



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

Semi-Annual Report

July 2012

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

On June 6, 2000, the Senate of Canada issued the report *Quality End-of-Life Care: The Right of Every Canadian*ⁱ. This report was an update of the Senate's 1995 report, *Of Life and Death*ⁱⁱ. In the intervening five years, the Senate discovered that little progress had been made on its 1995 recommendations. The 2000 report contains strong recommendations to ensure that Canadians have access to high quality end-of-life care. The Quality End-of-Life Care Coalition of Canada (QELCCC) supports the recommendations made in the 2000 Senate Report.

The first recommendation of the Senate report is that the federal government, in collaboration with the provinces and territories, develop a national strategy for end-of-life care. The Canadian Hospice Palliative Care Association (CHPCA) discussed the Senate report with several of its national partner groups such as the Canadian Cancer Society, the Heart and Stroke Foundation of Canada, the ALS Society of Canada, and the Canadian Association of Retired Persons. It quickly became clear that national voluntary sector groups are concerned about end-of-life care and wish to see a well-funded, sustainable Canadian strategy that would include a strong voice of the voluntary sector and of patients and their families.

In December of 2000, a group of 24 national stakeholders met in Toronto to begin 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 (QELCCC)* and a working document entitled *Blueprint for Action (2000)*ⁱⁱⁱ. Within the QELCCC an Executive Committee and five Working Groups were established. The QELCCC has been meeting on an annual basis since 2000. The membership of the QELCCC remains strong and currently is made up of 36 member organizations.

In 2001, Health Canada announced the creation of the Secretariat on Palliative and End-of-Life Care^{iv} with the mandate to move this issue forward. The Secretariat established five Working Groups to address the following priorities: Best Practices and Quality Care; Education for Formal Caregivers; Public Information and Awareness; Research; and Surveillance. A Coordinating Committee, made up of the Co-Chairs from the Working Groups oversaw progress and provided general direction to the Working Groups. Health Canada funded the Secretariat and the Working Groups until March 2007. The Secretariat has since been disbanded.

In 2009/2010, the QELCCC 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 QELCCC 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 QELCCC 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.

On June 12, 2012 at the Hospice at May Court, the Honourable Leona Aglukkaq, Minister of Health, announced the three year initiative *The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada*. Over the course of three years, the federal government will make a commitment for one-time funding of \$3 million to help support the development of new community-integrated palliative care models across Canada. This initiative of the QELCCC will be managed by the Canadian Hospice Palliative Care Association. For more information on *The Way Forward* Initiative, please turn to page 5.

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

The QELCCC 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 palliative and end-of-life care. It is the mission of the QELCCC to work together in partnership to achieve this goal.

Member Organizations

ALS Society of Canada	Canadian Society of Respiratory Therapists
Alzheimer Society of Canada	Canadian Virtual Hospice
Canadian AIDS Society	Canadian Working Group on HIV and Rehabilitation
Canadian Arthritis Patients Alliance	Catholic Health Alliance of Canada
Canadian Association of the Deaf	Childhood Cancer Foundation Candlelighters Canada
Canadian Association of Occupational Therapists	College of Family Physicians of Canada
Canadian Association for Spiritual Care (CASC)	The GlaxoSmithKline Foundation
Canadian Association of Social Workers	Heart and Stroke Foundation of Canada
Canadian Breast Cancer Network	Huntington Society of Canada
Canadian Cancer Society	Kidney Foundation of Canada
Canadian Caregiver Coalition	Long Term Care Planning Network
Canadian Healthcare Association	Mental Health Commission of Canada
Canadian Home Care Association	National Initiative for the Care of the Elderly
Canadian Hospice Palliative Care Association	Ovarian Cancer Canada
Canadian Lung Association	The Pallium Foundation
Canadian Medical Association	Saint Elizabeth Health Care
Canadian Nurses Association	VON Canada
Canadian Pharmacists Association	
Canadian Society of Palliative Care Physicians	

Annual Meeting Report: Looking Back and Forging Ahead

An Executive Summary of the QELCCC Annual Meeting, January 19-21, 2012

Member representatives from 30 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 19-21, 2012. Members worked in both plenary sessions and individual committee groups (Advocacy, Communications and Public Awareness, Education, Family and Caregiver Support 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.

In contrast to past years, the Coalition added on an extra day to their annual meeting to discuss the proposal put through to Health Canada regarding *The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada* Initiative which was awaiting final funding approval through an Omnibus bill on January 26th, 2012. On January 19th, 2012, Sharon Baxter and project proposal writer Louise Hanvey gave the Coalition the background information on the initiative and informed them of the workplan and next steps. Some questions that were posed to the QELCCC were: What is the commitment of the coalition members to get involved and stay engaged, and is it up to the coalition to get engaged and to bring people to the table? For more information on *The Way Forward* Initiative, please turn to page 4.

In addition to the continued work on distributing the *Blueprint for Action 2010 – 2020*, each committee is committed to a number of initiatives to support the overall QELCCC goals and the priorities described in the Blueprint. A sampling of these undertakings includes: the Advocacy Committee will continue to work on an approach to making policy recommendations for the 2014 health accord; the Communications Committee will continue to Support QELCCC initiatives with timely dissemination of communications; the Education Committee assist in developing a Position Statement/Discussion Document on the Integration of Palliative Care into Chronic Diseases for *The Way Forward* Initiative; the Family Caregiver Support Committee will advocate for a caregiver strategy that provides supports for caregivers – financial and non-financial.; and finally, the Research Committee will continue to explore ways in which it can play a role in knowledge translation of the final findings of the CIHR Net Grants in Palliative Care.

With *The Way Forward* Initiative nearly in place, 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

As the population ages, the prevalence of chronic and life-limiting illnesses will increase. In response, Canada must work towards a system of community-integrated hospice palliative care. High quality hospice palliative and end-of-life care must be an integral part of health care, and available in all settings of care, including hospital, long-term/continuing care, residential hospices, shelters and individual homes. It also means that the palliative approach to care must be part of the treatment repertoire of any health care professional, supported by consultation or referral to a specialist palliative care team when necessary.

On June 12, 2012, the Honourable Leona Aglukkaq, Minister of Health, announced the three year initiative *The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada*. The Government of Canada is providing one-time funding from a Budget 2011 commitment of \$3 million to the Canadian Hospice Palliative Care Association and its partners to support the development of community-integrated palliative care models for the health care sector. Funding will be implemented through Health Canada's Health Care Policy Contribution Program (HCPCP) - Health Care System Innovation Fund, which is designed to support the Government of Canada's commitment to improving the health care system by fostering strategic and evidence-based decision-making and innovation in quality health care.

This initiative will engage all settings, sectors, professionals and governments in a dialogue regarding the implementation of community-integrated palliative and end-of-life care. Over the course of the initiative, engagement and dialogue based upon sound evidence and promising practices will also be encouraged. This will result in a Framework with targets and strategies that all stakeholders will have a hand in shaping, and that therefore reflect their needs and challenges, resulting in the ability to implement these strategies at all levels.

Over the course of the Way Forward Integration Initiative, the QELCCC and the CHPCA will:

- Change the understanding and approaches to aging among key stakeholders as it relates to:
 - chronic, serious and life-limiting illness and dying
 - hospice palliative and end-of-life care and advance care planning
- Develop a comprehensive National Framework that will enable stakeholders to move towards the community-integration of hospice palliative care across all health care settings.

Under the leadership of the 36 organizations that make up the QELCCC, this initiative will be the first time in Canada that community-integrated palliative care will be addressed in all settings of care. We will recognize all professions; all illnesses; provincial and territorial governments; and all communities, including urban, rural and remote.

This initiative will result in an understanding of community-integrated palliative and end-of-life care by all stakeholders and will therefore ultimately transform the way Canadians receive care and the quality of their life and death. It is time to move forward.

To learn more about *The Way Forward* Initiative, please contact Savannah Ashton, Project Assistant at (613) 241-3663 ext. 228 or email info@hpcintegration.ca.

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 a number of times between January and June, 2012. 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 help ensure access to quality hospice palliative and end-of-life care in Canada. Part of the role of the Executive Committee is to invite and review all requests to join the QELCCC. In late June 2012, the QELCCC welcomed the Women's Inter-Church Council of Canada as their newest member.

The Executive is responsible for addressing the issue of fundraising and sustainability for the Coalition. The Executive Committee successfully obtained funding from Health Canada for the annual meeting in January, allowing for travel subsidies to be provided to members who attended the face-to-face meeting.

The Executive also assisted with *The Way Forward* proposal which resulted in a 3 million dollar commitment from Health Canada. The members of the Executive Committee of the QELCCC will play a crucial role in *The Way Forward* Initiative through their participation on the Initiative's Advisory Committee. The Advisory Committee had their first face-to-face meeting on March 22, 2012 in Toronto, Ontario.

Advocacy Committee

- Melody Isinger (Chair)
- Stephen Alexander
- Bobbi Greenberg
- Nadine Henningsen
- Denise Page
- Sharon Baxter (Secretariat)

1. Influence Government

Objective: Use of QELCCC messaging.

Activities:

- Use key messages, asks and vignettes (leave behind packages). Remind member organizations developing briefs to the finance committee to identify palliative care issues. Packages sent to MP's and Senators in April 2012. Timeline: Ongoing
- Coordinate a "hill day" for the fall and invite selected ministers of parliament and senators. Timeline: Fall 2012

2. Election Toolkit

Objective: Identify end-of-life care as a socio-economic issue.

Activities:

- Adapt and update existing tools and circulate to members to encourage them to include it in their election packets.

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

Objective: Raise awareness of the QELCCC to Members of Parliament

Activities:

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

Next Steps:

- Monitor Hansards and send out letters as required. Timeline: Ongoing.
- Create a list of parliamentary champions in hospice palliative care. Add any MP or Canadian Celebrity who mentions HPC or ACP. Timeline: Completed

4. 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. Timeline: Fall 2012
- Facilitate uptake of new Model from the updated Norms of practice. Timeline: Summer 2013
- Engage in discussion of national indicators and surveillance. Timeline: Spring 2013

Next Steps:

- At a National meeting on March 23, 2012, the discussion began on accreditation and indicators. The committee will take up this topic in the fall of 2012.
- Create a blog post linking the QELCCC member groups. Timeline: Fall 2012

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: Fall 2012

Communications Committee

- Bobbi Greenberg (Chair)
- Shelagh Campbell-Palmer
- Alison Pozzobon
- Judy Donovan-Whitty
- Sharon Baxter (Secretariat)

1. Timely Dissemination of Relevant Communications to QELCCC Members

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

Activities:

- Collaboration with Coalition Committees to align effective, consistent messaging through E-blasts and updates.
- Ensure member's communications' lead contacts are current. Reminders to be sent out in spring and fall E-blasts.
- 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.
- News Updates - QELCCC E-Blasts, important news and articles of interest from the various committees.

Next Steps:

- Update communications lead list as member organizations experience personnel changes. Timeline: Completed Spring 2012, updates ongoing
- Continue to ensure members have the most current QELCCC collateral. Timeline: Ongoing as new collateral becomes available
- Continue to collaborate with Coalition committees to align effective, consistent messaging. Timeline: Ongoing
- Continue to send out quarterly QELCCC e-blasts. Next issue: Fall 2012

2. Build Awareness of the QELCCC and Coalition Initiatives

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

Activities:

- Secure grant for communications strategy for the QELCCC to leverage web technology for raising public awareness of end-of-life care. Website currently being re-developed for easier accessibility. Timeline: Summer 2012
- Continue to encourage members to incorporate a "declaration" of respective organization as QELCCC member, declaration sent out with the spring E-blast. Timeline: Ongoing
- Build profile of the QELCCC through media. The Committee continues searching for media coverage opportunities. Article published in April issue of Hospital News. There was also media coverage around *The Way Forward* announcement in June 2012. Timeline: Ongoing
- Awards committee has been struck and will begin brainstorming for QELCCC awards. Timeline: Summer 2012

Next Steps:

- Continue the use of the information E-blast when appropriate. Next issue: Fall 2012

- Interview HPC patients and create vignettes or articles. Timeline: Fall 2012

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:

- Following ACP Awareness Campaign launch, conduct survey with members re response/uptake of campaign. Timeline: Survey completed, to be sent to membership in Fall e-blast.
- Included an update on the success of the ACP launch and ACP day in the Spring E-blast.

Next Steps:

- Continue to share strategic updates on ACP project milestones. Timeline: Ongoing
- Encourage member organizations to promote and publicize the upcoming ACP day, April 16, 2013

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

Objective: To develop consistent messages and understanding.

Activities:

- Wrote letters to 51 committee members asking them to be champions and speak to 10 people "the power of 10" in the lead up to a fall hill day. Timeline: Completed
- Insert hospice palliative care information into MP "householders." Timeline: Fall 2012

Next Steps:

- Continue to promote the report and liaise with the Committee on next steps. Timeline: Ongoing

5. Communications Strategy

Objective: To develop a sustainable Communications Strategy for the Coalition

Activities:

- Secure grant for communications strategy for QELCCC to leverage web technology for raising public awareness of end-of-life care. (Hike for Hospice, Blueprint for Action 2010, social marketing, webinars) Timeline: Completed
- Develop a communications strategy for QELCCC and Integration Project. Timeline: Fall 2012
- *Canadian Healthcare Network* (e-newsletter) – explore re; publishing communications. Timeline: Spring 2013

Professional Education

- Doreen Oneschuk (Chair)
- Romayne Gallagher
- Marilyn Sapsford
- Mary Schulz
- Srinu Chary
- Sharon Baxter (Secretariat)

1. Conduct an Environmental Scan of QELCCC Members of Available Educational Tools and Resources

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

Activities:

- Environmental scan redeveloped and redistributed to members. Includes two rounds of follow up with the member organizations that did not respond.
- Will review and refresh annually. 2012 Annual refresh completed and distributed to members in March 2012.

Next Steps:

- Send requests for updates through E-blasts. Timeline: Ongoing

2. Brief/Issues Paper on Palliative Approach/End-of-Life Care Integration in emerging Chronic Disease Prevention and Management (CDPM)

Objective: Ensure more realistic Federal/Provincial/Territorial level CDPM framework inputs.

Activities:

- Two papers have stemmed from this topic idea, one on chronic disease management and the other on the palliative approach. The first paper has been completed and is currently under review. Timeline: Ongoing.

Next Steps:

- Continue to follow and review palliative approach document currently being written by Jean Bacon. Timeline: Fall 2012

Family Caregiver Support Committee

Bonnie Schroeder (Chair) (January-March 2012)
Denise Page (Chair) (June 2012-present)
Doug Kellough
Anne Roberts

Tanny Nadon
Marlene Chatterson
Shelly Cory
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 Caregiving Day through member organizations.
- The CHPCA led a very successful Caregiver day campaign that included a webinar, tweetchat and marketing materials. The Canadian Virtual Hospice released a series of successful caregiver videos.

Next Steps:

- Identify key messages about caregiving in Canada. Timeline: Ongoing
- Include caregiving statistics and information in advocacy kits. Timeline: Ongoing

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
- Liaise with finance department to promote and new tax credit. Timeline: Ongoing
- Fact sheet on CCB – to help advocacy at both national and provincial. Timeline: Ongoing
- In 2013 host a national day on the hill. Timeline: Spring 2013

Next Steps:

- Continue to promote and increase awareness of information available for caregivers to the Coalition members and to the public. Timeline: Ongoing
- Submit a brief to the finance committee. Timeline: Fall 2012

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

Objective: Increased awareness of available caregiver resources.

Activities:

- Created a dedicated space of the QELCCC E-blast for caregiving resources. Timeline: Completed

Next Steps:

- Continue to communicate information and resources to coalition members and the hospice palliative care community. Timeline: Ongoing
- Monitor and assist with CHPCA's Caregiving KT efforts. Timeline: Summer-Fall 2012

Research Utilization Committee

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

1. a) Continue to Foster Linkages with CIHR-funded Net Grants and Other Relevant Research Projects

b) Continue to Foster Linkages and Build on past Relationship with CIHR

Objective: Continue to build relationships between QELCCC and CIHR-funded Net Grants and other research projects around hospice palliative and end-of-life care.

Activities:

- Advocate for the synthesis of the findings of the 2009 list of Net grants. Timeline: Ongoing
- Continued to search for relevant CIHR grant applications
- Foster relationships with granting agencies (i.e., CIHR) and knowledge translation partners to develop and maintain HPC as a priority. Timeline: Ongoing

Next Steps:

- Reach out to other QELCCC members to share current research projects and findings. Timeline: Fall 2012
- Continue to meet with CIHR to foster linkages, when appropriate
- Write a letter to CIHR detailing why HPC is so important and the impact research has had on health care. Timeline: Fall 2012
- Continue to encourage QELCCC members to submit new and upcoming research initiatives and research findings relevant to the blueprint priorities to the Secretariat. Timeline: Ongoing

2. QELCCC Role in Knowledge Translation of Findings Generated by CIHR Research Projects

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

Activities:

- CHPCA research initiative concentrated on Pediatrics, CARENET/ACP and Caregiving issues - story lines for National Caregiver Day (April 5th, 2011) and National Advance Care Planning Day (April 12th, 2011) were distributed to the Committee for review and then distributed widely.
- The Committee is also reviewing past grants and research.

Next Steps:

- Review of past grants and research to be completed. Timeline: Ongoing
- Encourage QELCC members to submit new and upcoming research initiatives and research findings relevant to the blueprint priorities to the Secretariat (submitted criteria must be summarized 3-5 bullet points, include blueprint priority label, and reference/link—no documents). Timeline: Summer-Fall 2012

3. Liaise with QELCCC members to ascertain their interest in poster and workshop presentations at their conferences

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

Activities:

- NICE presented the QELCCC posters at their national conference.
- CHPCA presented the posters at their Learning Institute.
- The QELCCC posters have been accepted to the International Palliative Care Congress in October 2012.

Next Steps:

- Encourage coalition members to use the posters, workshops and presentations at their own conferences and meetings. Timeline: Ongoing
- Revise QELCCC Poster – Add Integration Initiative to outcomes. Integration poster creation TBD. Timeline: Fall 2012

4. Explore the current state of general indicators for palliative care

Objective: Improved knowledge of indicators.

Activities:

- The committee discussed this item briefly and has placed it aside for the time being, will take up this discussion in Winter 2012.

Next Steps:

- Collaborate with the CHPCA and other groups around developing indicators for hospice palliative and end-of-life Care (Accreditation Canada). Timeline: Ongoing

5. Blueprint Recommendation, Implementation and Next Steps

Objective: Advocate for continued research funding in hospice palliative care.

Activities:

- Added a recommendation in the 2011 Election Kit about research funding.

Next Steps:

- Look for research findings to validate our position (s) and advocate for access, funding and caregiving. Timeline: Ongoing

ⁱ Website: <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm>

ⁱⁱ Website: <http://www.parl.gc.ca/35/1/parlbus/commbus/senate/Com-e/euth-e/rep-e/LAD-TC-E.HTM>

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

^{iv} Website: http://www.hc-sc.gc.ca/hcs-sss/palliat/index_e.html