



Quality End-of-Life  
Care Coalition of Canada  
La Coalition pour des soins  
de fin de vie de qualité du Canada

# Quality End-of-Life Care Coalition of Canada

---

**2015 Annual Report**

January to  
December  
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.....	2
Advocacy Committee.....	3
Education Committee .....	4
Caregiving Committee .....	5
Research and Knowledge Translation Committee .....	6

## **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](http://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 (34)**

### *Full Members*

ALS Society of Canada  
Canadian AIDS Society  
Canadian Association for the Deaf –  
Association des Sourds du Canada  
Canadian Association of Occupational  
Therapists  
Canadian Association for Spiritual Care  
Canadian Association of Social Workers  
Canadian Breast Cancer Network  
Canadian Cancer Action Network  
Canadian Cancer Society  
College of Family Physicians of Canada  
HealthCareCAN  
Canadian Home Care Association  
Canadian Hospice Palliative Care Association  
Canadian Lung Association  
Canadian Medical Association  
Canadian Nurses Association  
Canadian Pharmacists Association  
Alzheimer Society of Canada

Canadian Partnership Against Cancer  
Canadian Society of Palliative Care Physicians  
Canadian Society of Respiratory Therapists  
Canadian Working Group on HIV and  
Rehabilitation  
Catholic Health Alliance of Canada  
Heart and Stroke Foundation of Canada  
Huntington Society of Canada  
The Kidney Foundation of Canada  
Mental Health Commission of Canada  
National Initiative for the Care of the Elderly  
(NICE)  
Ovarian Cancer Canada  
Pallium Foundation of Canada  
Saint Elizabeth Health Care  
Women's Inter-Church Council of Canada  
Technology Evaluation in the Elderly  
Network (TVN)  
Inuit Tapiriit Kanatami

### *Association Members (4)*

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

## **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 30-31<sup>st</sup>, 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 Mary Schulz, this committee focused on refreshing the inventory of resources on the QELCCC website and organized a webinar that took place on October 29<sup>th</sup> that focused on interdisciplinary teams implementing a palliative approach to care.

-**The Caregiver committee** chaired by Srinivasa 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 the 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](http://www.qelccc.ca). For more information about The Way Forward initiative, please see below or visit [www.hpcintegration.ca](http://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 five times between January and December, 2015. The Executive Committee's main focus for this year was 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. To this end, the Executive Committee took into consider the application of the Therapeutic Touch Networks of Canada (TTNC) this year and after deliberating decided it would work with the TTNC in order to find an over-reaching therapeutic umbrella organization to join the QELCCC to serve as the voice for all similar organizations.

The executive committee also reached out to a few lapse members in 2015 inquiring about whether or not they are still interested in being active members of the coalition.

The Executive committee is always actively seeking out new members, suggestions are welcomed, please contact the secretariat.

## Advocacy Committee

Melody Isinger (Co-Chair – until May 2015)	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:

- A. Developed a communication piece to accompany the election kit to specify what the kit is and what is it 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:

- 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 stands in regards to end-of-life care. The letter was sent in September before the federal election and the committee received responses from the Liberal Party of Canada and the New Democratic Party which were posted to the QELCCC website.

## 3. IPHC: A Challenge Issue in the June “Great Canadian Healthcare Debate”

### 2015 Activities:

- A. A draft submission was 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. Our motion did not make the final selection but all were pleased with the motion content.

## 4. The Way Forward Framework

### 2015 Activities:

- A. The Way Forward Framework was disseminated by QELCCC members after its conclusion in March of 2015.  
B. A new poster with the final framework and resources was created and displayed at the Canadian Hospice Palliative Care Conference in October of 2015 and will be used by QELCCC members at upcoming conferences. These posters are available for coalition members to take to external conferences and meetings.

## 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 Momotiuks	Sharon Baxter (Secretariat)
Ruth Barker	

## 1. Increase awareness of need for universal access to palliative care

### 2015 Activities:

- The Education Committee wrote a letter to Health Ministers and Deputy Ministers regarding the importance of and need for universal access to palliative care in Canada. The letter was

sent to over 120 addresses. Responses are continuing to be received and will be analyzed for common themes..

- 
- 

## 2. Develop a Webinar for Family Caregivers

### 2015 Activities:

- A. The Education and Caregiver Committees have collaborated this year on planning a webinar together that would help families who are caring for a person at or near end of life. The focus, goals and desired outcomes for the webinar are now finalized and a proposed date in April is being targeted to host the webinar to coincide with caregiver day..The webinar working title is "Who's looking after the caregiver?"
- B. The committee is currently confirming a clinician and caregiver to co-present.

## 3. Palliative Care Core competencies in professional curriculum

### 2015 Activities:

- A. The committee also drafted a letter to professional regulatory bodies regarding the importance of including palliative care in curricula. The letter also asked about those barriers that may preclude palliative care competencies from being embedded in professional curricula.
- B. Very few replies were received to the above letter. However, meetings were held with the Canadian Association of Social Workers and the Canadian Association of Social Work Educators who are keen to include palliative care in their curricula. Due to the limited effectiveness of this effort, the committee has decided that it likely will not focus on this issue in 2016. A SWers satellite was held at the Canadian Hospice Palliative Care Conference in Ottawa in October 2015.

## 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:

- The committee looked into an environmental scan regarding best practices around the recognition for Compassionate Companies and education regarding the FCG issues.
- The committee met with Marty Parker that runs Canada's 10 Most Admired Cultures and discussed how they can include rewarding companies for having a compassionate culture and also brought it up at the Canadian Home Care Association Meeting. Marty suggested approaching companies under the premise of corporate and social responsibility.

- Pallium Canada hosted a session at the CHPCA conference on October 28<sup>th</sup>, called "Mobilizing Your Compassionate Community." And distributed flyers to committee members to disseminate.

## 2. Profile of a Caregiver

### 2015 Activities:

- Relating to the uptake of caregiver issues – it's a way of being able to address caregiver issues and promote national caregiver day. The committee will continue to disseminate the Memories of a Caregiver initiative as it progresses in 2016.
- The committee looked into hosting a caregiver webinar for Caregiver day in 2016 that could use some of the people included in the Memories of a Caregiver project. This item will be discussed as an item at the 2016 annual face-to-face meeting.

## 3. Compassionate Care Benefits

### 2015 Activities:

- The Committee sent a letter to the Minister of ESDC inquiring about how and when the update to CCB will be applied by the government, asserting that it needs to 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 with great pickup.

## 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:

- 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 distributed the results 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.
- This will be presented as an item at the 2016 annual face-to-face.

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

### 2015 Activities:

- This item will need a steering committee to get it moving in the long run and will be discussed further after the 2016 annual face-to-face meeting.

### **3. Influence Research Funding Bodies**

#### **2015 Activities:**

- The committee will try to influence a few groups and research bodies and will discuss further in the year. A letter was drafted and sent out to a few individuals at CIHR to inquire about possible collaboration efforts. Meetings will take place in 2016.