



# **Annual Report**

**December 2007**

## 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
Executive Committee Report .....	3
Advocacy Committee (AC).....	4
1.0 Build Awareness within the Federal Government – Pan-Canadian Partnership for Palliative and End-of-Life Care .....	4
2.0 Report Card on Pan-Canadian Gold Standards for Palliative Home Care .....	4
3.0 Government Relations: Federal, Provincial/Territorial, Regional (Political and Bureaucratic) .....	4
4.0 Federal Election Fact Sheet .....	5
5.0 Policy Paper.....	5
6.0 Brief to the Finance Committee .....	5
7.0 Brief to the Privy Council .....	5
8.0 Further Develop Network Contacts.....	6
Communications and Public Awareness Committee (CPAC).....	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 .....	6
Family & Caregiver Support Committee (F&CSC).....	7
1.0 Promotion of Government Initiatives.....	7
2.0 Expansion of the Compassionate Care Benefit .....	7
3.0 Update and Promote the CHPCA Caregiver Resource Inventory.....	7
4.0 Promote Client and Caregiver Programs.....	8
Professional Education Committee (PEC).....	7
1.0 Awareness of Educational Initiatives .....	8
2.0 Survey of Continuing Education Programs for Health Professionals .....	8
3.0 CAUCE Annual National Conference Workshop.....	9
4.0 Monitor and Engage – Canadian Partnership Against Cancer(CPAC).....	9
5.0 Briefing for Association of Universities and Colleges of Canada (AUCC) .....	9
6.0 Stock Article for Various Trade Magazines.....	9
Research Utilization Committee (RUC) .....	9
1.0 Foster Linkage with CANPERbc .....	9
2.0 QELCCC Web Site Links to Research-Oriented Web Sites.....	10
3.0 CHPCA 2007 National Conference .....	10

## Background

On June 6, 2000, the Senate of Canada issued the report *Quality End-of-Life Care: The Right of Every Canadian*<sup>i</sup>. This report was an update of the Senate's 1995 report, *Of Life and Death*<sup>ii</sup>. 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)*<sup>iii</sup>. 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<sup>iv</sup> 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 six times between January and December, 2007. Part of the role of the Executive Committee is to solicit new Coalition members and this year, it is continuing in its efforts to broaden the membership base of the Coalition. At the invitation of the QELCCC, the Alzheimer Society of Canada joined the QELCCC in early fall. 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. However, a proposal for funding for the *Pan-Canadian Gold Standard for Palliative Home Care* report card project was successful (see Advocacy Committee work item #2).

## Advocacy Committee (AC)

### Committee Members:

Melody Isinger (Chair)  
Karen Chow  
Romaine Gallagher

James Roche  
Evelyne Gounetzi  
Stephen Alexander

Pat Van Den Elzen  
Deirdre Freiheit  
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.
- An introduction letter and copy of the newly revised “*Pan-Canadian Partnership for Palliative and End-of-Life Care*” was 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.
- A press release was issued about the Partnership document release.
- Follow-up meetings about the recommendations in the documents were held with Dani Shaw (Senior Policy Advisor to Minister of Health) and Christiane Gagnon (Bloc Quebecois Health Critic).

### **2.0 Report Card on Pan-Canadian Gold Standard 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 Standard for Palliative Home Care” among the federal, provincial and territorial governments.*

#### **Activities:**

- The Secretariat successfully submitted a proposal for funding, and was able to begin work on this project before the end of 2007. Survey questions were developed and distributed to all provincial, territorial and federal governments.

#### **Next Steps:**

- 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: April 2008

### **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:**

- 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: February 2008

#### **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 early 2008

#### **6.0 Brief to the Finance Committee**

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

**Activities:**

- This item was unable to be completed due to the proroguing of government.

**Next Steps:**

- Develop a Brief for presentation to the Finance Committee. Timeline: Tabled until Fall 2008

#### **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.*

**Activities:**

- This item was unable to be completed due to the proroguing of government.

**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:**

- An executive summary and complementary one-paragraph introductory summary was created and translated in both official languages. They were distributed to member organizations for use in their member communications vehicles.

## **Communications and Public Awareness Committee (CPAC)**

### Committee Members:

Nadine Henningsen (Chair)  
Sharon Baxter (Secretariat)

Bobbi Greenberg

Karen Chow

### **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.
- A protocol for communications delivery was established.

### **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:**

- An executive summary which reiterates the QELCCC mission/vision and key messages has been developed in both official languages, as well as an introductory 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.
- QELCCC web site has been enhanced and updated with all current documents.

### **3.0 New News**

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

#### **Ongoing item:**

- 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)  
Palmier Stevenson-Young  
Sharon Baxter (Secretariat)

Doris Rossi  
Karen Henderson

Joan MacDonald  
Jean Burt

## **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 to approximately 2,400 e-mail addresses on April 30<sup>th</sup>.
- The CHPCA included an article about the new CCB brochure in the October issue of AVISO (CHPCA Newsletter).
- The Secretariat has been developing communications tools, such as canned ads, that QELCCC members can use within their own organizations (both internally and externally).

## **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: Ongoing into 2008

## **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
- The Secretariat sent the CHPCA AVISO article out to QELCCC members to include in their communications tools (internal and external).
- The Secretariat developed an on-line survey that was linked to the caregiver inventory pages on the CHPCA web site to try to get feedback regarding the content of the inventory.
- CHPCA informed members of the new survey in the Fall issue of AVISO.

#### **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.
- The F&CSC worked with the CPAC to develop communication tools describing available caregiver programs that QELCCC members can use within their own organizations.

**Next Steps:**

- The F&CSC will identify national caregiver organizations in order to contact them for details about their activities that can be passed on to QELCCC members.
- The F&CSC will identify national or provincial bereavement organizations in order to contact them for details about their activities that can be passed on to QELCCC members.
- Where appropriate, the Secretariat will set up meetings with various national caregiver groups or bereavement groups to explore possible partnerships for future work together.
- The F&CSC will review the final version of a new guide for caregivers that deals with legal and ethical issues related to caregiving at the end of life. Timeline: summer 2008

## **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. These links have been added to the QELCCC web site.
- 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.

#### **2.0 Survey of Continuing Education Programs for Health Professionals**

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

- This item has been tabled and will be discussed further at the January 2008 PEC meeting.

### **3.0 CAUCE Annual National Conference Workshop**

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

**Activities:**

- An abstract developed by Michael Aherne was accepted for a one-hour workshop at the 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 was held with the Canadian Cancer Society in late August to discuss possible modes of mutual engagement.
- The Canadian Cancer Society has developed a plan to move palliative care forward within the scope of their work. The QELCCC will engage with them where appropriate.

### **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*

**Activities:**

- The QELCCC met with representatives of the ACUU in January 2008. Follow-up from this meeting will be addressed by the PEC within the 2008 workplan.

### **6.0 Stock Article for Various Trade Magazines**

*Objective: Engagement with a variety of trade and association magazines*

**Next Steps:**

- The PEC will identify target trade and association magazines.
- The PEC will work with the CPAC to develop a set or series of stock articles for submission to identified magazines.

## **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 contacted 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.*

### **Activities:**

- A Links section was created on the QELCCC web site to research oriented websites, including: CIHR; NETS, CVH, CHSRF, Growth House and SSHRC.

## **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

---

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

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

<sup>iii</sup> Download: [http://www.chpca.net/qelccc/information\\_and\\_resources/7\\_Blueprint\\_for\\_Action\\_Dec\\_2000.pdf](http://www.chpca.net/qelccc/information_and_resources/7_Blueprint_for_Action_Dec_2000.pdf)

<sup>iv</sup> Website: [http://www.hc-sc.gc.ca/hcs-sss/palliat/index\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/palliat/index_e.html)