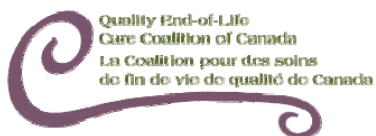


Quality End-of-Life  
Care Coalition of Canada  
La Coalition pour des soins  
de fin de vie de qualité de Canada

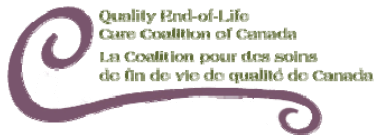
# **Annual Report**

**December 2011**



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## Background

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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.

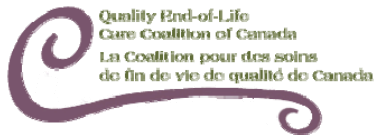
The first recommendation of the Senate report is that the federal government, in collaboration with the provinces and territories, develop a national strategy for end-of-life care. The Canadian Hospice Palliative Care Association (formerly the Canadian Palliative Care Association) discussed the Senate 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 from the voluntary sector and from patients and their families.

In December of 2000, a group of 24 national stakeholders met in Toronto 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 is currently 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<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. The Secretariat has since been disbanded.

In 2009/2010, the QELCCC produced the document *Blueprint for Action 2010 – 2020*. To continue to improve care at the end of life for all Canadians, the progress report outlines four priorities of the QELCCC over the next 10 years.

- Ensure all Canadians have access to high quality hospice palliative end-of-life care.
- Provide more support for family caregivers.



- Improve the quality and consistency of hospice palliative end-of-life care in Canada. Canadians should expect to receive high quality care in all parts of the country.
- Encourage Canadians to discuss and plan for end of life. Hospice palliative end-of-life care will not be a priority in our health care system until it is a priority for Canadians.
- Through this report and other endeavors, the QELCCC aims to change the standard of end-of-life care in Canada.

The full *Blueprint for Action: 2010 – 2020* can be found at [www.qelccc.ca](http://www.qelccc.ca).

## **Mission and Mandate of the Quality End-of-Life Care Coalition of Canada**

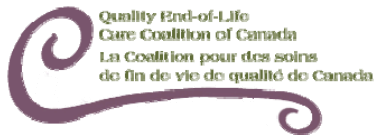
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The Quality End-of-Life Care Coalition of Canada believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones and in the setting of their choice. The Coalition 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**

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ALS Society of Canada	Canadian Medical Association
Alzheimer Society of Canada	Canadian Nurses Association
Canadian AIDS Society	Canadian Pharmacists Association
Canadian Arthritis Patients Alliance	Canadian Society of Palliative Care Physicians
Canadian Association of the Deaf	Canadian Society of Respiratory Therapists
Canadian Association of Occupational Therapists	Catholic Health Alliance of Canada
Canadian Association for Spiritual Care (CASC)	Childhood Cancer Foundation Candlelighters Canada
Canadian Association of Social Workers	College of Family Physicians of Canada
Canadian Breast Cancer Network	The GlaxoSmithKline Foundation
Canadian Cancer Society	Heart and Stroke Foundation of Canada
Canadian Caregiver Coalition	Huntington Society of Canada
Canadian Healthcare Association	Kidney Foundation of Canada
Canadian Home Care Association	Long Term Care Planning Network
Canadian Hospice Palliative Care Association	Mental Health Commission of Canada
Canadian Lung Association	



National Initiative for the Care of the Elderly

Ovarian Cancer Canada

The Pallium Foundation

Saint Elizabeth Health Care

VON Canada

## More Information:

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<http://www.qelccc.ca>

## Annual Meeting Report: Looking Back and Forging Ahead

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*An Executive Summary of the QELCCC Annual Meeting, January 21-22, 2011*

Member representatives from 20 different organizations with an interest in end-of-life care met at a highly productive annual meeting of the Quality End-of-Life Care Coalition of Canada (QELCCC) in Ottawa, on January 21-22, 2011. Members worked in both plenary sessions and individual committee groups (Advocacy, Communications and Public Awareness, Education, Family and Caregiver Support and Research) to efficiently review the activities and accomplishments of the QELCCC over the past year and set committee workplans for the year to come.

In addition to the continued work on distributing the *Blueprint for Action 2010 – 2020*, each individual committee is also committed to a number of initiatives to support the overall goals of the QELCCC and the priorities described in the *Blueprint*. A sampling of these undertakings includes: the Advocacy Committee will work on an approach to making policy recommendations for the 2014 health accord; the Communications Committee will continue to support the QELCCC initiatives with timely dissemination of communications; the Education Committee will continue developing a Position Statement/Discussion Document on the Integration of Palliative Care into Chronic Diseases; the Family Caregiver Support Committee will advocate for a caregiver strategy that provides supports for caregivers – financial and non-financial.; and finally, the Research Committee will continue to explore ways in which it can play a role in knowledge translation of the final findings of the CIHR Net Grants in Palliative Care.

With the *Blueprint* in place, the advocacy efforts of the QELCCC, and the workplan items of its committees, the QELCCC is well-poised to continue its work toward improving access to quality end-of-life care for all Canadians.

For more information about the QELCCC and to view a complete workplan, please visit [www.qelccc.ca](http://www.qelccc.ca).

## Executive Committee Report

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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 throughout 2011. Part of the role of the Executive Committee is to invite and review all requests to join the QELCCC. The Executive Committee's main focus for this year will remain ensuring the ongoing efficient and effective administration of the Coalition, and to leverage opportunities to develop partnerships that help ensure access to quality hospice palliative and end-of-life care in Canada. The Committee also welcomed two new members in 2011: The National Initiative for the Care of the Elderly and The Kidney Foundation of Canada.

The Executive Committee also began work on a proposal to Health Canada on Community-Integrated Palliative Care, a project which has an estimated start date of January 2012.

The Executive Committee is responsible for addressing the issue of fundraising and sustainability for the Coalition. The Executive Committee successfully obtained funding from Health Canada for the annual meeting in January, allowing for travel subsidies to be provided to members who attended the face-to-face meeting. The Committee will explore future prospects as opportunities arise.

## Advocacy Committee (AC)

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### Committee Members:

Melody Isinger (Chair)  
Stephen Alexander  
Bobbi Greenberg  
Nadine Henningsen  
Denise Page  
Sharon Baxter (Secretariat)

<b>1. Influence Government</b>
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*Objective: Use of QELCCC messaging.*

### Activities:

- Use key messages, asks and vignettes (leave behind packages). Remind member organizations developing briefs for the finance committee to identify palliative care issues. Timeline: Ongoing

- Information packages will continue to be shared at any meeting with the federal government, House of Commons and Senate of Canada representatives. Timeline: Ongoing.
- QELCCC to begin a 3 million dollar Federal Government initiative on community-integrated palliative care based on QELCCC recommendations. Timeline: January 2012

**Next Steps:**

- Ongoing activities.

## **2. Election Toolkit**

*Objective: Identify end-of-life care as a socio-economic issue.*

**Activities:**

- Adapt and update existing tools and circulate to members to encourage them to include it in their election packets. Timeline: Completed

**Next Steps:**

- Committee will send follow-up kits for the fall elections. Timeline: Completed.

## **3. Monitor Parliament for members comments about end-of-life care**

*Objective: Raise awareness of the QELCCC to Members of Parliament*

**Activities:**

- Identify anyone who has mentioned Advance Care Planning or End-of-Life Issues in parliament. Timeline: Ongoing
- Develop a letter with the Communications Committee to be sent MP's and Senators who speak about ACP or HPC issues. This letter would thank them and urge them to continue advocating for these issues. First draft in progress. Timeline: Completed

**Next Steps**

- Monitor Hansards and send out letters as required. Timeline: Ongoing.

## **4. Prepare an advocacy strategy for the 2014 Health Accord**

*Objective: Build awareness for the need to integrate end-of-life care.*

**Activities:**

- Discussion paper on how the QELCCC's asks can influence the funding and delivery of health care; especially recognizing end-of-life care as integral to health care. Timeline: Ongoing

**Next Steps**

- Develop a one-pager in conjunction with the advocacy and research committees to identify the topics that should be in the paper. To be completed Fall/Winter 2011/2012.

## Communications Committee

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### Committee Members:

Bobbi Greenberg (Chair)  
Shelagh Campbell-Palmer  
Kathy Scalzo  
Judy Donovan-Whitty  
Sharon Baxter (Secretariat)

### **1. Timely Dissemination of Relevant Communications to QELCCC Members**

*Objective: Ensure that QELCCC member organizations are aligned, informed and engaged.*

#### Activities:

- Collaboration with Coalition Committees to align effective, consistent messaging through E-blasts and updates.
- Ensure member's communications' lead contacts are current. Reminders to be sent out in spring and fall E-blasts.
- Continue to ensure members have most current QELCCC collateral: Executive Summary, Matte Article, Poster/abstract, Protocol for members sign-on for Coalition public documents/releases.
- News Updates - QELCCC E-Blasts, important news and articles of interest from the various committees.
- Prepare PowerPoint presentation about the Blueprint for Action for members' to build profile. Timeline: Completed

#### Next Steps:

- Update communications lead list as member organizations experience personnel changes. Timeline: Ongoing
- Continue to ensure members have the most current QELCCC collateral. Timeline: Ongoing
- Continue to collaborate with Coalition committees to align effective, consistent messaging. Timeline: Ongoing

### **2. Build Awareness of the QELCCC and Coalition Initiatives**

*Objective: Raise awareness of the QELCCC with the public and major stakeholders.*

#### Activities:

- Secure grant for communications strategy for the QELCCC to leverage web technology for raising public awareness of end-of-life care. Pitched to Health Canada, still searching for other sources. Timeline: Ongoing



- Encourage members to incorporate a “declaration” of respective organization as QELCCC member, declaration sent out with the spring E-blast. Timeline: Completed
- Still working to identify and foster champions for end of life care. The Committee will send a notice out via the E-blast and have individuals bring suggestions forward. Timeline: Fall
- Build profile of the QELCCC through media. The Committee continues searching for media coverage opportunities. Article published in May issue of Hospital News and was sent to the QELCCC in the Spring E-blast. The Committee also garnered media coverage when the Parliamentary Committee Report was released in November 2011. Timeline: Ongoing

**Next Steps:**

- Continue the use of the information E-blast when appropriate. Next issue: Winter 2012
- Strike all-committee task force to explore framework for possible award program. Timeline: 2015

### **3. Advance Care Planning in Canada**

*Objective: Ensure strong representation of the views of QELCCC member organizations in the ongoing work of CHPCA’s Advance Care Planning Project.*

**Activities:**

- Advance Care Planning project – Share strategic updates on ACP project milestones.
- Continue to ask Coalition members if they wish to join ACP distribution list.
- Following ACP Awareness Campaign launch, conduct survey with members re response/uptake of campaign.
- Included an update on the success of the ACP launch and ACP day in the Spring E-blast.

**Next Steps:**

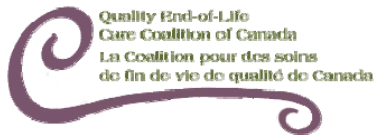
- Continue to share strategic updates on ACP project milestones. Timeline: Ongoing
- Encourage member organizations to promote and publicize the upcoming ACP day, April 16, 2012

### **4. Continue to liaise with Parliamentary Committee on Palliative and Compassionate Care**

*Objective: To develop consistent messages and understanding.*

**Activities:**

- Assisted with the launch of the Parliamentary Committee Report.
- Crafted a press release and disseminated all information to committee members.
- Arranged media interviews with willing members.
- Wrote letters to all involved thanking them for their support.



### Next Steps:

- Continue to promote the report and liaise with the Committee on next steps. Timeline: Ongoing

## Professional Education

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### Committee Members:

Doreen Oneschuk (Chair)  
Romaine Gallagher  
Debbie Gravelle  
Ken Hahlweg  
Doug Kellough  
Mary Schulz  
Pat Strachan  
Sharon Baxter (Secretariat)

### **1. Conduct an Environmental Scan of QELCCC Members of Available Educational Tools and Resources**

*Objective: Identify, via an environmental scan, QELCCC member's professional education needs i.e. wish list.*

#### Activities:

- Environmental scan redeveloped and redistributed to members. Includes two rounds of follow up with the member organizations that did not respond.
- Will review and refresh annually

#### Next Steps:

- Send requests for updates through E-blasts. Timeline: Ongoing

### **2. Brief/Issues Paper on Palliative Approach/End-of-Life Care Integration in emerging Chronic Disease Prevention and Management (CDPM)**

*Objective: Ensure more realistic Federal/Provincial/Territorial level CDPM framework inputs.*

#### Activities:

- The Committee created a letter of intent and is currently searching for funding. Possible lead from Health Canada. Timeline: Ongoing
- Romaine Gallagher has written a detailed outline for the paper and presented it to the Committee for review.

#### Next Steps:

- Continue discussions at the face-to-face meeting.
- Write out a description and RFP contingent on funding of the community-integration project. The Committee will then proceed with a literature review. Timeline: Ongoing

## Family Caregiver Support Committee (FCSC)

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### Committee Members:

Bonnie Schroeder (Chair)  
Denise Page  
Diana Rasmussen  
Marlene Chatterson  
Tanny Nadon  
Sharon Baxter (Secretariat)

### **1. Promote and recognize the role of family caregiving to Canadian society.**

*Objective: Designated caregiver day and increased awareness of caregivers. Consistent messages & understanding.*

#### Activities:

- The Committee sent out several press releases about caregiving and Caregiving Day through member organizations.
- The Canadian Cancer Society (CCS) released a social marketing campaign around family caregiving in early 2011. This included a facebook page and a website [www.cancerconnection.ca](http://www.cancerconnection.ca), which is used for caregivers as a place to search out resources and the like.
- The Committee also sent out an election survey to all the parties and heard from everyone except the Conservatives. The CCS also updated their website [www.ifightcancer.ca](http://www.ifightcancer.ca) to include letters that can be personalized and sent to local candidates. Recently they released a video in conjunction with the Canadian Caregiver Coalition and the CHPCA about financial aid for caregivers.
- The Committee monitored several political developments that recognized the role of family caregivers including:
  - the introduction of the Primary Caregiver Tax Credit in the 2011 Federal budget
  - The passing of the Manitoba Caregiver Recognition Act in mid-June 2011.

#### Next Steps:

- Identify key messages about caregiving in Canada. Timeline: Ongoing

### **2. Advocate for a caregiver strategy that provides supports for caregivers – financial and non-financial.**

*Objective: Increase the capacity of the members to present the economic analysis of our issues.*

#### Activities:

- Liaise with other organizations and coalitions (such as Canadian Caregiver Coalition, partner organizations)

- CHPCA Fact sheet economic costs of caregiving/giving care at the end of life – focused on out of pocket expenses for patients and families to build the economic argument for financial policy options for caregivers – tax credits and CCB, and CPP. – insert into election readiness. These statistics were added to the Fall 2011 CHPCA Fact Sheet. Timeline: Completed
- Sent out press releases surrounding the release of the Federal Budget and the inclusion of the family caregiver tax credit. Timeline: Ongoing

#### Next Steps:

- Continue to promote and increase awareness of information available for caregivers to the Coalition members and to the public. Timeline: Ongoing
- Will advocate through Caregiver Day – April 5, 2012

### **3. Promote and increase awareness of information services and resources for caregivers**

*Objective: Increased awareness of available caregiver resources.*

#### Activities:

- Created a dedicated space of the QELCCC E-blast for caregiving resources. Timeline: Completed
- The committee will send out a request in the e-blast for any ideas for resources for caregivers to be submitted to the committee. These resources can be used to build up better links on the webpage for caregivers. Timeline: Winter 2012

#### Next Steps:

- Continue to communicate information and resources to coalition members and the hospice palliative care community. Timeline: Ongoing

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

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#### Committee Members:

Joan Lesmond (Chair)  
Mireille Lecours  
Brenda McGibbon Lammi  
Nuala Kenny  
Sharon Baxter (Secretariat)

### **1. a) Continue to Foster Linkages with CIHR-funded Net Grants and Other Relevant Research Projects**

### **b) Continue to Foster Linkages and Build on past Relationship with CIHR**

*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 Adrian Moda from Ian Graham's office. They discussed Knowledge Translation (KT) issues and the CHPCA's recent KT initiatives. Adrian expressed and interest in this. The large KT network grant was not funded by CIHR. CHPCA applied for some KT funding in Fall 2011.
- Continued to search for relevant CIHR grant applications

**Next Steps:**

- Reach out to other QELCCC members to share current research projects and findings
- Continue to meet with CIHR to foster linkages, when appropriate
- Timelines: Ongoing

**2. QELCCC Role in Knowledge Translation of Findings Generated by CIHR Research Projects**

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

**Activities:**

- CHPCA research initiative concentrated on Pediatrics, CARENET/ACP and Caregiving issues - story lines for National Caregiver Day (April 5<sup>th</sup>, 2011) and National Advance Care Planning Day (April 12<sup>th</sup>, 2011) were distributed to the Committee for review and then distributed widely.
- The Committee is also reviewing past grants and research.

**Next Steps:**

- Review of past grants and research to be completed. Timeline: Ongoing

**3. Liaise with QELCCC members to ascertain their interest in poster and workshop presentations at their conferences**

*Objective: To ensure better knowledge of research related to hospice palliative end-of-life care.*

**Activities:**

- The Committee is currently working towards completing a poster presentation
- Posters were presented at the CHPCA's National Conference in St. John's, Newfoundland and Labrador, September 9-11, 2011
- The Committee will submit the QELCCC posters to the 19th International Palliative Care Congress

**Next Steps:**

- Encourage coalition members to use the posters, workshops and presentations at their own conferences and meetings. Timeline: Ongoing

**4. Explore the current state of general indicators for palliative care**

*Objective: Improved knowledge of indicators.*

**Activities:**

- Currently reviewing Preliminary List of Indicators for Hospice Palliative Care and End of Life Care submitted to Health Canada by Canadian Council on Health Services Accreditation March, 2004.
- Nuala Kenny is researching the role of advance directives in providing good palliative end-of-life care and assessing what is known regarding the costs of this care compared with failure to acknowledge dying and costs in continuing acute care environments.

**Next Steps:**

- Collaborate with the CHPCA and other groups around developing indicators for hospice palliative and end-of-life Care (Accreditation Canada). Timeline: Ongoing

**5. Blueprint Recommendation, Implementation and Next Steps**

*Objective: Advocate for continued research funding in hospice palliative care.*

**Activities:**

- Added a recommendation in the 2011 Election Kit about research funding.
- Waiting for the release of the Parliamentary Report. Timeline: Fall 2011

**Next Steps:**

- Look for research findings to validate our position (s) and advocate for access, funding and caregiving. Timeline: Ongoing

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<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)