



Semi-Annual Report

July 2009

Table of Contents

Background	1
Mission and Mandate of the Quality End-of-Life Care Coalition of Canada	1
Quality End-of-Life Care Coalition of Canada: Member Organizations	2
More Information:	2
Annual Meeting Report: Looking Back and Forging Ahead	3
Executive Committee Report	4
Advocacy Committee (AC).....	5
1.0 Brief to Privy Council	5
2.0 Influence Finance Committee	5
3.0 Review Blueprint for Action (2000)	5
4.0 Review Key Messages and Asks.....	5
5.0 Liaise and Rebuild Relationship with Health Canada.....	6
6.0 Introduce Social Dimensions of Death and Dying into the Dialogue of Palliative Care	6
Communications	6
1.0 Internal Relations: Engage Current Members to Communicate QELCCC Platforms to Respective and Network Organizations	6
2.0 Develop New/Enhance Current Outreach Vehicles for Resourcing and Engagement	6
3.0 New News	7
4.0 Coalition Engagement.....	7
5.0 Coalition Messaging	7
Education	7
1.0 National Associations Engagement Strategy	8
2.0 Brief/Issues Paper on Palliative Approach/End-of-Life Care Integration in emerging Chronic Disease Prevention and Management (CDPM)	8
Family & Caregiver Support Committee (F&CSC)	8
1.0 Caregiver Recognition	8
2.0 Canadian Strategy for Support Services for Canadian Informal/Family Caregivers	9
3.0 Caregiver Web Portal.....	9
4.0 Compassionate Care Benefit – Ongoing Expansion and Improvement of the Benefit.....	9
Research Utilization Committee (RUC)	10
1.0 Continue to Foster Linkage with CIHR-funded Net Grants and Other Relevant Research Projects.....	10
2.0 QELCCC Role in Knowledge Translation of Findings Generated by CIHR Research Projects.....	10
3.0 Share Research Information with QELCCC Member Organizations	10

Background

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 (formerly the Canadian Palliative Care Association) 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 Quality End-of-Life Care Coalition of Canada an Executive Committee and five Working Groups were established. The QELCCC 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 *Blueprint for Action*. The membership of the Quality End-of-Life Care Coalition of Canada remains strong and currently is made up of thirty-one member organizations. (Refer to membership list for details)

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 remains operational, but with severely limited financial resources to provide project funding.

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

The Quality End-of-Life Care Coalition of Canada 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 Quality End-of-Life Care Coalition of Canada to work together in partnership to achieve this goal.

Quality End-of-Life Care Coalition of Canada: Member Organizations

ALS Society of Canada
Alzheimer Society of Canada
Canadian AIDS Society
Canadian Arthritis Patients Alliance
Canadian Association of the Deaf
Canadian Association of Occupational Therapists
Canadian Association for Pastoral
Practice and Education (CAPPE)
Canadian Association of Social Workers
Canadian Breast Cancer Network
Canadian Cancer Society
Canadian Caregiver Coalition
Canadian Healthcare Association
Canadian Home Care 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
Caregiver Network
CARP: Canada's Association for the Fifty-Plus
Catholic Health Association of Canada
Childhood Cancer Foundation Candlelighters Canada
College of Family Physicians of Canada
The GlaxoSmithKline Foundation
Heart and Stroke Foundation of Canada
Huntington Society of Canada
National Council of Women of Canada
The Pallium Project
VON Canada

More Information:

<http://www.gelccc.ca>

Annual Meeting Report: Looking Back and Forging Ahead

An Executive Summary of the QELCCC Annual Meeting, January 23-24, 2009

Member representatives from 20 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 23-24, 2009. 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.

One of the most notable accomplishments was the production and distribution of *Hospice Palliative Home Care in Canada: A Progress Report*. The report garnered significant media attention nationally, drawing attention to not only the issue of disparity in hospice palliative home care programs, services and pharmaceuticals available among the provinces, but also to the issue of end-of-life care generally.

Members also reviewed the *Blueprint for Action*, an inventory of gaps in end-of-life care in Canada that was created in 2000, with the formation of the QELCCC. A quick superficial review of the *Blueprint* revealed that some needs for end-of-life care have been addressed through a variety of Canadian initiatives; however, it also revealed that gaps still exist, and members agreed that working toward filling those gaps would benefit from the guidance of an updated *Blueprint*. To that end, QELCCC members decided that in the coming months, it will conduct a thorough environmental scan, and then forge a new *Blueprint*, ready to guide the QELCCC committees and to release to the end-of-life care community in early 2010.

In addition to the anticipated work on the *Blueprint*, each individual committee is also committed to a number of initiatives to support the overall QELCCC goals. A sampling of these undertakings includes: the Advocacy Committee will work on approaches to having death and dying recognized as a socio-economic determinant of health; the Communications Committee will explore more efficient and effective means of internal and external communication; the Education Committee will create an issues paper on end-of-life care integration in emerging Chronic Disease Prevention and Management; the Family and Caregiver Support Committee will seek new avenues to recognize the contribution of caregivers to Canadian society; and finally, the Research Committee will 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 a new *Blueprint* in place, the advocacy efforts of the QELCCC, 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 its complete workplan, please visit www.qelccc.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 (Canadian Hospice Palliative Care Association [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 three times between January and July, 2009. Part of the role of the Executive Committee is to ensure the clarity of the terms of reference for membership. The Executive Committee completed a major revision to the QELCCC Terms of Reference, as well as the Terms of Reference for the Committee itself. All requests to join the QELCCC were postponed until the QELCCC Terms of Reference review was complete; the Executive Committee will review all requests in the second half of this year.

Another role of the Executive Committee is to address fundraising and sustainability issues. The Executive Committee successfully obtained funding for its annual meeting in January, allowing for deaf translation costs to be covered.

Finally, the Executive Committee has begun work on its biggest undertaking of the year: reviewing and revising the *Blueprint for Action (2000)*. As discussed by the members at the annual meeting in January, after nearly a decade of having its activities guided by the *Blueprint for Action (2000)*, many of the conditions that existed when the Blueprint was created have now changed, necessitating some alteration of the QELCCC's activities. A thorough environmental scan will be completed; each of the working committees will review the portion most relevant to their focus, and a review will be conducted to ascertain new programs and services that may have appeared in the intervening years. The Executive Committee has begun the review with a survey distributed to all QELCCC member groups, and will evaluate the results, as well as seek new information, to prepare for a more thorough review in the fall.

Advocacy Committee (AC)

Committee Members:

Melody Isinger (Chair)
Stephen Alexander

Evelyne Gounetenzi
Sharon Baxter (Secretariat)

1.0 Brief to Privy Council

Objective: Raise awareness of social dimensions of death and dying.

Activities:

- Use key messages and asks developed in the past year to create tailored leave-behind packages for bureaucrats, public officials and elected representatives. Timeline: 2009

2.0 Influence Finance Committee

Objective: Raise awareness of how multi-faceted palliative care is and increase funding.

Activities:

- Remind member organizations developing briefs to the Finance Committee to identify palliative care issues. Timeline: Ongoing

3.0 Review Blueprint for Action (2000)

Objective: Assess Blueprint for Action (2000) for relevance and changed environment in relation to advocacy goals.

Next Steps:

- Under the leadership of the Executive Committee, which is overseeing the Blueprint review, review the Advocacy section, making note of any changes to social and political context, as well as provide advice to the Executive Committee about new goals to incorporate. Timeline: Fall 2009.

4.0 Review Key Messages and Asks

Objective: Review to assess validity; survey member organisations to discover if and when key messages and asks were used.

Activities:

- QELCCC Member organisation representatives were surveyed at the annual meeting. Several had made use of the key asks, whether individually or collectively. Some had incorporated them into their pre-existing material, while others had made use of them in their QELCCC draft form.
- The key asks were also reviewed for phrasing. It was determined that it was necessary to abbreviate them, so as not to lose the message in the midst of too many words.

Next Steps:

- The key messages will be shortened and circulated for approval. Timeline: Summer 2009

5.0 Liaise and Rebuild Relationship with Health Canada

Objective: Strengthened relationship with HC, particularly the Palliative and End-of-Life Care Unit.

Next Steps:

- Submit proposals for possible projects for Health Canada funding. Timeline: Ongoing

6.0 Introduce Social Dimensions of Death and Dying into the Dialogue of Palliative Care

Objective: Have death and dying recognized as a social determinate of health

Next Steps:

- Create a collection of vignettes of the impact of death and dying on family (of choice) caregivers. Timeline: Fall 2009

Communications

Committee Members:

Karen Chow (Chair)
Shelagh Campbell-Palmer

Bobbi Greenberg
James Roche

Sharon Baxter (Secretariat)

1.0 Internal Relations: Engage Current Members to Communicate QELCCC Platforms to Respective and Network Organizations

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

Activities:

- Members were asked to confirm organizational main contact and communications leads.
- Members identified their organization's communications lead, and a "communications" contact list has been established for each member organization and network organizations.
- A matte article was written, summarizing the January meeting. It is included at the beginning of this report.
- A statement was drafted regarding the QELCCC position on assisted suicide/euthanasia.

Next Steps:

- Update communications lead list as member organizations experience personnel changes. Timeline: Ongoing
- The matte article will be included in the semi-annual report. Timeline: July 2009

2.0 Develop New/Enhance Current Outreach Vehicles for Resourcing and Engagement

Objective: Increase awareness and visibility of QELCCC within current and network organizations

Activities:

- The communication protocol for external documents that was developed last year, was explicitly stated in a document.
- Explore ways to highlight and communicate to members "new news" on the QELCCC website (eg. Semi-annual email blast) – timed to coincide with the semi-annual and annual reports

- Wrote and submitted a proposal to Health Canada for research on feasibility of utilizing social networking for increasing public awareness of end-in-life care.
- Pitched article idea about advance care planning to Family Caregiver editor. No interest was expressed.
- A “flash” link was created from the CHPCA website to the QELCCC website.

Next Steps:

- Upon approval of the wording in the communication protocol, it will be distributed to all QELCCC members. Timeline: August 2009
- Upon approval of the wording in the position statement regarding assisted suicide/euthanasia, it will be distributed to all QELCCC members. Timeline: September 2009

3.0 New News

Objective: Increase awareness and visibility of QELCCC within current and network organizations

Activities:

- Information packages regarding National Hospice Palliative Care Week were distributed to all QELCCC members.

Next Steps:

- Implement regular e-mail updates to all QELCCC members (following Executive teleconferences). Timeline: August 2009
- World Hospice Palliative Care Day materials will be distributed to all QELCCC members. Timeline: September 2009

4.0 Coalition Engagement

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

Next Steps:

- Share strategic framework from March expert roundtable, as well as environmental scan and meeting report, when available.

5.0 Coalition Messaging

Objective: Ensure clarity of key messages to enable their effective use by QELCCC member organizations.

Next Steps:

- Work with Advocacy Committee to readdress/revise QELCCC Key Message #3. Timeline: September 2009

Education

Committee Members:

Doreen Oneschuk (Michael Aherne until May 2009) (Chair)

Trina Epstein
Romaine Gallagher

Debbie Gravelle
Buffy Harper

1.0 National Associations Engagement Strategy

Objective: Foster a deeper understanding of, and commitment to, end-of-life care at the associational level among QELCCC and other relevant national associations.

Activities:

- Environmental scan started, as part of the process of reviewing the *Blueprint for Action (2000)*.

Next Steps:

- Identify specific champions within QELCCC and other organizations who are willing and able to promote the inclusion of end-of-life care considerations in the association's activities. Timeline: Fall 2009
- Meet with champions and QELCCC to establish common foundations/ understanding/priorities and agree to goals. Timeline: Winter 2009 (as part of the *Blueprint for Action (2000)* review)
- Develop new foundational document to outline long term (*Blueprint 2020*) priorities. Timeline:

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

Objective: Ensure more realistic F/P/T level CDPM framework inputs.

Activities:

- Proposal submitted to Health Canada for possible funding for this project.

Next Steps:

- Search existing literature for relevant research, current practices, etc. Timeline: Fall 2009
- Create "Draft for Discussion". Timeline: Fall 2009
- Consult with other QELCCC member organizations, as well as other relevant national associations; revise Draft based on their input. Timeline: Winter 2010
- Distribute Issues Paper via CHPCA communication channels. Timeline: Winter 2010

Family & Caregiver Support Committee (F&CSC)

Committee Members:

Denise Page (Chair)

Shirley Browne

Maggie Fietz (Marlene Chatterson until May 2009)

Karen Henderson

Joan MacDonald

Colleen Murray

Diana Rasmussen

Doris Rossi

Jo Anne Watton

Sharon Baxter (Secretariat)

1.0 Caregiver Recognition

Objective: Promote recognition and acknowledgement of the contribution of caregivers to Canadian society (economic, social, health care system, etc.)

Activities:

- Worked with the Canadian Cancer Society, the Canadian Caregiver Coalition and Raymonde Folco, MP, to organize a Lunch on the Hill for MPs and Senators, to educate them about caregiver issues.

Next Steps:

- Submit request for a Canadian Caregiver Day. Timeline: Fall 2009
- Identify key messages about caregiving in Canada. Timeline: Fall 2009

2.0 Canadian Strategy for Support Services for Canadian Informal/Family Caregivers

Objective: Ensure that a basket of services, containing a variety of supports, both financial and non-financial, is available to every Canadian informal/family caregiver..

Activities:

- Worked together with Raymonde Folco, MP, (and/or Peter Stoffer, MP) to support her efforts to introduce legislation requiring the government to provide a variety of supports for informal/family caregivers. The legislation will be drafted over the summer.

Next Steps:

- Obtain information from disease-specific organizations to determine what their needs are for supporting their caregivers. Timeline: Fall 2009
- Research caregiver support (e.g. respite care, financial support, etc.) in other first-world countries. Timeline: Fall 2009

3.0 Caregiver Web Portal

Objective: Improve access to information for caregivers, via an easily accessible web-based information portal/collection of information relevant to all caregiver concerns (e.g. information on caregiver support services in your area, respite services, dementia information) e.g. Carers Australia.

Activities:

- It has been established that VON's caregiver portal may be suitable for end-of-life caregiver purposes. VON has agreed to join the next teleconference to provide more detail to the committee.

Next Steps:

- Review VON caregiver portal to determine its potential for end-of-life care issues. Timeline: Fall 2009

4.0 Compassionate Care Benefit – Ongoing Expansion and Improvement of the Benefit

Objective: Increase provincial and local advocacy efforts for expanding upon or adding to the Compassionate Care Benefit

Activities:

- Monitored Service Canada regarding updates to the Compassionate Care Benefit. No changes have been made.

Next Steps:

- Continue to monitor proposed changes to the Compassionate Care Benefit. Timeline: Ongoing

Research Utilization Committee (RUC)

Committee Members:

Diane Hartling

Joan Lesmond

Sharon Baxter (Secretariat &

Mireille Lecours

Kathy Van Bentham

Chair)

1.0 Continue to Foster Linkage with CIHR-funded Net Grants and Other Relevant Research Projects

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:

- Met with Judy Bray regarding continuation of funding for Net Grants.
- Held teleconference with

Next Steps:

- Continue to share info from the Research Utilization Committee and the research list serve. Timeline: Ongoing.

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

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

Activities:

- Met with Ian Graham regarding knowledge translation concerns for the CIHR funded Net Grants.

Next Steps:

- Disseminate the mid term findings of the net grants
- Work with interim outcomes and distill knowledge translation policy and clinical gems. Timeline: Ongoing

3.0 Share Research Information with QELCCC Member Organizations

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

Activities:

- Liaised with QELCCC coalition members to ascertain their interest in poster, workshop and presentations at their conferences.

Next Steps:

- Share research information with QELCCC member organizations. 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