative care professionals, providers and volunteers, are mobilized to invest in all regions of Canada, ensuring that there is adequate presence across urban, rural, remote, English, French, Bilingual and Indigenous serving communities.

- 3. The palliative care atlas with regional and provincial report cards identifies innovation, leadership and gaps.
- 4. Most effective delivery models are identified to ensure high return on resource model investment.
- 5. Leadership and success in integration of palliative care in health and social care sectors are celebrated.
- 6. The voices and wisdom of Indigenous perspectives are integrated into palliative care and healthcare professionals are educated in cultural sensitivities. Pallium wishes to highlight these inspirational values plus introduce new Canadians to the contributions that palliative care can provide.

Palliative care has shifted beyond palliative care specialists to the larger community.

- 1. **Palliative care awareness and skills are recognized and employed across communities.** Pallium accelerates these efforts through online eLearning and LEAP course adaptations designed for community.
- 2. **Compassionate Communities concepts are launched across Canada**, with a focus on education to support LEAP Schools, Corporations, and Neighbourhoods.
- 3. "Speak Up" Advanced Care Planning is widely adopted across Canada.

Canada is a leader globally<sup>8</sup> for advances in palliative and end-of-life care policy and program innovations, yet its ranking has slipped over the past 5 years, now overtaken by the US and 9 other countries.<sup>9</sup> Many Canadians are not aware of services or how to access them, often leading to inappropriate service utilization, increased healthcare costs, and unnecessary patient suffering.<sup>10</sup>

#### Pallium's Plan

Fortunately, the physician that George visited (Dr. Jose Pereira; co-applicant on this proposal) enrolled in a palliative care course shortly after seeing George. With new skills, Pereira was able to control George's pain and care for him in his rural community until his death 3 months later. The education made all the difference for George and his family. In 2001, Pallium was launched by Dr. Pereira and colleagues to fulfil George's dream that one day all health care professionals could better take care of patients like him. Supporting the dying and most vulnerable in our society also reflect the values and practices transmitted to future generations. <sup>11</sup>

This funding will enable Pallium Canada to scale up all work to date, and with key partners, to realize Vision 2020: To educate health professionals and carers across home care, community care and institutional care settings, empower Canadian communities to care for ailing persons by mobilizing social, education and business sectors, accelerate the integration of palliative care in health and social services, and build long-term sustainability.

The Parliamentary Committee on Palliative and Compassionate Care stated in 2011 that "palliative care requires mobilization and recommends stable funding to Pallium Canada to sustain and extend this innovative and cost-effective work across Canada."<sup>12</sup>

Nothing Impacts us and our families more intimately than the death of a loved one.

<sup>&</sup>lt;sup>8</sup> Mapping Levels Of Palliative Care Development: A Global Update 2011 Palliative care development all levels, World Palliative Care Association

<sup>&</sup>lt;sup>9</sup> Economist, Quality of Death Index, 2015

<sup>&</sup>lt;sup>10</sup> Cardus Health Report, 2015

<sup>&</sup>lt;sup>11</sup>Pereira, J., (Nov. 6, 2009). <u>Planning for Investments in Support of the Seriously III and Dying as a Public Policy Response to Sustaining Canadian</u>
<u>Productivity, Economic Competitiveness and Quality-of-Living,</u> House of Commons Standing Committee on Finance, Pre-Budget Consultation 2009
Submission, The Pallium Foundation of Canada

<sup>&</sup>lt;sup>12</sup> The Parliamentary Committee on Palliative and Compassionate Care, 2011