



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

Annual Report

December 2008

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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 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
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
Health Charities Coalition of Canada
Heart and Stroke Foundation of Canada
Huntington Society of Canada
Long Term Care Planning Network Inc.
National Council of Women of Canada
The Pallium Project
VON Canada

More Information:

<http://www.gelccc.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 twice between January and July, 2008. 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. The Canadian Society of Respiratory Therapists joined the Coalition in January, and the College of Family Physicians of Canada, in May.

Another role of the Executive Committee is to address fundraising and sustainability issues. The Executive Committee successfully obtained funding to complete a project to produce *Hospice Palliative Home Care in Canada: A Progress Report*, as well as to work with a public relations firm to ensure its successful media launch.

Advocacy Committee (AC)

Committee Members:

Melody Isinger (Chair)

Stephen Alexander

Romayne Gallagher

Evelyne Gounetenzi

Bobbi Greenberg

Denise Page

Sharon Baxter (Secretariat)

1.0 Develop Key Messages for Advocacy Related to Election

Objective: Create a set of clearly defined key messages and asks of the federal government, to help focus messaging among Coalition members as they create their own advocacy and election strategies, thus amplifying the key messages.

Activities:

- Received and reviewed draft Asks statement developed by Canadian Cancer Society and CHPCA.
- Added language about holding consultations (community, consumer) to look at bundling programs, such as improving the compassionate care benefit to support caregivers
- Developed key message to present to the coalition as an “ask” in case of an early election (e.g., a year at the beginning of life, a year at the end of life – but not an employment based program; right setting, right time, right services [to reinforce the need for services in all five settings])
- Developed short-term “asks” (e.g. enhance compassionate care benefit, fund coordinator for coalition, fund roundtable consultation) and long-term “asks” (e.g. tax credits and/or benefits programs – so not all benefits are tied to earning income) from the federal government
- Asked member organizations to incorporate key messages into their election strategies

Next Steps:

- Create a policy paper, detailing a roster of approaches to meet the needs of Canadians.
Timeline: 2009

2.0 Progress Report on Pan-Canadian Gold Standards for Palliative Home Care

Objective: Produce an evaluative report on the level of compliance with and implementation of the recommendations contained in the “Pan-Canadian Gold Standards for Palliative Home Care” among the federal, provincial and territorial governments, and use the report as a tool to advance advocacy efforts.

Activities:

- Served as advisory committee, guiding the creation of the Progress Report.
- Received and reviewed Progress Report, offering feedback to its writer and the project coordinator, as required.
- Assisted with the development and review of key messages for the media
- Identified groups or individuals in provincial and federal governments and associations to target messages to, in order to better leverage change
- A presentation was developed and delivered at the Canadian Hospice Palliative Care Conference that offered ideas on using the Progress Report as an advocacy tool.

Next Steps:

- Identify ongoing opportunities to leverage the results contained in the Progress Report to advance advocacy efforts. Timeline: Ongoing

3.0 Brief to the Privy Council

Objective: To further leverage awareness at the federal Cabinet level of the issues related to end-of-life care.

Next Steps:

Develop a Brief for presentation to the Privy Council Committee. Timeline: 2009

4.0 Brief to the Finance Committee

Objective: Encourage the federal government to dedicate funding to hospice palliative programs, services and research

Next Steps:

- Develop a Brief for presentation to the Finance Committee. Timeline: 2009

Communications and Public Awareness Committee (CPAC)

Committee Members:

Karen Chow (Chair)

Bobbi Greenberg

Shelagh Campbell-Palmer

James Roche

Sharon Baxter (Secretariat)

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

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

Activities:

- Members were asked to confirm organizational main contact and communications leads.
- Information regarding new membership category was communicated to the QELCCC membership
- Members have identified their organization's communications lead, and a "communications" contact list has been established for each member organization and network organizations.
- The QELCCC member organization contact list was updated and distributed.

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 QELCCC sign-on policy (coalition terms of reference) was re-communicated to the QELCCC membership.

- The Executive Summary was revised to clarify that it is not expected that member organizations must sign on to every QELCCC document.
- Created new QELCCC poster for submission to the Canadian Hospice Palliative Care Conference and distribution to QELCCC members, listing the QELCCC's successes and activity outcomes since its inception.
- Created new QELCCC poster for submission to the Canadian Hospice Palliative Care Conference, summarizing the process and information learned through the Progress Report (*May 2008*), as well as listing the lessons learned through the process itself.

Next Steps:

- Create a protocol for external documents i.e. Each press release includes coalition backgrounder, and body of release lists members who have signed onto that release. Timeline: January 2009
- Explore ways to highlight and communicate to members “what’s new” on the QELCCC website (eg. Semi-annual email, etc.). Timeline: January 2009
- Explore feasibility for pilot utilizing social networking as a vehicle for raising public awareness. Timeline: 2009

3.0 New News

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

Activities:

- Worked cooperatively with the public relations agency and the Advocacy Committee to create/revise background and media materials to support the media launch of the Pan-Canadian Gold Standard Report Card on Palliative Home Care.
- Explored options for QELCCC role in World Hospice Palliative Care Day in October.

Next Steps:

- Select option(s) for QELCCC role in World Hospice Palliative Care Day to recommend to QELCCC membership, and implement. Timeline: January 2009
- Explore potential QELCCC role in supporting National Hospice Palliative Care Week. Timeline: January 2009

Family & Caregiver Support Committee (F&CSC)

Committee Members:

Diana Rasmussen (Chair)
 Judy Cutler
 Colleen Murray
 Sharon Baxter (Secretariat)

Marlene Chatterson
 Karen Henderson
 Doris Rossi

Shirley Browne
 Joan MacDonald
 Jo Anne Watton

1.0 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 information pamphlet. No changes have been made.

Next Steps:

- Gather information or data re: the needs of family members regarding availability, etc. – for use by the Communications and Advocacy committees. Timeline: February 2009.
- Review of the Compassionate Care Benefit Evaluation Reports to identify future action items. Timeline: February 2009.

2.0 Progress Report Project – Review, Comment and Sign-on

Objective: Produce an evaluative report on the level of compliance with and implementation of the recommendations contained in the “Pan-Canadian Gold Standards for Palliative Home Care” among the federal, provincial and territorial governments.

Activities:

- Provided feedback regarding contents of the *Progress Report*.

3.0 Caregiver Resource Inventory

Objective: Increase awareness of the existing resources for caregivers, professionals and organizations

Activities:

- The CHPCA has received funding to create searchable on-line databases of inventories of Aboriginal, pediatric and education resources. The caregiver resources will be added, once they have been reviewed.

Next Steps:

- Review existing inventory of caregiver resources for relevance and currency. Timeline: March 2009

4.0 Promote Client and Caregiver Programs

Objective: Increase awareness of the availability of caregiver respite programs

Next Steps:

- Identify national caregiver organizations in order to contact them to share activities. Timeline: 2009
- Identify national or provincial bereavement programs or organizations to share information. Timeline: 2009
- Provide support to the development of the legal and ethical caregiver guide. Timeline: Ongoing.

Education Committee (EC)

Committee Members:

Michael Aherne (Chair)

Barry Power

Sharon Baxter (Secretariat)

Buffy Harper

Cori Schroder

Larry Librach

Mary Schulz

1.0 National Associations Engagement Strategy

Objective: Develop a strategy to enable stronger engagement between the QELCCC and other relevant national associations.

1.1 Help Champion the Development of Second Generation National Inter-Professional Education Initiative

Objective: Steward the process for an application to Health Canada for an inter-professional education initiative. Champion a proposal for next level of EFPPEC-like program at the national level.

Activities:

- Liaised with the CHPCA and Health Canada to participate in an inter-professional education workshop (The Future of Interprofessional Education in Palliative and End-of-Life Care in Canada).

Next step:

- Monitor Health Canada's process and respond to any calls for proposal. Timeline: Ongoing

1.2 Help Share the Model Elements/Success Story of Collaborative Educational Initiatives

Objective: Engage and organize like-minded organizations who are interested in another inter-professional education pan-Canadian initiative.

Activities:

- Participated in planning of an inter-professional education symposium, *Inter-professional Education and Practice in Hospice Palliative Care National Symposium*, in conjunction with the Canadian Hospice Palliative Care Conference.
- Participated in *Inter-professional Education and Practice in Hospice Palliative Care National Symposium*.

2.0 Supporting Earlier and Improved Family and Client Education for Care Planning

Objective: Support the CHPCA efforts in the area of advance care planning awareness and education.

Activities:

- Identified the creation of an advance care planning position statement as a positive support for the CHPCA and a means of raising awareness of advance care planning.

Next Steps:

- Work with QELCCC's Advocacy Committee and Communications Committee to develop and distribute for sign-on a position statement regarding advance care planning. Timeline: 2009

3.0 Unregulated Health Providers Quality Assurance

Objective: Ascertain the level of quality assurance that exists for Home Support Worker Training Kit providers, and identify and develop methods to help improve quality assurance.

3.1 Care in the Home Planning Sheet

Objective: Improve the level of care provided by home support workers to individuals in private homes.

Activities:

Next Steps:

- Determine if a need exists to identify and partner with appropriate caregiver group to create a care in the home planning sheet. Timeline: January 2009.

3.2 CHPCA process review of HSW Training Kit provider utilization

Objective: Ascertain the level of quality assurance that exists for Home Support Worker Training Kit providers.

Activities:

- In response to the QELCCC inquiry, the CHPCA has indicated that it is not a regulatory body, and as such, cannot enforce quality assurance practices. However, it will explore the possibility of offering certification and/or accreditation.

Next Steps:

- Contact regional health authorities to educate them about the need to hire appropriately-trained Home Support Worker Training Kit providers. Timeline: January 2009

Research Utilization Committee (RUC)

Committee Members:

Joan Lesmond

Sharon Baxter (Secretariat)

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

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

Next Steps:

- Continue to share info from the Research Utilization Committee and the research list serve (recently developed at CHPCA). 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:

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 Liaise with CHPC Conference Research Committee

Objective: To assist the CHPCA with the planning of their 2007 National Conference, ensuring a strong research stream.

Activities:

- A member of the RUC participated in National Conference Research Sub-Committee meetings.
- Information about the conference was shared with QELCCC member organizations
- Several abstracts were submitted for a workshop or poster at the CHPC Conference from QELCCC

Next Steps:

- Submit abstracts for workshops or posters to QELCCC member organization conferences, where appropriate. 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