



Quality End-of-Life Care Coalition of Canada

2018 Annual Report

December 2018

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Background and History of the Quality End-of-Life Care Coalition of Canada

In December of 2000, a group of 24 national stakeholders met to set the groundwork for the development of a Canadian strategy for end-of-life care. The result of this meeting was the creation of the Quality End-of-Life Care Coalition of Canada (the Coalition) and a working document entitled *Blueprint for Action (2000)*.

Within the Coalition an Executive Committee and five Working Groups were established. The Coalition has been meeting on an annual basis since 2000. The goal of each annual meeting is to create a work plan for the coming year based on the current iteration of the *Blueprint for Action*. The membership of the Coalition remains strong and is currently made up of 36 member organizations.

Since its establishment in 2000, the Coalition has seen some remarkable successes. These successes include: a role in the establishment of the Secretariat on Palliative and End-of-Life Care in 2001; the production of *Hospice Palliative Home Care in Canada: A Progress Report and Dying for Care - Status Report*; participating in the development of the report, *Not to be Forgotten: Care of vulnerable Canadians*; production of the *Blueprint for Action: 2010-2020*; participating in the development of the *Advance Care Planning Framework* and the *Speak Up* campaign; spearheading *The Way Forward: An integrated palliative approach to care in Canada* Initiative; strongly supported Bill C-277 until its Royal Assent in December 2017 and assisted MP Charlie Angus with Motion M-456. The Coalition members have also attended countless parliamentary events, round table discussions, educational conferences, and research symposia, all in the interest of advancing end-of-life care in Canada.

In 2009/2010, the Coalition produced the document *Blueprint for Action 2010 – 2020*. To continue to improve care at the end of life for all Canadians the progress report outlines four priorities of the Coalition over the next 10 years:

- Ensure all Canadians have access to high quality hospice palliative end-of-life care.
- Provide more support for family caregivers.
- Improve the quality and consistency of hospice palliative end-of-life care in Canada. Canadians should expect to receive high quality care in all parts of the country.
- Encourage Canadians to discuss and plan for end of life. Hospice palliative end-of-life care will not be a priority in our health care system until it is a priority for Canadians.

Through this report and other endeavors, the Coalition aims to change the standard of end-of-life care in Canada. The full *Blueprint for Action: 2010 – 2020* can be found at www.qelccc.ca.

The Way Forward: An integrated palliative approach to care in Canada (TWF) led by the Coalition and managed by the Canadian Hospice Palliative Care Association (CHPCA), officially concluded in early 2015. The initiative developed a national framework to enhance better integration of hospice palliative care for individuals, families and caregivers, so that they can live well until the end of life. It is a road map to an integrated palliative approach that supports earlier, and more frequent conversations about the goals of care when patients and families are faced with a life-threatening illness. It includes: a tool kit of resources and best practices; offers suggestions for removing the barriers to integrated hospice palliative care; and encourages groups to build opportunities for their own communities. TWF helps Canadians with life-limiting illnesses understand the

importance of advance care planning, and informs them on the type of hospice palliative care services that are available to them.

The full TWF framework can be found at www.nationalframework.ca

Mission and Mandate of the Quality End-of-Life Care Coalition of Canada

The Coalition believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. The Coalition also believes that to achieve quality end-of-life care for all Canadians there must be a well-funded, sustainable national strategy for an integrated palliative approach to care. It is the mission of the Coalition to work together in partnership with other like-minded national organizations and institutions to achieve this goal.

Member Organizations (36)

Full Members (32)

| | |
|---|---|
| ALS Society of Canada | Canadian Society of Palliative Care Physicians |
| Alzheimer Society of Canada | Canadian Society of Respiratory Therapists |
| Canadian AIDS Society | Catholic Health Alliance of Canada |
| Canadian Association for Spiritual Care | College of Family Physicians of Canada |
| Canadian Association of Occupational Therapists | Health Care CAN |
| Canadian Association of Social Workers | Heart and Stroke Foundation of Canada |
| Canadian Association of the Deaf | Huntington Society of Canada |
| Canadian Breast Cancer Network | Inuit Tapiriit Kanatami |
| Canadian Cancer Society | Kidney Foundation of Canada |
| Canadian Frailty Network | Mental Health Commission of Canada |
| Canadian Home Care Association | National Initiative for the Care of the Elderly |
| Canadian Hospice Palliative Care Association | Ovarian Cancer Canada |
| Canadian Lung Association | Pallium Canada |
| Canadian Nurses Association | Realize |
| Canadian Partnership Against Cancer | Royal College of Physicians and Surgeons |
| Canadian Pharmacists Association | SE Health |

Associate Members (4)

| | |
|--------------------------------------|--|
| Canadian Arthritis Patients Alliance | Canadian Network of Palliative Care for Children |
| Carers Canada | Canadian Virtual Hospice |

Annual Meeting Report: Looking Back and Forging Ahead

Summary:

For more information about the QELCCC and to view the complete work plan, please visit www.qelccc.ca. For more information on the Secretariat please visit CHPCA's website at www.chpca.net.

Executive Committee Report

The Coalition has four active sub-committees, which are the Advocacy Committee, the Research and Knowledge Translation (KT), Education Committee and the Executive Committee. The chairs of the three main sub-committees, as well as a representative from the Coalition Secretariat (CHPCA), make up the members of the Executive (Committee).

The Executive Committee oversees the work of the Coalition when it is not in session. Toward this effort, the Executive Committee members met approximately every two to three months in 2018. The Executive Committee's main focus for this year was to manage the efficient and effective administration of the Coalition, as well as to seek opportunities and develop partnerships that actively promote access to quality hospice palliative and end-of-life care in Canada. Lastly, part of the role of the Executive Committee is to invite and review all requests to join the QELCCC and throughout 2018 the Executive Committee continued to seek out new members. The Executive Committee is also responsible for reviewing nominations and selecting the recipient of the QELCCC Award of Excellence in Advocacy that is presented at the annual face-to-face meeting.

Advocacy Committee Report

| Helena Sonea (Co-Chair) | Kelly Masotti (Co-Chair) |
|--------------------------------|---------------------------------|
| Amy Henderson | Jana Papke |
| Charles Thompson | Kim Taylor |
| Christina Vadeboncoeur | Lisa Benedet |
| Gavin Arthur | Sally Guy |
| Hazel Markwell | Vicki Lejambe |

OBJECTIVE: The advocacy committee will leverage opportunities to develop and execute advocacy strategies to ensure access to quality hospice palliative care in Canada, in every setting.

Goal 1: Provide Palliative 4 Canada with key messages re Bill C-277 on behalf of the QELCCC

2018 Activities to Date:

- The committee completed the "[Integrated Palliative Approach to Care in Home and Community Settings Key Messages](#)" document.
 - The key messages document received sign on from almost all committee members.
 - Committee members used the Key Messages document as part of their submissions for Health Canada's consultation for the new framework for Palliative Care in Canada.
 - The Key messages document was then used by the P4C on behalf of the QELCCC to present at the Health Canada Palliative Care in Canada Framework consultation meetings.
 - The committee and the P4C also created [Goals and Guiding Principles for the Canadian Palliative Care Implementation Collaborative](#) to be presented along with the Key Messages document.
 - The committee also hosted a Breakfast on the Hill to advocate for the importance of Palliative care in Canada, and presented the key messages document here along with the Guiding Principles document.

- Committee members included the need for funding for the new Framework for Palliative Care in Canada in their pre-budget submissions and were successful in having this need recognized in the FINA report.

Goal 2: Build public awareness and engagement using existing materials. Participate in and promote NHPC Week, National Bereavement Day, ACP Day, and Carers Day

2018 Activities to Date:

- Committee members participated in Carers Canada National Carer Day awareness campaign:
 - Reinforced the theme “Connecting Carers” through social media and broad dissemination of information tools
- Committee members also actively supported CHPCA’s National hospice Palliative Care Week, National Bereavement Day, and ACP “Speak Up” campaigns.

GOAL 3: Include/emphasize Carers in key messages (including the 2 weeks for CCB after death); caregiver day

2018 Activities to Date:

- The committee continues to advocate for Carers including mentioning them in the key messages document
- The committee is also continuing to work on getting the extension for 2 weeks after death to be added to the CCB.
 - The secretariat and committee members have had meetings to discuss the extension with various stakeholders.
 - The committee wrote a letter to Minister Duclos’ office re: amendment of two week bereavement period for the CCB. Minister Duclos is responsible for the special benefit oversight of the Employment Insurance system.

Education Committee Report

| Julie Wilding (Co-Chair) | Peter Barns (Co-Chair) |
|---------------------------------|-------------------------------|
| Carolyn McCoy | Judy Donovan-Whitty |
| Doug Momotiuk | Raquel Shaw-Moxam |
| Ed Mantler | Riley Malvern |
| Jeff Moat | Sharon Baxter (Secretariat) |
| Josette Roussel | |

OBJECTIVE: The education committee will promote hospice palliative care education across the learning continuum from undergraduate to post graduate, and continuous professional development. They will also raise public awareness of hospice palliative care as an early and positive intervention. They will provide a forum to disseminate best practices related to palliative care education across the learning continuum, and to identify solutions to challenges.

Goal 1: Raising awareness of Grief and Bereavement

2018 Activities to Date:

- The education committee actively promoted a variety of materials and resources prepared by the CHPCA for National Bereavement Day.
 - These included: a News Release, Poster, a Template Newsletter, an FAQ Document, and a Resources page.
 - The social media activity for Bereavement Day was highly elevated and a significant amount of the QELCCC membership actively participated in the online campaign.

Goal 2: Build Public education/awareness of palliative approach to care

2018 Activities to Date:

- The committee continued to determine coalition members' education needs, showcased and created a repository of member initiatives on the members' only website.
- The Committee continued work on a creating a means of promoting and integrating a palliative approach to care through awareness and education to coalition members of complementary non-medical integrated therapies.
 - This included: planning the creation and potential development of a document and other resources to educate members on specific complementary therapy modalities, including information on less traditional means of normalizing death i.e., Death Café, St Elizabeth Reflection Rooms and Compassionate Communities.

Goal 3: Core Competencies and Continuing Education

2018 Activities to Date:

- The committee continued to monitor the activities of provincial governments with regard to inter-professional competencies.
- The committee continued to encourage the provincial governments with regard to the establishment of working groups on inter-professional competencies

Research and Knowledge Translation Committee Report

Christopher Klinger (Chair)

Carol Barrie

Shelly Cory

Chad Hammond

Srini Chary

Kate Murzin

Sharon Baxter (Secretariat)

Noush Mirhosseini

OBJECTIVE: The research and KT committee will facilitate research and knowledge translation toward the QELCCC and its member organizations, and to engage in broader stakeholder consultations in the area.

Goal 1: Advocacy with the Environmental Scan on HPC Research Funding

2018 Activities to Date:

- The committee has had many great opportunities to have this poster displayed at conferences through the past year; a key messages document is also available.

- The poster will also be shown at the QELCCC face-to-face meeting, where member organizations will be reminded to think about funding hospice palliative care research. The poster was displayed at the following:
 - CHPCC 2017,
 - CHPCA Learning Institute 2018,
 - NICE Annual Knowledge Exchange 2018.

Goal 2: Increase awareness of research and KT activities and tools/resources related to hospice palliative care

2018 Activities to Date:

- Attended Pan-Canadian Palliative Care Research Collaborative meetings.
- Spoke to Dr. James Downar about potentially aligning the next Collaborative meeting with the CHPCC 2019.
- The Environmental Scan poster and key messages document are available for display at member organization conferences alongside further QELCCC posters such as the *Blueprint for Action*.

Goal 3: Influence research bodies

2018 Activities to Date:

- A letter to Dr. Yves Joannette - Director of the CIHR Institute on Aging - was sent in June, with a follow up call that took place in October, reminding him of a prospective funding package toward bereavement care and lobbying for the reestablishment of the palliative care review panel within CIHR.
- A virtual meeting with all Institute Directors regarding hospice palliative care issues is now scheduled for February 28.

Goal 4: Analyze Research Gaps

2018 Activities to Date:

- A scoping review toward research gaps is well under way with the support of a UofT student, with approximately 25 articles to be included in the analysis, including the old report by CHPCA in 1999. The goal is to have the document ready for spring/presentation at CHPCC 2019.

Goal 5: Communication across all QELCCC Committees and information-sharing

2018 Activities to Date:

- Committee information shared at Executive Committee meetings;
- Further joint advocacy opportunities to be explored, especially with regard to seed/proof of concept research funding.