



Quality End-of-Life Care Coalition of Canada

2015 Semi-Annual Report

July 2015

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 1

The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada..... 2

Executive Committee Report..... 3

Advocacy Committee..... 3

Education Committee 4

Caregiving Committee 5

Research and Knowledge Translation Committee 5

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; 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 Honourable Leona Aglukkaq, former Minister of Health, officially announced *The Way Forward* on June 12, 2012 at the Hospice at May Court in Ottawa. The federal government made a one-time funding commitment of \$3 million over the course of three years will help support the development of integrated palliative approach care models across Canada.

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 will help Canadians with life-limiting illnesses understand the importance of advance care planning, and the 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 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

Full Members

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

Association Members

Canadian Caregiver Coalition
Canadian Arthritis Patients Alliance

Annual Meeting Report: The End of an Initiative

Member representatives from 27 different organizations with an interest in end-of-life care met at a highly productive annual meeting of the Quality End-of-Life Care Coalition of Canada (QELCCC) in Ottawa, on January 30-31st, 2015. Members worked in both plenary sessions and individual committee groups (Advocacy, Education, Caregiving and Research and Knowledge Translation) to efficiently review the activities and accomplishments of the QELCCC over the past year and set committee workplans for the year to come.

As in past years, each committee gave a wrap up report on the current activities they are undertaking and the previous accomplishments since the last annual meeting. Amongst other things the main updates for each committee were as follows:

-The Advocacy committee chaired by Melody Isinger and Nadine Henningsen announced that their main goal for this year would be to create “asks” for the election since it is now election year. The “asks” would be based on the Blueprint for action.

-The Education committee chaired by Kate Murzin stated that they focused on refreshing the inventory of resources on the QELCCC website and organized a webinar that took place on October 29th that focused on interdisciplinary teams implementing a palliative approach to care.

-The Caregiver committee chaired by Srini Chary and Diana Rasmussen announced that the Compassionate Companies report was a big project for them that was highly successful and that they will build upon this momentum.

-Lastly, **the Research Committee** chaired by Sharon Baxter and Patricia Strathan, had mapped research and funding opportunities and the committee planned to follow up with them. They will work with other organizations on a repository for research outcomes.

After committee updates, the meeting moved onto round table updates from each organization. This was followed up by the QELCCC Excellence in Advocacy award being presented to the Honourable Sharon Carstairs, P.C. At the same time, Sharon Baxter announced that they award would be renamed “The Honourable Sharon Carstairs, P.C. Award of Excellence in Advocacy” in future years.

During the plenary discussions and updates, the QELCCC heard from the Advance Care Planning initiative and provincial coalition updates from Ontario and BC.

As The Way forward initiative was wrapping up in 2015, an update on the project was delivered by Leanne Clarke followed by her moderating the “Catalyst for Change” panel in which different organizations were invited to give examples and share how they had used the framework including the Canadian Home Care Association, the Canadian Nurses Association and Alberta Health Services. They all highlighted some best practice and gold standard examples of how the palliative approach

and *The Way Forward* can be disseminated and made relevant across settings of care. These examples can be found in the Coalition’s meeting minutes, which can be obtained through the secretariat.

The following day, an open plenary session regarding the QELCCC Election Kit key messages and “asks” was held. During this, QELCCC members discussed how to make the “asks” relevant and how to better articulate the questions to the federal parties in the document.

Lastly, the QELCCC worked within their respective committee on new workplans for the upcoming years and shared what their upcoming goals and initiatives would be with the rest of the coalition.

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: Impact and Lessons Learned

Although the formal funded part of *The Way Forward* initiative is ending, the concept of the integrated palliative approach is taking flight. Other people and organizations including QELCCC member organizations are stepping up to integrate and disseminate from this initiative. Its impact will continue as people across the country work to integrate the palliative approach into different care settings.

The CHPCA and the QELCCC will continue to be a catalyst for change. 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, the QELCCC will keep pushing. One of the challenges they will face is keeping the policy briefs, research summaries and framework – the toolkit supporting the change – evergreen and current now that *The Way Forward* funding has ended. It also remains to be seen what is lost from no longer having an active, central nexus or voice for the issue.

In the view of those who have shepherded *The Way Forward* initiative, the best next step – and the way to have the greatest ongoing impact – would be a much closer integration between two inter-related initiatives: the integrated palliative approach to care and advance care planning. Each needs the other to actually meet Canadians’ expectations that they will have the kind of care they want and need when faced with a life-threatening chronic disease or frailty.

While the recent Supreme Court decision on the issue of physician-assisted death has captured most of the media attention over the past few months, a relatively small number of Canadians are likely to meet the criteria for those services. But everyone has the potential to 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 – at all stages along their illness trajectory and in all settings of care.

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

Executive Committee Report

The Coalition has four active sub-committees, as well as 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 2015, the Executive Committee is comprised of Sharon Baxter, Nadine Henningsen, Diana Rasmussen, and Mary Schulz.

The Executive Committee oversees the work of the Coalition when it is not in session. To this end, its members met twice between January and June, 2015. The Executive Committee's main focus for this year will remain ensuring the ongoing efficient and effective administration of the Coalition, and to leverage opportunities to develop partnerships that helps 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 2015, the Executive will be actively seeking out new members, suggestions are welcomed, please contact the secretariat.

Advocacy Committee

Melody Isinger (Co-Chair)	Nadine Henningsen (Co-Chair)
Patrick McIntyre	Jennifer Kitts
Kim Taylor	Denise Page
Marli Robertson	Sharon Baxter (Secretariat)
Denis Page	Kathryn Downer
James Roche	

1. Finalize and Disseminate the Election Kit

2015 Activities to Date:

- A. Developed a communication piece to accompany the election kit to specify what the kit is and what it is not.
- B. Finalized and distributed the official QELCCC election kit to all members after updating the document to include more refined "asks" and more of a focus on the integrated palliative approach to care.
- C. Sent out survey to QELCCC members to find out individual organization election strategies and how they plan to use the QELCCC election kit. This was done in order to find synergies between the QELCCC and its members for potential collaboration and to encourage members to become engaged.

2. Determine Federal Party Positions

2015 Activities to Date:

- A. Drafted a letter to be sent out to party presidents and party MPs with the "asks" from the election kit in order to determine where each party sends in regards to end-of-life care. The letter is currently being finalized and will be sent out during the summer. The responses will be shared with the QELCCC members and on the QELCCC website.

3. IPHC: A Challenge Issue in the June "Great Canadian Healthcare Debate"

2015 Activities to Date:

- A. A draft submission when sent in by the committee on February 2015 for the call for issue.
- B. The submission was officially accepted in April and the Advocacy Committee was asked to put together a motion brief for all attendees on the integrated palliative approach to care and its relevance and importance. This was distributed during the conference in June.

Education Committee

Mary Schulz (Chair)	Janice Nesbitt
Brenda Hearson	Kate Murzin
Norma Freeman	Judy Donovan Whitty
Kathryn Downer	David Henderson
Julie Wilding	Vicki Lejambe
Doug Momotiuk	Sharon Baxter (Secretariat)
Ruth Barker	

1. Encourage inclusion of Palliative Care Core Competencies in Profession Curriculum

2015 Activities to date:

- The Education Committee began by reviewing previous letters, who they were sent to and what the response was, if any.
- The committee then drafted a letter to the regulatory bodies regarding why palliative care is important and their respective professional role in providing it. Through the letter, questions about what barriers the professions face regarding the inclusion of palliative care competencies in curricula.
- The letter was sent out to all QELCCC members for review and to ask each member to sign on for their organization to be included.

2. Develop a Webinar for Family Caregivers

2015 Activities to date:

- A. The Education Committee has reached out to the Caregiver Committee in order to collaborate on a joint webinar. The goal of the webinar series would be to help families find navigation tools and local resources.
- B. The Education Committee has drafted a few ideas for topics for the webinar including holistic care and multidisciplinary care, and has set up a call with the Caregiver Committee in order to further plan it.

Caregiving Committee

Marjorie Morrison (Co-Chair)	Karine Levesque
Diana Rasmussen (Co-Chair)	
Sandeep Sodhi	Anthony Milonas
Shirley DeMerchant	Kathryn Downer
Sharon Baxter (Secretariat)	

1. Promote Compassionate Companies and Educate Companies to do more for FCGs

2015 Activities to date:

- The committee is currently looking into an environmental scan regarding best practices around the recognition for Compassionate Companies and education regarding the FCG issues.
- Anthony and Nadine will have a lunch on July 16th to see the best approach on next steps for this project. Will report back afterwards.

2. Profile of a Caregiver

2015 Activities to date:

- Relating to the uptake of caregiver issues – it's a way of being able to address caregiver issues and promote national caregiver day. The CHPCA summer student is currently working on reaching out to create caregiver profiles that will be posted on ehospice in the fall. He will also cross post CCC and ehospice articles on the QELCCC website.

Research and Knowledge Translation Committee

Pat Strachan (Co-chair)	Noush Mirhosseini
Sharon Baxter (Co-chair)	Christopher Klinger
Vicki Lejambe	Srini Chary

1. Complete Environmental Scan of Funding Opportunities

2015 Activities to date:

- A survey was created for membership to target the QELCCC members to see where they're at in terms of research and funding opportunities.
- Tara sent out the final report and survey and 14 out of 37 organizations responded. Pat will distribute the results sometime this summer regarding the work two undergrad students did on data that was received from non-tri council sources.
- There are only five groups that will allocate funding to palliative care and the next step is to get the report in a format that can be distributed to other groups.

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

2015 Activities to date:

- Vicki will book a meeting regarding the repository and it will be the end outcome for people to access information.

3. Influence Research Funding Bodies

2015 Activities to date:

- The committee decided that this item can be joined with the letters being written this summer. The committee will try to influence a few groups and research bodies and will discuss further in the year.