



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

Annual Report

December 2009

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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 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 Inc.
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
Ovarian Cancer Canada
The Pallium Project
Saint Elizabeth Health Care
VON Canada

More Information:

<http://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 a number of times between January and December, 2009. Part of the role of the Executive Committee is to solicit new Coalition members and this year, is continuing in its efforts to broaden the membership base of the Coalition. Saint Elizabeth Health Care joined the Coalition in November, and the Ovarian Cancer Canada, in December.

The Executive Committee was responsible for overseeing the review of the *Blueprint for Action* and the development of *10 Years Later: A Progress Report on the Blueprint for Action – 2000*. With a number of consultation periods for comment from the members, this remained the Executives main focus. A proposal was developed and approved by Health Canada for funding of the launch of the *Progress Report*, taking place on January 28th, 2010

Advocacy Committee (AC)

Committee Members:

Melody Isinger (Chair)
Evelyne Gounetenzi

Stephen Alexander
Bobbi Greenberg

Nadine Henningsen
Sharon Baxter (Secretariat)

1.0 Brief to Privy Council

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

Activities:

- Continue to use key messages and asks developed in the past year to create tailored leave-behind packages for bureaucrats, public officials and elected representatives. Timeline: Ongoing
- Finalize the vignettes for use with the key messages. Timeline: Winter 2010

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.

Activities:

- Under the leadership of the Executive Committee, which oversaw the Blueprint review, reviewed 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.

Next Steps:

- Work together with the Communications Committee to disseminate the *Blueprint Progress Report*. Timeline: Winter 2010

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:

- The key messages were circulated and approved. Members continue to use the key messages and asks when meeting with political figures and other organizations.

5.0 Liaise and Rebuild Relationship with Health Canada

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

Activities:

- Met with Clarke Olsen, Minister of Health's Office. With an interest and an understanding of end-of-life care, he has provided inside support for the QELCCC to get meetings with departmental officials that have been difficult to get meetings with in the past.

Next Steps:

- Continue communications with Health Canada and other departments on issues related to end-of-life care. Timeline: Ongoing
- Schedule meetings with the Public Health Agency of Canada, Seniors Division and Chronic Disease Management Division of Health Canada and Senator Lebreton with the help of Clarke Olsen. Timeline: Winter 2010
- 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

Activities:

- Developed key interview questions, performed the interviews and created three draft vignettes.

Next Steps:

- Finalize the draft vignettes for use in meetings with government and others to create an impact of death and dying on family (of choice) caregivers. Timeline: Winter 2010

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:

- Engage QELCCC members in the dissemination process of the Blueprint progress report.

Next Steps:

- Update communications lead list as member organizations experience personnel changes. Timeline: Ongoing

- Develop and provide members with communication tools (ie. articles, executive summary etc) about the blueprint progress report to help members extend information to their networks. Timeline: Winter 2010

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:

- Explore ways to highlight and communicate to members “new news” on the QELCCC website (eg. Semi-annual email blast, quarterly email blast) – timed to coincide with the semi-annual and annual reports. Timeline: Ongoing
- Wrote and submitted a proposal to Health Canada for research on feasibility of utilizing social networking for increasing public awareness of end-of-life care. However, the Health Canada proposal protocol has changed; the committee will revisit this in 2010.
- A “flash” link has been created on the CHPCA website home page to the QELCCC website.

Next Steps:

- Upon approval of the wording in the position statement regarding assisted suicide/euthanasia, it will be distributed to all QELCCC members. Timeline: Winter 2010
- Look into opportunities for coordinating formal media training for QELCCC members/spokespeople. Timeline: 2010
- Revisit the Health Canada proposal for research on feasibility of utilizing social networking for increasing public awareness of end-of-life care. Timeline: 2010

3.0 New News

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

Activities:

- Information packages regarding National Hospice Palliative Care Week were distributed to all QELCCC members.
- An updated electronic Election kit was distributed to all QELCCC members.

Next Steps:

- Implement regular (quarterly) e-mail updates to all QELCCC members (following Executive teleconferences). Timeline: 2010
- Distribute information packages regarding the 2010 National Hospice Palliative Care Week to all QELCCC members. Timeline: March 2010

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 (ACP) Project.

Next Steps:

- Share strategic framework from March expert roundtable, as well as environmental scan and meeting report, when available. Timeline: Winter 2010

- Continue to send information regarding the ACP project consultations to the QELCCC members as information becomes available. Timeline: Ongoing

5.0 Review Blueprint for Action (2000)

Objective: Assess Blueprint for Action (2000) for relevance and changed environment in relation to communication goals. Develop a communication/dissemination strategy for the Blueprint progress report.

Activities:

- Reviewed the progress report paying close attention to areas relating to communication and making note of any changes to social and political context.
- Developed a communication and dissemination strategy for the Blueprint progress report.

Next Steps:

- Develop communication tools for the QELCCC members to disseminate the progress report and recommendations within their networks. Timeline: Winter 2010
- Determine criteria for QELCCC spokespeople. Timeline: Winter 2010

Education

Committee Members:

Doreen Oneschuk (Michael

Aherne until May 2009) (Chair)

Trina Epstein

Romayne Gallagher

Debbie Gravelle

Buffy Harper

Larry Librach

Mary Schulz

Sharon Baxter (Secretariat)

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:

- Questions developed and environmental scan distributed to a list of organizations with an interest in end-of-life care/education. The Environmental scan did not garner the responses the committee had hoped, as a result, the committee will seek guidance on the formation of new questions and resend a more focused survey to particular champions as follow up.

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: 2010
- Meet with champions and QELCCC to establish common foundations/understanding/priorities and agree to goals. Timeline: Winter 2010
- Develop new foundational document to outline long term (Blueprint 2020) priorities. Timeline: 2010

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.

Next Steps:

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

Family & Caregiver Support Committee (F&CSC)

Committee Members:

Denise Page (Chair)
Shirley Browne
Maggie Fietz (Marlene
Chatterson until May 2009)
Karen Henderson

Bonnie Schroeder (Joan
MacDonald until September
2009)
Colleen Maloney
Diana Rasmussen

Doris Rossi
Jo Anne Watton
Holly Vengroff
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: Winter 2010
- Identify key messages about caregiving in Canada. Timeline: Winter 2010

2.0 Canadian Strategy for Support Services for Canadian Family Caregivers

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

Activities:

- Presented to the Senate’s Standing Committee on Finance regarding Bill C-56, An Act to amend the Act on Employment Insurance.

Next Steps:

- Obtain information from disease-specific organizations to determine what their needs are for supporting their caregivers. Timeline: Fall 2010
- Research caregiver support (e.g. respite care, financial support, etc.) in other first-world countries. Timeline: Fall 2010

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 agreed to provide more information on their portal at the January face-to-face meeting.

Next Steps:

- The committee will work towards increasing the awareness of others to the availability of useful web tools and resources such as VON's Caregiver Portal, *Carers Australia*. Timeline: Winter 2010

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.
- Presented to the Senate's Standing Committee on Finance regarding Bill C-56, An Act to amend the Act on Employment Insurance and highlighted the need to increase the benefit period for the Compassionate Care Benefit.

Next Steps:

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

Research Utilization Committee (RUC)

Committee Members:

Michael Aherne
Diane Hartling

Mireille Lecours
Joan Lesmond

Janet Jull
Sharon Baxter (Secretariat & 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.

Next Steps:

- Continue to share info from the Research Utilization Committee and the research list serve. Timeline: Ongoing.
- Review the recommendations in the CIHR's highlights and conclusions report developed following the completion of the Net Grants. Recommendations to be considered while developing the committee's workplan for 2010. Timeline: Winter 2010

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:

Next Steps:

- Discuss how the committee and the QELCCC support knowledge translation and what our role is.
- 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:

- Disseminate the CIHR's highlights and conclusions report developed following the completion of the Net Grants.
- 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