The Time for Action is Now: Bill C-277

Brief to the Senate Social Affairs, Science and Technology (SOCl) Committee by
the Canadian Hospice Palliative Care Association

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Introduction
The Canadian Hospice Palliative Care Association (CHPCA) is the national association that provides leadership in hospice palliative care in Canada in the pursuit of excellence in care of persons approaching death so that the burdens of suffering, loneliness and grief are lessened. Hospice palliative care is aimed at the relief of suffering and improving the quality of life for persons who are living with or dying from an advanced illness or are bereaved.

We are truly encouraged by the attention paid over the last year to the pressing issue of palliative care by both the upper and lower houses of parliament, and pleased that there is a desire to develop and implement a strategy designed to guarantee all Canadians access to high-quality palliative care. The provision of specialist hospice palliative care in acute care hospitals and residential hospices and the palliative approach to care provided in the community including home care, long term care and other settings has not received the attention, funding and support that it needs in light of Canada's aging population: We often hear baby boomers referred to as the "silver tsunami" - but nowhere will that be more apparent, than when dealing with Canadians at the end of their lives. Like the term "tsunami", the consequences for a lack of action will be severe.

Now, if I may, I would like to highlight some existing information and resources which will help with the development and implementation of a palliative care strategy, some of which is noted in the bill's current iteration, and some suggestions for minor adjustments. To be clear, we are not starting from scratch.

Quality End-of-Life Care Coalition of Canada (QELCCC)
As the secretariat for the 39 member Quality End-of-Life Care Coalition of Canada or QELCCC [Kew-ee-ELLE-Triple-SEE], CHPCA regularly facilitates an exchange of end-of-life care information among members. These include national medical professional associations, disease-specific groups, home care and faith-based organizations. A full list of members is available at the end of the brief. The QELCCC's guiding document Blueprint for Action 2010-2020 identified four priority areas of focus:

- Ensuring all Canadians have access to high quality hospice palliative and end-of-life care;
- Providing more support for family caregivers including bereavement support through the federal compassionate care benefit and other opportunities;
- Improving the quality and consistency of hospice palliative end-of-life care in Canada including research, training and education; and
- Encouraging Canadians to discuss their wishes for their care in the future including at end-of-life, often referred to as advance care planning (ACP).

The Way Forward Initiative
Between 2012-2015, the Government of Canada provided funding for a three-year initiative called The Way Forward: An Integrated Palliative Approach to Care that culminated in the development of a National Framework and the dissemination of practical resources and tools to help governments,
policymakers, regional planners, health service organizations and health care providers adopt a palliative approach to care. This is particularly applicable to providing palliative care in rural and remote settings, and across cultural communities, including first nations, and for marginalized or at risk populations. The Way Forward was intended to be a catalyst for action by raising the awareness and understanding of a palliative approach to care. To be clear, a palliative approach to care refers to end-of-life care not provided in an acute care setting, or known as specialist care palliative care. This is an important distinction because while only around 35% of Canadians require this specialist palliative care, the vast majority of Canadians – 65% or so, do not require it, and to offer it would be a terrible waste of resources in a health care system already stretched too thin. The palliative approach to care, however, integrates care into whichever setting of care a patient is in including through home care, on reserves, in long term care, in prisons or shelters and can be administered by an interdisciplinary care team including a family physician or nurse practitioner.

The Way Forward initiative also defined the terms hospice palliative care, a palliative approach to care and advance care planning. I refer you to The Way Forward Lexicon for further useful definitions (provided at the end of this brief) as you continue your study of Bill C-277, keeping in mind that good definitions of terms already exist for palliative care administered in a variety of settings, and this does not need to be integrated into the text of the bill.

More recently, CHPCA undertook an environmental scan of all provinces and territories as well as the QELCCC members to determine where they stood in the implementation of a palliative approach to care. Given that health is a provincial and territorial responsibility it is absolutely imperative to understand where their priorities lie to best determine how to proceed federally.

In summary, the two surveys offered the following insights:

- While public awareness is one driver of adoption of a palliative approach, there is more to do to enhance the understanding of a palliative approach to care and advance care planning with the public and health care providers.
- National education curriculum, and ongoing continuing professional development through enhanced skills and training are needed for all health care providers across all settings of care to improve competence and confidence to deliver a palliative approach to care.
- Conversations about a palliative approach need to be better integrated with usual medical care. This would help to make a palliative approach part of ongoing treatment and not seen as a separate, specialized or referral-based program.
- Ongoing advocacy efforts for a palliative approach to care must continue, particularly in light of the legal availability of Medical Assistance in Dying (MAiD), which has created a need to clarify what hospice palliative care is about, where it is available, and what more needs to be done to ensure it is accessible to all Canadians, provided in the setting of their choice, and meeting their care needs.
- Current care pathways need to include a palliative approach, and tools and materials for health care systems and professionals must enable adoption.
- Finally, we must **ensure resources are available** and dedicated to hospice palliative care, and flexible to meet diverse population health needs, including for Canadians who are members of indigenous, cultural, or vulnerable groups, or in rural or remote settings of care.

The final report was submitted to Health Canada in early 2017.

**Community Partners**

Bill C-277 is a positive step reinforcing that and health care associations and organizations are all partners in this. Given how much palliative care is delivered in and by local communities, they should be named in any final iteration of the bill. CHPCA and its provincial palliative care associations would strongly support the inclusion of language in the final iteration of C-277 which recognizes the role that community must play in the successful development and implementation of a palliative care strategy.

Also of note: the majority of the funding for residential hospices - one setting of care where palliative care is delivered - is raised within the communities in which they are located through donations from the public. It is a good model, but requires a lot of work, and a lot of buy-in from those communities. Home care is another setting of care in which palliative care is delivered, and must be taken into consideration. We feel that the community needs to be an equal and valued partner in any strategy being developed alongside the federal, provincial and territorial governments and often refer to adoption of an “F-P-T-C” model.

Even corporate Canada has a role to play. The CHPCA’s Champion’s Council, made up of leaders from industry and commerce, launched a program called “Canadian Compassionate Companies” in November 2016 which recognizes companies and organizations that accommodate and support the caregiving at end-of-life roles of their employees by providing supports over and above what is available provincially and federally. At this point there are five national companies that can call themselves Canadian Compassionate Companies.

**Conclusion**

In summary, the studies and reports have all been done, the ample evidence clearly points to one course of action: **Support and funding for the agreed upon priorities to make hospice palliative care accessible to all Canadians. Bill C-277 will be a good first step toward making this a reality.** With the development of an administratively-lean, action-oriented national palliative care secretariat to implement an evidence-based plan, major progress can be made before we have an end-of-life crisis on our hands. CHPCA and partner organizations strongly support Bill C-277 and commend all parliamentarians who are throwing their support behind it. I’d also like to thank the Senate Social Affairs, Science and Technology committee for your work in reviewing this legislation.
Documents and Organizations Referenced

Canadian Hospice Palliative Care Association – [http://www.chpca.net](http://www.chpca.net)

Advance Care Planning in Canada - [http://www.advancecareplanning.ca/](http://www.advancecareplanning.ca/)


Lexicon of Terms - [http://hpcintegration.ca/resources/lexicon.aspx](http://hpcintegration.ca/resources/lexicon.aspx)


Full QELCCC Members

ALS Society of Canada
Alzheimer Society of Canada
Canadian AIDS Society
Canadian Association of the Deaf
Canadian Association of Occupational Therapists
Canadian Association for Spiritual Care
Canadian Association of Social Workers
Canadian Breast Cancer Network
Canadian Cancer Society
Canadian Cancer Action Network
The College of Family Physicians of Canada
Canadian Healthcare Association
Canadian Home Care Association
Canadian Hospice Palliative Care Association
Canadian Lung Association
Canadian Medical Association
Canadian Nurses Association
Canadian Pharmacists Association
Canadian Society of Palliative Care Physicians
Canadian Society of Respiratory Therapists
REALIZE (Canadian Working Group on HIV and Rehabilitation)
Catholic Health Alliance of Canada
Heart and Stroke Foundation of Canada
Huntington Society of Canada
Inuit Tapiriit Kanatami (ITK)
Kidney Foundation of Canada
Mental Health Commission of Canada
National Initiative for Care of the Elderly
Ovarian Cancer Canada
Saint Elizabeth Health Care
The Pallium Foundation
Women’s Inter-Church Council of Canada
Canadian Frailty Network
Royal College of Physicians and Surgeons of Canada
Canadian Partnership Against Cancer

**Associate QELCCC Members**
Canadian Arthritis Patients Alliance
Carers Canada
Canadian Network of Palliative Care for Children
Canadian Virtual Hospice
Definitions

**Hospice Palliative Care** aims to relieve suffering and improve the quality of living and dying. Hospice palliative care strives to help patients and families:

- Address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fear.
- Prepare for and manage self-determined life closure and the dying process.
- Cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- Treat all active issues.
- Prevent new issues from occurring.
- Promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care 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.

Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

Hospice palliative care 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. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.

Source: [http://www.chpca.net/about-us.aspx](http://www.chpca.net/about-us.aspx)

An **Integrated palliative approach to care** focuses on meeting a person’s and family’s full range of needs – physical, psychosocial and spiritual – at all stages of illness or stages of frailty, not just at the end of life.

**Advance care planning (ACP)** is the process of reflecting on values and wishes for future health and personal care and sharing these wishes with others. It includes deciding on a substitute decision maker.

Source: [http://hpcintegration.ca/resources/lexicon.aspx](http://hpcintegration.ca/resources/lexicon.aspx)