

PROPOSAL TO THE HOUSE OF COMMONS

Standing Committee on Finance
Pre-budget Consultation 2015 Submission

Supporting Families and Helping Vulnerable Canadians We Can All Make a Difference

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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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Supporting Families and Helping Vulnerable Canadians We Can All Make A Difference:

Imagine a time when everyone has the core competencies and everyone can care.

We know what this vision looks like. It is one where Compassionate Communities value and support one another, their families and neighbours, through good and difficult times. Compassionate Communities are equipped and empowered to care, upholding fundamental human values of dignity and worth, embracing all life from cradle to grave.

We have the expert, experienced leadership necessary to do this work. Pallium Canada is a national community of clinicians, carers, educators, academics, administrators, volunteers and citizen leaders working together throughout Canada since 2001 to build palliative and end-of-life capacity as an integral part of a sustainable health system and Compassionate Communities. Pallium Canada is well positioned nationally with proper federal financial support to improve living and dying well by helping healthy, vibrant communities throughout Canada engage and creatively respond to more serious illness and dying.

We have a plan to get there. This plan will build on the recommendation of the 2011 Parliamentary Committee on Palliative and Compassionate Care, "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 health care culture." We will engage communities, families/caregivers, educators, employers, volunteers and interprofessional care teams to build capacity through community development and education so that Canadians receive planned, earlier, integrated support and the palliative approach to care.

Canada is a leader globally² for its advances in palliative and end-of-life care, policy and programmatic innovations and yet, currently only 16 to 30% of Canadians have access to palliative care and most only receive these services within the last days or weeks of life.³ Together we can all make a difference and realize a time when everyone has the core competencies to support best practice care for our families and vulnerable Canadians.

Stakeholders of the Pallium Foundation of Canada encourage parliamentarians to give due consideration to the following recommendation in the pre-budget consultation process:

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 undertake priority health-provider, public engagement and capacity-building activities, essential for Canada to support and help families and vulnerable Canadians experience quality-of-living to life's end in the face of historically unprecedented demographic changes.

¹ The Parliamentary Committee on Palliative and Compassionate Care, 2011

² Mapping Levels Of Palliative Care Development: A Global Update 2011 Palliative care development all levels, World Palliative Care Association

³ Canadian Hospice Palliative Care Assoc. (CHPCA) 2012

Context for this Work

Canada is an aging society. It is projected that by 2041 25% of the Canadian population will be over 65. Furthermore, by 2036 there will be 3.3 million Canadians over 80.4

While improvements in public health, advances in health care technologies and treatments, and socio-economic influences have all helped extend the lives of Canadians, all Canadians will eventually die. And Canadians are dying in greater numbers. 242,074 Canadians died in 2011, and it is estimated that there will be a 40% increase in deaths by 2020.⁵

In the past Canadians were likely to die suddenly as a result of infections, accidents and childbirth. Today Canadians are more likely to develop chronic illnesses and die slowly.⁶ Over three in ten Canadians (32%) personally suffer from chronic illness while four in ten (39%) have someone in their immediate family with chronic illness. Taken together, six in ten Canadians (57%) either personally suffer from chronic illness or have a sufferer in their immediate family. Trajectories of various chronic, life-limiting illnesses are different and it has been speculated that by 2025, only 20% of Canadians will die with an illness that has a recognizable terminal phase. Two-thirds of Canadians who die will have two or more chronic diseases and will have lived for months or years in a state of fragile health or "vulnerable frailty." ⁷

The Canadian healthcare system has historically developed with a focus on cure, treatment and prolonging life. Given the reality of the burden of chronic illness, and the unpredictability of death facing Canadians today – even in the face of advances in treatment – most Canadians with chronic, life-threatening illnesses do not receive the kind of care services that can lead to a "good death" – that is, quality palliative care.

Canada embraces World Health Organization's (WHO) palliative care definition; 'an approach that improves the quality of life of patients and their families facing life-threatening illness, through prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help families cope during the patients illness and in their own bereavement;
- uses a team approach to address patient and family needs;

Certified General Accountants of Canada, (2005) Growing Up: The Social and Economic Implications of an Aging Population. http://www.cga-canada.org/en-ca

⁵ Health Canada. Canadian Strategy on Palliative and End-of-Life Care. 2007

⁶ The Way Forward. The Palliative Approach: Improving Care for Canadians with Life-Limiting Illnesses. August 2012. http://www.hpcintegration.ca/resources/discussion-papers/palliative-approach-to-care.aspx

⁷ Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. 2012.

- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁸

A 2014 Harris/Decima poll revealed that 96% of Canadians support palliative care. The vast majority of Canadians also believe that palliative care has a positive impact in reducing stress and burden on families (93%) and improving quality of life (94%).⁹

Public health approaches to palliative care have been steadily implemented in many regions and countries around the world over the past 10 years to better meet aging populations' needs. The Health Promoting Palliative Care (HPPC) approach based on the WHO Ottawa Charter for Health Promotion¹⁰ aims to provide education, information and policy-making that supports wellbeing and optimal health despite illness and up to the very end of life.

Compassionate Communities is a HPPC model developed on the WHO Health cities model and is regarded as critical to normalizing experiences and needs of our aging citizens, plus ultimately producing sustainable care systems.¹¹

The challenge of serious-illness and dying within Canada's population is much larger than the current capacity of Canada's palliative and end-of-life care community to effectively respond. Continuing with a 'business as usual' approach will soon overwhelm existing capacity. Canada's palliative care leaders have been, and are committed to furthering practical and cost-effective means to improved palliative care in health and social care systems.

Our Vision

Our vision is that all Canadians will be able to articulate and access palliative care. By focussing on palliative care education and training; health care providers, families and caregivers will be equipped and supported to care for vulnerable Canadians. Schools and workplaces will become caring places of learning and work and by extension will create Compassionate Communities engaging all citizens.

Our Plan

The federally funded Way Forward Initiative identified an integrated palliative approach to care to result in better quality of life and death for Canadians and more efficient use of resources. The same practitioners providing care now – including primary care physicians, nurses, personal support workers, long-term care staff, hospital staff and the people responsible for health care in shelters and prisons – would provide the palliative approach to care. The Way Forward identified integrated palliative approach to care will need:

1. A shift in practice culture;

⁸ http://www.who.int/cancer/palliative/definition/en/

⁹ Fast Facts. Hospice Palliative Care in Canada. 2014. http://www.hpcintegration.ca/media/50839/TWF%20Survey%20Fast%20Facts%20FINAL%20Eng%2017012014.p

¹⁰ WHO, The Ottawa Charter for Health Promotion, 1986

¹¹ 2013 TVN Catalyst Grant Program Application, D. Marshall

- 2. Common language;
- 3. Education and support for providers;
- 4. Canadians engaged in advance care planning;
- 5. Establishing Caring communities;
- 6. Adapting the integrated palliative approach to provide culturally-safe care; including with and for Canada's First Peoples;
- 7. Outcome measures that monitor change. 12

Pallium Canada will contribute significantly to this plan the following approaches:

Building Compassionate Community Capacity

Modern public health principles and collaborative approaches that engage professionals and the public will be used to form strong partnerships across palliative care service providers, health professionals, community organizations, caregivers, volunteers and educators. The focus will be on building Compassionate Community capacity through education, information and awareness building on evidence from jurisdictions around the world, such as Spain, and Australia. We will integrate the concepts of rehabilitative palliative care – whereby all people are supported to live to their fullest to their death.

Supporting Caregivers

Caregivers (family, informal or unpaid) provide ongoing care and assistance for family members and friends in need of support due to physical, cognitive, or mental health conditions. In 2007, 23% of Canadians said they had cared for a family member or close friend with a serious health problem in the last 12 months – 2.7 million were Canadian family caregivers over the age of 45.

Pallium Canada will partner and support caregivers to proactively care for their loved ones. We will learn and work with national and provincial organizations such as the Quebec Caregiver Association to build caregiver capacity through increasing awareness, education, and facilitation of programs that support caregiving.

Engaging family physicians and primary care providers in all settings, as the first point of entry – to make that entry better

Pallium Canada partners with organizations including the College of Family Physicians of Canada, Royal College of Physicians and Surgeons, Canadian Nurses Association and the Canadian Society of Palliative Care Physicians to facilitate the development and implementation of training, tools and incentives that support primary care providers to integrate a palliative approach into their practice. Across Canada we will work in partnership with family health teams, primary care providers, and cancer care teams – to create mechanisms that facilitate palliative care integration into primary care.

"Education resources developed federally, provincially or territorially can help reduce costly duplication at other levels in the health care system and promote more consistency in how the integrated palliative approach is understood and delivered. There are already strong

 $^{^{12}}$ The Way Forward Framework for A Palliative Approach to Care, 2014

education programs developed in Canada, such as the *Learning Essential Approaches to Palliative and End-of-Life Care* (LEAP) program developed by Pallium Canada".¹³

Pallium Canada will continue to provide interprofessional education to primary care providers so that standardized, nationally accepted educational resources, tools and curriculum essential to support best practice, best patient and family care are accessible to growing numbers of Canadians living with chronic and complex life-limiting conditions.

Pallium Canada - Well Placed to Lead this Work

Pallium Canada, has a strong track-record of catalyzing and facilitating innovation, change and education in palliative and end-of-life care at a national level. From 2001 to 2003 the Program implemented a rural palliative care initiative across the Prairie Provinces and started the development of standardized education materials for rural and remote based health professionals. This initiative expanded across all provinces and territories from 2003 to 2008 through \$4.2M from Health Canada's Primary Health Transition Fund. Federal funding announced in Economic Action Plan 2013, led by a strong representative volunteer Board of Directors, Pallium Canada, leveraging its past successes and current infrastructure renewal, is well positioned to provide national leadership through its collaborative pan-Canadian network and partnerships to catalyze positive systemic change. *Since 2001, Pallium Canada has been the sole national organization supporting continuing interprofessional palliative care educational development across Canada* working closely with national partners to promote stakeholder investment in Canadian Gold Standard palliative and end-of-life care standard setting.

In Conclusion

Issues about serious-illness and dying are understandably complex, but the conclusion about public investment is simple. Canada can invest in priority infrastructures to support the seriously-ill and dying now, or it will predictably pay much higher financial and human-suffering costs within the foreseeable future. Canadians have only started to explore the outer boundaries of what well-designed, developed and executed palliative and end-of-life care can do. Sensible, focused investments in enhanced Canadian palliative and end-of-life care knowledge/service infrastructure capacity are essential to sustaining Canadian productivity, economic competitiveness and quality-of-living.

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 $^{^{13}}$ The Way Forward Framework for A Palliative Approach to Care, 2014