



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

August 6, 2014

Sent by email to [finapbc-cpb@parl.gc.ca](mailto:finapbc-cpb@parl.gc.ca)

The House of Commons Standing Committee on Finance  
Sixth Floor, 131 Queen Street  
**House of Commons**  
Ottawa, ON  
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**RE: 2014 Pre-Budget Consultation Submission from the Canadian Hospice Palliative Care Association**

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Dear Members of the Standing Committee on Finance,

The Canadian Hospice Palliative Care Association (CHPCA) is pleased to submit the following proposal for consideration by the Standing Committee on Finance in the development of the 2015 federal budget. The submission falls under the theme of “Supporting families and helping vulnerable Canadians by focusing on health, education and training”.

The CHPCA recognizes the important commitment made by the Government of Canada from the 2011 budget for palliative care through funding of *The Way Forward initiative: moving toward community-integrated hospice palliative care*. The National Framework developed within the initiative is a roadmap for implementing the integrated palliative approach to care. Originally developed in the spring of 2013 by *The Way Forward* advisory committee with advice from members of the Quality End-of-Life Care Coalition of Canada (QELCCC), the Framework has been revised and now reflects ideas and feedback from governments, healthcare professionals and organizations across the country, including First Nations groups. It also captures the experience of Canadians facing care issues associated with aging, frailty and chronic illnesses.

Much progress has been made, however more needs to be done to ensure all Canadians, no matter where they live, have access to high quality hospice palliative and end-of-life care. There has been much discussion and dialogue over the past year about end-of-life care among Canadians, however there is also confusion about what hospice palliative care offers, where it can be provided and by whom. As our population ages, we must ensure that all Canadians have access to palliative services integrated with their other care that will help them manage symptoms, enhance their lives, give them a greater sense of control, and enable them to make informed decisions about the care they want. More equitable access to palliative care integrated with their other care will enable more Canadians to live well with their illness up to the end of life.

The submission builds on the momentum of *The Way Forward* initiative and work advanced by CHPCA, the Quality End-of-Life Care Coalition of Canada and the national advance care planning project.

We would welcome the opportunity to appear before the Committee to further discuss the importance of funding for community-integrated hospice palliative care and advance care planning. Should the Members of the Standing Committee on Finance have any questions, I can be reached at [sbaxter@bruyere.org](mailto:sbaxter@bruyere.org).

Sincerely,

A handwritten signature in blue ink, appearing to read "Sharon Baxter".

Sharon Baxter, Executive Director  
Canadian Hospice Palliative Care Association

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**Theme**

Supporting families and helping vulnerable Canadians by focusing on health, education and training

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**Executive Summary**

The Canadian Hospice Palliative Care Association (CHPCA) and the Quality End-of-Life Care Coalition of Canada (QELCCC) have made significant progress advancing a community-integrated palliative approach to care in Canada through the Government of Canada initiative – *The Way Forward*. Acting as a ‘catalyst project’, *The Way Forward* has engaged provincial and territorial governments, health system planners and policymakers, health-care professionals, and Canadians to improve the understanding and awareness of aging, living with chronic life-limiting illnesses, and hospice palliative care (HPC) and advance care planning (ACP). CHPCA believes there is an ongoing and pivotal role for the Government of Canada to bring national leadership, enhanced coordination and continued engagement with Canadians through a second phase of work. In a recent survey undertaken by *The Way Forward* and conducted by Harris/Decima, it was discovered that the majority of Canadians (73%) feel that governments place too little priority on end-of-life care, including over one-third (35%) who feel that it is far too little.<sup>1</sup> While it is acknowledged that the implementation and delivery of hospice palliative and end-of-life care generally falls to provincial and territorial governments, there remains a great deal of work to advance high quality HPC. Efforts to raise awareness among Canadians about palliative care and planning for end-of-life care through advance care plans, and continuing to support implementation of the action steps identified in the national framework developed by *The Way Forward* with consistent tools and resources, remain key priorities.

In addition to improved access to HPC, many Canadian families have not discussed their end-of-life care wishes, although they understand the importance of doing so. With significant public support for discussions about palliative and end-of-life care, it is an opportune time to promote a national campaign and disseminate information, tools and resources that will encourage and facilitate end-of-life care conversations among all Canadians so that they are aware of their options and choices. Furthermore, research indicates that patients who have end-of-life conversations with health professionals and family members are much more likely to be satisfied with their care, require fewer aggressive medical interventions at the end of life, and are more likely to take advantage of hospice resources in communities or die at home. This overall benefit could stand to save the health-care systems millions of dollars in emergency room visits, unplanned hospitalizations and unnecessary health interventions for palliative patients. Living well until death should not be a benefit for only a small percentage of Canadians – it should be a reality for all.

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**Proposal 1: Making Advance Care Planning Matter**

Advance Care Planning (ACP) is a process of reflection in which a person with decision-making capacity expresses their wishes regarding their future health care in the event that they become incapable of consenting to or refusing treatment or other care. The process includes conversations with family and friends, and particularly the person who will act as a substitute decision maker. It should also include conversations with the person's health-care providers and perhaps with lawyers who prepare wills and powers of attorney. Current research clearly shows that ACP results in increased patient and family satisfaction, less stress and anxiety for families and caregivers, an improved quality of life and death, fewer decision-making conflicts, fewer medical interventions and more appropriate use of health care resources in the final weeks of life. Yet, less than half (49%) of Canadians have discussed end-of-life care with a family member, only 9% have discussed it with a healthcare professional, and 80% do not have a written plan for their care. Based on *The Way Forward* initiative's poll of Canadians conducted by Harris/Decima, while the majority of Canadians (52%) indicate that the ACP process should begin when a person is healthy, only 13% of Canadians have an advance care plan prepared.<sup>ii</sup> The national consultations conducted through *The Way Forward* identified advance care planning as central to facilitating the introduction of an integrated palliative approach to care. ACP is attracting some attention nationally, and a number of provinces are starting to work on spreading the CHPCA's led national "Speak Up" campaign. However much more is needed to ensure that all Canadians develop their advance care plan while they are healthy and revisit their goals over time with their families and health-care providers throughout the trajectory of illness or aging.

**Proposed Activities**

The CHPCA proposes coordination of an 'Advance Care Planning in Canada' campaign, which would aim to raise public and health professional awareness of the importance of advance care planning. The targets would be two-fold – the general public and caregivers, and those working in health systems and the community who support Canadians and families living with chronic life-limiting illnesses or who are aging. Health care professionals, government officials, and private sector corporations would be important stakeholders. We hope to foster partnerships across Canada with governments, professional groups, non-government organizations, corporate Canada and communities to facilitate advance care planning conversations among Canadians and their families.

The "Speak Up" campaign and National Advance Care Planning Day (April 16) are growing, but the initiative would benefit from a better-coordinated and broader awareness campaign to reach the intended audiences. Materials would be co-branded with the Government of Canada to emphasize the leadership that the federal

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government is taking on behalf of all Canadians. Through the use of these existing materials, we can ensure consistency across the country and facilitate partnership adoption and local adaptation. In addition to this awareness campaign, funding would support the development of national awareness tools. These tools would be developed in consultation with professionals and Canadians, including with and for First Nations, Inuit and Métis peoples. Since the legal construct is different in each province/territory, and there are also important issues of cultural-safety, templates would be developed that can be customized depending on the jurisdiction. The funding would also support developing electronic resources that can be easily used by all stakeholders – such as videos, tablet and smartphone apps, interactive on-line resources and training modules. A national repository of all resources will be available to both professionals and the general public on [www.advancecareplanning.ca](http://www.advancecareplanning.ca).

**Project Goal**

The ultimate goal of ACP in Canada is to raise awareness that planning appropriately for a serious illness or aging will improve health care outcomes and help families through a difficult and vulnerable time. Engaging community partners will improve best practices, tools and resources available to all Canadians. The CHPCA and its partners can encourage proper planning and decrease unnecessary hospitalizations and emergency room visits and other avoidable crises that occur when families are faced with difficult decisions at the end of life. Through this project, we can support Canadians so that they live well into their final days.

**Collaborators and Partners**

The ACP in Canada Task Group (see Appendix A for a list of members) and the Canadian Hospice Palliative Care Association (proposed recipient).

**Budget**

The Advance Care Planning in Canada initiative would require a \$3-5 million investment over a three year period to achieve its goals.

**Proposal 2: Moving *The Way Forward* into Action: Phase II**

In 2012, the Government of Canada announced \$3 million in funding to develop a framework to support community-integrated palliative care across settings. From 2012-2015, the activities of *The Way Forward: An Integrated Palliative Approach to Care* have focused on working with numerous stakeholders including provincial and territorial governments, regional health systems, policymakers and program planners, national professional and patient organizations, among others to develop a practical and implementable framework for action.

The palliative approach is described as an approach to care focused on improving the quality of life of persons and their families who are aging or living with chronic

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conditions. It is provided in all health care settings. It involves physical, psychological, social, and spiritual care. The palliative approach is not delayed until the end stages of an illness but is applied earlier to provide active comfort-focused care and a positive approach to reducing suffering. It reinforces the person's autonomy and right to be actively involved in his or her own care - and strives to give individuals and their families a greater sense of control by making informed care choices.

Health care providers in the primary care or community setting, supported by specialist palliative care teams when needed, deliver care in a wide variety of settings from a patient's home or in long-term care facilities, to hospitals in cities, rural communities and remote areas. We have developed the road map in the national framework, yet there continues to be a need to raise awareness and accelerate the adoption across settings of care. A recent survey conducted by Ipsos Reid by *The Way Forward* found that family physicians and nurses in primary care are very supportive of the health system and patient benefits of hospice palliative care, yet only 25% are comfortable providing palliative and end-of-life care<sup>iii</sup>. Based on the research, there are several gaps to fill with support, education and resources that would benefit family physicians, nurses and their patients including:

- ° Overall comfort level in discussing palliative care and end-of-life issues
- ° Initiating discussions about a palliative approach and hands-on experience with ACP
- ° Managing challenging issues such as control of pain and depression
- ° Identifying resources in the community to provide support to patients and families

Through the ongoing funding of phase 2 of *The Way Forward*, the Government of Canada can continue to lead on the implementation of a number of key national efforts. By implementing a palliative approach to care across health systems and being able to measure and report on progress, Canadians will benefit from high quality access to hospice palliative care programs. In turn, governments can better manage healthcare priorities and pressures, including the growing costs of providing care at end-of-life, particularly as the Canadian population ages.

**Proposed Activities**

Additional funding would assist in further disseminating adoption and adaptation of the national framework and promoting policy and practice change across health systems, including with and for Aboriginal Canadians. Proposed activities would support exploring models that integrate a palliative approach to care while building in mechanisms to support long-term sustainability.

Based on Phase I of *The Way Forward*, quality improvements will be identified across all settings of care through a series of indicators. Establishing standardized models will be especially crucial for Canadians and their families in home care, long-term care, and in

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Aboriginal, rural, and remote communities. These would be developed in collaboration with national bodies such as Accreditation Canada and the Canadian Institute for Health Information.

**Project Goal**

As the Harris/Decima survey demonstrated, three-quarters of Canadians would turn to their family physician (FP) for more information about hospice palliative care services and ACP. Yet a recent Ipsos Reid survey of FP found that 52% of FPs had some experience and were not very comfortable with these conversations, and a further 24% had no experience and were not comfortable. Clearly, there is a gap to be addressed in order to best support Canadians who are aging or living with chronic life-limiting illnesses.

Our goal is to facilitate access, awareness and understanding of the palliative approach to care, across all settings of care, so that physicians and other health care professionals are prepared to assist patients with chronic and life-limiting illnesses or who are aging, to live well until death.

**Collaborators and Partners**

Canadian Hospice Palliative Care Association (proposed recipient) and the QELCCC, working with national and pan-Canadian stakeholders (see Appendix B for member organizations).

**Budget**

Extended funding of an additional \$3 million over three years.

Word count of proposal: 1,998 words

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**Appendix A**

**Advance Care Planning in Canada:  
Task Group Members**

Sharon Baxter  
Canadian Hospice Palliative Care Association

Denise Page  
Canadian Cancer Society

Bev Berg  
Alberta Health Services

Jennifer Dent  
The GlaxoSmithKline Foundation

Maryse Bouvette  
Bruyère Continuing Care

Lonny Rosen  
Rosen Sunshine LLP and Canadian Bar  
Association

Earl Campbell  
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Jessica Simon  
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Carolyn M. Tayler  
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Project Assistant, Advance Care Planning in  
Canada, Canadian Hospice Palliative Care  
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Canada, Canadian Hospice Palliative Care  
Association

Daren Heyland  
Queen's University, Canadian Researchers at  
the End of Life Network (CARENET)

Melody Isinger  
Quality End-of-Life Care Coalition of Canada  
Michelle L. MacDonald  
TECH VALUE NET

Laurie Anne O'Brien  
Canadian Hospice Palliative Care Association  
Nurses Interest Group



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**Appendix B  
Quality End of Life Care Coalition of Canada Members**

ALS Society of Canada	Canadian Society of Respiratory Therapists
Alzheimer Society of Canada	Canadian Working Group on HIV and Rehabilitation
Canadian AIDS Society	Catholic Health Alliance of Canada
Canadian Association of the Deaf	The GlaxoSmithKline Foundation
Canadian Association of Occupational Therapists	Heart and Stroke Foundation of Canada
Canadian Association for Spiritual Care	Huntington Society of Canada
Canadian Association of Social Workers	Kidney Foundation of Canada
Canadian Breast Cancer Network	Mental Health Commission of Canada
Canadian Cancer Society	National Initiative for Care of the Elderly
Canadian Cancer Action Network	Ovarian Cancer Canada
The College of Family Physicians of Canada	Saint Elizabeth Health Care
Canadian Healthcare Association	VON Canada
Canadian Home Care Association	The Pallium Foundation
Canadian Hospice Palliative Care Association	Women's Inter-Church Council of Canada
Canadian Lung Association	<b>Associate Members</b>
Canadian Medical Association	Canadian Arthritis Patients Alliance
Canadian Nurses Association	Canadian Caregiver Coalition
The Canadian Partnership Against Cancer	Canadian Virtual Hospice
Canadian Pharmacists Association	Long Term Care Planning Network
Canadian Society of Palliative Care Physicians	Canadian Network of Palliative Care for Children

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<sup>i</sup> Ibid. 49

<sup>ii</sup> A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). Ibid. 33, 35

<sup>iii</sup> Online survey of n=286 GP/FPs and n=200 nurses in primary care settings across Canada conducted between April 24-May 27, 2014 by Ipsos Reid. Overall data has been weighted to reflect true regional distribution of GP/FPs and nurses.