

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

Annual Report

December 2013

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Background and History of the Quality End-of-life Care Coalition

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)*ⁱ.

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 Careⁱⁱ 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; and spearheading *The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada* Initiative. 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), 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

There are three types of membership in the Coalition:

Full membership – This membership is open to any national organization that supports the principle of quality end-of-life care for all Canadians. Full members are eligible to have their involvement in Coalition activities (i.e. face-to-face annual meeting) subsidized. Full members receive all consultative and final product communications. There are no annual membership fees.

Associate membership – This membership is open to any organization that supports the principle of quality end-of-life care for all Canadians but are not a national organization or cannot participate fully in the Coalition’s committee structure. These members’ involvement in Coalition activities will not be subsidized. They will receive all consultative and final product communications. There are no annual membership fees.

Affiliate membership – This membership is open to any organization that supports the principle of quality end-of-life care for all Canadians but is not a national organization or cannot participate fully in the Coalition’s committee structure. These members’ involvement in Coalition activities will not be subsidized. They will receive only final product communications. There are no annual membership fees. Affiliate members may be invited to sign on to selected QELCCC documents, as invited by the Executive Committee.

Full members

ALS Society of Canada

Alzheimer Society of Canada

Canadian AIDS Society

Canadian Association of the Deaf

Canadian Association of Occupational
Therapists

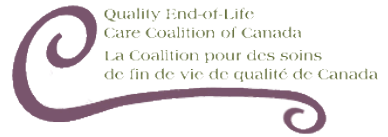
Canadian Association for Spiritual Care

Canadian Association of Social Workers

Canadian Breast Cancer Network

Canadian Cancer Society

Canadian Cancer Action Network



The College of Family Physicians of Canada
Canadian Healthcare Association
Canadian Home Care Association
Canadian Hospice Palliative Care Association
Canadian Lung Association
Canadian Medical Association
Canadian Nurses Association
The Canadian Partnership Against Cancer
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
The GlaxoSmithKline Foundation
Heart and Stroke Foundation of Canada

Huntington Society of Canada
Kidney Foundation of Canada
Mental Health Commission of Canada
National Initiative for Care of the Elderly
Ovarian Cancer Canada
Saint Elizabeth Health Care
VON Canada
The Pallium Foundation
Women's Inter-Church Council of Canada

Associate Members

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

Annual Meeting Report: Looking Back and Forging Ahead

Member representatives from 26 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 24-26, 2013. Members worked in both plenary sessions and individual committee groups (Advocacy, Communications, Education, Caregiving and Research) to efficiently review the activities and accomplishments of the QELCCC over the past year and set committee workplans for the year to come.

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 24th, Sharon Baxter and Project Manager Leanne Kitchen Clarke, gave the Coalition an overview of the initiative framework and informed its members of the workplan, communications strategy and next steps. The Coalition also discussed stakeholder outreach and tools, spending most of the day in groups discussing questions such as: How can the initiative support the mandate of your organization? Will it be of interest to your members/constituents? If so, what aspects are most relevant? What do you need to help you describe the initiative? Do the messages and Q&A help support your conversation? Responses and feedback can be found in the Coalition's meeting minutes, which can be obtained through vsherry@bruyere.org.

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 explore avenues to connect with the Council of the Federation;
- the Communications Committee will continue to ensure members have most current QELCCC collateral/news updates;
- the Education Committee will plan and conduct a webinar to present/generate discussion/ explore uptake of their discussion document on the Integration of Palliative Care into Chronic Diseases for *The Way Forward* Initiative;
- the Caregiver Committee will increase their involvement in National Caregiver Day and engage fellow Coalition members; and
- the Research Committee will encourage the research community to submit new and upcoming research initiatives and research findings.

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. For more information about The Way Forward Initiative, please see below or visit www.hpcintegration.ca/.

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

By early 2013, much of the foundational work of TWF has been completed, including a series of discussion documents that provide context for community-integrated care supported by the palliative approach, a communications strategy, and a performance and evaluation plan. The discussion documents are central to the project as they provide a snapshot of the landscape within which a national framework on community-integrated palliative care will be developed. All of the discussion documents are available in both official languages on the Initiative's website. Importantly, this past year, the first iteration of the national framework was developed with input from members of the QELCCC. Once the next draft is completed, it will be sent for further discussion, input and revisions. The framework is intended to be a practical roadmap with action steps that can be implemented by jurisdictions, policymakers, organizations, and providers in various healthcare settings.

Other important work was initiated this past year, including contracting for a large national public opinion survey. Harris Decima was contracted in March 2013 to conduct this national survey of Canadians, asking them about their attitudes towards hospice palliative and end-of-life care. A sample size of 3,000 Canadians were surveyed from across the country, with appropriate breakdown of demographics and sampling. The survey will be completed by August 2013, with a subsequent discussion document of the public opinion poll and media launch at the January 2014 Annual Meeting.

In keeping with the goal of reaching out to various stakeholders about the initiative, TWF project continued to present to key groups throughout 2013 including provincial and territorial Ministries of Health, the Federal Minister of Health's staff and Health Canada, policy and provider groups, and QELCCC member associations. There has been a great deal of positive feedback and support for the initiative and a strong expression of interest for a framework with tools and resources that are actionable and implementable across settings. Each of the provinces and territories has expressed interest in being linked to a community of practice to continue dialogue about how to support community-integrated palliative care. One of the areas of interest across jurisdictions was an understanding of which indicators were being collected and used to inform quality initiatives or performance frameworks for hospice palliative care. As a result, TWF initiated work to undertake an international literature review of performance frameworks in various countries, in addition to developing an environmental scan of indicators that currently exist, measuring the quality of care and experience of hospice palliative care across all provinces and territories. This scan also includes a snapshot of national organizations that gather data about hospice palliative care such as, the Canadian Institute for Health Information and the Canadian Partnership Against Cancer. The resulting document includes: the tools cited most frequently by provinces/territories; and strengths, weaknesses, gaps, and considerations for how to advance quality initiatives. TWF initiative will not be gathering data, only providing this information to inform implementation across the country by jurisdictions. The full document was finished in June 2013, and will be sent to relevant contacts in all provinces and territories, along with the current draft of The Way Forward Framework.

The finalization of a performance measurement plan was completed in March 2013. An annual survey to measure the level of awareness and understanding of the initiative among QELCCC members was created and will continue to be sent out over the next two years. The first year survey results will provide a baseline against which future year results can be measured. The annual survey is an effort to track the activities and progress of TWF initiative, and to understand the degree of distribution and dissemination of The Way Forward's knowledge products, tools, and innovations through QELCCC member networks.

In October 2013, The Way Forward hosted an interactive workshop in Ottawa ahead of the Canadian Hospice Palliative Care National Conference. Participants included key stakeholders from across the country - from governments, to professional associations, to national organizations, and from across all settings of care. The workshop was a success in identifying new opportunities and practical actions for stakeholders to advance an integrated palliative approach to care. The contributions and ideas discussed by participants will be incorporated into the next iteration of The Way Forward National Framework, to be released in early 2014.

The focus of work this year has been to finalize discussion documents, finalize the development of a performance measurement and evaluation plan, begin dialogue and engagement around the initiative, and finalize the spring draft of the National Framework for TWF that will be broadly circulated for feedback during the next year.

Executive Committee Report

The Coalition has six active sub-committees, including the Executive Committee. The chairs of the five 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. To this end, its members met five times in 2013. The Executive Committee's main focus for this year was to ensure 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 2013 the Executive Committee welcomed the Canadian Network of Palliative Care for Children and the Canadian Partnership against Cancer to the Coalition. In 2014 the Executive will be meeting with representatives from the National Association of Federal Retirees to discuss potential membership.

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

Advocacy Committee

- Melody Isinger (Chair)
- Don Wildfong
- Ingrid DeKock
- Nadine Henningsen
- Denise Page
- Sharon Baxter (Secretariat)

1. Influence Government

Objective: Use of QELCCC messaging.

2013 Activities to Date:

- Use key messages, asks and vignettes (leave behind packages). Timeline: Ongoing.
- Remind member organizations developing briefs to Parliamentary Committees and MPs to identify palliative care issues. Timeline: Ongoing.
- The committee has taken first steps towards asking whether the Parliamentary Committee on Palliative and Compassionate Care can be added as a permanent sub-committee. Timeline: Spring 2014.
- Explore avenues to connect with the Council of the Federation. The Committee is currently exploring this through our CNA representative's connections. Timeline: Ongoing into 2014.
- The Advocacy Committee would like to host a hill lobby day in early 2014. Preliminary discussions were had and more detail will be discussed at the Annual Meeting. Timeline: Ongoing.

2. Monitor Parliament for members comments about end-of-life care

Objective: Raise awareness of the QELCCC to Members of Parliament

2013 Activities to Date:

- Identify anyone who has mentioned Advance Care Planning or End-of-Life Issues in parliament. Timeline: Ongoing. Letters have been sent each time mentioned.
- Monitor news feeds for celebrities or notable people who mention HPC or ACP. Timeline: Ongoing.

3. Identify potential stakeholders to assist with integration of HPC

Build awareness for the need to integrate end-of-life care.

Activities:

- Advocate for better Accreditation Standards. Committee reviewed *The Way Forward* accreditation standards document. Timeline: Completed.
- Facilitate uptake of new Model from the updated Norms of practice. Timeline: Ongoing.

5. Liaise with provincial QELCCs or other relevant organizations

Encourage all provinces to have a QELCC

Activities:

- An Advocacy Committee representative will attend future provincial QELCC teleconferences to share ideas and best practices. Timeline: Ongoing

- Expansion of drug coverage for patients suffering from a life limiting illness. Workplan item still under development. Timeline: Ongoing

Communications Committee

- Shelagh Campbell Palmer (Chair)
- Kelly Grover
- Kim Thomas
- Alison Pozzobon
- Judy Donovan-Whitty
- Frank Folino
- Sharon Baxter (Secretariat)

1. Timely Dissemination of Relevant Communications to QELCCC Members

Objective: Ensure that QELCCC member organizations are aligned, informed and engaged.

Activities:

- Gather contacts for communications leads for member organizations to build awareness and use distribution list for dissemination. Timeline: Completed.
- Collaboration with Coalition committees to align effective, consistent messaging through e-blasts and updates. Timeline: Ongoing.
- Continue to ensure members have most current QELCCC collateral: Executive Summary, Matte Article, Poster/abstract, and Protocol for members sign-on for Coalition public documents /releases. Coalition documents now available on a share file easily accessible by all members.
- News Updates - QELCCC E-Blasts, are now bimonthly to ensure that members are updated more frequently. Timeline: Ongoing.

2. Build Awareness of the QELCCC and Coalition Initiatives

Objective: Raise awareness of the QELCCC with the public and major stakeholders.

Activities:

- Continue to encourage members of organizations to incorporate a “declaration” as QELCCC member and profile Blueprint for Action and 4 “asks” on their websites. The declaration was sent out with each e-blast and the committee will continue to send out the declaration and encourage members in future e-blasts. Timeline: Complete.
- Develop a Q&A, a general statement or a boiler plate, and a one pager explaining the coalition and its relationship to the CHPCA – visual diagram. Timeline: Complete. Can be found on the QELCCC file share.
- Awards committee chose a winner of the 2013 QELCCC Excellence in Advocacy Award. To be presented at the Annual Meeting. Timeline: Complete.
- Build a mini 2013 Social Media strategy – The committee has created some standard Tweets for members to post to their social media sites, these tools are available on the share file.
- Encourage members to submit articles for ehospice. Timeline: ongoing.

3. Advance Care Planning in Canada

Objective: Ensure strong representation of the views of QELCCC member organizations in the ongoing work of CHPCA’s Advance Care Planning Project.

Activities:

- Liaise with the Speak Up Team on various Advance Care Planning initiatives as necessary. Coalition members were encouraged to participate in National Advance Care Planning Day 2013.

Committee will continue to ensure that there are ACP updates in all future e-blasts. Timeline: Ongoing.

4. Continue to liaise with Parliamentary Committee on Palliative and Compassionate Care

Objective: To develop consistent messages and understanding.

Activities:

- Will continue to work with the Advocacy committee on this task. Timeline: Ongoing.

Education Committee

- Doreen Oneschuk (Chair from January-June 2013)
- Brenda Hearson
- Norma Freeman
- Kathryn Downer
- Nadine Valk
- Srinu Chary
- Sharon Baxter (Secretariat)

1. Continue to Update Available Educational Tools and Resources

Objective: Identify, via an environmental scan, QELCCC member's professional education needs i.e. wish list.

Activities:

- Will review and refresh annually. 2013 Annual refresh completed and distributed to members in March 2013.
- Each member who contributes to the Educational Resource Inventory will have their resources featured in a future edition of the e-blast to increase awareness. Timeline: Ongoing.

2. Discussion Document dissemination: The Palliative Approach Improving Care for Canadians with Life-limiting Illness

Objective: Disseminate the document and increase awareness for the palliative approach

Activities:

- Plan and conduct webinar(s) to present/generate discussion/ explore uptake of chronic disease discussion group. The Committee hosted a webinar on December 10, 2013 that was very well attended.
- Committee to maintain linkages with The Way Forward (through the Chair) for further direction and collaboration with them re: dissemination. Timeline: Ongoing.
- Café Scientific application. To be discussed.

3. Environmental scan to identify next key discussion document.

Objective: Determine future needs for hospice palliative care discussion documents

Activities:

- To be determined at a future date.

Caregiving Committee

Srini Chary and Diana Rasmussen (Co-Chairs)
Shirley DeMerchant
Doug Kellough

Tanny Nadon
Mariam Paul
Sharon Baxter (Secretariat)

1. Promote and recognize the role of family caregiving to Canadian society.

Objective: Designated caregiver day and increased awareness of caregivers. Consistent messages & understanding.

Activities:

- The Committee sent out several press releases about caregiving and National Caregiver Day through member organizations. MP Mike Wallace also made a statement in the House of Commons on the importance of National Caregiver Day. Timeline: Completed.
- The CHPCA led a very successful Caregiver Day campaign that included a webinar and marketing materials. The Committee also created a series of tweets that were sent to all Coalition members for their use. Timeline: Completed.
- Identify key messages about caregiving in Canada and liaise with CCC. Timeline: Early 2014.

2. Advocate for a caregiver strategy that provides supports for caregivers – financial and non-financial.

Objective: Increase the capacity of the members to present the economic analysis of our issues.

Activities:

- Liaise with other organizations and coalitions (such as Canadian Caregiver Coalition, partner organizations). Timeline: Ongoing
- Enhance fact sheet on CCB – to help advocacy at both national and provincial levels; include more information for elderly and end of life care leave; advocate for challenging the timeline on CCB; advocate for people who are not employed (ex: self-employed, unemployed, or retired). Timeline: Completed.

3. Promote and increase awareness of information services and resources for caregivers

Objective: Increased awareness of available caregiver resources.

Activities:

- Continue to ensure that a caregiving section is included in the e-blasts. Timeline: Ongoing
- Fact finding exercise for services and accommodations that are available for caregivers when they travel, providing treatment for patients/family members according to each P/T. This information should then be included on the website "eolcaregiver.com". This activity has been tabled until a later date.

Research Committee

- Pat Strachan (Co-chair)
- Sharon Baxter (Co-chair)
- Mireille Lecours
- Vicki Lejambe
- Nuala Kenny
- Anna Park Lala
- Christopher Klinger
- Kate Rexe
- Sharon Baxter (Secretariat)

1. Blueprint Recommendations and Next Steps

Objective: Continued research funding in hospice palliative care to advance the Blueprint priorities.

Activities:

- Liaise with the Advocacy Committee on research funding opportunities as necessary
- Send letter to funders/granting agencies congratulating them for their support of end-of-life care research. Timeline: Completed Spring 2013
- When appropriate, continue to meet with CIHR to foster linkages. Timeline: Ongoing

2. Continue to foster linkages with funding bodies focused on hospice palliative and end-of-life care.

Objective: Increase awareness of research results in the hospice palliative care field.

Activities:

- Foster relationships and influence the agenda of granting agencies (e.g CIHR) and knowledge translation partners to develop and maintain hospice palliative care as a priority. Sharon Baxter and Christopher Klinger were invited to the Best Brains Summit in winter 2013 and have followed up with letters to all CIHR institutes. Timeline: Ongoing.
- QELCCC Representatives were also invited to a CIHR strategic planning session.
- Christopher Klinger and Sharon Baxter attended a meeting with Dr. Yves Joannette, Director of the CIHR Institute of Aging, where they discussed CIHR's Aging Strategy. Timeline: Completed.

3. QELCCC role in knowledge translation of research findings relevant to hospice, palliative and end-of-life care

Objective: To ensure better knowledge of research related to hospice palliative end-of-life care.

Activities:

- Inventory of past research grantees through CIHR was created in 2012. As follow up, the Committee asked them, "Which three pieces of research would you like to share with our Committee and Why?" Committee reviewed responses and agreed to post them intermittently to ehospice and QELCCC e-blast as articles of interest. Timeline: Completed.
- Develop a template to disseminate research to members to promote interdisciplinary connections/research/support. Timeline: In progress
- Will continue to disseminate research findings in the e-blasts. Timeline: Ongoing

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.

Activities:

- Document was completed in the summer of 2013 and has been sent to all Coalition members. Committee will resume dissemination discussion in Fall 2013.

ⁱ Download: http://www.chpca.net/qelccc/information_and_resources/7_Blueprint_for_Action_Dec_2000.pdf

ⁱⁱ Website: http://www.hc-sc.gc.ca/hcs-sss/palliat/index_e.html