



# **Semi-Annual Report**

**July 2006**

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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*. This report was an update of the Senate's 1995 report, *Of Life and Death*. 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 & territories, develop a Canadian 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, Ontario 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)*. Within the Quality End-of-Life Care Coalition of Canada an Executive Committee and four 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 continues to grow 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 with the mandate to move this issue forward. The Secretariat on Palliative and End-of-Life Care is currently funded to a level of approximately \$1 million dollars per year, with no future commitments.

## 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	Canadian Medical Association
Canadian AIDS Society	Canadian Nurses Association
Canadian Arthritis Patients Alliance	Canadian Pharmacists Association
Canadian Association for Community Care	Canadian Society of Palliative Care Physicians
Canadian Association of the Deaf	Caregiver Network Inc.
Canadian Association of Occupational Therapists	CARP: Canada's Association for the Fifty-Plus
Canadian Association for Pastoral Practice and Education (CAPPE)	Catholic Health Association of Canada
Canadian Association of Social Workers	Childhood Cancer Foundation Candlelighters Canada
Canadian Breast Cancer Network	The GlaxoSmithKline Foundation
Canadian Cancer Society	Health Charities Coalition of Canada
Canadian Caregiver Coalition	Heart and Stroke Foundation of Canada
Canadian Healthcare Association	Huntington Society of Canada
Canadian Home Care Association	National Advisory Council on Aging
Canadian Hospice Palliative Care Association	National Council of Women of Canada
Canadian Lung Association	The Pallium Project
	VON Canada

### More Information:

[http://www.chpca.net/quality\\_end-of-life\\_care\\_coalition\\_of\\_canada.htm](http://www.chpca.net/quality_end-of-life_care_coalition_of_canada.htm)

## **Executive Committee Report**

The Coalition has four active committees. The chairs of these four committees and a representative from the Canadian Hospice Palliative Care Association (CHPCA) make up the Executive Committee.

The Executive Committee oversees the work of the coalition on an ongoing basis between the annual face to face meetings. The Executive solicits new members and this year will look to increase our membership around mental health and Aboriginal groups.

The Executive Committee met face to face in early March to work on a coalition wide communication survey and to work on sustainability issues. The communication survey was completed in April and the outcomes of the survey was distributed to members shortly thereafter. The Executive is analyzing the survey results in an effort to incorporate suggestions. Subsequent to the survey, the QELCCC website has been re-designed and updated.

The Executive Committee has overseen the writing of two Letters of Intent in order to solicit ongoing, sustaining funding. To date no new funders have been found.

The Secretariat has completed a proposal to Health Canada in order to secure funding for the winter 2006-2007 face to face meeting of the QELCCC.

Please refer to the 2006 Workplan for more detailed workplan descriptions at [www.chpca.net](http://www.chpca.net).

## Advocacy Committee (AC)

### Committee Members:

Nadine Henningsen (Chair)

James Roche

Pat Van Den Elzen

Melody Isinger

Karen Chow

Evelyn Gounetenzi

Deirdre Freiheit

Sharon Baxter (Secretariat)

### **1.0 Government Relations: Establish or Renew Relationships**

#### **1.1 Build Awareness with the Federal Government - National Framework for End of Life Care:**

*Objective – Build awareness of the Coalition’s work on the “Framework for a National Strategy on Palliative and End-of-Life Care”, and promote this concept to the new federal government.*

#### **Activities:**

- The “*Framework for a National Strategy on Palliative and End-of-Life Care*” was revised to de-personalize it and remove specific references to the name of the past Minister of Health...
- An introduction letter and revised copy of the “*Framework for a National Strategy on Palliative and End-of-Life Care*” was sent to Minister Tony Clement with a request for a face-to-face meeting.
- May 2006 the QELCCC was granted a meeting with Ms. Jo Kennelly (Director of Policy, Minister of Health) attended by James Roche and Sharon Baxter. More contact and information sharing with the Minister’s office is required to bring the new government up to speed on the activities of the QELCCC, and Health Canada’s National Strategy on Palliative and End-of-Life Care. This was a preliminary meeting and the QELCCC will need to increase pressure on the Minister of Health’s Office to raise their awareness of hospice palliative care.

#### **Next Steps:**

- Develop a send a letter to Prime Minister Harper, with a copy to the Minister of Health, that focuses on addressing the outstanding issues related to the Compassionate Care Benefit as an issue of family values, and meets the objectives of the Conservative Party’s platform. The letter will also focus on the recent national policy successes in the area of hospice palliative care. This letter needs to be reviewed and approved by the full QELCCC.

Timeline: Fall 2006

#### **1.2 Leverage the Government’s Previous Commitments for Tactics**

*Objective – Support and maintain the relationships with Palliative Care Secretariat at Health Canada*

#### **Activities:**

The QELCCC responded to the news of a possible budget cut to the Secretariat on Palliative and End-of-Life Care by writing a strong letter of concern to Minister Clement (June 23, 2006), with copies of the letter sent to: Morris Rosenberg, Deputy Minister of Health; Ian Shugart, Assistant

Deputy Minister of Health; Meena Ballantyne, Director General, Health Care Policy Directorate; and Jo Kennelly, Director of Policy, Office of the Minister of Health.

**Next Steps:**

- The QELCCC will follow-up with Health Canada to determine the final budget allocation and the status of the Secretariat on Palliative and End-of-Life Care.

## **2.0 Engage Other Stakeholders - Build Linkages and Partner with Other Stakeholders to Integrate the Hospice Palliative Care Agenda into their Agenda**

*Objective: Increase the awareness and priority of quality end-of-life care within the member organizations of the Quality End-of-Life Care Coalition of Canada. Leverage the member organizations advocacy efforts where possible.*

**Activities:**

- The results from a spring survey of Coalition Members results were reviewed - 63% of respondents reported that hospice palliative care was a medium to low priority for their organization.
- The committee agreed to leverage the disabled community in Canada to build linkages with them and increase their presence on the QELCCC as full members.

**Next Steps:**

- The committee will develop an action plan from the results of the QELCCC survey to increase the awareness of quality end-of-life care within the workplans and agendas of each of the Coalition members, and leverage their advocacy efforts.
- Coalition member organizations will be provided with materials from the CHPCA (QELCC PowerPoint Presentation and 2004 Ipsos-Reid Survey) to raise awareness of hospice palliative care as a possible component of their workplans and agendas.

## **3.0 General Awareness: Leverage CHPCA's Gold Standards Project**

*Objective: Promote the results of the Pan-Canadian Gold Standards Project to increase awareness of the required services for home-based palliative care and support the provincial and territorial governments in their implementation of the agreements made in "A 10 Year Plan to Strengthen Health Care"*

**Activities:**

- The CHPCA has completed the *Palliative-Specific Pharmaceutical Gold Standard: Pan-Canadian Gold Standards in Palliative Home Care* phase of their project. A copy of the pan-Canadian gold standard document was sent to federal, provincial and territorial Health Ministers, Premiers and the Prime Minister prior to the Health Minister's meeting regarding national drug policies held in June 2006.
- The *Nursing Gold Standard: Pan-Canadian Gold Standards in Palliative Home Care* is currently in the consultation phase.

- The Home Support and Case Management Gold Standards will be developed in the early fall.

**Next Steps:**

- The Advocacy Committee will develop strategies to raise awareness and assist with the launch the complete set of Gold Standards

## **Family & Caregiver Support Committee (F&CSC)**

Committee Members:

Diana Rasmussen (Chair)  
 Palmier Stevenson-Young  
 Jean Burt

Doris Rossi  
 Natalie Parry  
 Sharon Baxter (Secretariat)

Joan MacDonald  
 Karen Henderson

### **1.0 Income Protection and the Compassionate Care Benefit (CCB)**

*Objective: Expand eligibility, promote awareness, and monitor the federal, provincial and territorial governments with regard to the ongoing implementation of the Compassionate Care Benefit.*

**Activities & Next Steps:**

**1-A&B Expand eligibility and promote awareness of the Compassionate Care Benefit**

Some inroads with regard to the CCB (Employment Insurance) have been made. On June 14<sup>th</sup>, 2006, The Hon. Diane Finley, Minister of Human Resources and Social Development announced that the federal government had implemented regulatory changes that re-definition “family”, within the confines of the CCBB, to include any person designated by the dying person. No longer will other family members, friends or neighbours be disqualified from receiving the benefit as a result of not being considered “family”. Those who provide care to a brother, sister, grandparent, grandchild, in-law, ant, uncle niece, nephew, foster parent, ward, guardian or a gravely ill person who considers the claimant to be like a family member are able to claim the benefit. The benefit remains available to those caring for a parent, child or spouse.

**1-C Monitor Implementation of the recommendations from CCB Evaluation Reports**

The F&CSC will continue to monitor the implementation of the recommendations from the internal and external evaluation reports and will recommend that the QELCCC respond to issues or concerns when appropriate.

**1-D Provincial Labor Codes and the CCB**

Additional work can be done now in light of the recent announcements made regarding the CCB. The F&CSC will continue to monitor the effectiveness of the provincial governments with regard to changes in the provincial labour codes.



## **2.0 VSI Caregiver Inventory Project – Website Update**

*Objective: To raise awareness and disseminate information regarding the Caregiver Inventory available on the CHPCA web sites.*

### **Activities & Next Steps:**

The F&CSC will be working with the CHPCA to create a Canned Ad for distribution to QELCCC member organizations for inclusion in newsletters and other communication networks.

## **3.0 Addressing Caregiver Burnout – Disseminating Legal, Moral, Ethical Challenges of Caregiver Documents.**

*Objective: To disseminate the CHPCA document “Legal, Moral and Ethical Challenges of Caregiving” to QELCCC member organizations and solicit next steps.*

### **Activities & Next Steps:**

The F&CSC will be developing a list of questions for QELCCC members to consider when reviewing the CHPCA document “*Legal, Moral and Ethical Challenges of Caregiving*”. Once the questions have been developed the document and questions will be sent to QELCCC members for review and feedback.

## **4.0 Cultural Diversity and End-of-Life Care**

*Objective: To monitor initiatives undertaken by Health Canada and the Canadian Institutes for Health Research (CIHR)*

### **Activities & Next Steps:**

The F&CSC will continue to monitor the work of Health Canada and the CIHR with regard to cultural issues and end-of-life care and will work with the Research Utilization Committee once more information is available.

## **5.0 Accreditation Standards for Volunteers**

*Objective: The F&CSC to review and comment on the accreditation standards for volunteers.*

### **Activities & Next Steps:**

The F&CSC will review and comment on the accreditation standards for volunteers currently being developed by the Best Practices and Quality Care Task Group on the Volunteer Component (Secretariat on Palliative and End-of-Life Care, Health Canada). It is expected that these standards will be available in the spring of 2007.

## **6.0 Issues regarding Bereaved Parents who are living with the Death of a Child**

*Objective: To determine key issues faced by bereaved parents who are living with the death of a child.*

### **Activities & Next Steps:**

Members of the F&CSC have volunteered to work on this item and will report back to the committee once they have completed their initial investigation.

## **Professional Education Committee (PEC)**

### Committee Members:

Barry Power (Chair)  
Michael Aherne

Cynthia Stilwell  
Buffy Harper

Shirley Browne  
Sharon Baxter (Secretariat)

### **1.0 Review Scope of PEC to align it with the Secretariat's Best Practices and Quality Care Working Group**

*Objective: To monitor developments regarding the National Strategy*

#### **Activities & Next Steps:**

The review scope of the Professional Education Committee to align it with mandate of Secretariat's Best Practice and Quality Care Working Group (Health Canada) has not been addressed at this time as plans and budgets for the Working Group have yet to be finalized by Health Canada.

### **2.0 Secure Representation on Health Canada's Education for formal Caregivers Working Group**

*Objective: To be granted a seat on the Education for Formal Caregivers Working Group as they move through their transition year.*

#### **Activities & Next Steps:**

A letter requesting representation for the QELCCC on the Working Group is currently being drafted.

### **3.0 Follow-up – With Canadian Universities regarding the position of Palliative Care Education within their Curriculum**

*Objective: to determine where end-of-life care issues are situated in the curriculum across faculties.*

### **Activities & Next Steps:**

This Workplan item is to follow-up on a package that was sent to Canadian universities in 2005 that included a DVD of Senator Carstairs speaking about the need for end-of-life care. The scope of this Workplan item is currently under review pending funding implications.

## **Research Utilization Committee (RUC)**

### Committee Members:

Nancy Kilpatrick (Chair)

Joan Lesmond

Joan Campbell

Julie Lachance (ex-officio)

Sharon Baxter (Secretariat)

### **1.0 Establish a Linkage with CANPERbc**

*Objective: To establish a regular link with CANPERbc*

#### **Activities & Next Steps:**

- The RUC has been successful in connecting with CANPERbc and they have agreed to add the RUC to their mailing list.
- Nancy Kilpatrick will be the key liaison between CANPERbc and the RUC.

### **2.0 Establish linkage with the Knowledge Translation Steering Committee**

*Objective: To establish a link with the Knowledge Translation Steering Committee (KTSC) of the New Emerging Teams, and to evaluate the effectiveness of the tools in translation of knowledge to the QELCCC*

#### **Activities & Next Steps:**

- The RUC was successful in connecting with the directors of the Steering Committee. They are willing to include the RUC as part of their communication plan.
- The RUC has received the documentation regarding the descriptions of the 10 New Emerging Team (NET) Grants.

### **3.0 Development within the QELCCC web pages linkages to research oriented websites**

*Objective: To develop relevant links to the web sites of other organizations that conduct research in the area of end-of-life care.*

#### **Activities & Next Steps:**

The RUC continues to work on this item. A list of research-based web sites will be sent to the Secretariat for inclusion on the QELCCC web site.

#### **4.0 Review the Literature on Coalitions and Networks**

*Objective: Review existing literature regarding networks and coalitions and elements of success and limitations*

##### **Activities & Next Steps:**

- Three electronic documents regarding this issue have been shared with committee members.
- These have been reviewed for the information they provide on coalitions and networks.
- The intent of this review was to identify from the literature the characteristics of successful coalitions and cross reference this with the findings in the Evaluation Report of the QELCCC for the purpose of submitting a poster abstract for the 16<sup>th</sup> *International Congress on Care of the Terminally Ill*.
- After review, it was agreed by the RUC that the poster abstract would focus on the Coalition Evaluation report findings only.

#### **5.0 Showcase the Coalition at the Montreal Congress by presenting in the form of a poster presentation**

*Objective: To present a poster at the 16<sup>th</sup> International Congress on Care of the Terminally Ill.*

##### **Activities & Next Steps:**

- The RUC, on behalf of the QELCCC, prepared and submitted the abstract “*Showcasing the Findings of the Evaluation of the Quality End-of-Life Care Coalition Canada (QELCCC) and Based on the Demonstrated Strengths, Challenges and Successes Recommend Strategies for other Coalitions.*”
- The RUC has received notice of acceptance for presentation of the poster at the Montreal International Congress.
- Development of the poster will begin immediately.

#### **6.0 CHPCA 2007 National Conference**

*Objective: To assist the CHPCA with the planning of their 2007 National Conference.*

##### **Activities & Next Steps:**

This is a new Workplan item for the RUC. Sharon Baxter, Executive Director for the Canadian Hospice Palliative Care Association, has asked for representation from the QELCCC-RUC to assist with the planning of the CHPCA’ 2007 Canadian Hospice Palliative Care Conference. Joan Lesmond and Julie Lachance have volunteered to work with Sharon and CHPCA in this capacity.