



# Quality End-of-Life Care Coalition of Canada

2019 Annual Report

January 2020

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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 35 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*; participation 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*; strong support of Bill C-277 until its Royal Assent in December 2017 and assisting 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](http://www.qelccc.ca). The latest *Blueprint for Action (2020-2025)* will be available on the QELCCC website in January 2020.

*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](http://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 (35)

### Full Members (32)

ALS Society of Canada	Canadian Pharmacists Association
Alzheimer Society of Canada	Canadian Society of Palliative Care Physicians
Canadian AIDS Society	Canadian Society of Respiratory Therapists
Canadian Association for Spiritual Care	Catholic Health Alliance of Canada
Canadian Association of Occupational Therapists	College of Family Physicians of Canada
Canadian Association of Psychosocial Oncology	HealthCare 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	Kidney Foundation of Canada
Canadian Cancer Society	Mental Health Commission of Canada
Canadian Frailty Network	National Initiative for the Care of the Elderly
Canadian Home Care Association	Ovarian Cancer Canada
Canadian Hospice Palliative Care Association	Pallium Canada
Canadian Lung Association	Realize
Canadian Nurses Association	Royal College of Physicians and Surgeons
Canadian Partnership Against Cancer	SE Health

### Associate Members (3)

Canadian Virtual Hospice	Canadian Network of Palliative Care for Children
Carers Canada	

## 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](http://www.qelccc.ca). For more information on the Secretariat, please visit CHPCA's website at [www.chpca.net](http://www.chpca.net). Please note a new CHPCA website will be launched in January 2020; updated links will be provided.

## 2019 Activities and Committee Reports

### Executive Committee Report

The Coalition has four active sub-committees, which are the Advocacy Committee, the Research and Knowledge Translation (KT), the 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 2019. 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 2019 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.

- 1. Election 2019 Advocacy - Amendment to the Employment Insurance Compassionate Care Benefit (CCB)**
  - The Committee developed key messages for the Coalition to assist with meeting elected officials and bureaucrats around the 2019 federal election. The Committee met with key representatives of each major political parties to discuss the two priorities of the Coalition.
  - The Committee focused on amending the Compassionate Care Benefit (CCB) as part of its federal advocacy for the federal 2019 election.

The Advocacy Committee created two main documents that were used by members of the Coalition, those documents were:

- [Integrated Palliative Approach to Care in Home and Community Settings](#)
- [Key Messages](#) – a comprehensive document on the integrated palliative



- The Coalition put out a press release on the website and social media thanking the Conservative Party for its commitment to the Palliative Care Implementation Collaborative.
- Election kit key messaging was updated to align with the Coalition priorities and sent to all federal MPs and Senators.
- The Committee sent out welcoming letters to the new government and official opposition parties.

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

- The Committee members participated in National Hospice Palliative Care Week (NHPCW), Bereavement Day, Carers Day, Advance Care Planning Day (ACP Day) and many of the other public awareness campaigns throughout the year (2019).

**3. Implementation of the National Palliative Care Framework**

- In response to the Health Canada Action Plan, the Coalition set up a sub-committee to analyse the action plan and tie in the Blueprint for Action. A letter was sent to Health Canada based on the sub-committee analysis to seek opportunities around collaboration.
- The Blueprint for Action is complete and set to roll out in January 2020.

**4. The Advocacy Committee and the Research and Knowledge Translation Committee combine their efforts toward seed funding for palliative care research**

- The Advocacy Committee seeks to combine efforts with the Research and Knowledge Translation Committee to put in place outreach strategies about HPC research.
- Sharon Baxter and Chris Klinger co-chaired a CIHR sponsored WebX around the importance of palliative care as a cross cutting issue across multiple institutes (please refer to the Research and Knowledge Translation Committee report for more details).
- The Coalition invited member organizations, especially research-focused organizations, to include research in their budgets in hope to secure seed/proof of concept funding for HPC research.

**5. Others:**

approach to care in both home and community settings.

- Goals and Guiding Principles for the Canadian Palliative Care Implementation Collaborative
- Many of the members used these documents in their responses to the government consultation on the national Palliative Care Framework.



Pre-budget 2020 submission



The Coalition seeks to empower member organizations by supplying them with key messages/a template to include in their own pre-budget submissions.

- National Association of Pharmacy Regulatory Authorities (NAPRA) Update
  - New standards have been put out by NAPRA; the length of time for pre-filled syringes to be used has been shortened which might impact palliative care in home environments.
  - CSPCP and CHPCA submitted a letter in February 2019 to NAPRA questioning the change that has been made.
- CHPC Conference opening plenary “Policy/Advocacy: Where We Are and Mobilizing Around the National Framework” was conducted by Christina Lawand, Manager, Stakeholder Communications at Canadian Institute for Health Information, Helena Sonea, Senior Manager Public Issues, Canadian Cancer Society, Chair of the QELCCC Advocacy Committee and Sharon Baxter, CHPCA Executive Director, Secretariat of the QELCCC and advocacy specialist. For more details please refer to the Conference program at: <https://conference.chpca.net/plenaries/>.
- MP Matt Jeneroux Private Members’ Bill aims to amend the Canada Labour Code to allow employees using the Compassionate Care Leave to extend their leave beyond the death of their loved one. This will be introduced in spring 2020.

## Education Committee Report

<b>Julie Wilding (Co-Chair)</b>	<b>Peter Barns (Co-Chair)</b>
Carolyn McCoy	Judy Donovan-Whitty
Doug Momotiuk	Raquel Shaw-Moxam
Ellen Paulley	Riley Malvern
Jeff Moat	Diana Rasmussen
Josette Roussel	Sharon Baxter (Secretariat)
Vicki Lejambe	

**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.

### 1. Raising awareness of Grief and Bereavement

- 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, template press release, an FAQ document, and a resources page.
  - The Committee also introduced new resources e.g. Alzheimer’s caregiving and grief resources, mental health impact on grief and bereavement (Initiative to include complicated grief).
- The social media activity for Bereavement Day highly elevated the campaign. Bereavement initiative is being developed with CMHA.

### 2. Build public education/awareness of palliative approach to care

- The Committee continued to promote a palliative approach/QELCCC at member conferences and events.
- The Committee is in the process of developing a handout for coalition members to more readily access resources for conferences.
- The Committee continued to determine Coalition members' education needs and created a repository of member initiatives on the members' only website.
- The Committee continued to identify and profile organizational initiatives, share resources and work on education for vulnerable populations. Designated contacts within member organizations are to be identified for dissemination of resources.
- The Committee explored the use of art and film as creative modalities to engage in discussions about death by collaborating with the Director of a movie (Exit Music) to use the movie for teaching purposes/panel discussion.
- The Committee has been discussing the need and the development of an on-line Pallium LEAP module (co-developed by CASC and CAOT) on Psychosocial and Spiritual Care with a focus on enhanced skills for spiritual care for generalist health care providers.
- The Committee continued to work on creating a means of promoting and integrating a palliative approach to care through awareness and education of complementary non-medical integrated therapies (Taster sessions at face to face meeting and workshop at CHPCA conference).
- The Committee planned the creation and development of a document and resources to educate members on specific complementary therapy modalities, providing information on less traditional means of normalizing death, i.e., Death Café, SE Health Reflection Rooms and Compassionate Communities.

### 3. Core Competencies and Continuing Education

- Promoting inclusion of core competencies in the professional curriculum.
- The Committee continued to monitor the activities of the provincial governments with regard to inter-professional competencies.
- The Committee continued to encourage the provincial governments to establish working groups on inter-professional competencies.
- The Committee continued to incorporate core competencies into continuing education post licensure. OT practice network.
- Development of blueprint for teaching/service delivery.
- A sub-committee was created to identify inter-professional and discipline specific core competencies by province.

## Research and Knowledge Translation (KT) Committee Report

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### Christopher Klinger (Chair)

Carol Barrie

Lisa Benedet

**Elizabeth Racz**

Christina Vadeboncoeur

Chad Hammond

Darian Taylor

Kate Murzin

Karla Thorpe

Noush Mirhosseini

Sharon Baxter (Secretariat)

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

### **1. Advocacy with the Environmental Scan on HPC Research Funding**

The environmental scan on hospice palliative care funding is complete and has been rolled out in a poster and a one-page key messages document format.

- The Committee has had many great opportunities to have this poster displayed at conferences through the past year, e.g., the CHPCA Conference, the Pan-Canadian Palliative Care Research Collaborative, the CAOT Conference, and the Canadian Mental Health Conference.
- There is a decline of hospice palliative care research funding across the board, and the Committee has noticed it's been hard to get funding from organizations like CIHR, and the Social Sciences and Humanities Research Council. This is very important for the Coalition to notice, because we cannot move forward with some of our initiatives without funding from groups like these. There is a particular shortage of seed/proof of concept funding that is also not tied to matching funds.



The environmental scan is one of the Committee's advocacy messages, developed over the past two years and it shows that funding for hospice palliative care research is declining in Canada.

### **2. Increase awareness of research and KT activities and tools/resources related to hospice palliative care**

- Combined efforts with Advocacy Committee with regard to seed/proof of concept funding for HPC research in Canada.
- Minimum Data Set (MDS) for Children: Chris has reached out to Kim Widger at the University of Toronto to discuss opportunities with regard to a MDS for children.
- The Committee is in contact with the Pan-Canadian Palliative Care Research Collaborative (PCPCRC). Chris and Sharon have had the opportunity to attend three of their meetings so far, to see what is going on in palliative care research, and also to strengthen the bond between researchers in the field and those connected to knowledge translation. The PCPCRC Fall meeting occurred as a Pre-Conference to the 2019 Canadian Hospice Palliative Care Conference.

### **3. Influence research bodies**

- A virtual meeting with the CIHR Institute
  - Directors on 28th of February 2019, highlighted hospice palliative care research and the need for the re-establishment for the review panel on hospice palliative care.

- A follow up with the new Director for the Institute on Aging has been arranged as well as a meeting with Dr. Rick Glazier, who is the new Director of the Institute for Health Services and Policy Research.
  - There is now a round table between CIHR and the Social Sciences and Humanities Research Council, and the Committee hopes to get in touch with them in the future to stress overarching issues.
  - QELCCC membership organizations with a research portfolio are strongly encouraged to revisit/revise their commitment to hospice palliative care research.

#### **4. Analyze research gaps (scoping review of the literature)**

- A scoping review on research gaps was conducted with the support of a UofT student. Approximately 25 articles were included in the analysis, including an old report by CHPCA from 1999. The analysis of research gaps has now been submitted to the Journal of Palliative Care. The completion of the work is a great step as it aligns well with the Health Canada Palliative Care Framework. Efforts will be made to roll out research results to a broad audience in the coming year.

#### **5. Scoping review of the literature on (informal) caregiving in HPC in Canada**

- The caregiver scoping reviews are well under way, the first is on caregiving issues itself; and the second is on potential interventions for caregivers (to be completed in summer 2020).

#### **6. Communication across all QELCCC Committees and information sharing**

- The Committee discussed ways to communicate more with other Committees, as there are a lot of overarching issues. The inclusion of Committee reports to the agenda of all Committee meetings is seen as a first step to keep everyone in the loop, with the QELCCC 6-Months Review online meeting (first conducted in 2019) as a second one.

All Committees' minutes are also available online for ready reference.

- The Committee also focused on sharing findings, data and advocacy work currently being done with members of the Coalition. This will help encourage all organizations to promote the message of hospice palliative care more actively, and provide more interconnectivity.
- A poster about the QELCCC was again displayed at the Annual NICE Knowledge Exchange and QELCCC member organizations are encouraged to display QELCCC materials at their respective conferences.

#### **7. Others:**

- Canadian Hospice Palliative Care Conference September 2019
  - The Committee spearheaded the Poster Awards at the Canadian Hospice Palliative Care Conference. Three Awards were given this year: Best Poster and Best Trainee Poster (plus a Runner-Up Award).
  - The QELCCC was highlighted at the booth and in two posters (Blueprint Process and Environmental Scan).
  - A plenary session on advocacy was presented at the CHPCC by CIHI, Helena, and Sharon.
  - For more information please visit <https://conference.chpca.net>.