



Quality End-of-Life Care Coalition of Canada

DRAFT – 2019 Semi-Annual Report

June 2019

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

Beginning 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. This led to the creation of the Quality End-of-Life Care Coalition of Canada ('the Coalition'). Since then, the Quality End-of-Life Care Coalition of Canada (QELCCC) has grown to a group of over 34 national organizations dedicated to advocating that "all Canadians have the right to die with dignity, free of pain, in a setting of their choice and surrounded by their loved ones" (QELCCC, *The Way Forward Project*, 2015). The Coalition believes that to achieve quality end-of-life care for all Canadians, there must be a well-funded, sustainable national strategy for hospice palliative care.

During the last 19 years, the QELCCC has observed some remarkable successes. These successes include:

- 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*.
- Spearheading *The Way Forward: An integrated palliative approach to care in Canada* Initiative; and assisting MP Charlie Angus with Motion M-456.
- Canadian Institutes of Health Research (CIHR) *Palliative and End-of-Life Care Initiative* (2009): This targeted research investment started building clinical research capacity and partnerships with stakeholders and the community, including decision-makers and patients.
- Canadian Partnership Against Cancer (CPAC) *Advance Care Planning Initiative* (2013): This initiative raised the awareness of Canadians about the importance of Advance Care Planning (ACP) and equipped them with the tools they need to effectively engage in the process through the *Speak Up!* Campaign.
- In response to the continuing increase of the senior population and caregivers receiving the Compassionate Care Benefits (CCB), the Coalition sent a letter to the Minister of Employment and Social Development of Canada (ESDC) inquiring about how and when the update to CCB will be applied by the government. The Coalition asserted that the implementation of the benefit must be done in a way that will fully inform Canadian citizens of their rights. The Liberal government announced the extension of the CCB to 26 weeks effective January 2016. A social media initiative was completed in January 2016 that resulted in increased awareness amongst Canadians.
- Quality End-of-Life Care Coalition of Canada (QELCCC) *The Way Forward Project* (2016): This roadmap for an integrated palliative approach to care highlighted community effort and information on the current hospice palliative care landscape in Canada. A number of discussion papers were developed for this initiative, including a thorough description of the palliative approach to care, a review of health economics, considerations for caregivers, and best practice models from within Canada and internationally.

- Health Canada’s tabled *Framework on Palliative Care in Canada* (2018) which serves as a blueprint to help shape planning, decision making and organization change related to hospice palliative care in Canada. This framework recognized the Coalition as an ‘expert’ in the field of hospice palliative care due to the work it had accomplished, and lists the QELCCC in the resource section.
- The Coalition members have also attended countless parliamentary events, in-person parliamentary meetings, round table discussions, educational conferences, and research symposia, all in the interest of advancing end-of-life care in Canada.

Through these endeavors, the Coalition aims to change the standard of end-of-life care in Canada.

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 (34)

Full Members (31)

ALS Society of Canada	Canadian Society of Respiratory Therapists
Alzheimer Society of Canada	Catholic Health Alliance of Canada
Canadian AIDS Society	College of Family Physicians of Canada
Canadian Association for Spiritual Care	Health Care CAN
Canadian Association of Occupational Therapists	Heart and Stroke Foundation of Canada
Canadian Association of Social Workers	Huntington Society of Canada
Canadian Association of the Deaf	Canadian Association of Psychosocial Oncology
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 Lung Association	Pallium Canada
Canadian Nurses Association	Realize
Canadian Partnership Against Cancer	Royal College of Physicians and Surgeons of Canada
Canadian Pharmacists Association	SE Health
Canadian Society of Palliative Care Physicians	

Associate Members (3)

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

Annual Meeting Report: Looking Back and Forging Ahead

Member representatives from 34 different organizations with an interest in end-of-life care as well as representative from Health Canada and the Canadian Institute for Health Information (CIHI) met at a highly productive annual meeting of the Quality End-of-Life Care Coalition of Canada (QELCCC) in Ottawa, on February 1st 2019. Members worked in both plenary sessions and individual committee groups (Advocacy, Education, and Research/Knowledge Translation) to fully review the valuable work done by the QELCCC in 2018 and set committee work plans for 2019 and the upcoming *Blueprint for Action 2020-2025*. For more information about the QELCCC and to view the complete work plans, please visit www.qelccc.ca. For more information on the Secretariat please visit CHPCA's website at www.chpca.net.

2019 Activities and Committee Reports

Advocacy Committee Report (*Helena Sonea*)

2018 activities included:

- To provide Palliative 4 Canada (P4C) with key messages re Bill C-277 on behalf of the QELCCC.
 - As a result of this goal 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 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.
 - The committee also coordinated a breakfast in October 2018, on Parliament Hill where MPs and Senators were invited to learn about the importance and rationale of the National Palliative Care Framework.
 - Guests heard a powerful presentation from Paul Adams who is an Ottawa based caregiver and his story was incredibly moving.
 - During the public consultation process, the committee was also able to provide all members with some content for the pre-budget process for the federal government of Canada.
 - The Standing Committee report from the Committee of Finance included a recommendation (recommendation 71) to improve access to palliative care with targeted federal investment.
- 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 past year.
- Include/emphasize Carers in key messages (including the 2 weeks for CCB after death); and caregiver day

- The committee focused on emphasizing the needs of carers in our key messages document that was created for the whole coalition.
- The committee is looking to seek a two week amendment to the Compassionate Care Benefit, to two weeks after death
 - The committee has ongoing dialogue with relevant Ministries on this topic.

Education Committee Report (*Peter Barnes and Julie Wilding*)

2018 activities included:

- 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 social media activity for Bereavement Day highly elevated the campaign and a significant amount of the QELCCC membership actively participated.
- Build public education/awareness of palliative approach to care
 - 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 work on creating a means of promoting and integrating a palliative approach to care through awareness and education of complementary non-medical integrated therapies.
 - They planed 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.
- Core Competencies and Continuing Education
 - 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

Research and Knowledge Translation Committee Report (*Christopher Klinger*)

2018 activities included:

- Advocacy with the Environmental Scan on HPC Research Funding
 - The environmental scan on Hospice Palliative Care Funding is now complete, and has been rolled out in a poster and a one page key messages document.
 - The committee has had many great opportunities to have this poster displayed at conferences through the past year.
 - There is a decline of hospice palliative care funding across the board, and the committee has noticed they are having a very hard time getting funding out of 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.
- Increase awareness of research and KT activities and tools/resources related to hospice palliative care

- The committee has had some great opportunities to talk about these issues and move things forward.
- The committee is now in contact with a new group – the Pan-Canadian Palliative Care Research Collaborative (PCPCRC).
 - Chris and Sharon have had the opportunity to attend two 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.
 - We are really hoping they will attend the next CHPC Conference. Their attendance will strengthen the opportunities for researchers' participation, making it broader and better research representation, while also providing opportunity to talk about upcoming QELCCC initiatives.
- Influence research bodies
 - 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. The meeting was to remind 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 is now scheduled for February 28 with the CIHR Institute Directors regarding hospice palliative care issues.
 - We will be talking about hospice palliative care research and the need for the reestablishment for the panel on hospice palliative care.
- Analyze research gaps
 - A scoping review toward research gaps is well under way with the support of a UofT student. There are approximately 25 articles to be included in the analysis, including an old report by CHPCA from 1999. The goal is to have the document ready for fall/presentation at CHPCC 2019.
- Communication across all QELCCC Committees and information-sharing
 - The committee is working on finding ways for all of the committees to communicate more, as there are a lot of overarching issues.
 - We want to focus on sharing the findings we have, 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 more interconnectivity.

Executive Committee Report (*Sharon Baxter*)

2018 activities included:

- The executive committee is made up of the chairs of each committee and Sharon as the secretariat; they meet every 6 – 8 weeks.
- All chairs debrief on what each committee is currently doing, and look for synergies between the ongoing works.
- We have also added Diana Rasmussen, who is focused on care giver issues, as this is an overarching topic. Including Diana in all committees as this is an overarching issue has been very successful this year.
- The executive committee meets to look at the membership of the coalition, and have decided to tackle the 5 groups that have lapsed membership, and get them active again.

- The committee also works with expanding partnerships, and worked with CHPCA and the advocacy committee on the Breakfast on the Hill event.

‘Hot Topics’ and Interactive Sessions

Following a short break for lunch, *The Hon. Sharon Carstairs Award of Excellence in Advocacy* for 2018 was subsequently presented to MP Marilyn Gladu, accepted by Ben Maritn. During the afternoon’s session, the QELCCC heard from Christina Lawson from the Canadian Institute for Health Information (CIHI). Following, the Coalition had a round table discussion of “hot topics” prior to committee work plan discussions.

1. National Framework follow up:

- The framework came out December 6th, 2018 meeting the deadline, of December 12th 2018, (*For the full document, see [Framework on Palliative Care in Canada](#)*)
- There were a few things that were missed or dealt with lightly in the framework, however it seems we can still advocate and try to expand what they are saying in the framework during the implementation phase.
- CHPCA did a summary of the Framework on Palliative Care in Canada.
- Health Canada is currently saying ‘no new money’ is appointed to the framework implementation, however, Sharon has met with the Minister of Health’s Policy Staff and discussed the lack of money attached to the Framework, they seemed to imply there would be money in the future but it would not be going to the provinces and territories, and asked for a breakdown of the ideal amount needed before the budget, we are not going to be held to this; just want a vision with a ball park figure.
- It is really important that the new vision for the framework includes the provinces, territories, and the communities as meaningful partners. What we don’t want is the same strategy from before with a Health Canada lead federal strategy that did little to engage the provinces, territories, and communities.

2. Blueprint 2020-2025:

- The current Blueprint for Action ends in 2020. This year we need to make work on creating the next edition. In the past we have done editions that are 10 years, however as the industry is changing in such a short term currently we are going to consider a 5 year term instead.
- We are looking to set up a mini work group to sign up to help with the renewal of the document.

3. Coalition Sustainability:

- The finance information provided is until December 31st, 2018. There was a donation of \$10,000 from CHPCA to the coalition, to get the coalition out of the hole that the coalition was in, and to also sustain us to have the ‘Breakfast on the Hill’, teleconferencing and at the end of the year we had about \$1,000 in the bank. With the face-to-face meeting, we would not have been able to do it without the latest donation.
- The executive committee met recently to float some ideas in advance to help with future funding, and the upcoming projects and we are also looking for the members as a collective to help with ideas on how to improve funding. One of the points that came up in earlier discussions is the idea of organizations stepping up with a grant if your organization has the opportunity to do that, or to consider sponsorship opportunities

for the face-to-face meeting, or the bursaries to help the smaller organizations get here. If you are writing budgets for next year, please be thinking about this as an opportunity and there would be recognition from the coalition for that, and these are just some things to think about going forward. An alternative idea to think about is tagging a researcher to the conference.

- It was suggested to ask each member if they would be able to attend these meetings if they were not offered any funding, and the topic of membership fees was brought up in the past and it didn't work out, however, even \$250 – \$500 from each group, it would still make a difference in the funding we have, especially if it keeps these meetings going. There are pros and cons to the different coalition models and this is just a preliminary conversation to be transparent and ensuring we can continue to do the great work that is done.
- It was suggested that instead of a membership cost, each member should ensure the cost for the attending the face-to-face every year was written into your organization's budgets, it would still make a difference financially. If the members feel that the face-to-face meeting is a priority, then all members need to start making it a priority and start to find funding for it in their budgets.
- Another question is with the amount of people who were sick and had cancelled flights due to weather, should we consider changing the time of year we have the meeting, should we change it to December or have it in conjunction with the CHPC Conference/September every year.
- Sponsorship is a possible however for events like the 'Breakfast on the Hill' there is a concern about biases to your organization's message which could cause some potential problems in the future.
- There are some follow-up questions added to the face-to-face meetings evaluations to gather some more information, or if you organization would like to have follow up conversations with Chris K and Helena that option is available as well.
- If members are interested in donating to the QELCCC, they will be able to receive a donation receipt from CHPCA for any funding donated.
- It was brought up from one of the members representing a provincial association, that with all of the funding going to the provincial organizations for implementation of palliative care, it might be beneficial to think about being more deliberate with involving the provincial representatives. A lot of the information presented to us today is very useful and there is no other table to get this information, and it may not be distilled to them from their federal/provincial/territorial representatives, and these groups may be able to offer some funding to attend the meetings.
- There is a level of membership called 'affiliate' that currently have no one in, this level is for groups that are not at a national level, and it might be good to have the provincial groups in that category, and charge a small fee for memberships or to attend the meeting.
- The executive committee will make a commitment to make a plan going forward and will stay fully transparent and communicating with the coalition for the whole plan moving forward.
- From a communications perspective, it might be beneficial for the chairs to discuss the work each committee is doing at their individual meetings, and we will look at doing this going forward.

- The executive committee are asking people to really try to attend meeting if your organization said ‘yes’ to the Doodle Poll and invite. There were a few cancelled calls because quorum was not met and this is a waste of time and money to call in and have it cancelled because of lack of attendance.
4. The Way Forward and Advance Care Planning (ACP) in Canada
- The Way Forward Initiative is still a legacy with QELCCC, and the framework is still there. The executive committee applied for some federal funding to create a second version of it, however we did not receive it, but that doesn’t mean we will give up. We feel there is more work to do, and we are pleased to see it has found its way into the provincial work and other projects. And we will continue to advocate for the project and future endeavors.
 - CHPCA received funding for the ACP project for the next three years, and will be starting a project on capacity building and moving forward on preparing Canadians for their future health and personal care planning.

Committee Work Plan Discussions

Advocacy Committee

Helena Sonea (chair)	
Amy Henderson	Diana Rassmusen
Charles Thompson	Kim Taylor
Gary Lacasse	Gavin Arthur
Kelly Massotti	Shelly Guy
Jane Papke	Vicki Lejambe
Lydia Lauder	Mary Ann Murray

Objective 1: Election 2019 Advocacy – Amendment to the Employment Insurance Compassionate Care Benefit (CCB)

2019 Activities to date:

- Assemble list of key staff to meet with, key Member of Parliament’s and key Ministers and meetings in constituency offices
- Develop key messages document and brief for meetings with elected officials
- Meet elected officials to influence platform development of political parties, highlight two priorities CCB and Palliative Care Framework implementation

Goal 2: Implementation of National Palliative Care Framework

2019 Activities to date:

- Develop proposal for implementation of the Collaborative
- Proposal complete and shared with Coalition and Minister of Health’s office

- Proposal shared at all meetings with elected officials

Education Committee

Peter Barnes (Chair)	Julie Wilding (Chair)
Peter Barnes	Doug Momotiuk
Carolyn McCoy	Raquel Shaw Moxam
Judy Donovan Whitty	Sharon Baxter (Secretariat)
Jeff Moat	Diana Rasmussen
Shelly Lejambe	Josette Roussel
Deborah Dudgeon	Riley Malvern

Goal 1: Ensure integration of Palliative care education across all care settings, professions and all patient populations

2019 Activities to date:

- Feedback from committee members
- Resources on grief and bereavement -complicated grief (Peter),
- Responding to grief and loss as a healthcare professional (Julie OT initiative)
- Establish link to the framework document
- Collaboration with CMH for next steps

Goal 2: Align education strategies across QELCCC member organizations.

2019 Activities to date: Posters and resources. QELCCC members champion the palliative care approach at their respective conferences.

- The Environmental Scan on research funding was presented at the Canadian Association Occupational Therapists conference in May 2019.
- Oral presentation made at the Pan-Canadian Palliative Care Research Collaborative in Spring of 2019.
- The QELCCC Blueprint Poster was presented at the National Initiative for the Care of the Elderly's (NICE) Knowledge Exchange in May 2019.
- Develop a standard template for coalition to promote easy access to posters/resources.
- Making materials readily available for national and provincial conferences.
- Disseminate on member web page.
- Distribute through social media.
- Identify links between member organizations and learning opportunities.
- Foster the interconnection of member organizations by recruiting an education representative to act as contact for the dissemination of education to our member organizations.
- Conferences featuring QELCCC materials:

Goal 3: Advocate to those who oversee undergrad, post grad and CPD education and bodies to accredit it.

2019 Activities to date:

- Letter/survey from QELCCC to those bodies that accredit and certify education. Target letter/survey to multiple individuals/champions within the organization.
- Align with provincial working group on inter-professional core competencies.
- Linking with provincial PC associations about core competency education.

Goal 4: Identify opportunities for partnership and collaboration to advance palliative care across the learning cycle.

2019 Activities to date:

- Identify education needs re complementary therapies. Taster sessions at annual Face-to-face meeting to introduce concept and experience of complimentary therapies to coalition members.
- Movie screening 'Exit Music' – Film paired with panel discussion after the screening that includes panel discussion promoting awareness use of creative modalities art/film.

Goal 5: Identify strategic ways of engaging and educating Canadians.

2019 Activities to date:

- Identify education needs re complementary therapies.
- Taster sessions at annual Face-to-face meeting to introduce concept and experience of complimentary therapies to coalition members.

Research and Knowledge Translation Committee

Christopher Klinger (Chair)	Sharon Baxter (Secretariat)
Carol Barrie	Noush Mirhosseini
Christina Vadeboncoeur	Kate Murzin
Karla Thorpe	Lisa Benedet

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

2019 Activities to date:

- Internal: QELCCC – e.g., Environmental Scan poster/key messages document to be displayed at further upcoming membership conferences (e.g. Canadian Hospice Palliative Care Conference and Canadian Mental Health Conference in September).
- Environmental scan on research funding landscape was also presented at:
 - Canadian Association of Occupational Therapists Conference (May 2019)

- Pan-Canadian Palliative Care Research Collaborative (PCPCRC) Spring Meeting (May 2019)
- Canadian Society of Respiratory Therapists' 55 Annual Education Conference (May 2019)

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

2019 Activities to date:

- Continue to advocate for a National Minimum Data Set (MDS) - including pediatric palliative care - in collaboration with the Advocacy Committee .
- Enhance visibility of measurement and research activities in Framework on Palliative Care in Canada implementation.
- Support the update of educational resources on the QELCCC website in collaboration with the Education Committee.
- Create awareness toward the QELCCC as a potential KT partner for researchers (e.g., PCPCRC Fall meeting will be held as a satellite to the 2019 Canadian Hospice Palliative Care Conference in Ottawa).

Goal 3: Influence research bodies

2019 Activities to date:

- Follow up with CIHR Institute on Aging about status of bereavement funding (scheduled for June 2019).
- Meeting with Directors of the CIHR Institutes (combined: February 28, 2019) regarding hospice palliative care activities and the reestablishment of the CIHR Review Panel on Palliative Care
- Meetings with other research bodies (including QELCCC membership ones). A particular shortage are seed funding and proof of concept studies.

Goal 4: Analyze research gaps (scoping review of the literature)

2019 Activities to date:

- Complete scoping review with focus on clinical and health system/services gaps by Summer 2019.
- Abstract for 2019 CHPCA Conference has been submitted (January 31, 2019).
- Presentation at 2019 CHPCA Conference and write-up.

Goal 5: Scoping review of the literature on (informal) caregiving in HPC in Canada

2019 Activities to date:

- Establishment of research team and determination of scope (including clinical and caregiver gaps, “cultural safety/sensitivity”, gender, etc.)

Goal 6: Communication across all QELCCC Committees and information sharing

2019 Activities to date:

- Information on all QELCCC Committees' progress to be shared at the beginning of each Committee teleconference.
- QELCCC online meeting at 6 months mark to review progress to date.