



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



ANNUAL REPORT

DECEMBER 2012

www.qelccc.ca



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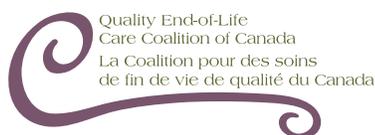
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HISTORY OF THE COALITION

In December of 2000, a group of 24 national stakeholders met 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 (the Coalition)* and a working document entitled *Blueprint for Action (2000)*ⁱ.

Within the Coalition an Executive Committee and five Working Groups were established. The Coalition 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 current iteration of the *Blueprint for Action*. The membership of the Coalition remains strong and is currently made up of 35 member organizations.

Since their establishment in 2000, the Coalition has seen some remarkable successes. These successes include: a role in the establishment of the Secretariat on Palliative and End-of-Life Careⁱⁱ in 2001; the producing *Hospice Palliative Home Care in Canada: A Progress Report*; produced *Dying for Care - Status Report*; participating in the development of the report, *Not to be Forgotten: Care of vulnerable Canadians*; produced the *Blueprint for Action: 2010-2020*; participating in the development of the Advance Care Planning Framework and the *Speak Up* campaign; and spearheading *The Way Forward: An Integrated Palliative Approach to Care Initiative*. The Coalition members have also attended countless parliamentary events, round table discussions, educational conferences, and research symposia, all in the interest of advancing end-of-life care in Canada.

In 2009/2010, the Coalition 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 Coalition 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 Coalition 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.

ⁱDownload: http://www.chpca.net/qelccc/information_and_resources/7_Blueprint_for_Action_Dec_2000.pdf

ⁱⁱWebsite: http://www.hc-sc.gc.ca/hcs-sss/palliat/index_e.html

The Honourable Leona Aglukkaq, Minister of Health, officially announced *The Way Forward* on June 12 at the Hospice at May Court in Ottawa. Over the course of three years, the federal government will be making a commitment for one-time funding of \$3 million to help support the development of integrated palliative approach care models across Canada.



The Way Forward: An Integrated Palliative Approach to Care, led by the Coalition and managed by the Canadian Hospice Palliative Care Association (CHPCA), will develop a national framework to enhance better integration of hospice palliative care for individuals, families and caregivers, so that they can live well until the end of life. *The Way Forward* will be a road map to an integrated palliative approach that supports earlier and more frequent conversations about the goals of care when patients and families are faced with a life-threatening illness. It will include a tool kit of resources and best practices. It will offer suggestions for removing the barriers to integrated hospice palliative care, and encourage groups to build opportunities for their own communities. *The Way Forward* will help Canadians with life-limiting illnesses understand the importance of advance care planning, and the hospice palliative care services that are available to them.

MISSION AND MANDATE OF THE QUALITY END-OF-LIFE CARE COALITION OF CANADA

The Coalition 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 an integrated palliative approach to care. It is the mission of the Coalition to work together in partnership to achieve this goal.

QUALITY END-OF-LIFE CARE COALITION OF CANADA MEMBER ORGANIZATIONS

| | |
|---|--|
| ALS Society of Canada | Canadian Society of Palliative Care Physicians |
| Alzheimer Society of Canada | Canadian Society of Respiratory Therapists |
| Canadian AIDS Society | Canadian Virtual Hospice |
| Canadian Arthritis Patients Alliance | Canadian Working Group on HIV and Rehabilitation |
| Canadian Association of the Deaf | Catholic Health Alliance of Canada |
| Canadian Association of Occupational Therapists | College of Family Physicians of Canada |
| Canadian Association for Spiritual Care | The GlaxoSmithKline Foundation |
| Canadian Association of Social Workers | Heart and Stroke Foundation of Canada |
| Canadian Breast Cancer Network | Huntington Society of Canada |
| Canadian Cancer Society | Kidney Foundation of Canada |
| Canadian Caregiver Coalition | Long Term Care Planning Network |
| Canadian Healthcare Association | Mental Health Commission of Canada |
| Canadian Home Care Association | National Initiative for the Care of the Elderly |
| Canadian Hospice Palliative Care Association | Ovarian Cancer Canada |
| Canadian Lung Association | The Pallium Foundation |
| Canadian Medical Association | Saint Elizabeth Health Care |
| Canadian Nurses Association | VON Canada |
| Canadian Pharmacists Association | Women's Inter-Church Council of Canada |

ANNUAL MEETING REPORT: LOOKING BACK AND FORGING AHEAD

An Executive Summary of the QELCCC Annual Meeting, July 19-21, 2012

Member representatives from 30 different organizations with an interest in end-of-life care met at a highly productive annual meeting of the Coalition in Ottawa, on January 19-21, 2012. Members worked in both plenary sessions and individual committee groups (Advocacy, Communications, Education, Family and Caregiver Support and Research Utilization) to efficiently review the activities and accomplishments of the Coalition over the past year and set committee workplans for the year to come.

In contrast to past years, the Coalition added on an extra day to their annual meeting to discuss the proposal put through to Health Canada regarding *The Way Forward: An Integrated Palliative Approach to Care* Initiative which was awaiting final funding approval through an Omnibus bill on January 26, 2012. On January 19, 2012, Sharon Baxter, Executive Director of the Canadian Hospice Palliative Care Association, and project proposal writer Louise Hanvey gave the Coalition the background information on the initiative and informed them of the workplan and next steps. For more information on *The Way Forward* Initiative, please turn to page 6.

In addition to the continued work on distributing the *Blueprint for Action: 2010-2020*, each committee is committed to a number of initiatives to support the overall Coalition goals and the priorities described in the Blueprint. A sampling of these undertakings include: the Advocacy Committee will consider presenting the framework and best practice to the Council of the Federation; the Communications Committee will continue to Support Coalition initiatives with timely dissemination of communications; the Education Committee will assist in developing a Position Statement/Discussion Document on the Integration of Palliative Care into Chronic Diseases for *The Way Forward* Initiative; the Family Caregiver Support Committee will advocate for a caregiver strategy that provides supports for caregivers – financial and non-financial; and finally, the Research Utilization Committee will continue to explore ways in which it can play a role in knowledge translation of the final findings of the CIHR (Canadian Institutes of Health Research) Net Grants in Palliative Care.

With *The Way Forward* Initiative nearly in place, the continued use of the *Blueprint for Action: 2010-2020* as an advocacy tool, and the workplan items of its committees, the Coalition is well-poised to continue its work toward improving access to quality end-of-life care for all Canadians.

For more information about the Coalition and to view a complete workplan, please visit www.qelccc.ca.

For more information about *The Way Forward* Initiative, please see the next page or visit www.hpcintegration.ca/.

THE WAY FORWARD: FIRST YEAR SUMMARY

The Honourable Leona Aglukkaq, Minister of Health, officially announced *The Way Forward* on June 12, 2012 at the Hospice at May Court in Ottawa. Over the course of three years, the federal government will be making a commitment for one-time funding of \$3 million to help support the development of integrated palliative approach care models across Canada.

Coalition members met in January 2012, just prior to the approval of the project funding in February, to engage coalition members in *The Way Forward* from the outset. Coalition members are represented on an Integration Initiative Advisory Committee by the chairs of the five Coalition Committees. The Advisory Committee met in March to develop a high-level workplan and a detailed engagement plan of key stakeholders. The Initiative staff team began work in May with an emphasis on identifying the partners that would help create the national framework and influence its implementation. The Advisory Committee and several Coalition members helped to provide context for a communications plan that will help guide strategies and activities to reach out to key audiences. An online platform for *The Way Forward*, including a website and Twitter account, were developed and launched following the federal announcement of the project. New features and content continue to be added to the website, and this will continue throughout 2013 to enhance it as a gathering place for a community of interest, and a place where resources can be found to support the implementation of an integrated palliative approach to care.

A first opportunity to connect with hospice palliative care stakeholders took place at the CHPCA Learning Institute in early June. During the closing plenary, over 150 participants were provided with context about the palliative approach to care and were then asked to brainstorm the opportunities and barriers to implement community-integrated hospice palliative care. Additionally, the group identified other partners who need to be involved to ensure high quality care across settings. *The Way Forward* has been presented to key stakeholder groups including: International Palliative Congress in Montreal, Health Council of Canada, Canadian Home Care Association Home Care Summit in Vancouver, and the Canadian Medical Association. During the fall of 2012, several meetings have taken place with key national organizations and federal, provincial and territorial governments. There has been positive feedback and support for the initiative and a strong expression of interest for a framework with tools and resources that are actionable and implementable across settings.

By the end of 2012, much of the foundational work for *The Way Forward* has been completed, including a series of discussion documents that provide context for an integrated palliative approach to care, a communications strategy and a performance and evaluation plan. Discussion documents include a synthesis of parliamentary and senate reports and recommendations, the palliative approach to care, impact on caregivers, education needs for health care professionals, innovative models from Canada and internationally, and an economic report. The published documents are available on the initiative's website at www.hpcintegration.ca. Additionally, the first draft of the national framework for an integrated palliative approach to care in Canada will be available in February 2013, after it has been reviewed by the members of the Coalition.

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 (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 March and December, 2012. 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. Part of the role of the Executive Committee is to invite and review all requests to join the QELCCC. In late June 2012, the QELCCC welcomed the Women's Inter-Church Council of Canada as their newest member. The committee also reviewed the Terms of Reference and cancelled the National Council of Women of Canada and the Childhood Cancer Foundation's memberships due to inactivity.

The Executive also assisted with *The Way Forward* proposal which resulted in a \$3 million dollar commitment from Health Canada. The members of the Executive Committee of the QELCCC will play a crucial role in *The Way Forward* Initiative through their participation on the Initiative's Advisory Committee. The Executive Committee members attended several committee meetings to plan the Initiative's first year of activity.

ADVOCACY COMMITTEE

- Melody Isinger (Chair)
- Margot McNamee
- Bobbi Greenberg
- Nadine Henningsen
- Denise Page
- Sharon Baxter (Secretariat)

1. INFLUENCE GOVERNMENT

Objective: Use of QELCCC messaging.

2012 Activities:

- Throughout 2012, the committee used key messages, asks and vignettes (leave behind packages). They reminded member organizations developing briefs to the finance committee to identify palliative care issues. The committee sent packages to MP's and Senators in April 2012 to increase profile in conjunction with National Hospice Palliative Care Week.
- The committee assisted with the Parliamentary reception hosted, in honour of the Parliamentary Committee on Palliative and Compassionate Care, on November 21, 2012 with Mr. Joe Comartin and Mr. Harold Albrecht. Over 95 stakeholders and MP's were present, and all of whom had a dedicated interest in hospice palliative care.

2. ELECTION TOOLKIT

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

2012 Activities:

- The committee continued to adapt and update existing tools and circulate to members to encourage them to include it in their election packets.
- The Election Kit was distributed to provincial QELCCC's as necessary, with many member groups also using the kit. After discussion, the committee decided that this item will be removed from future workplans and moved into a section labeled, "for future consideration."

3. MONITOR PARLIAMENT FOR MEMBERS COMMENTS ABOUT END-OF-LIFE CARE

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

2012 Activities:

- The committee continued to identify anyone who has mentioned Advance Care Planning or End-of-Life Issues in parliament. Several letters were sent throughout 2012, we will continue to monitor Hansards and send letters as needed.
- The committee continued to monitor news feeds for celebrities or notable people who mention hospice palliative care (HPC) or advance care planning (ACP). Several letters were sent out throughout 2012.
- The committee created a list of parliamentary champions in hospice palliative care. The committee will add any MP's or Canadian Celebrities who mention HPC or ACP, the committee has sent out 3 letters to date and may expand this to include companies with advanced compassionate care benefits in 2013.

4. LIAISE WITH PROVINCIAL QELCCs OR OTHER RELEVANT ORGANIZATIONS

Objective: Encourage all provinces to have a QELCC.

2012 Activities:

- An Advocacy Committee representative offered to attend future provincial QELCC teleconferences to share ideas and best practices. The next provincial QELCC meeting should be held in January 2013. Provincial Coalitions are active in Ontario, Nova Scotia, and Alberta.

COMMUNICATIONS COMMITTEE

- Bobbi Greenberg (Chair)
- Shelagh Campbell-Palmer
- Alison Pozzobon
- Judy Donovan-Whitty
- Teresa Patch
- Sharon Baxter (Secretariat)

1. TIMELY DISSEMINATION OF RELEVANT COMMUNICATIONS TO QELCCC MEMBERS

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

2012 Activities:

- Continuously collaborated with Coalition Committees to align effective, consistent messaging through E-blasts and updates.
- Ensured member's communications' lead contacts were current. Reminders were sent out in spring and fall E-blasts.
- Continued to ensure members have most current QELCCC collateral: Executive Summary, Poster/abstract, and Protocol for members sign-on for Coalition public documents /releases.
- A matte article was written for Committee member's use and can be obtained through the secretariat.
- News Updates - QELCCC E-Blasts were sent March 2012, September 2012, and December 2012.

2. BUILD AWARENESS OF THE QELCCC AND COALITION INITIATIVES

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

2012 Activities:

- Communications strategy was developed for the Coalition by Blueprint Public Relations. The strategy will be discussed and distributed at the 2013 Annual Meeting.
- The committee continued to encourage members to incorporate a "declaration" of respective organization as QELCCC member. The declaration sent out with the spring and fall E-Blasts.
- The Committee continued searching for media coverage opportunities and monitored the media closely for palliative and end-of-life care news.
- Awards committee was established over the summer of 2012. This committee established award criteria and chose a recipient to be announced at the Annual Meeting. *(cont'd on next page)*

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

2012 Activities:

- Following the ACP Awareness Campaign launch, the committee conducted survey with members re response/uptake of campaign. There were no respondents to the survey.
- The committee also included an update on the success of the ACP launch and ACP day in the Spring E-blast.
- The committee will continue to encourage member organizations to promote and publicize the upcoming ACP day, April 16, 2013

4. CONTINUE TO LIAISE WITH PARLIAMENTARY COMMITTEE ON PALLIATIVE AND COMPASSIONATE CARE

Objective: To develop consistent messages and understanding

2012 Activities:

- Wrote letters to 51 committee members asking them to be champions and speak to 10 people "the power of 10" in the lead up to a fall hill day, these were sent in April 2012.
- The communications committee also assisted with the planning and execution of the November 21 Parliamentary Reception which honored the PCPCC report and their dedication to palliative care.

5. COMMUNICATIONS STRATEGY

Objective: To develop a sustainable Communications Strategy for the Coalition.

2012 Activities:

- Communications strategy was developed for the Coalition by Blueprint Public Relations. The strategy will be discussed and distributed at the 2013 Annual Meeting.

PROFESSIONAL EDUCATION COMMITTEE

- Doreen Oneschuk (Chair)
- Romaine Gallagher
- Marilyn Sapsford
- Mary Schultz
- Srini Chary
- 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.

2012 Activities:

- Environmental scan redeveloped and redistributed to members. Includes two rounds of follow up with the member organizations that did not respond. Annual refresh completed and distributed to members in March 2012.

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.

2012 Activities:

- Two papers have stemmed from this topic idea, one on chronic disease management and the other on the palliative approach. Both papers are completed through *The Way Forward* Initiative and have been reviewed by the committee. They will be available at the Annual Meeting.

FAMILY CAREGIVER SUPPORT COMMITTEE

- Bonnie Schroeder (Chair) (January-March 2012)
- Denise Page (Chair) (June 2012-present)
- Doug Kellough
- Shirley DeMerchant
- Tanny Nadon
- Marlene Chatterson
- Shelly Cory
- 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.

2012 Activities:

- The Committee sent out several press releases about caregiving and Caregiving Day on April 5, 2012 through member organizations.
- The CHPCA led a very successful Caregiver day campaign that included a webinar, tweetchat and marketing materials. The Canadian Virtual Hospice released a series of successful caregiver videos.
- The committee sent a survey to Coalition members asking if they would like to have a theme for the 2013 campaign, there were no respondents.

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.

2012 Activities:

- The committee liaised with other organizations and coalitions throughout 2012 (such as the Canadian Caregiver Coalition, partner organizations).
- Liaise with finance department to promote and new tax credit. In 2012, the federal government announced that they would expand EI benefits to the parents of critically ill children to 35 weeks.
- Fact sheet on CCB – to help advocacy at both national and provincial level, new caregiving statistics were added to the CHPCA fact sheet and will be updated again in March 2013. *(cont'd on next page)*

3. PROMOTE AND INCREASE AWARENESS OF INFORMATION SERVICES AND RESOURCES FOR CAREGIVERS

Objective: Increased awareness of available caregiver resources.

2012 Activities:

- Caregiver news was regularly featured in many of the Coalition e-blasts.

RESEARCH UTILIZATION COMMITTEE

- Pat Strachan (Co-chair)
- Sharon Baxter (Co-chair)
- Mireille Lecours
- Vicki Lajambe
- Nuala Kenny
- Anna Park Lala
- Christopher Klinger
- Le-Ann Dolan
- 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.

2012 Activities:

- The committee continued to search for relevant CIHR grant applications
- Foster relationships with granting agencies (i.e., CIHR) and knowledge translation partners to develop and maintain HPC as a priority. The committee recruited several Coalition members to attend the CIHR Speaking of Aging Tour in Fall 2012. There was a member in attendance in: Edmonton, Regina, Hamilton, Toronto, Ottawa, and Montreal. End-of-life care remains a priority and the Committee sent a follow up letter thanking CIHR for their continued commitment.

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:

- The committee obtained the list of all past CIHR grantees and sent them letters inviting them to collaborate with the Coalition engage in knowledge translation initiatives with them.
- Committee now has a comprehensive contact database of professionals who have research palliative end-of-life care.

3. ENCOURAGE QELCCC MEMBERS TO SUBMIT NEW AND UPCOMING RESEARCH INITIATIVES AND RESEARCH FINDINGS RELEVANT TO THE BLUEPRINT PRIORITIES TO THE SECRETARIAT

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

2012 Activities:

- Through various e-blasts, the committee continued to invite and encourage other members to submit research findings.

4. 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:

- QELCCC Posters were present at several conferences across Canada.
- The committee refreshed and recirculated one of the Coalition posters.

5. EXPLORE THE CURRENT STATE OF GENERAL INDICATORS FOR PALLIATIVE CARE

Objective: Improved knowledge of indicators.

Activities:

- The committee discussed this item briefly and has placed it aside for the time being. *The Way Forward* will create a document on indicators which the committee will review in spring 2013.

6. BLUEPRINT RECOMMENDATION, IMPLEMENTATION AND NEXT STEPS

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

2012 Activities:

- The committee advocated for better research funding by attending 7 of the cross Canada CIHR meetings throughout the "Speaking of Aging" tour.