



# Quality End-of-Life Care Coalition of Canada

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2014 Semi-Annual Report

July 2014

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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; 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), is developing 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 will be 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 will include: a tool kit of

resources and best practices; offer suggestions for removing the barriers to integrated hospice palliative care; and encourage 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.

## 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                           | Alzheimer Society of Canada                              |
| Canadian AIDS Society                           | Canadian Association for the Deaf                        |
| 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          | Canadian Healthcare Association                          |
| Canadian Homecare Association                   | Canadian Hospice Palliative Care Association             |
| Canadian Lung Association                       | Canadian Medical Association Canadian Nurses Association |
| Canadian Pharmacists Association                | 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                           | The Pallium Foundation                                   |
| Saint Elizabeth Health Care                     | Women's Inter-Church Council of Canada                   |

### *Associate Members*

|                              |                                      |
|------------------------------|--------------------------------------|
| Canadian Caregiver Coalition | Canadian Arthritis Patients Alliance |
| Canadian Virtual Hospice     | Long Term Care Planning Network      |
| Victorian Order of Nurses    |                                      |

## Annual Meeting Report: Looking Back and Forging Ahead

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 23-25, 2014. 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.

Once again, an extra day was added to the Coalition's annual meeting to discuss the progress of *The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada*. On January 23rd, Sharon Baxter and Project Manager Leanne Kitchen Clarke, gave the Coalition an overview of the initiative framework and informed its members of new framework developments, workplan for the last year of the initiative, and announced the results of a national survey commissioned by *the Way Forward* which asked Canadians their views on hospice palliative care and advance care planning. A few of the QELCCC members were asked to present what their organizations have done to advance *The Way Forward* and how the palliative approach fits within their organizational context. They 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. Responses and feedback can be found in the Coalition's meeting minutes, which can be obtained through the secretariat.

In addition to the continued work on distributing the *Blueprint for Action 2010 – 2020*, each committee is dedicated to a number of initiatives that support the overall QELCCC goals and priorities as described in the *Blueprint*. A sampling of these undertakings includes:

- the Advocacy Committee will Undertake a Strategy Inquiry to define our “Asks” for the federal party platform propositions (Based on the *Blueprint for Action*);
- the Education Committee will plan and deliver another webinar that addresses integration into various settings using patient case examples based in various teams/settings;
- the Caregiver Committee will advocate to improve the uptake of National Caregiver Day;
- the Research and Knowledge Translation Committee will create a plan for development of knowledge repository of hospice palliative care related evidence

The Coalition members agreed to disband the Communications Committee. The secretariat will continue to disseminate relevant communications to the Coalition through quarterly e-blasts.

With *The Way Forward* Initiative well underway, the continued use of the *Blueprint for Action: 2010-2020* as an advocacy tool, and the workplan items of its committees, the QELCCC is well-poised to continue its work toward improving access to quality end-of-life care for all Canadians.

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: Moving Towards Community-Integrated Hospice Palliative Care in Canada**

Over the final year of the initiative, the team will continue to speak about the palliative approach to care and the national framework. Ongoing discussions and priority setting with stakeholders to inform the final draft will continue this year, that includes engaging organizations and individuals to champion elements of the Framework. Targeted efforts to engage various settings, sectors, and providers will be a priority throughout the year:

- Reaching out to caregivers through the Canadian Home Care Association;

- Embedding the palliative approach into ACP and further disseminating;
- Primary care qualitative and quantitative report regarding palliative approach barriers and enablers.

Other important work was completed this past year, including a large national public opinion survey. A sample size of 3,000 Canadians were surveyed from across the country, with appropriate breakdown of demographics and sampling. The survey was completed for the 2014 annual meeting, with the provincial breakdown of data now also available. Here are some key findings:

- Over three in ten Canadians (32%) personally suffer from a chronic illness while four in ten (39%) have a sufferer in their immediate family. When taken together, six in ten Canadians (57%) either personally suffer from a chronic illness or have a sufferer in their immediate family.
- If the death occurred in the home, Canadians (90%) are more likely to say that the setting matched the family member's preference. Seven in ten (69%) of those whose family member died in a hospital believe the same.
- Half of Canadians (50%) feel that their family member's death involved some pain, but that it was managed well. The remaining groups feel that the family member's death was either pain and symptom free (27%) or that there were some issues relating to pain and symptom management (24%).
- The average number of hours per week that Canadians expect for caring for a dying family member is 54.4.
- In 2013, expectations of commitment have increased. More Canadians this year expect that proper care will require two or more days of commitment each week (73%) compared to 10 years ago (59%).
- When asked whether they feel they could devote that much time to caring for a dying loved one, the majority of Canadians (65%) indicate that they would not be able to.
- The topic of end-of-life is on people's minds. Three-quarters of Canadians (74%) report having thought about end-of-life.
- Among those Canadians that have a preference of where they die, the majority would prefer to die in their home (75%).
- Many of the Canadians surveyed feel that most of the statements are a strong or very strong influence on why people die in a hospital rather than in their home. The most important reason why this seemingly occurs is that when death is imminent, the patient is transferred to a hospital to provide the required treatment. Half of Canadians (50%) feel that this is a very strong reason for deaths occurring in hospital, with another one-third (31%) saying this is a strong reason.
- When asked about the importance of discussing end-of-life care with different types of individuals, six in ten Canadians surveyed (61%) say that having the discussion is extremely important with at least one individual.
- The majority of Canadians (52%) indicate that the advance care planning process should begin when a person is healthy, yet Only a 13% have an advance care plan prepared.
- Almost half of Canadians (47%) say hospice palliative care is available to all those at the end of their life regardless of their illness. Only 19% say it is available to those dying of life threatening illnesses. However, one-third of Canadians (34%) are not sure to whom hospice palliative care services are available.
- Three-quarters of Canadians would turn to their family physician (73%), for more information on hospice palliative care services.
- Support for hospice palliative care is almost unanimous, with the vast majority of Canadians (96%) being supportive, including 66% who are very supportive.
- The vast majority of Canadians believe that hospice palliative care has a positive impact.

- The following are statements about hospice palliative care that see a large majority of Canadians either agreeing or strongly agreeing. They feel that it:
  - Greatly reduces the stress and burden placed on the family (93%);
  - Should involve all care providers (94%);
  - Improves quality of life for patients (94%);
  - Should be provided in the patient's setting of choice (93%);
  - Should be integrated for all people with chronic, life-limiting conditions (90%);
  - Helps a patient manage their choices along the way (93%); and
  - Should be available early in the course of a disease (87%).
- The majority of Canadians (73%) feel that the provincial governments place too little priority on this end-of-life care, including over one-third (35%) who feel that it is far too little.

All statistics above from a quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region).

All of the discussion documents and resources have been developed to encourage stakeholder dialogue and inform the development of the National Framework and are all available on the initiative website. The website is continuously updated, therefore please check back frequently for new discussion documents, resources, and interactive stakeholder opportunities. Also, if you have resources to share on the website repository, you can do so here:

<http://www.hpcintegration.ca/resources/submit-resource.aspx>.

## **Executive Committee Report**

The Coalition has four active sub-committees, including 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 2014, the Executive Committee is comprised of Sharon Baxter, Melody Isinger or Nadine Henningsen, Diana Rasmussen or Srini Chary, and Mary Schulz. Committee co-chairs decide which one will attend Executive Committee meetings.

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, 2014. 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 2014, the Executive will be actively seeking out new members, suggestions are welcomed, please contact the secretariat.

The Executive members also continue to sit on the Advisory Committee for The Way Forward Initiative.

## Advocacy Committee

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|                           |                              |
|---------------------------|------------------------------|
| Melody Isinger (Co-Chair) | Nadine Henningsen (Co-Chair) |
| Patrick McIntyre          | Jennifer Kitts               |
| Kim Taylor                | Denise Page                  |
| Marli Robertson           | Sharon Baxter (Secretariat)  |

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### 1. Undertake a Strategy Inquiry to define our “Asks” for the federal party platform propositions (Based on the Blueprint for Action).

#### 2014 Activities to Date:

- A. Determined capacity and level of engagement of QELCCC members in advocacy. Surveyed membership to determine interest and capacity to support the advocacy efforts of the coalition and whether they are planning on developing an election strategy. Seven QELCCC members identified opportunities to work with the advocacy committee on a federal election strategy and communicating our “asks”:
  - Canadian Society of Palliative Care Physicians
  - Heart and Stroke Foundation
  - Alzheimer Society of Canada
  - Canadian Healthcare Association
  - Canadian Hospice Palliative Care Association
  - Canadian Association of Occupational Therapists (CAOT)
  - Canadian Breast Cancer Network (CBCN)
  - National Initiative for the Care of the Elderly (NICE)
- B. Generated support for NDP motion M-456 calling for Pan-Canadian standards on palliative care
  - Excellent response from QELCCC members in signing onto joint letter of support
  - Collaborated with NDP MP Charlie Angus to discuss motion wording and direction. Motion was passed on May 28th with a vote of 272-1.
- C. Luncheon on Parliament Hill – May 6
  - Participated in a luncheon for family caregivers on parliament hill hosted by the Speaker of the House and Irwin Colter, Liberal MP. Successful non-partisan event sponsored and coordinated by the Canadian Caregiver Coalition and Canadian Cancer Society.
- D. Support National Hospice PC Week May 4-10
  - Disseminated information to coalition members encouraging them to raise awareness.

### 2. Build awareness with Professional Organizations regarding interdisciplinary education and competencies

#### 2014 Activities to Date:

- A. Collaborating with the Education Committee to determine the most appropriate use of the advocacy committee in support of dissemination of information to key stakeholders. The bulk of this work will be completed in the summer/fall of 2014.

### 3. Next steps for Advocacy Committee

1. Refresh and disseminate the QELCCC “asks” for the federal government
2. Target engaged QELCCC Members with communications on our advocacy ‘asks’
3. Determine party positions on Quality End of Life and specifically our “asks”
4. Organize a number of meetings on parliament hill in September to share our “asks” and gain feedback from MPPs.
5. Source patient and caregiver stories (access information from The Way Forward)

## Education Committee

|                     |                             |
|---------------------|-----------------------------|
| Mary Schulz (Chair) | Nadine Valk                 |
| Brenda Hearson      | Kate Murzin                 |
| Norma Freeman       | Judy Donovan Whitty         |
| Kathryn Downer      | David Henderson             |
| Julie Wilding       | Doreen Oneschuk             |
| Doug Momotiuk       | Sharon Baxter (Secretariat) |

### 1. Inventory of Educational Tools

2014 Activities to date:

- This inventory, developed some years ago, has been refreshed to include a section for additional resources (with live links, where possible) beyond those created by the QELCCC member organizations <http://www.qelccc.ca/projects-and-resources/educational-inventory-of-resources.aspx>
- We have posted it on the QELCCC website for greater accessibility and are encouraging members to link to the tool from their websites. We will be measuring use of this revised tool over the course of the year.

### 2. Plan and deliver a webinar that addresses integration into various settings

2014 Activities to date:

- We are planning another webinar this year, building on the positive reception of the webinar done on the Framework last year. The focus will be to encourage an interdisciplinary approach to palliative care through the use of case studies from both the home/community and long term care home sectors. Speakers are being finalized and the webinar will take place in late October. Evaluation questions will again provide feedback on the usefulness of the webinar to attendees' practice. The webinar will be archived for future reference.

### 3. Letter sent from QELCCC to endorse inclusion of palliative care in undergraduate curriculum of key disciplines

2014 Activities to date:

- A letter has been drafted and is being sent to a list of national bodies representing key disciplines, requesting that they have palliative care competencies embedded in their curricula.

## Caregiving Committee

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|   |                    |
|---|--------------------|
| Srini Chary and Diana Rasmussen (Co-Chairs) | Jennifer Campanolo |
| Marjorie Morrison                           | Sandeep Sodhi      |
| Shirley DeMerchant                          | Karine Levesque    |
| Sharon Baxter (Secretariat)                 |                    |

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### 1. Improve the uptake of National Caregiver Day

2014 Activities to date:

- Supported the CHPCA with the Campaign and assisted with materials dissemination
- Worked with CCC and CHPCA for marketing, uptake, social media and webinar
- Developed a caregiving fact sheet with demographics and myths.
- Developed an infographic and dedicated e-blast for National Caregiver Day

### 2. Media Uptake of Caregiver issues

2014 Activities to date:

- Ongoing pitches to Globe and Mail, CBC and others. Pitches surrounded Caregiver Day. Will refocus pitches on canned articles to be completed by committee members this fall.

### 3. Disseminate information for Caregivers

2014 Activities to date:

- This item has not been active yet, will take it up in Fall 2014
- Raise awareness of organizations that provide services - Travel at short notice due to family member death & cost
- Repository of caregiving resources

### 4. Compassionate Companies project

2014 Activities to date:

- Assisted the CHPCA with their efforts in this project
- In the fall will send a survey to our members asking what compassionate benefits they give employees to add to pre-existing data from CHPCA

## Research and Knowledge Translation Committee

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|                          |                             |
|--------------------------|-----------------------------|
| Pat Strachan (Co-chair)  | Scott Secord                |
| Sharon Baxter (Co-chair) | Christopher Klinger         |
| Nuala Kenny              | Sharon Baxter (Secretariat) |
| Vicki Lejambe            |                             |

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### 1. Implement Blueprint actions and next steps

2014 Activities to date:

- Mapping of research activities and funding opportunities of the membership through a survey. This survey was sent in May 2014. Results are pending.

### 2. Influencing research funding bodies

2014 Activities to date:

- Sent an email to the Coalition asking whether they had any research opportunities. Research opportunities were then disseminated to the membership.
- Asked membership for nominees to the Canadian Institutes of Health Research college of reviewers
- Followed up with CIHR, IOA, TVN, IHSPR and any other funding bodies about funding opportunities and future research

### 3. Disseminate HPC related evidence

2014 Activities to date:

- Create a plan for development of knowledge repository of HPC related evidence. Currently in discussions with TVN.

### 4. Liaise with the current work being done on indicators by the Way Forward and offer advice and guidance re: dissemination Objective: Improved knowledge of indicators.

2014 Activities to date:

- Liaise with the current work being done on indicators by the Way Forward and offer advice and guidance re: dissemination