



Quality End-of-Life Care Coalition of Canada

2016 Annual Report

January to
December
2016

Table of Contents

Background and History of the Quality End-of-Life Care Coalition of Canada..... 2

Mission and Mandate of the Quality End-of-Life Care Coalition of Canada..... 3

Member Organizations..... 3

Annual Meeting Report: Looking Back and Forging Ahead 4

The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada..... 5

Executive Committee Report..... 6

Advocacy Committee..... 7

Education Committee 7

Caregiving Committee 8

Research and Knowledge Translation Committee 9

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-eight 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; 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.

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) was made possible through a one-time funding commitment of \$3 million over the course of three years by the federal government from 2012-2015. 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.

You can access the official framework and supporting documents here: www.nationalframework.ca and www.hpcintegration.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 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 to achieve this goal.

Member Organizations (38)

Full Members (34)

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	Realize (formerly the Canadian Working Group on HIV and Rehabilitation)
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	HealthCareCAN
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	Saint Elizabeth Health Care
Canadian Pharmacists Association	Women's Inter-Church Council of Canada

Associate Members (4)

Canadian Arthritis Patients Alliance	Canadian Network of Palliative Care for Children
Canadian Caregiver Coalition	Canadian Virtual Hospice

Annual Meeting Report: Looking Back and Forging Ahead

Member representatives from 32 different organizations with an interest in end-of-life care as well as a representative from Health Canada met at a highly productive annual meeting of the Quality End-of-Life Care Coalition of Canada (QELCCC) in Ottawa, on January 21st - 22nd, 2016. Members worked in both plenary sessions and individual committee groups (Advocacy, Education, Caregiving and Research and Knowledge Translation) to fully review the valuable work done by the QELCCC in 2015 and set committee workplans for 2016.

Following new member orientation and member introductions, Sharon Baxter (Secretariat) gave an update on *The Way Forward* Final Framework and an overview of coalition activities. Following her opening report, each committee gave a summary review of its past and current work:

Kim Taylor from the Advocacy committee announced that a finalized election kit had been distributed, a letter sent to federal party leaders and MPs with election asks for the October 2015 general election. The committee also planned to resubmit a palliative care motion for the Great Canadian Healthcare Debate in 2016.

Brenda Hearson of the Education committee reported that the committee wrote a letter to health ministers and deputy ministers about universal access to palliative care. It was sent to over 120 addresses. She also touched on the planned webinar taking place in April in conjunction with National Caregiver Day. Finally, it was noted that a letter to professional regulatory bodies regarding the importance of including palliative care in the curricula was sent.

Diana Rasmussen of the Caregiver committee reported that the committee looked into an environmental scan regarding best practices around the Compassionate Care Benefit. The committee met with Marty Parker, President and CEO of Canada's 10 Most Admired Corporate Cultures, to discuss how they can reward companies for having the CCB in place. The committee also sent a letter to the Minister of Employment and Social Development Canada inquiring about the CCB, and the new Liberal government announced its extension to 26 weeks. A proposed two-week extension to cover a bereavement period will be proposed in the coming year.

Sharon Baxter and Patricia Strachan of the Research and Knowledge Translation Committee reported on their ongoing environmental scan for hospice palliative care research funding opportunities. The committee has reached out to three of the Canadian Institutes of Health Research (Institute on Aging, Institute on Health Services and Policy Research and Institute on Population and Public Health) asking for meetings in the coming year.

Lastly, Sharon Baxter of the Executive committee reported on reaching out to organizations with lapsed membership including the Canadian Lung Association and the Mental Health Commission of Canada who will both remain a part of the QELCCC. Sharon also welcomed ITK who joined the coalition and noted that the QELCCC doesn't have a ceiling on membership but is now at 38 members.

After committee updates, the meeting moved on to round table updates from each organization including current priorities and emerging issues around hospice palliative and end-of-life care. A description of each item can be found in the meeting minutes for the January 2016 face-to-face meeting.

The Hon. Sharon Carstairs Award of Excellence in Advocacy for 2015 was subsequently presented to Sharon Baxter of the Canadian Hospice Palliative Care Association by Diana Rasmussen.

During the afternoon's Key Issues Skills Training, the QELCCC reviewed the Blueprint for Action 2010-2020 for new members, and Diana Rasmussen provided an assessment of the current environment. Finally, Nadine Henningsen provided an overview of the QELCCC's plans to move forward with new advocacy items, and provided information about how coalition members could leverage existing resources to further advocate for end-of-life care.

The afternoon provided an opportunity to hear about Advance Care Planning from Louise Hanvey, a roundtable discussion on Caregiver Day activities, an update on Compassionate Communities from Kathryn Downer, and provincial coalition updates. Before concluding for the day, sign up for the 2016 committees was held.

The following morning, Sharon Baxter provided the Secretariat's financial update and then committee workplan discussions and finalization took place. Friday afternoon's Plenary discussion about 2016 workplan synthesis for all four committees ended the face-to-face meeting with a renewed sense of purpose and clear direction.

For more information about the QELCCC and to view a complete workplan, please visit www.qelccc.ca. For more information about *The Way Forward Initiative*, please see below or visit www.hpcintegration.ca.

The Way Forward: Next Steps

The formal funded part of *The Way Forward* initiative has now ended, and the concept of the integrated palliative approach is ready to be put into practice, with some provinces already implementing it.

Federal Medical Assistance in Dying (MAID) legislation has been in place since December 2015 in Quebec and June 2016 in the rest of Canada, and efforts are ongoing to monitor and assess implementation. As focus shifts to other health priorities, the Federal and Provincial governments have had little success in negotiation of new 10 year health accords, with the exception of Nova Scotia, New Brunswick, Newfoundland and Labrador and the Territories, who each signed agreements with the federal government following the breakdown of talks with all provinces in late 2016 and into early 2017. The Federal government continues to promote its specific interest in mental health and home care issues, but talk of funding for palliative care has unfortunately fallen off the radar.

With these political realities in mind, CHPCA undertook a survey of QELCCC member organizations and of provinces and territories in December 2016 with the support of Health Canada to determine where each province (and key end of life care stakeholder) was in the implementation of *The Way Forward* recommendations, and about palliative care priorities in general. Findings of these surveys will directly inform Health Canada in how it prioritizes the issue of palliative care as Health Accord negotiations resume in 2017 between the federal and remaining provincial governments.

The Federal Minister of Health and her staff have been made aware of *The Way Forward's* final framework and its recommendations, and their suitability in settings of particular interest to the federal government – namely in the home care setting, in remote communities, and in shelters to give three key examples.

All Canadians could potentially benefit from the growing willingness to acknowledge that dying is part of living, and that people deserve and should receive the integrated palliative approach to care when they need it – at all stages along their illness trajectory and in all settings of care.

The CHPCA and the QELCCC will continue to advocate for this change in attitude until all Canadians have access to the integrated palliative approach to care across settings and people are comfortable having conversations about the kind of care they want towards the end of life.

Executive Committee Report

The Coalition has four active sub-committees, plus the Executive Committee. The chairs of the four main sub-committees, as well as a representative from the Coalition Secretariat (CHPCA), make up the members of the Executive Committee. For 2016, the Executive Committee is comprised of Kathryn Downer and Julie Wilding (Education Committee), Nadine Henningsen (Advocacy Committee), Diana Rasmussen (Caregiver Committee), Christopher Klinger (Research and Knowledge Translation Committee), Sharon Baxter (Secretariat), Sarah Levesque and Liz Balsom.

The Executive Committee oversees the work of the Coalition when it is not in session. To this end, its members met four times in 2016. The Executive Committee's main focus for this year continued to be the efficient and effective administration of the Coalition, and seeking opportunities to develop partnerships that help ensure access to quality hospice palliative and end-of-life care in Canada. Part of the role of the Executive Committee is to invite and review all requests to join the QELCCC. In 2017, the Executive will continue to seek out new members. Suggestions for new members should be brought to the attention of the Secretariat.

Advocacy Committee

Nadine Henningsen (Chair)	
Kathryn Downer	Jennifer Kitts
Angele Benard	Kim Taylor
Sally Guy	Christina Vadeboncoeur
Amy Henderson	Sharon Baxter (Secretariat)

GOAL: Advocate for universal access to integrated palliative approach to care regardless of age, diagnosis, preferred location of care.

1. National awareness and inclusion in dialogue

2016 Activities:

- A. Submitted a motion to the National Healthcare Leaders "Great Debate" which made the Top 10, which was noted by the Health Minister who provided opening remarks at the conference.
- B. Refreshed the QELCCC election kit content and "Asks" to emphasize an integrated palliative approach to care which has been widely shared.
- C. Consideration to support private Member's Bill C-277 with a letter and appear before the Health Committee when the bill went to committee for review in the fall of 2016.

2. Influence the new Health Accord discussions

2016 Activities:

- A letter was sent to provincial Health Ministers and other relevant provincial policy-makers encouraging the inclusion of an Integrated Palliative Approach in Health Accord Discussions.

- Promoted the inclusion of “Palliative Care First” in MAiD dialogue, throughout the legislative process including Secretariat meetings with both the Justice and Health ministers, and with senior Health Canada ADM Abby Hoffman.
- Supported the introduction of private Member’s Bill C-277, the Palliative Care Framework Legislation, and continue to advocate for its passage throughout the legislative process.

3. Continue to Promote *The Way Forward*

2016 Activities:

- The Secretariat, with the support of the QELCCC Advocacy committee, wrote to provincial health ministers in July urging them to review *The Way Forward* as they engage with the Federal government around the new Health Accord negotiations.
- Members of the Advocacy committee and QELCCC generally participated in CHPCA’s Health Canada-sponsored survey about implementation of *The Way Forward* and palliative care priorities generally. This initiative also saw a spike in traffic to www.hpcintegration.ca.

4. Support CHPCA Public Awareness Events

2016 Activities:

- All committee member organizations actively promoted ACP Day, National Caregiver Day, National Hospice Palliative Care Week 2016 and the month-long “Hospice Palliative Care FIRST: A Month of Action” campaign.

Education Committee

Julie Wilding (Co-Chair)	Kathryn Downer (Co-Chair)
Peter Barnes	Raquel Shaw-Moxam
Elaine Campbell	Josette Roussel
Katherine Cullihall	Mary Schultz
Judy Donovan- Whitty	Sharon Baxter (Secretariat)
Doug Momotiuk	

1. Raising awareness of Bereavement Issue

2016 Activities:

- A letter was sent to Employment and Social Development Canada (ESDC) asking for an additional two weeks (bereavement) as a part of the Compassionate Care Benefit.
- An article about bereavement by Peter Barnes is almost complete.
- A two-part webinar series about bereavement in early 2017 is almost finalized.

2. Develop a Webinar for Family Caregivers

2016 Activities:

- Two webinars were held the week of National Caregiver Day 2016 in April in collaboration with the QELCCC Caregiving Committee highlighting the role of the Caregiver and Bereavement.

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

2016 Activities:

- A document with palliative care core competencies was updated and continues to undergo a rigorous approvals process.
- Palliative Care conferences are to be approached to encourage them to have attendees include HPC in core competencies.

4. Letter to Provincial health ministers about accessibility of hospice palliative care

2016 Activities:

- Over 100 letters were sent with a 25% response rate and some input from each of the provinces indicating support for the issue or directing the issue to the attention of another department or Minister.

Caregiving Committee

Diana Rasmussen (Chair)

Looee Okalik

Donna Shaddick

Sandeep Sodhi

Sharon Baxter (Secretariat)

1. Follow up with Provincial governments about expansion of the Compassionate Care Benefit:

2016 Activities:

- Committee members have reached out to provincial governments and responses, where available, were shared with the committee members in the fall of 2016.
- Met with Nancy Milroy-Swainson, the Director General, Seniors and Pensions Policy Secretariat, Income Security and Social Development Branch of Employment and Social Development Canada about the Compassionate Care Benefit and other caregiver issues.

2. Promoting National Caregiver Day and Webinar

2016 Activities:

- Two webinars were held in the week following National Caregiver Day 2016 in collaboration with the QELCCC Education Committee. The topics included “Who’s Looking After the Caregiver?” and “Reinventing a Life After Loss: A bereaved Caregiver’s Path Through the Palliative Care Journey and Beyond.”

3. Compassionate Company Identification:

2016 Activities:

- Efforts were made to reach out to companies who have programs that fit the Criteria for a Compassionate company – challenges are in identification of such companies, but Manitoba Hydro was ID’d as one such company.

- Following the official launch of the Canadian Compassionate Companies (CCC) initiative in the Fall of 2016, identified companies were encouraged to apply.

Research and Knowledge Translation Committee

Christopher Klinger (Chair)	Sharon Baxter (Co-chair / Secretariat)
Carol Barrie	Noush Mirhosseini
Srini Chary	Pat Strachan
Vicki Lejambe	

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

2016 Activities:

- The report was finalized by Chris Klinger and Pat Strachan and was presented to fellow committee members.

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

2016 Activities:

- The QELCCC *The Way Forward* poster was featured at the 2016 Annual NICE Knowledge Exchange in Toronto in May 2016 alongside materials advocating for a palliative approach to care.

3. Influence Research Funding Bodies

2016 Activities:

- A meeting was held with Dr. Yves Joannette and Joanne Goldberg of the CIHR Institute of Aging about funding opportunities, limitations and other contacts the QELCCC should be reaching out to in this regard.
- CFHI will also present at the upcoming QELCCC Annual Meeting in January 2017 regarding the call for innovative models of palliative care, opening in early February 2017.