



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

2018 Pre-Budget Consultation Submission
to the House of Commons Standing Committee on
Finance (FINA)

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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 through *The Way Forward* project which was completed in 2015. By engaging provincial and territorial (PT) governments, health system planners and policymakers, health-care professionals, and Canadians, there is an improvement in understanding and awareness of aging, living with chronic life-limiting illnesses, hospice palliative care (HPC) and advance care planning (ACP) across Canada. Policy implementation and delivery of hospice palliative care delivery fall to PT governments, but national leadership is badly needed in the wake of national Medical Assistance in Dying (MAiD) legislation.

CHPCA proposes a national awareness campaign about Advance Care Planning (ACP) and how to start the ACP process [[Proposal 1](#)]. Similarly, Canadians need to know what Hospice Palliative Care (HPC) can do for most of us at end of life. Finally, additional supports for unpaid caregivers in Canada who are shouldering the majority of care for critically ill family members, often while employed, are needed. The current structure of the Compassionate Care Benefit (CCB) [[Proposal 2](#)] is having a direct impact on Canada's economic productivity, competitiveness and the mental health of its workforce. Corporate Canada can also be encouraged by the federal government to promote better HR policies for their employees who are caring for critically-ill loved ones [[Proposal 3](#)].

Proposal 1: Understanding Advance Care Planning and Hospice Palliative Care

Current research clearly shows that ACP results in increased patient/family satisfaction, less stress and anxiety for families and caregivers, an improved quality of life and death, fewer decision-making conflicts and 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 health care professional, and 80% do not have a written plan for their care. ACP has attracted some attention nationally, and a number of provinces are working to spread the CHPCA-led national "Speak Up" campaign including BC, Manitoba, Ontario, Nova Scotia, PEI and Newfoundland & Labrador, with Quebec currently exploring adaption of Speak Up resources for their context. 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 family and health care providers throughout the trajectory of illness or aging.

Proposed Activities

CHPCA proposes coordination of an 'Advance Care Planning in Canada' campaign, to raise public and health care professional awareness of the importance of ACP. The targets would be twofold:

- 1) The general public and caregivers, and
- 2) Those working in health systems and the community who support aging and/or chronically ill Canadians and their families.

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.

The "Speak Up" and National ACP Day (April 16) campaigns are growing, but the initiative would benefit from a broader, centralized awareness campaign to reach the intended audiences. Co-branding with the Government of Canada to emphasize the leadership undertaken on behalf of all Canadians would give the campaign the gravity needed to reach more Canadians. Using existing,

well-tested materials, we can ensure national consistency and facilitate partnership adoption and local or regional adaptation.

Funding would also support the continued development of national awareness tools. These tools would be developed in consultation with health professionals and Canadians, including with and for Canada's Indigenous and marginalized or at-risk communities. 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 by jurisdiction. The funding would also support development of electronic resources that can be easily used by all stakeholders including videos, mobile apps, and interactive online resources and training modules. A national repository of all resources will be available to both professionals and the general public on 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 vulnerable time. Further 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 costly and unnecessary hospitalizations and emergency room visits and other avoidable crises that occur when families are faced with difficult decisions at the end of life.

Collaborators and Partners

- Canadian Hospice Palliative Care Association (proposed recipient)
- ACP in Canada Task Group
- Quality End-of-Life Care Coalition of Canada (39 members)

Budget

Target 1:

\$4-6 million over 3 years. The cost depends on the reach of the Canada-wide campaign. This should be targeted at times of health transition or when patients are given a life-threatening diagnosis.

Target 2:

\$3 million over 3 years. The cost of targeting physicians, nurses, allied health care professionals, and different settings of care (acute care hospitals, long-term care homes, home care services, hospices prisons and shelters).

Proposal 2: Compassionate Care Benefit (CCB)

Over 260,000 Canadians die each year which can include being supported by as many as five caregivers in the last year or two of life. Supporting these unpaid caregivers is important for the patient, their family, friends, and community - and for Canada in general. The Federal government has already expressed support for this community of caregivers through the expansion of the Compassionate Care Benefit (CCB), but further regulatory changes are needed.

Proposed Activities

CHPCA is proposing a no-cost change to the Compassionate Care Benefit (CCB) to allow the final two (2) weeks to be taken past the death of the loved one. This would help caregivers better transition following the death of a loved one with a terminal illness, to better re-adjust to the workplace upon their return to full-time employment. It would also have positive mental health implications while dealing with bereavement issues for many working Canadians. Given the Federal Government's emphasis on both productivity and the mental health of Canadians, this policy change makes sense on both social and economic levels.

Project Goal

As of 2016, 16% of Canadians said that they had cared for a family member or close friend with a serious health problem in the last 12 months. As well, adverse effects on the well-being of caregivers include: using personal savings to survive (40%) and missing one or more month of work (22%). These serious economic impacts on almost a fifth of Canada's population mean Canada's productivity and competitiveness are being negatively impacted for Canada's caregivers who are still actively working.

Collaborators and Partners

The Federal Government (Employment and Social Development Canada)

Budget

\$0. As a regulatory change, no additional investment would be needed.

Proposal 3: Canadian Compassionate Companies (CCC) Program

In supporting Canada's unpaid caregivers, employers also have an important role to play. Companies need to recognize that employees may occasionally require more time off from work than is strictly accommodated by their regular leave policies in order to provide care or support to specified family members who are gravely ill and terminally ill with a significant certainty of death within twenty-six (26) weeks.

The average number of hours per week that Canadians expect needs to be provided to ensure proper care for a dying family member is 54.4.. An Ontario study determined that a majority of palliative care clients were cared for primarily by a spouse or their children/children-in-law.

As such, CHPCA introduced the Canadian Compassionate Company designation in 2016 to encourage Canada's employers to better respond to the needs of their employees who are also unpaid caregivers for ill loved ones.

Proposed Activity

In order to scale up the Canadian Compassionate Company (CCC) program and encourage employers to change their policy and encourage culture change among corporate Canada, CHPCA is looking for investment to better promote the program beyond our current

Project Goal

CHPCA would like to see a culture shift at the corporate level across Canada. Better-supported employees means greater economic productivity and sustainability for all Canadians, and an overall improvement to the mental health of Canada's working population.

Collaborators and Partners

Public Works and Government Services Canada (PWGSC) – Advertising
Industry Canada

Current CCC-designated companies:

- GSK
- Pfizer Canada
- Fidelity Investments
- Human Resources Professionals Association (HRPA)

Budget

\$400,000 for program development and dissemination

Furthermore, our organization, CHPCA supports the submission of the Health Charities Coalition of Canada, of which we are a member. We support their recommendations for greater access to medicines for all Canadians and for the investment in research that will provide jobs and stimulate the economy, setting the stage for improved prosperity and innovation in the future.

Definitions:

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 and with the person's health-care providers and perhaps with lawyers who prepare wills and powers of attorney.

Caregiver is an individual who provides ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions.

Integrated palliative approach to care or community-integrated palliative care is Care that focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management. As the person's illness progresses, it includes regular opportunities to review the person's goals and plan of care and referrals, if required, to expert palliative care services.

Hospice palliative care (HPC) aims to relieve suffering and improve the quality of living and dying. It strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fear. It helps prepare for and manage self-determined life closure and the dying process. It helps patients and families cope with loss and grief during the illness and bereavement. HPC is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care. HPC may complement and enhance disease-modifying therapy or it may become the total focus of care. HPC is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice.

About the Canadian Hospice Palliative Care Association

The Canadian Hospice Palliative Care Association (CHPCA) is the national voice for hospice palliative care in Canada. It is a bilingual, national charitable non-profit association whose mission is the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.