

2006-2007

- The “*Framework for a National Strategy on Palliative and End-of-Life Care*” was updated and sent to Minister Clement with a request for a face-to-face meeting.
- In May 2006 the QELCCC was granted a meeting with the Director of Policy for the Minister of Health.
- The QELCCC responded to the news of a possible budget cut to the Secretariat on Palliative and End-of-Life Care by writing a letter of concern to Minister Clement, 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.
- The CHPCA completed its project to develop *The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home*. Copies of these new standards have been sent to the federal, provincial and territorial Health Ministers with a copy to each Premier and the Prime Minister. The cover letter strongly encouraged the governments to incorporate the standards into their own provincial or federal guidelines. Each government was informed that they will be tested on their compliance with a report card which will be issued in Dec 2007.
- Some inroads with regard to the CCB (Employment Insurance) have been made. On June 14th, 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 CCB, 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.
- The Professional Education Committee completed its review of the scope of the Professional Education Committee and has aligned it with the mandate of Secretariat’s Best Practice and Quality Care Working Group (Health Canada). The PEC will continue to monitor outcomes from the Best Practices and Quality Care Working Group.
- An official letter of request asking for representation from the QELCCC-PEC on the Education for Formal Caregiver’s Working Group was submitted.
- The RUC has been successful in connecting with CANPERbc and they have agreed to add the RUC to their mailing list.
- The RUC, on behalf of the QELCCC, successfully 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.” to the International Congress on Care of the Terminally Ill.

2005-2006

- Compilation and distribution of the proceedings of the Quality End-of-Life Care Coalition of Canada Meeting held on January 29th-31st, 2004
- Updated the Action Plan for 2005-2006 after the Coalition meeting in January 2005
- Creation and adoption of a logo and letterhead for the QELCCC
- Disseminated the 2005-2006 Action Plan to Coalition members, CHPCA Board of Directors, provincial hospice palliative care organizations, Health Canada and other key stakeholders
- Produced two updates (January & June) on the work of the QELCCC
- Dissemination of the QELCCC Evaluation Project from last fiscal year continued throughout this year including presentations to the Canadian Patients Advocacy Forum and others
- Disseminated the 2005 National Hospice Palliative Care Week information kits to Coalition members
- Brief updates on the QELCCC activities were included in the electronic Monthly Update distributed by the CHPCA (2,400 subscribers)
- Updated QELCCC web pages located on the CHPCA web site
- Preparation and regular updates to the QELCCC Information Kit including updated Terms of Reference and regular membership update
- QELCCC Executive Committee met regularly by teleconference (every 6 to 8 weeks)
- Submitted a brief to Senator Sharon Carstairs for her June 2005 report “Still Not There – Quality End-of-Life Care: A Progress Report”
- Met with the Minister of State (Families & Caregivers), The Honourable Tony Ianno, and his policy advisors to highlight shortcomings with Compassionate Care Benefit and raise awareness of the unique issues faced by caregivers when caring for a loved one at the end of life
- Responded to the release of Senator Carstairs report “Still Not There: Quality End-of-Life Care: A Progress Report” resulting in media attention to this issue
- Wrote letters to the Health Council of Canada to highlight end-of-life care issues resulting in a meeting with the Council in August
- QELCCC representatives met with the Minister of Health, Ujjal Dosanjh in June 2005. At this meeting Minister Dosanjh challenged the QELCCC to develop a framework outlining what a national strategy for end-of-life care would encompass
- QELCCC met with the Prime Minister’s Office to highlight end-of-life care.
- Completed a project that raises awareness of hospice palliative and end-of-life care issues and their importance in academic curriculum considerations at post-secondary institutions
- The QELCCC welcomed the Canadian Arthritis Patients Alliance to the Coalition
- Conducted a survey of QELCCC members with regard to research funding and potential areas of interest in hospice palliative and end-of-life care research
- Continued exploring common competencies between various professional groups
- Continued to monitor the implementation of the Compassionate Care Benefit

- Launched its “Framework for a National Strategy on Palliative and End-of-Life Care” at CHPCA’s national conference in Edmonton, AB in September 2005
- National media exposure resulted from this launch including a media article in The National Post
- Health Canada agreed to host the 2006 face-to-face meeting of the Coalition to be held in January 2006

2004-2005

- Compilation and distribution of the proceedings of the Quality End-of-Life Care Coalition of Canada Meeting held on January 24-25, 2004
- Updated the Action Plan for 2004-2005 after the Coalition meeting in January 2004
- Disseminated the 2004-2005 Action Plan to Coalition members, CHPCA Board of Directors, provincial hospice palliative care organizations, Health Canada and other key stakeholders
- Produced two updates (January & June) on the work of the QELCCC
- Brief updates on the QELCCC activities were included in the electronic Monthly Update distributed by the CHPCA (1,800 subscribers)
- Updated QELCCC web pages located on the CHPCA web site
- Preparation and regular updates to the QELCCC Information Kit
- QELCCC Executive Committee met regularly by teleconference (every 6 to 8 weeks)
- Letters were sent to each provincial Minister of Health asking that they respond to key questions regarding the availability of end-of-life care services in their province to be used in the QELCCC’s upcoming status report
- QELCCC wrote each Premier and provincial health minister to highlight the findings and recommendations in the *Dying for Care* report and to reiterate the report as an important step in supporting the development on a national strategy on palliative and end-of-life care. The letter also requested that the report, its findings, and recommendations be reviewed at the Premiers meetings in July 2004
- QELCCC released “Dying for Care” report which highlighted the inequities Canadians face in accessing hospice palliative care services as well as providing recommendations to policy makers to address these inequities
- A national press conference was held in Ottawa highlighting the release of *Dying for Care*. The story was picked up by over 50 media outlets including national television, radio, print, and web media
- QELCCC wrote letters to senior bureaucrats in Health Canada as well as the Minister of Health to highlight its concern regarding cuts to the National Strategy of Palliative and End-of-Life Care Working Groups and its impact on moving their important work forward
- QELCCC wrote letters to the directors of the Canadian Institutes of Health Research (CIHR) to solicit the latest information on research directives of the individual Institutes regarding palliative and end-of-life care
- QELCCC monitored and responded where appropriate to the new Compassionate Leave Benefit announced by the federal government in the spring of 2003 and launched on January 4th, 2004

- Increased the membership of the Coalition with two new groups joining. These are: Canadian Association of Occupation Therapists and Pallium
- Polled federal parties prior to the election regarding their position on end-of-life care issues
- Conducted a survey of QELCCC members with regard to research funding and potential areas of interest in palliative and end-of-life care research
- QELCCC disseminated National Hospice Palliative Care Week kits to Coalition members as well as attendees of 2003 National Hospice Palliative Care Week breakfast hosted by Senator Sharon Carstairs
- Letters sent to the 55 participants of the National Hospice Palliative Care week breakfast on Parliament Hill, hosted by Senator Sharon Carstairs, to ask them to champion end-of-life care the QELCCC's cause
- Began the process of exploring common competencies between various professional groups
- QELCCC completed an evaluation of itself to document the strengths, challenges and successes of how the Coalition works; why it works; and how it can work better. Over 80% of the Coalition participated in the evaluation
- QELCCC continued to monitor the implementation of Compassionate Care Program
- Health Canada agreed to host the 2005 face-to-face meeting of the Coalition
- QELCCC approved a new logo that will be used to undertake more branding activities with the Coalition

2003-2004

- Compilation and distribution of the proceedings of the Quality End-of-Life Care Coalition of Canada Meeting held on January 18-19, 2003.
- Updated the Action Plan for 2003-2004 after the Coalition meeting in January 2003.
- Disseminated the 2003-2004 Action Plan to Coalition members, CHPCA Board of Directors, provincial hospice palliative care organizations, Health Canada and other key stakeholders.
- Produced two updates (January & June) on the work of the QELCCC.
- Presentation (October 2003) to the Canadian Strategy on Palliative and End-of-Life Care Coordinating Body Meeting. The QELCCC continues to liaise with the Canadian Strategy on Palliative and End-of-Life Care. Diana Rasmussen represents the Coalition on the Coordinating Body. Diana continues to raise important issues as it pertains to end-of-life care.
- Coalition activities were reported in the CHPCA newsletter (AVISO) – 3,000 subscribers.
- Brief updates on the QELCCC activities were included in the electronic Monthly Update distributed by the CHPCA (1,500 subscribers)
- Discussion with provincial hospice palliative care associations to assist them in setting up provincial coalitions patterned after the QELCCC – ongoing
- Encouraged each QELCCC member to meet and update their provincial counterparts regarding the QELCCC's mandate and Action Plan.
- Policy “champions” identified in each province with over 1,200 on the champions e-mail list.

- Updated QELCCC web pages located on the CHPCA web site.
- Preparation and regular updates to the QELCCC Information Kit.
- Information Kit Distribution:
 - given to key parliamentarians in a number of ways including being distributed to Minister Anne McLellan and Minister Jane Stewart in recent meetings and through ongoing correspondence with their departments.
 - distributed in May 2003 at a Parliamentary Breakfast to celebrate National Hospice Palliative Care Week.
 - included in the National Hospice Palliative Care Week packages sent to all 301 federal MPs and all 103 federal Senators.
 - distributed at the CHPCA booth at the National Hospice Palliative Care Conference in Quebec City. The Information Kits are available in both official languages.
 - distributed at a number of provincial hospice palliative care conferences.
 - distributed to all members of the QELCCC.
 - sent to all new members of the QELCCC with their letter of invitation.
- QELCCC Executive Committee met regularly by teleconference (every 6 to 8 weeks)
- Letters were sent to each provincial Minister of Health in January 2003 prior to the federal/provincial health summit asking them to make end-of-life care a priority in their deliberations.
- QELCCC is working on a status report for this year that outlines the state of access and funding for end-of-life care services. This status report will be the foundation of an annual report card.
- QELCCC was involved in the basket of services process – Executive Committee & Advocacy Committee members were kept up-to-date on activities. CHPCA met with Health Canada officials on a number of occasions.
- QELCCC monitored and responded where appropriate to the new Compassionate Leave Benefit announced by the federal government in the spring of 2003 and launched on January 4th, 2004. The QELCCC sent a letter to Minister Jane Stewart in regards to the Compassionate Leave Benefit in September 2003
- QELCCC Research Committee supported the work of the Canadian strategy working group on research that is launching a Palliative and End-of-Life Research Network.
- Increased the membership of the Coalition with four new groups joining. They are: the Canadian Lung Association; Canadian Medical Association; Canadian Nurses Association; and the Canadian Society of Palliative Care Physicians.
- Distributed information on new Federal Tax Credits. (CHPCA Monthly Update – April 2003)
- Conducted a survey of QELCCC Members with regard to research funding, communication vehicles and informal caregiver information needs.
- Regular communication with the various Canadian Strategy Working Groups.
- Health Canada agreed to host the 2004 face-to-face meeting of the Coalition

2002-2003

- Updated the Action Plan 2001-2002 after the Coalition last face-to-face meeting held in February 2002 and disseminated this action plan to coalition members, CHPCA Board members and provincial associations and other key stakeholders

- Produced regular updates on activities in spring, fall and winter of 2002
- Articles on the coalition activities in CHPCA quarterly newsletter AVISO as well as regular monthly email updates to over 1,000 people on CHPCA email system
- Prepared and submitted brief for the Romanow Commission on the Future of Health Care in Canada available on Coalition webpage on the CHPCA website
- Prepared a how to guide to setting up Quality End-of-Life Care Coalition of Canada in each province
- Meeting with provincial associations to assist them in setting up Quality End-of-Life Care Coalitions committees in each provinces - ongoing
- Contact with each provincial association president to discuss key policy issues including the work of the Quality End-of-Life Care Coalition of Canada
- Encourage each coalition member to meet and update their provincial counterparts around the coalition mandate and action plan
- Policy Champions identified in each province – email list – ongoing activity
- Quality End-of-Life Care Coalition of Canada Webpage and information on CHPCA Website including the 2001 Blueprint for Action and links to the 2000 Senate Report
- Press Releases from the Coalition on webpage
- Links to Coalition member groups website
- Preparation and dissemination of Coalition information kits
- Fall 2002 - Met with Senator Sharon Carstairs to discuss the coalition work
- Ongoing liaison with Senator Sharon Carstairs staff
- Ongoing liaison with National Strategy on palliative and end-of-life care, Health Canada staff
- Met with Abby Hoffman and Barbara Ouellet, Health Canada to discuss the national strategy on palliative and end-of-life care.
- Attended the Hospice Palliative Care Week breakfast on Parliament Hill
- Disseminated the coalition kit to parliamentarians
- Wrote to each provincial Minister of Health requesting an update on where end-of-life programs and services fall on their health care agenda, asking for them to put this issue on the agenda of the fall 2002 Ministers of Health agenda and to consider creating some sort of working group on the issue.
- Received responses from all provincial Ministers of Health and two of three territorial governments. This provincial letter kit was then disseminated to coalition members, CHPCA Board members, provincial associations and other key stakeholders including the Prime Ministers Office and Health Canada
- Met with the Prime Ministers Office to discuss end-of-life issues generally and the Speech from the Throne specifically
- Disseminated the September 2002 Speech from the Throne widely including a description of the proposed caregiver protection plan
- CHPCA prepared a brief analysis to the October 2002 Kirby Report as it pertains to end-of-life care and this was disseminated to all coalition members
- CHPCA press released also disseminated to all coalition members
- CHPCA prepared a brief analysis to the November 2002 Romanow Report as it pertains to end-of-life care issues and this was disseminated to all coalition members
- Ongoing work around the development of a public policy/government relations and communication strategy for the coalition

2001-2002

- CHPCA has met with each provincial representatives on the Board of Directors on this issue and asked the provincial reps to take this issue back to their associations
- Provided the Blueprint for Action to all provincial associations
- Summer 2001 lead article in CHPCA quarterly newsletter AVISO
- Prepared a update of issues for the Romanow Commission on the Future of Health Care in Canada available on CHPCA website
- Meeting with provincial associations to assist them in setting up Quality End-of-Life Care Coalitions committees in each provinces - ongoing
- Phone contact with each provincial association president to discuss key policy issues including the work of the Quality End-of-Life Care Coalition of Canada
- Request for Policy Champions to be identified in each province
- Monthly email updates on various items including the Quality End-of-Life Care Coalition of Canada reaching approximately 800 groups/people directly
- Quality End-of-Life Care Coalition of Canada Webpage and information on CHPCA Website including the 2001 Blueprint for Action and links to the 2000 Senate Report
- Press Releases from the Coalition also on CHPCA website
- Links to Coalition member groups website
- Preparation of Coalition information packages
- Policy Alert 1 and 2 on the Romanow commission consultation phase sent to provincial associations and other key policy people to encourage them to submit abstracts to present.

2000 – 2001

- Compilation of the proceedings of the national stakeholders' meeting on December 1-2, 2000
- Development of Terms of Reference for the Coalition
- Development of a draft Action Plan for a national strategy for end-of-life care, entitled *Discussion Paper: Canada's National Strategy for End-of-Life Care, A Blueprint for Action*
- Letters were sent by Coalition members to the Prime Minister, the Minister of Health and the Director of Policy and Research in the Prime Minister's Office encouraging the government to implement the recommendations of the June 2000 Senate report on end-of-life care and offering to contribute to the discussion of a national strategy. No responses have been received.
- A meeting of the Coalition Working Group was held on January 18, 2001 at which terms of reference for the Coalition were circulated for further work. It was agreed that additional national groups would be invited to join the Coalition, and that meetings for the Working Group would be requested with Allan Rock, Herb Gray, Opposition Health Critics, Chair of the Commons Health Committee, Senators and MPs who have expressed a special interest in end-of-life care. These meetings are expected to take place in late February.
- The Canadian Home Care Association has representation on the Working Group.

- Several teleconferences with the Coalition Working Group to plan further activity
- Enlisting new members for the Coalition (Coalition fact sheet attached)
- Meetings with Senator Sharon Carstairs and officials from Minister Allan Rock's office
- Letter-writing initiative by Coalition partners following the announcement by the Prime Minister of the appointment of Senator Sharon Carstairs to the position of Minister with Special Responsibility for Palliative Care. These letters were in support of the announcement.
- Issuing of a news release following the Prime Minister's announcement
- Planning a Day on the Hill for members of the Coalition Working Group
- Meeting senior elected officials and public servants on April 4 in Ottawa to press for implementation of the Senate report and for the creation of a multisectoral group to study the possibility of a national strategy. The Coalition Working Group met:
 - Senator Carstairs and Health Canada ADM Ian Shugart
 - Senators Lucie Pépin and Wilbert Keon
 - Deputy Prime Minister Herb Gray
 - Commons Health Committee Chair Bonnie Brown, MP
 - Director of Research and Policy, Prime Minister's Office
 - Peter Stoffer, MP (private member's bills on family caregiver protection)
 - Kathryn Moore, legislative assistant to Allan Rock
- Participation in the June 5, 2001 announcement by Senator Carstairs and Minister Rock of the creation of a Secretariat on Palliative Care within Health Canada with an annual budget of \$1 million. In the Health Canada news release (copy attached), the Canadian Palliative Care Association and the Quality End-of-Life Care Coalition of Canada were cited for their leadership on this issue and for the partnership role they were expected to play with the new Secretariat.
- Ongoing relations with the Senate, MPs and senior public servants
- Communication with national partner groups
- Recruiting new members for the Coalition
- Meetings with Sue Morrison, head of the new Health Canada Secretariat on Palliative Care.
- Preparation of Draft submission to the Romanow Commission on the Future of Health Care in Canada
- Planning for the 2002 face to face meeting of the Coalition