

Back on Track:

Education, data and community care options for improved hospice palliative care in Canada.

Written Submission to the House of Commons Standing Committee on Finance (FINA) for Pre-Budget Consultations in Advance of the 2019 Budget

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List of Recommendations

Recommendation 1: That the government include health care provider knowledge enhancement, establish core competencies, and ensure standard data collection around hospice palliative care as a part of the implementation of the Framework on Palliative Care in Canada Act.

Recommendation 2: That the Federal government fund an implementation phase of *The Way Forward* National Framework to ensure provinces, territories, communities and hospice palliative care programs are supported in the adoption of TWF palliative care recommendations, thereby improving cost-effectiveness across health care systems, and ensuring provincial gaps in standard and levels of care are narrowed and eventually closed across Canada. The Federal government-commissioned The Way Forward initiative in 2012 clearly articulated why hospice palliative care is not simply a health issue: "It is a complex social and economic issue that will affect individuals, families, communities and the workplace. Hospice palliative care programs allow patients to gain more control over their lives, manage pain and symptoms more effectively, and provide support to families and caregivers." ⁱ Research has shown that this whole person care, which extends to families and caregivers during the illness and after the death of their loved one has lead to vastly improved experiences. This applies to both the end of life experiences for both patients and families, and is often less expensive than the all too common experience of costly, unplanned emergency room visits. The Canadians in these scenarios are supported by up to 5 caregivers - often still members of Canada's workforce - and supported by provincial and local health care systems which are already stretched to fiscal capacity. All of these factors have an untold impact on Canada's economy and certainly on the social fabric of the country and caregivers and systems strain to keep up. Despite the clear social, economic and health care system advantages, our current health care is still very much based on a cure model with the almost solitary goal of cure; "guestions of guality of life at the end of one's life are often secondary."ⁱⁱⁱ And yet you can't cure death.

Improving access to hospice palliative care through community integration is a goal that has been identified by leading organizations across Canada - the Quality End-of-Life Care Coalition of Canada (QELCCC), Pallium Canada, the Canadian Hospice Palliative Care Association (CHPCA). It has also received attention at the parliamentary level with several Senate reports about the issue, and most recently in the all-party support of a private member's bill adopted by both houses of Parliament, the <u>Framework on Palliative Care in Canada Act.</u>ⁱⁱⁱ

While the impacts of good hospice palliative care from coast to coast to coast would be nationally economically and socially significant, healthcare remains firmly within the provinces' jurisdiction; what role can and should the Federal government play in furthering this important file before the economic impacts of the "silver tsunami" are felt on our health care services? In pursuit of a strong and competitive Canada, the following two initiatives are very much within the federal government's jurisdiction, and the actions suggested below could be undertaken with national partners (including national bodies, provinces, communities and existing organizations):

- As a part of the development of the implementation of the Framework on Palliative Care in Canada Act, more comprehensive palliative knowledge through better training for medical and allied healthcare providers and volunteers is needed. Additionally, working with professional medical, nursing and allied health professional colleges and associations to establish interdisciplinary palliative care core competencies could improve consistency of training. Finally, stronger data collection and analysis can be achieved at the national level by continuing to fund CIHI so fact-based policy decisions can be made at the national level.
- 2. In the short term, the Federal government can create the conditions for national implementation of a palliative approach to care through funding of the second phase of *The Way Forward* initiative, thereby improving cost-effectiveness across health care systems, and ensuring provincial gaps in standards and levels of care are closed.

Recommendation 1: That the government implement supports to enhance health care provider knowledge, through the establishment of core competencies in palliative care, in relation to supporting a palliative approach to end of life care across all settings, and continue to fund data collection for better fact-based policy development.

The How and Why of Palliative Core Competencies:

The establishment of national benchmarks for palliative care education for all health care providers at all stages of their professional education will go a long way in ensuring appropriate hospice palliative care options are offered to Canadians and their caregivers. The alternative will continue to be defaulting to costly, invasive, and futile options based on a cure model often delivered in an acute care hospital setting. Establishing or setting palliative care competencies for all health care providers and setting a consistent minimum standard across professions will mean that good and cost-effective hospice palliative care at end of life can be offered by appropriate and effective interdisciplinary teams where Canadians live - in their homes, in long term care facilities, on reserves, in hospices, in prisons and shelters - <u>at a fraction of the current cost</u>. ^{iv}

All health care providers including some allied health care providers such as nurses, personal support workers (PSW), social workers, physiotherapists, pharmacists and others are trained in the basic principles and practices of palliative care; Additional skills training is provided and required for those who frequently care for people with advanced conditions, including children or spouses. Help to expand the expert training required by palliative care specialists and educators for a more comprehensive understanding of end-of-life care would be beneficial.

CHPCA has been involved in the development of several sets of palliative core competencies with partner organizations over the last decade. CHPCA and the Association of Canadian Medical Colleges (ACMC) partnered in the development of EFFPEC; SCOPE was develoed by CHPCA with the Canadian Association of Social Workers; and the CHPCA Nurses Interest Group were involved in the development of nursing palliative competencies with the Canadian Association of Schools of Nursing (CASN). The Government of Canada would work in collaboration with theses professional, educational and regulatory groups who have already laid much of the groundwork including others such as CSPCP, CHPCA and Pallium Canada. These processes could easily be expanded and applied to other professional bodies with a minimal investment on the part of the Federal government. Working with these organizations, and with medical school faculties to encourage an improvement in Palliative care education for medical and allied health professionals, volunteers and Canadians would go a long way in improving palliative care knowledge in Canada.

The How and Why of fact-based policy-making:

Economically and socially sound policy must be based on reliable and up-to-date data. Such data about end-of-life care for Canadians at the national level has been largely lacking. Following adoption of the <u>Medical Assistance in Dying</u>^V legislation in 2017, the Canadian Institute for Health Information (CIHI) expressed an interest in improving its end-of-life care data - both about MAiD, and palliative care. In order to do so, CIHI must be able to count on stable

funding from the Government of Canada, now and going forward, in order to provide the best possible data to policy makers and legislators. This will have a direct impact in ensuring strong and economically sustainable health care systems across all of Canada's provinces, territories, for all Canadians, including vulnerable communities and for Canada's Indigenous peoples.

Recommendation 2: That the Federal government fund an implementation phase of *The Way Forward* National Framework to ensure provinces are supported in the implementation of its palliative care recommendations.

The How and Why of an implementation phase of *The Way Forward* National Framework: From 2012-2015, under the guidance of the QELCCC, and managed by CHPCA, *The Way Forward* National Framework was developed with input from health care providers, policymakers, organizations, and families and caregivers across all sectors – including federal, provincial and territorial governments, home care, primary/acute care, long term care and organizations representing Canada's Indigenous peoples. This roadmap about how to implement a palliative approach to care has been used by several provinces and national organizations, but adoption - and therefore effectiveness - remains uneven between provinces, territories, communities and health networks.

After undertaking a Health Canada-funded a survey of provinces' and territories' progress in the implementation of recommendations from *The Way Forward* National Framework, CHPCA determined that a second, shorter phase of *The Way Forward* focused solely on implementation, backed by the initial research would greatly enhance the provinces' and territories' ability to implement a palliative approach to end-of-life care. Currently, the provinces have vastly differing approaches leading to major gaps in care delivery based on geography, population density, and availability of resources, contrary to the principles of the Health Act.

Palliative care is most effective when administered in the setting of choice for patients: In hospitals, on reserve, in long-term care facilities, in homes, in residential hospices, in shelters or prisons: Wherever Canadians live, there should be reasonable access to quality hospice palliative care services. However, in many cases, the resources required to fully support those in their last months, weeks or days are minimal - and our cure model system continues to default to the most expensive treatments available. Basic investments by the provinces in community-based services to allow Canadians who wish to die at home, or in other locations outside of hospitals and other facilities, improved end-of-life experiences for hundreds of thousands of Canadians in the first decade of implementation, but would alleviate significant pressure on provincial acute care resources, so they are directed where truly needed, with cost savings to these systems which can be better invested in other, more pressing areas of health systems in each province.

While finite resources are available to fund countless health initiatives by governments, adoption of *The Way Forward* National Framework's recommendations would go a long way in rapidly fulfilling the Government's obligation to implement the Framework on Palliative Care in Canada Act, within the allotted time period following passage of the bill. Furthermore, it would help to

mitigate the coming crisis to our provincial health system as pressure from an large aging demographic will inevitably impact all Canadians, regardless of age, gender, socioeconomic status or cultural background.

Documents Referenced:

i - The Way Forward Initiative, 2012-2015, http://hpcintegration.ca

ii - The Way Forward Initiative, 2012-2015, http://hpcintegration.ca

iii - Framework on Palliative Care in Canada Act , <u>http://www.parl.ca/DocumentViewer/en/42-1/bill/C-277/royal-assent</u>

iv - The Way Forward, Economic Review (one-pager),

http://hpcintegration.ca/resources/discussion-papers/economic-review.aspx

v - An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) <u>http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent</u>