

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

Annual Report

December 2010

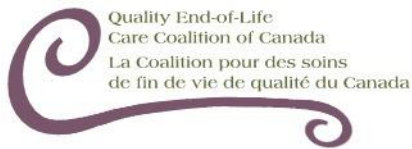
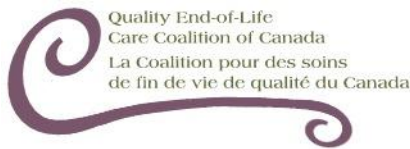


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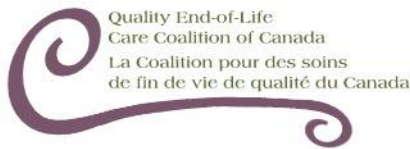
Background

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-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^{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 has since been disbanded.



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 Pharmacists Association
Alzheimer Society of Canada	Canadian Society of Palliative Care Physicians
Canadian AIDS Society	Canadian Society of Respiratory Therapists
Canadian Arthritis Patients Alliance	Caregiver Network
Canadian Association of the Deaf	CARP: A New Vision of Aging for Canada
Canadian Association of Occupational Therapists	Catholic Health Alliance of Canada
Canadian Association for Spiritual Care (CASC) Formerly the Canadian Association for Pastoral Practice and Education (CAPPE)	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	National Council of Women of Canada
Canadian Home Care Association	Mental Health Commission of Canada
Canadian Hospice Palliative Care Association	Ovarian Cancer Canada
Canadian Lung Association	The Pallium Project
Canadian Medical Association	Saint Elizabeth Health Care
Canadian Nurses Association	VON Canada

More Information:

<http://www.gelccc.ca>

Annual Meeting Report: Looking Back and Forging Ahead

An Executive Summary of the QELCCC Annual Meeting, January 28-30, 2010

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 28-30, 2010. 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.

One of the most notable accomplishments for the 2009/2010 fiscal year was the production of the *Blueprint for Action 2010 – 2020*. The January 28th, 2010 session was dedicated to the launch of the *Blueprint for Action 2010 – 2020*. The members present participated in a vibrant discussion resulting in the creation of a communication plan for disseminating the Blueprint to various stakeholders. The goal of the communications plan is to garner significant attention nationally, provincially/territorially and locally, drawing attention to not only the issue of disparity in hospice palliative home care programs, services, but also to the issue of end-of-life care generally. 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.

In addition to the continued work on distributing the *Blueprint*, each individual committee is also committed to a number of initiatives to support the overall QELCCC goals and the priorities described in the *Blueprint*. A sampling of these undertakings includes: the Advocacy Committee will work on approaches to having death and dying recognized as a socio-economic determinant of health; the Communications Committee will explore more efficient and effective means of internal and external communication; the Education Committee will conduct a revised environmental scan of QELCCC members of educational tools and resources; the Family Caregiver Support Committee will seek new avenues to recognize the contribution of caregivers to Canadian society; 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 a new *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. Throughout 2010, the QELCCC continued to disseminate and advocate for the priorities and recommendations described with the *Blueprint*.

For more information about the QELCCC and to view a complete workplan, please visit www.qelccc.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 a number of times between January and December, 2010. 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 Executive Committee was pleased to welcome one new member this year, The Mental Health Commission of Canada and will explore other prospective new members as opportunities arise.

The Executive Committee followed the activities of the Parliamentary Committee on Palliative and Compassionate Care, including involvement in the June 15, 2010 QELCCC presentation.

The Executive Committee is responsible for addressing the issue of fundraising and sustainability for the Coalition. The Executive Committee successfully obtained funding for the annual meeting in January, allowing for travel reimbursements to be provided to members attending from out of town. The Committee will explore future prospects as opportunities arise.

Advocacy Committee (AC)

Committee Members:

Melody Isinger (Chair)
Stephen Alexander

Evelyne Gounetenzi
Bobbi Greenberg

Nadine Henningsen
Sharon Baxter (Secretariat)

1. **Brief to Privy Council**

Objective: Raise awareness of social dimensions of death and dying.

Activities:

- Use key messages, asks and vignettes developed in the past year to create tailored leave-behind packages for bureaucrats, public officials and elected representatives. This includes inclusion in the over 500 kits sent to Members of Parliament and Senate in May and special kits prepared for the Parliamentary Committee on Palliative and Compassionate Care. Information packages continue to be shared at any meeting with the federal government, House of Commons and Senate of Canada representatives. Timeline: Ongoing

2. Influence Finance Committee

Objective: Raise awareness of how multi-faceted palliative care is and advocate for increased funding.

Activities:

- QELCCC Members were reminded to identify palliative care issues and recommendations outlined in the *Blueprint for Action* when developing briefs to the Standing Committee on Finance for the pre-budget consultations as well as for any briefs or presentations made to the Parliamentary Committee on Palliative and Compassionate Care. Timeline: Complete

3. Develop a Key Message and Ask to Facilitate Advance Care Planning (ACP) in Canada

Objective: Encourage and facilitate advance care planning discussions in Canada.

Activities:

- Developed a key message and discussed the ask regarding advance care planning in Canada, ensuring it is aligned with priority 4 of the Blueprint for Action 2010 – 2020.

Next Steps

- Refine the key message and develop the ask relating to advance care planning in Canada. Timeline: 2011

4. Improve Key Messages and Asks to incorporate “sound bites”

Objective: Short, punchy, to the point key messages.

Activities:

- Key messages and asks are distributed in QELCCC information packages as ‘leave behinds’. This includes inclusion in the over 500 kits sent to Members of Parliament and the Senate of Canada in April 2010 and special kits prepared for the Parliamentary Committee on Palliative and Compassionate Care.

Next Steps

- Shorter versions of the key messages in the form of draft sound bites were developed by the committee. The committee will continue to refine these messages. Timeline: 2011

5. Liaise and Build Relationships with Health Canada, Public Health Agency of Canada and Other Relevant Government Departments

Objective: Strengthen relationship with various government departments, highlighting to them the need for attention to end-of-life care.

Activities:

- Presented to the Parliamentary Committee on Palliative and Compassionate Care during their hearing on palliative care in June 2010.

- Met with the Director of the Division of Aging and Seniors, Public Health Agency of Canada, HRSDC, meeting scheduled for July with Chronic Disease Management Division, Public Health Agency of Canada.
- Attended the 2nd annual Caregiver Luncheon organized by the Canadian Caregiver Coalition on Parliament Hill, May 6th, 2010. Hosted by Mme Raymonde Folco, the event educated MPs and Senators about caregiver issues. This event was followed by a meeting with Carolyn Bennett, MP, and was attended by representatives of the Caregiver Coalition and Denise Page who represented the key messages and asks of the QELCCC about caregivers.
- Sent a meeting request to Diane Ablonczy, Minister of State (Seniors), for a meeting. Have been unsuccessful to date, but individual members have met with her.
- Blueprint for Action priorities and recommendations used in QELCCC member's briefs and presentations to the Standing Committee on Finance for the pre-budget consultations and to the Parliamentary Committee on Palliative and Compassionate Care roundtable meetings.

Next Steps:

- Keep in touch with the Parliamentary Committee on Palliative and Compassionate Care and explore opportunities for contributing to the pick up of their final report and recommendations. Timeline: January/February 2011

6. Extend the Dialogue of Death and Dying

Objective: Develop vignettes addressing the difficulties associated with ACP and implementing an ACP and shortcoming of the Compassionate Care Benefit.

Next Steps:

- Develop vignette(s) addressing the difficulties associated with ACP, implementing an ACP and the shortcomings of the Compassionate Care Benefit. Timeline: Ongoing

Communications

Committee Members:

Karen Chow (Chair)
Shelagh Campbell-Palmer
Bobbi Greenberg

Dr. Nuala Kenny
Fran Turner
Dianne Hartling

Sharon Baxter (Secretariat)

1. Timely Dissemination of Relevant Communications to QELCCC Members

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

Activities:

- Members were asked to confirm organizational primary contact and communications leads.
- A list was established with each member organization and network organization's communications lead and a "communications" contact.
- The Committee reviewed and revised the QELCCC's Executive Summary to reflect the release of the Blueprint for Action 2010–2020.

- The Committee developed a lexicon of terms to be distributed to the members as a content piece in an information kit (includes Executive Summary, Blueprint for Action...)
- Reviewed and revised the Committee's Terms of Reference.
- In collaboration with the Advocacy and Executive Committees, the Communication Committee developed a cover letter for the MP and Senator Kits as well as letters to congratulate members of the newly-formed Parliamentary Committee on Palliative and Compassionate Care.
- Collaborated with the Advocacy Committee to develop a conference poster focusing on the Blueprint for Action.
- Developed a tool describing the purpose and process for recruiting vignettes to help Coalition members recruit volunteers.

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. Support QELCCC Initiatives with Appropriate, Effective and Timely Communications

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

Activities:

- Incorporated feedback and suggestions into the Blueprint for Action provided from members at the January 2010 face-to-face meeting. Draft key messages have been developed and are under review by the Advocacy Committee.
- Explored opportunities and implemented a method for highlighting and communicating to members with an information e-mail blast.
- A quick link was created from the CHPCA website to the QELCCC website and includes the QELCCC logo.
- Developed a one page description of the purpose of the vignette to facilitate the collection of stories.

Next Steps:

- Continue the use of the information e-blast when appropriate. Timeline: Ongoing
- Work with the Executive Committee to address raising public awareness/understanding of the issues and their rights. Timeline: Ongoing
- Encourage the use of the vignette overview by members to facilitate collection of stories from members: end-of-life challenges and positive stories. Timeline: Ongoing

3. Build Awareness of the QELCCC Initiatives

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

Activities:

- Information packages regarding National Hospice Palliative Care Week were distributed to all QELCCC members in the Spring and provided information regarding other end-of-life care events and awareness campaigns.
- Discussed criteria to support members to actively identify and foster Champions for end-of-life care. (National, Provincial, Regional)
- Encouraged QELCCC members to include a link to the coalition website from their respective sites.
- Explored opportunities and implemented a method for highlighting and communicating to members with an information e-mail blast.

Next Steps:

- Encourage QELCCC members to include a link to the coalition website from their respective sites. Timeline: Ongoing
- Continue the use of the information e-blast when appropriate. Timeline: Ongoing
- Continue discussions regarding criteria for identifying champions in end-of-life care. Timeline: January 2011

4. 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:

- Confirmed with all Coalition members if they would like to be included in the ACP project information and consultation distribution list.
- Strategic updates on the ACP project milestones continue to be communicated with members.

Next Steps:

- Continue to share strategic updates on ACP project milestones. Timeline: Ongoing

Professional Education

Committee Members:

Doreen Oneschuk (Chair)
Trina Epstein
Romyne Gallagher

Debbie Gravelle
Doug Kellough
Mary Schulz

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.

- Developed an education information inventory based on the member responses from the environmental scan.

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:

- Discussed and developed a plan on how best to proceed with this item. Identified several existing pieces of literature to review. Discussions to continue at face-to-face meeting in January 2011.

Next Steps:

- Continue discussions at the face-to-face meeting. Timeline: January 2011

Family Caregiver Support Committee (FCSC)

Committee Members:

Denise Page (Chair)
Bonnie Schroeder

Diana Rasmussen
Holly Vengroff

Marlene Chatterson
Sharon Baxter (Secretariat)

1. Promote Recognition and Acknowledgement of the Contribution of Caregivers to Canadian Society (economic, social, health care system etc.)

Objective: Advocate for a Canadian caregivers day to promote recognition and acknowledgement of the contribution of caregivers to Canadian society (economic, social, health care system, etc.).

Activities:

- Attended the 2nd annual Caregiver Luncheon organized by the Canadian Caregiver Coalition on Parliament Hill, May 6th, 2010. Hosted by Mme Raymonde Folco, the event educated MPs and Senators about caregiver issues.
- Discussed opportunities for organizing a caregiver's day. Result : Last April a motion has been introduced to seek the unanimous consent of the House of Commons to adopt the following motion : That this House highlight the importance of the so-called "invisible" unpaid work done by parents and caregivers on behalf of their children and aging family members by creating "Invisible Work Day"; That the first Tuesday in April be designated "Invisible Work Day" in recognition of the important role that this type of work plays in society; That, following the example of United Nations member nations at the international conference in Beijing in 1995, this annual event be a time to emphasize the extent of unpaid work in Canada. Unanimously the House of Commons has adopted this motion.

Next Steps:

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

2. Canadian Strategy for Support Services for Canadian Informal/Family Caregivers

Objective: Advocate for the creation of a caregiver strategy, containing a variety of supports, both financial and non-financial, that would be available to every Canadian informal/family caregiver.

Activities:

- Worked together with the Canadian Caregiver coalition to ensure a Canadian strategy provides support services for Canadian family caregivers, both financial and non-financial.
- Advocated for better supports for Canadian caregivers to the Parliamentary Committee on Palliative and Compassionate Care.
- A Community Facebook page has been created to support the cause of family caregivers. This page will share information and resources; it will be a source to find tools for advocacy and the results of our actions. Furthermore, if it becomes popular (attracting thousands of fans), this page will be adopted and maintained by the Facebook community, it will become The Family caregivers' Page. It is available in English and French.
En: <http://www.facebook.com/pages/Family-Caregivers/105818882820941>
FR: <http://www.facebook.com/?sk=messages#!/pages/Proches-Aidants/141456052570750>
- Obtain information from disease-specific organizations to determine what their needs are for supporting their caregivers. Completed through the Education Committee's survey question regarding resources the members wished was available.

3. Promote and Increase Awareness of Information Services Available for Caregivers

Objective: Disseminate information relevant to all caregiver concerns (e.g. information on caregiver support services in your area, respite services, dementia information etc.) e.g. VON, Canadian Virtual Hospice, Living Lessons ®, and others (via invitation).

Next Steps:

- Promote and increase awareness of information available for caregivers to the Coalition members by featuring information in a special section included in regular communication mechanism used with members. Timeline: Ongoing

4. Compassionate Care Benefit – Ongoing Expansion and Improvement of the Benefit

Objective: Advocate for changes to the Compassionate Care Benefit (CCB) improving access and flexibility.

Activities:

- Advocate for changes to the CCB to increase the flexibility of the program during various meetings with government and Parliament.
- Monitored Service Canada regarding updates to the Compassionate Care Benefit. No changes have been made.

Next Steps:

- Continue to advocate for changes to the CCB to increase the flexibility of the program. Timeline: Ongoing
- Continue to monitor proposed changes to the Compassionate Care Benefit. Timeline: Ongoing

5. **Create a Caregiver benefit similar to the Child Tax Benefit**

Objective: Advocate for the creation of a caregiver benefit similar to the Child Tax Benefit.

Next Steps:

- Research and acquire information.

Research Utilization Committee (RUC)

Committee Members:

Joan Lesmond (Chair)

Brenda Lammi (Janet Jull up to Sept)

Sharon Baxter (Secretariat)

Mireille Lecours

Bobbi Greenberg

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:

- Share information from the Research Utilization Committee and the CHPCA's research list serve.
- Met with Judy Bray, Director of the CIHR's Institute of Cancer Research.

Next Steps:

- Continue to share information from the Research Utilization Committee and the CHPCA's research list serve. Timeline: Ongoing.
- Schedule a meeting with Ian Graham. Timeline: Winter 2010/2011

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:

- Disseminate the findings of the net grants through the CHPCA networks and to the QELCCC members.

Next Steps:

- Work with the interim outcomes/distill knowledge translation policy/clinical 'gems'.
- Dissemination of information from the CHPCA's knowledge translation project through the QELCCC networks. 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:

- Submitted and had accepted a workshop abstract for the 2010 Canadian Hospice Palliative Care Conference about the Blueprint for Action and how it can be used as an advocacy tool.
- Submitted and had accepted three poster abstracts for the 2010 Canadian Hospice Palliative Care Conference about the QELCCC and the Coalition's work.

Next Steps:

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

4. Blueprint Recommendation Implementation and Next Steps

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

Next Steps:

- Look for research findings to validate our position (s) and advocate for access, funding and caregiving. Timeline: Ongoing
- Collaborate with CHPCA and other groups around developing indicators for hospice palliative and end-of-life care. 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