



Semi-Annual Report

July 2007

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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. Currently 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
CARP: Canada's Association for the Fifty-Plus
Catholic Health Association of Canada
Childhood Cancer Foundation Candlelighters 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.chpca.net/qelccc.htm>

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, 2007. 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. Another role of the Executive Committee is to address fundraising and sustainability issues. The Executive Committee has overseen the writing of two Letters of Intent soliciting ongoing, sustaining funding. To date, no new funders have been realized.

Advocacy Committee (AC)

Committee Members:

Melody Isinger (Chair)

James Roche

Pat Van Den Elzen

Karen Chow

Evelyne Gounetenzi

Deirdre Freiheit

Romayne Gallagher

Stephen Alexander

Sharon Baxter (Secretariat)

1.0 Build Awareness within the Federal Government – Pan-Canadian Partnership for Palliative and End-of-Life Care

Objective – Build awareness of the Coalition document, “Pan-Canadian Partnership for Palliative and End-of-Life Care” (2007), and encourage the federal government to continue its commitment to fund the National Strategy for Palliative and End-of-Life Care

Activities:

- The “*Framework for a National Strategy for Palliative and End-of-Life Care*” (2005) document was revised to replace language oriented to the previous federal government, with current language and concepts used by the present federal government.

Next Steps:

- An introduction letter and copy of the newly revised “*Pan-Canadian Partnership for Palliative and End-of-Life Care*” will be sent to the Prime Minister, Minister of Health, Minister of Human Resources and Skill Development, as well as all other Party Leaders and Health and Social Development Critics, the Leader of the Government in the Senate, and the Privy Council Office. Timeline: Fall 2007

2.0 Report Card 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.

Activities:

- A proposal for funding has been submitted by the Secretariat. The final outcome is expected to be available soon.

Next Steps:

- Assuming that funding is obtained, a survey will be developed and administered. A report will be written, based on the survey results. The report will be disseminated to the federal, provincial and territorial governments, QELCCC member organizations, the hospice palliative care community and the media. Timeline: December 2007

3.0 Government Relations: Federal, Provincial/Territorial, Regional (Political and Bureaucratic)

Objective: Recruit new champions within government and effect positive policy change.

Activities:

- Letters have been sent to the Ministers of Health, Indian Affairs and Northern Development, and Human Resources and Skill Development, as well as the Chief Public Health Officer.
- Meetings have been held with the Honourable Steven Fletcher, Parliamentary Secretary for Health, Mr. James Maunder (Senior Policy Advisor to the Honourable Senator Marjory LeBreton) and Sandra MacLeod with Public Health Agency of Canada (the Division of Aging and Seniors). Reception has been positive, and the Coalition looks forward to working more closely with some or all of these individuals.

Next Steps:

- Arrange to meet again with Mr. Maunder in the fall. Timeline: September 2007
- Continue to contact potential new champions, as well as policy-makers, as occasions arise and circumstances demand.

4.0 Federal Election Fact Sheet

Objective: Affect election platforms and awareness of end-of-life care issues.

Activities:

- A meeting has been held with the Honourable Penny Priddy, New Democratic Party Health Critic, and the Honourable Judy Wasylycia-Leis, New Democratic Party, to encourage the adoption of hospice palliative care issues into the NDP election platform.

Next Steps:

- Develop a Fact Sheet for the next federal election, including a list of questions to ask local nominees. Send to QELCCC member organizations, hospice palliative care community and the media. Timeline: Fall 2007

5.0 Policy Paper

Objective: Encourage the development of additional supports for Canadian families dealing with end-of-life issues

Next Steps:

- Create a policy paper, detailing a roster of approaches to meet the needs of Canadians. Timeline: Tabled until Fall 2007

6.0 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: Tabled until Fall 2007

7.0 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: Tabled until Fall 2007

8.0 Further Develop Network Contacts

Objective: To continue to strengthen the role of the Coalition within the voluntary sector and increase awareness of the broad implications and impact of quality end-of-life care on Canadians.

Activities:

- A first draft of an executive summary has been created and is in the revision phase. This summary will be distributed to member organizations to use their member communications vehicles.

Next Steps:

- Once the final draft is approved and translated into French, it will be distributed to all QELCCC members. Timeline: September 2007
- Develop one-paragraph summary, introducing QELCCC, for member organizations to use in their member communications vehicles. Translate and distribute with executive summary. Timeline: September 2007

Communications and Public Awareness Committee (CPAC)

Committee Members:

Nadine Henningsen (Chair)

Bobbi Greenberg

Karen Chow

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 have identified their organization's communications lead, and a "communications" contact list has been established for each member organization and network organizations.
- Invitations to join the QELCCC were sent to five organizations. As a result, the Alzheimer Society of Canada has become a member.

Next Steps:

- Establish protocol for communications delivery. Timeline: August 31, 2007

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:

- A first draft of an executive summary which reiterates the QELCCC mission/vision and key messages has been developed.
- A first draft of a one-paragraph summary which Coalition members can use in their respective electronic newsletters and that will link back to the Executive Summary on the QELCCC website has been developed.
- QELCCC web site has been enhanced and updated with all current documents.

Next Steps:

- Circulate draft executive summary among QELCCC member organizations for approval.
- Circulate draft one-paragraph summary among QELCCC member organizations for approval.
- Translate executive summary and one-paragraph summary into French. Timeline for all of the above: September 30, 2007

3.0 New News

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

Ongoing items

- QELCCC news announcements/milestones will be disseminated to members as both a full story and short “new news” briefing for members to place on their web, etc., linking back to the QELCCC web site.

Family & Caregiver Support Committee (F&CSC)

Committee Members:

Diana Rasmussen (Chair)

Doris Rossi

Joan MacDonald

Palmier Stevenson-Young

Karen Henderson

Jean Burt

Sharon Baxter (Secretariat)

1.0 Promotion of Government Initiatives

Objective: Increase awareness among Canadians of the various caregiver support programs available

Activities

- The CHPCA issued a Policy Alert highlighting items in the 2007 Federal budget that pertain to health care.
- The CHPCA received word from Service Canada that a new Compassionate Care Benefit (CCB) brochure was being distributed across Canada to more than 3,500 addresses. In response, the CHPCA provided Service Canada with the names and addresses of all QELCCC members with a request to send a brochure package to each organization. Service Canada has done this and some members have contacted Service Canada for additional copies for distribution. The

CHPCA included a brief article about the new brochures in the April Monthly Update that was sent out by e-mail on April 30th.

Next Steps:

- Include an article about the new CCB brochure in the October issue of AVISO (CHPCA Newsletter).
- Create communications tools, such as canned ads, that QELCCC members can use within their own organizations (both internally and externally). Timeline: September 14, 2007

2.0 Expansion of the Compassionate Care Benefit

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

- A letter was written to Minister Solberg (HRSDC) on February 28, 2007 requesting a meeting to discuss issues faced by caregivers and the current benefit. Unfortunately, we received a written response from his office saying that he is unable to meet with us at this time.

Next Steps:

- The communication tools developed for item number 1.0 will be used to move this issue forward. Timeline: Fall and ongoing

3.0 Update and Promote the CHPCA Caregiver Resource Inventory

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

Activities:

- CHPCA included an article in the June issue of AVISO reminding readers about the Caregiver Resource Inventory accessible through the CHPCA web site.
- A request has been sent to the CHPCA Web Weaver to try to ascertain how often the inventory is accessed

Next Steps:

- Send AVISO article out to QELCCC members to include in their communications tools (internal and external). Timeline: August 30, 2007
- Create a survey that can be added to the inventory pages on the CHPCA web site to try to get feedback regarding the content of the inventory. Include mention of the new survey in AVISO (October). Timeline: July 31, 2007

4.0 Promote Client and Caregiver Programs

Objective: Increase awareness of the availability of caregiver respite programs

Activities:

- QELCCC has obtained from the VON a one-page overview of its Care Renewal Project.

Next Steps:

- The Secretariat will connect with the Care Renewal Project to determine how the QELCCC can assist with the promotion of this program.
- The Secretariat will set up meetings with various national caregiver groups to explore possible partnerships for future work together. Timeline: September 14, 2007

Professional Education Committee (PEC)

Committee Members:

Michael Aherne (Chair)

Barry Power

Cynthia Stilwell

Shirley Browne

Buffy Harper

Corrine Schroder

Larry Librach

Sharon Baxter (Secretariat)

1.0 Awareness of Educational Initiatives

Objective: Increase awareness of existing professional awareness initiatives, and identify new professional education initiatives

Activities:

- QELCCC members have been asked to submit education links related to end-of-life care.
- The CASN PowerPoint presentation has been sent to all QELCCC members.
- An update from EFPPEC was sent to all QELCCC members, along with directions on how they can sign up for future updates.
- A QELCCC Links page was created and the EFPPEC web site was included as a link, in addition to all current professional educational links from the CHPCA links page.

Next Steps:

- Continue to disseminate newsletters and bulletins from projects/initiatives to QELCCC members

2.0 Survey of Continuing Education Programs for Health Professionals

Objective: Funding for a project to survey Continuing Education programs for health professionals

Next Steps:

- Draft a project proposal

3.0 CAUCE Annual National Conference Workshop

Objective: Raise awareness of opportunities for collaboration and development of Continuing Education programming

Activities:

- An abstract was prepared and accepted for a one-hour workshop at CAUCE Annual National Conference. The workshop was delivered by Michael Aherne on May 31, 2007.

4.0 Monitor and Engage – Canadian Partnership Against Cancer (CPAC)

Objective: Create linkages and engagement with the CPAC

Activities:

- A meeting has been scheduled with the Canadian Cancer Society in late August to discuss possible modes of mutual engagement.

Next Steps:

- Follow up on any actions decided upon, during the course of the August meeting.

5.0 Briefing for Association of Universities and Colleges of Canada (AUCC)

Objective: Build awareness at the AUCC of hospice palliative care issues and educational implications, and determine possible next steps

Next Steps:

- Create a briefing and arrange to meet with AUCC to discuss briefing contents in person.
Timeline: December 31, 2007

6.0 Stock Article for Various Trade Magazines

Objective: Engagement with a variety of trade and association magazines

Next Steps:

- Identify target trade and association magazines.
- Create a set of stock articles for submission to identified magazines. Timeline: October 30, 2007

Research Utilization Committee (RUC)

Committee Members:

Joan Lesmond

Sharon Baxter (Secretariat)

1.0 Foster Linkage with CANPERbc

Objective: Build partnership between QELCCC and CANPERbc.

Next Steps:

- A committee member will contact CANPERbc in the fall of 2007.

2.0 QELCCC Web Site Links to Research-Oriented Web Sites

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

Next Steps:

- Develop an Other Links section on the QELCCC web site to research oriented websites, including: CIHR; NETS, CVH, CHSRF, Growth House and SSHRC. Timeline: August 30, 2007

3.0 CHPCA 2007 National Conference

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

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