



Quality End-of-Life Care Coalition of Canada

2017 Annual Report

December
2017

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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 workplan 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 thirty-six 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.

You can access the official framework here: <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 (39)

Full Members (35)

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

Associate Members (4)

Canadian Arthritis Patients Alliance
Carers Canada (formally the Canadian Caregiver Coalition)

Canadian Network of Palliative Care for Children
Canadian Virtual Hospice

Annual Meeting Report: Looking Back and Forging Ahead

Summary:

For more information about the QELCCC and to view the complete workplan, please visit www.qelccc.ca. For more information about *The Way Forward Initiative*, please see below or visit www.hpcintegration.ca. For more information on the Secretariat please visit CHPCA's website at www.chpca.net.

The Way Forward: Next Steps

Summary of post-TWF survey progress

For more information on *The Way Forward*, please visit: <http://www.hpcintegration.ca/>

Executive Committee Report

The Coalition has four active sub-committees, including 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, Executive Committee members met roughly every two to three months throughout 2017. 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 promoted 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 2017, the Executive Committee continued to seek out new members.

Advocacy and Caregiver Committee

Nadine Henningsen (Co-Chair)	Diana Rasmussen (Co-Chair)
Vicki Lejambe	Shelly Cory
	Kim Taylor
Hazel Markwell	Christina Vadeboncoeur
Amy Henderson	Sharon Baxter (Secretariat)
Kelly Masotti	Jana Papke
Natalie Gierman	Marie Christine Monchalin

OBJECTIVE: The advocacy committee will work to influence the national dialogue and increase understanding of an integrated palliative approach (IPA) to care.

1. National awareness and inclusion in dialogue

GOAL Build awareness of the need for increased access to quality palliative care and advance a specific ask relative to home-based palliative care and Bill C-277 (Framework on Palliative Care in Canada Act)

2017 Activities to Date:

- Working document outlining targeted “asks” to advance an integrated palliative approach to care in the home and community care setting. Actions support the following key elements (as reflected in The Way Forward and Blue Print for Action 2010-2010)
 - Patients’ *health care wishes up to and at the end of life to be shared, understood, respected, and acted upon.*
 - Engaged caregivers are informed and supported.
 - Knowledgeable healthcare providers, supported by team-based care.
 - Integrated care teams (i.e. home care – primary care – specialist - community paramedics, others).
 - Flexible service delivery approaches that optimize resources.
 - Sufficient resources and accountable funding models.

Reinforce the importance of Bill – C-277 and encourage members to engage in testimonies before the House of Commons Health Committee and the Senate’s, Social Affairs Science and Technology Committee

- Promoted the inclusion of “Palliative Care First” in MAiD dialogue, throughout the federal/provincial legislative process
- Strongly promoted the inclusion of Hospice Palliative Care, as well as supports for Carers (family caregivers) in federal/provincial Health Accords as reflected in the “Common Statement of principles on Shared Health priorities”
- The Secretariat, with the support of the QELCCC Advocacy committee, engaged federal members of parliament with a letter campaign to heighten awareness of Advanced care Planning (supporting and understanding ACP as a fluid process, promoting discussions and implementing concrete objectives)

2. Recognition and Awareness of Carers (family caregivers)

GOAL: Build awareness of the needs and resources for Carers (caregivers) with emphasis on financial support and recognition

2017 Activities to date:

- Participated in Carers Canada National Carer Day awareness campaign including:
 - Attendance at a breakfast on Parliament Hill
 - Awareness of the Prime Minister’s statement on the role and value of carers
 - Breakfast on Parliament Hill was a great success and the QELCCC membership actively promoted the Prime Minister’s statement on carers on social media.
 - Reinforced the theme ““Caring at Home – Recognizing Caring Canadians” through social media and broad dissemination of information tools

- Actively supported CHPCA’s National Bereavement Day Campaign via social media campaign and ACP “Speak Up” campaign
- Promoted the Canadian Partnership Against Cancer’s report “ Palliative and End-of-Life Care September 2017 “ that reinforced the important role of carers
- Provided input into the CHPCA’s Champions Council’s letter writing campaign to federal and provincial health ministers requesting that funding for hospice, palliative care be included in the 2018 federal and provincial budgets.

Education Committee

Julie Wilding (Co-Chair)	
Raquel Shaw-Moxam	Judy Donovan Whitty
Peter Barnes	Doug Momotiuk
Josette Roussel	Laura Garcia
Ed Mantler	Sharon Baxter (Secretariat)

1. Raising awareness of Bereavement Issue

2017 Activities to date:

- The QELCCC membership actively promoted a variety of materials and resources prepared by the CHPCA for National Bereavement Day (2017). These included: a News Release, Poster, a Template Newsletter that can be sent by all the members to all politicians asking them to fund bereavement care, a FAQ Document, as well as a valuable Links to Resources page, both accessible on-line. The social media activity for Bereavement Day was highly elevated and a significant amount of the QELCCC membership actively participated in the twitter hashtag campaign
- Two webinars were created on the subject of bereavement: The Power of Grief (by Dawn Cruchet, BN, MED – April 12, 2017)) and Meaning Reconstruction and Illness: a Practice Discussion (Leah B. Lewis, PhD – May 2, 2017)

2. QELCCC Materials and Resources (Posters/Webinars)

2017 Activities to date:

- Successful QELCCC Poster Awards were held, including an award for best poster and another for best poster from a student/trainee category, for the CHPCA Conference.
- QELCCC Portal is now complete and login info sent to members. Information on each committee is now available to members.
- Article by QELCCC colleague, Dr. Peter Barnes “Healing the Pain of Grief and Bereavement” was widely circulated through Ehospice.
- Creation of a survey to determine coalition members education needs for use as a repository of information for all members

- Disseminated the “Taking Ownership” document (created by Pallium under the auspices of QELCCC) through the for members only portal on QELCCC website.
- Creation of a Non-medical integrated therapies document (to educate members on what exactly these are, including information on less traditional normalizing death means. i.e., Death Café, St Elizabeth Reflection Rooms and Compassionate Communities)

3. Encourage inclusion of palliative care core competencies in professional curricula.

2017 Activities to date

The QELCCC continued to monitor the activities of provincial governments with regard to inter-professional competencies. Currently, only BC, AL, ON, PEI and NS are actively working on this. The provincial Government of Nova Scotia recently released its document and the QELCCC distributed it throughout its membership.

The committee also plans to follow up on their letter to professional regulatory bodies regarding the inclusion of palliative care core competencies in professional curricula.

- Palliative Care conferences are to be approached to encourage them to have attendees include HPC in core competencies. Raquel and CPAC worked on promoting palliative care core competencies
- CPAC surveys (created in cooperation with CHPCA and Canadian Society of Palliative Care Physicians with a focus on Cancer centers and acute care institutions) had already been sent out to: the Nursing Industry, Medical Schools, Pharmaceutical Industry, Social Workers, as well as, Occupational Therapist, and Physical Therapists to determine what other like-minded organizations and institutions are doing to promote and integrate palliative care and what QELCCC needs to do better
- The QELCCC continued to encouraged the provincial governments with regard to the establishment of working groups on interdisciplinary competencies
- Discussed and debated the inclusion of spiritual care in core competencies
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4. Letter to Provincial health ministers about accessibility of hospice palliative care

2017 Activities to date:

- The QELCCC continued to correspond with various health departments and actively promoted the inclusion of palliative care in the health care agendas of provincial ministers.

Research and Knowledge Translation Committee

Christopher Klinger (Chair)	Sharon Baxter (Co-chair / Secretariat)
Carol Barrie	Noush Mirhosseini
Srini Chary	Kate Murzin

1. Completed the report from the environmental scan of the funding opportunities

2017 Activities to date:

- The report was completed by Chris and Pat Strachan (former Committee member) and presented to fellow committee members;
- Rolled-out with poster at the 2017 Canadian Hospice Palliative Care Conference in Ottawa;
- Key Message Document was completed by Kate; and
- Rolled-out at the 2017 Canadian Hospice Palliative Care Conference in Ottawa.
- Revised version is ready and can be used for further advocacy activities.

2. Increase Awareness of Research and KT activities and tools/resources related to Palliative and End-of-Life Care

2017 Activities to date:

- The survey following the 2017 QELCCC meeting was completed and submitted to Health Canada;
- CHPCA is monitoring CIHI's activities toward the creation of a Minimum-Data Set (MDS).

3. Influence Research Funding Bodies

2017 Activities to date:

- Follow-up meeting was held with Dr. Yves Joanette and Joanne Goldberg (CIHR Institute on Aging). Agreed that the goals of the QELCCC and the Institute are similar with regards to hospice palliative care but acknowledged that currently there is limited funding for palliative care. Seed/proof of concept funding is especially scarce.
- Dr. Joanette highlighted the role of the Canadian Frailty Network as a granting agency in this regard;
- The CIHR Institute on Aging also agreed that more research was needed with regard to MAiD; priority announcement toward bereavement care (still) pending;
- Important Note for QELCCC membership: CIHR is going back to its original funding model (College of Reviewers will remain, but review panels will be re-established);
- CIHR invited QELCCC to share names of key experts for review panels (these include: Psychosocial, Sociocultural & Behavioral Determinants of Health (PH1) and Social Dimensions in Aging (SDA) – still pending; unfortunately, the only panel not returning is Palliative Care – lobbying activities (?);
- In line with the public health approach to palliative care, next CIHR Institute to establish further communication with is the Institute on Population and Public Health;
- Communication with CFN and other QELCCC member organizations re. seed/proof of concept funding needs to be intensified.

4. Communication across all QELCCC Committees and information-sharing

2017 Activities to date:

- Committee information shared at Executive Committee meetings;
- Further joint advocacy opportunities to be explored.
- First CHPCA Best Poster Awards given at 2017 Canadian Hospice Palliative Care Conference; ties with research community enhanced.

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