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Canadian Strategy on Palliative and End-of-Life Care

Final Report

OF THE COORDINATING COMMITTEE

DECEMBER 2002 TO MARCH 2007



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Health Canada would also like to commend the generosity of each employer who supported these individuals in their contribution. Without the understanding and support of their workplaces, these community representatives would not have been capable of such full and productive engagement.

Together, Health Canada and the palliative care community have helped to build a strong foundation for better recognition, education, information, and quality related to palliative and end-of-life care in Canada. This vital work will no doubt have a lasting impact on Canada's capacity to provide accessible and compassionate care to those facing life threatening illness.

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INTRODUCTION

At all ages and stages of life, Canadians expect to have accessible and high quality health care services. Accordingly, this includes care at the end of life.

Recognizing that there are many different terms relating to care at the end-of-life – such as *hospice palliative care*, *palliative care*, *end-of-life care*, and *palliative and end-of-life care (PEOLC)* – for the purpose of this report, all are used interchangeably.

Fast Fact:

Awareness of palliative care is on the rise:

A 1997 poll indicated that only 30% of Canadians were familiar with palliative care, compared with 60% in a 2005 poll.

Canada, like many other countries, faces a number of challenges with respect to PEOLC. People of all ages require care at the end of life, and given the aging of the population, it is estimated that by the year 2020, there will be 40% more deaths annually than in 2003 (Statistics Canada). Furthermore, approximately 90% of Canadians will eventually die as a result of a prolonged illness. PEOLC can add significant quality of life to those years.

The overall goal of PEOLC is to improve the quality of living and dying for those facing life-threatening illness. PEOLC strives to minimize unnecessary suffering caused by life threatening illness, through the provision of the following services:

- pain and symptom management;
- psychological, social, emotional and spiritual support;
- support for caregivers; and
- bereavement support.

Often delivered by interdisciplinary teams, PEOLC occurs in a variety of settings such as hospitals, long-term care facilities, hospices, and the home. The composition of these teams may vary, but they typically include nurses, physicians, social workers, spiritual advisors, bereavement support workers, trained volunteers, other professionals as needed, and informal caregivers such as family members.

In recent decades, PEOLC has gained increased recognition. Health care providers, educators, governments, and the Canadian public have come to appreciate the value of providing appropriate and compassionate support to individuals facing life threatening illness, and their loved ones. In keeping with this shift in prominence, the Canadian Strategy on Palliative and End-of-Life Care (the Strategy) was implemented in 2002 to improve Canada's capacity to deliver quality end-of-life care.

Over five years, during a time of significant change within the health care system, the working groups supported many key palliative care achievements. In March 2007, these groups drew to a close, leaving an excellent legacy to guide future work on the issue – work that will involve continued engagement of palliative care stakeholders.

The Coordinating Committee for the Strategy is now pleased to present this final report, which outlines the key achievements of this important initiative.

THE EVOLUTION OF THE CANADIAN STRATEGY ON PALLIATIVE AND END-OF-LIFE CARE

Several developments led to the implementation of the Canadian Strategy on Palliative and End-of-Life Care.

June 1995

Senate Committee on Euthanasia and Assisted Suicide releases its report *Of Life and Death*.

June 2000

Progress since the 1995 report is reviewed by the Senate and presented in the report *Quality End-of-Life Care: the Right of Every Canadian*.

December 2000

The Quality End-of-Life Care Coalition is formed, and publishes *A Blueprint for Action*.

June 2001

Health Canada's Secretariat on Palliative and End-of-Life Care is established.

March 2002

The Secretariat hosts a planning workshop, leading to the establishment of 5 community working groups.

December 2002

The working groups meet for first time. See diagram on page 4 for key activities.

March 2007

After five years of providing time and expertise, the working groups sunset.

In June of 1995, the Special Senate Committee on Euthanasia and Assisted Suicide released its report *Of Life and Death*, after hearing testimonials from Canadians over a 15 month period. In addressing the issues around euthanasia and assisted suicide, it became clear that one of the most pressing reasons for persons to consider ending their life was the fear of a painful, lonely and degrading death. Consequently, the report made numerous recommendations to improve access to, standards for, and education regarding PEOLC.

In June 2000, following a review of progress since 1995, the Standing Senate Committee on Social Affairs, Science and Technology released the report *Quality End-of-Life Care: The Right of Every Canadian*. This document strongly recommended federal leadership and the collaborative development of a national strategy to improve PEOLC.

In December 2000, the Quality End-of-Life Care Coalition (QELCC) was formed. This coalition, renamed the QELCC of Canada (QELCCC) in 2005, represents a broad cross-section of 31 stakeholder organizations interested in PEOLC issues.

In June 2001, Health Canada established the Secretariat on Palliative and End-of-Life Care (the Secretariat) to act as a focal point and facilitator of collaborative action in PEOLC. In March 2002, the Secretariat hosted the *National Action Planning Workshop on End-of-Life Care*. This event, held in Winnipeg, Manitoba, brought together over 150 individuals including researchers, educators, practitioners, and

government representatives. The result of this workshop was a report identifying priorities for action. This report can be accessed on Health Canada's Web site at: http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2002-nat-plan-palliat/index_e.html

Stemming from the workshop, the Secretariat established five working groups addressing the priority areas identified for action. Over the past five years, the work of these groups has constituted the community component of the Strategy and has been centred on the following issues:

- best practices and quality care (including work to standardize care);
- education for formal caregivers (including work to develop curricula and training);
- public information and awareness (involving work to enhance Canadians' knowledge of palliative care issues);
- research (including work to increase the capacity for PEOLC research); and
- surveillance (including work to measure the need for, access to, and quality of, PEOLC services).

Working group members represented a variety of interests and included: researchers; educators; care providers; volunteers; corporations; professional associations; and regional, provincial and national organizations. For a list of working group members, please refer to Appendix A.

ACCOMPLISHMENTS

Funded by, and in collaboration with Health Canada, each of the five community-based working groups was instrumental in the achievements outlined in the following section. The timeline on the left side of this page outlines some of these key achievements, while the text provides more detail on the full range of activities.

Best Practices and Quality Care Working Group (BPQCWG)

December 2002

First meeting of the working groups is held.

April 2003

The BPQCWG begins collaboration with CCHSA for the development of a PEOLC accreditation process.

April 2003

With the support of the EFCWG, *Educating Future Physicians in Palliative and End-of-Life Care* is initiated.

March 2005

The PIAWG establishes the Advance Care Planning Task Group which holds its first forum.

December 2005

Supported by the Secretariat on PEOLC and the RWG, CIHR holds the first palliative care research panel.

March 2006

The BPQCWG completes the document *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice*.

March 2007

The SWG convenes a national data needs assessment workshop.

The purpose of this group was to promote, facilitate and coordinate activities related to best practices and quality care. To this end, the BPQCWG worked towards a vision of care that meets national standards of quality.

In March 2002, following a national consensus process, the Canadian Hospice Palliative Care Association (CHPCA) published *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*.

The term “norms of practice” refers to statements that present the “usual” practice for palliative caregivers and organizations. Norms can be used by organizations to develop their standards of practice and to guide patient, family and public expectations.

Using this guide, the BPQCWG built a strong foundation to enhance the quality of PEOLC in Canada. The following are key accomplishments of this working group:

A Core Set of Performance Measures to Support the Accreditation of Hospice Palliative and End-of-Life Care

In 2003, the BPQCWG began collaborating with the Canadian Council on Health Services Accreditation (CCHSA) on the development of an accreditation process for PEOLC. The CCHSA describes accreditation as “an effective and internationally recognized evaluation process used by many countries worldwide to assess the quality of health services.” By

gaining accreditation, an organization can demonstrate to its stakeholders that it is committed to the provision of high quality services.

This multi-phased project involved extensive consultation with stakeholders, work to strengthen surveillance and measurement capabilities, and pilot testing of identified standards and performance measures. A consensus-building process with over 400 health organizations resulted in the recommendation of the following five categories as a core set for systematic data collection to support ongoing quality improvement in PEOLC:

- accessibility of 24/7 PEOLC;
- continuity of care;
- assessment of pain and symptom burden;
- satisfaction of family and caregivers; and
- documentation of client and family goals.

As part of the accreditation process, participating health organizations are required to use this core set to measure performance, and report to the CCHSA.

This project, completed in 2006, resulted in the establishment of an accreditation process, including national standards and measurement tools, for PEOLC in Canada. This will help to ensure that accredited organizations meet national standards for the provision of quality end-of-life care.

Following the development of this process, in order to ensure its feasibility and appropriateness within hospices, the BPQCWG worked collaboratively with the CCHSA to pilot test these accreditation standards in the residential hospice setting.

Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice

A collaborative effort of the CHPCA, the BPQCWG, Health Canada, the Canadian Network of Palliative Care for Children, the Hospital for Sick Children in Toronto, and the Canuck Place Children's Hospice in Vancouver, this project was established in recognition of the fact that PEOLC is predominantly focussed on the needs of dying adults and that the care of children facing life-threatening illness has unique needs.

The goal of this work was to create national norms of practice for pediatric hospice palliative care. These norms were drawn from existing norms of practice being used by Canuck Place and the Hospital for Sick Children. They were validated and expanded through a consensus process involving key stakeholders.

The final result of this important initiative was the 2006 document *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice*, a resource for health organizations that promotes consistent and quality pediatric PEOLC in Canada.

A Model for Volunteer Best Practice and Collaboration in Canadian Hospice Palliative Care

Fast Fact:

Canadians Volunteer!

Volunteers in the health sector contribute roughly 3B hours every year and their total economic activity is estimated at \$20B to \$30B each year.

(Public Health Agency of Canada)

The goal of this work was to develop a framework to enhance the quality of service of volunteers in interdisciplinary palliative care teams. This framework includes standards for volunteer practice in PEOLC, as well as educational tools, which are appropriate for use across Canada.

This project was led by SCO Health Service in partnership with the BPQCWG, and was informed by a national group of experts including volunteers, volunteer managers, researchers and educational experts.

Completed in March 2007, this important initiative will help to raise the profile of volunteers as full members of the PEOLC interdisciplinary team, and will help to ensure that the many volunteers in PEOLC have the tools and skills necessary to work in an interdisciplinary setting.

A Roadmap for Best Practices in Quality Palliative Care

In 2005/06, the BQCWG initiated the creation of a “roadmap” for work in best practices. This resource, completed in March 2007, resulted in a support tool to help guide the development of PEOLC programs and policies, which are aligned with the national accreditation standards.

Education for Formal Caregivers Working Group (EFCWG)

This group worked to improve the quality and accessibility of education and training for formal caregivers in PEOLC. A formal caregiver is a provider of health care who is registered or affiliated with a professional body and is bound by specific rules of conduct. The EFCWG has helped to build a strong foundation for better PEOLC education and training in Canada through the following initiatives:

Core and Discipline Specific Competencies

Within the health context, core competencies are fundamental knowledge, skills and abilities that formal caregivers in PEOLC require to successfully perform their jobs. The EFCWG identified the core PEOLC competencies applying to physicians, nurses, social workers, pharmacists and pastoral care workers at the undergraduate and postgraduate levels. This process involved a thorough review of the relevant PEOLC education and training programs, identification of the core competencies, and a

national survey to achieve consensus. These competencies, based on CHPCA's *Norms of Practice*, are an important step toward ensuring that a standardized level of education in these disciplines is available across the country.

Following this preliminary work, the EFCWG engaged with physicians (through *Educating Future Physicians in Palliative and End-of-Life Care*), nurses (through the Canadian Association of Schools of Nursing) and social workers (through the British Columbia Association of Social Workers), to further develop discipline-specific competencies.

Palliative and End-of-Life Care Medical Curriculum

The EFCWG and the CHPCA worked collaboratively with the Association of Faculties of Medicine of Canada (AFMC) to secure \$1.25M in Health Canada funding for the project *Educating Future Physicians in Palliative and End-of-Life Care* (EFPPEC). The goal of this initiative is to ensure that by 2008, all undergraduate medical students and clinical post-graduate trainees at Canada's medical schools will receive education in PEOLC and graduate with competencies in these areas. For more detailed information on this work, please refer to www.efppec.ca.

Sharing of Knowledge through an Education Commons

Interdisciplinary care, which involves a team approach to providing care with the active participation of multiple disciplines, is seen as a key delivery method for PEOLC. It is important that health care providers are educated on how to work together in this manner. To this end, in September 2005, over 100 stakeholders from around the world met in Edmonton to share their work in the area of interdisciplinary education. This education "commons" provided the opportunity for sharing information, which can open the doors for others to leverage on and learn from existing and successful initiatives. Funded by Health Canada and implemented by the CHPCA in collaboration with the EFCWG, the education commons provided an excellent opportunity for Canadian and international stakeholders to learn about and collaborate on interdisciplinary educational initiatives.

Public Information and Awareness Working Group (PIAWG)

This working group was created to address methods to increase Canadians' awareness of PEOLC. These included identifying sources of, and tools to disseminate relevant information, with attention given to ethical and spiritual considerations as well as community and cultural sensitivities. The PIAWG helped to create building blocks for enhanced communication and awareness regarding end-of-life issues through the following initiatives:

Palliative and End-of-Life Care Public Information Awareness Raising Framework

Through a multi-phased process, this framework was created as a communication tool to enhance the ability of organizations to increase Canadians' awareness about PEOLC and its services. The specific goal of the framework is to promote, to the Canadian public and health care providers, thinking and dialogue about PEOLC, in advance of need. This communication tool includes key messages for specific audiences, recommended communications vehicles, and suggested processes. Organizations may use the framework in its entirety or simply extract relevant segments. In this way, the framework provides organizations with a flexible and user-friendly tool to help Canadians become aware of end-of-life issues.

Information Gathering

The PIAWG worked in partnership with the CHPCA and The GlaxoSmithKline Foundation to collect information regarding Canadians' awareness, understanding and use of palliative care; and to capture Canadians' understanding and views on advance care planning. This was accomplished using Ipsos-Reid's Canadian Omnibus poll, conducted from December 9 to 11, 2003. This poll identified a trend towards increased awareness of PEOLC. For the results of this poll, contact the CHPCA.

The Information Needs of Informal Caregivers

The PIAWG was directed by the Coordinating Committee to address the information needs of informal caregivers (family, friends and loved ones) in actual or anticipated palliative and end-of-life situations. Information needs and a number of gaps or challenges that create barriers for informal caregivers were identified. A subsequent synthesis report entitled *The Information Needs of Informal Caregivers Involved in Providing Support to a Critically Ill Loved One* is available on Health Canada's Web site at: http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2005-info-caregiver-aidant/index_e.html.

To assist informal caregivers with some of their immediate information needs, the CHPCA, in collaboration with the PIAWG, developed an inventory of information tools for informal caregivers involved in palliative care.

Advance Care Planning

A task group on advance care planning, a sub-group of the PIAWG, was created in 2005 to address issues around the process of coming to understand, reflect on, discuss and plan for the possibility that one may no longer be able to communicate and make medical decisions for oneself.

The task group held two fora, in 2005 and 2006, which were opportunities for stakeholders and experts in the field to network, share information, and identify key priorities. Participants identified the need for standardized terminology regarding advance care planning, and better training of health care providers around the issue. The identification of these priorities led to certain key projects.

In response to the need for common terminology, the task group facilitated the development of a glossary of terms entitled *Advance Care Planning: the Glossary Project*. This glossary takes into account the varying language used by each jurisdiction, and provides a baseline for collective understanding. This resource is available on Health Canada's Web site at: http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index_e.html

In response to needs around education, the PIAWG also undertook the development of an interprofessional education module on advance care planning. The result was a tool for enhanced education of health care professionals on the importance of and process surrounding advance care planning in serious illnesses. It includes tools for talking about complex and sensitive issues and discussing what actions need to be taken, particularly in the event that a patient is unable to make his or her own decisions.

Finally, the PIAWG collaborated with the British Columbia Cancer Agency to do research on multicultural considerations around advance care planning. This work contributes to a better understanding of cultural beliefs and offers interpretation of terminal illness, suffering and dying for larger ethnic populations in Canada.

Research Working Group (RWG)

The RWG was established to enhance research on PEOLC by: establishing needs and priorities; increasing the number of researchers and their supports; promoting collaboration; and improving the use of research. This working group has enhanced Canada's capacity for PEOLC research through the following initiatives:

Research Networking and Resources

The RWG facilitated the development and implementation of a virtual network of PEOLC researchers. Housed on the Web site of the Canadian Virtual Hospice (www.virtualhospice.ca), this network provides opportunities for collaboration, mentorship, support and the sharing of knowledge. It also acts as a repository for PEOLC research tools and resources.

The RWG has also facilitated a series of meetings of researchers to discuss how best to perform research on PEOLC. These events provided an opportunity for researchers to connect and share ideas on issues, methods and protocols.

Knowledge Translation

Just as important as increasing knowledge through research, is the ability to share this knowledge with a varied audience. Often, research has implications for not only academics, but for clinicians, policy-makers, and the general public, making it essential to ensure that knowledge can be translated for, and understood by, users from differing backgrounds. To address this need, the RWG undertook a series of activities. In 2005, a survey of knowledge translation activities among PEOLC researchers in Canada was administered, the results of which were discussed at a Fall 2005 meeting on the issue. This event included a panel discussion and half day workshop attended by experts in the field as well as researchers and their community liaisons who would be putting knowledge translation into practice. A major outcome from this meeting was the establishment of an independent steering committee to develop a framework and tools to guide future knowledge translation activities in PEOLC.

Canadian Network for Palliative and End-of-Life Research beyond cancer (CaNPERbc)

Historically, PEOLC has been strongly linked with cancer care. Many have come to recognize, however, that PEOLC should address the needs of all individuals facing life-threatening illnesses. In response to this aspiration, and to contribute to an expansion of the scope of PEOLC research, the RWG established CaNPERbc in February, 2005 to support the growing community of researchers addressing terminal illness other than cancer. Since its creation, the network has met regularly. CaNPERbc and the RWG also supported an extra print run of the September 2005 Journal of Palliative Care special issue on non-cancer PEOLC. Five hundred copies were distributed to interested individuals.

Canadian Institutes of Health Research Panel Funding

With funding from the RWG, the Canadian Institutes of Health Research established a panel of experts to review applications for the biannual operating grant competitions which are specific to PEOLC research. This helped to support due diligence in the pursuit of exemplary PEOLC research.

Surveillance Working Group (SWG)

The SWG was created to work towards the development of a system for collecting and using information about who needs PEOLC, who receives it, and how to measure its quality. This information will ultimately be helpful to policymakers and administrators at the regional health authority, provincial/territorial, and national levels, in order to plan programs and services for PEOLC. With input from Statistics Canada, the Canadian Institute for Health Information, the Public Health Agency of Canada, palliative program administrators, health care professionals, and researchers, the primary focus of the SWG was to lay the groundwork for the creation of such a system through efforts including the following:

Quality Performance Measurement

In 2005/06, the SWG reviewed methods to measure quality performance. This led to a meeting of stakeholders, hosted by Health Canada, where program administrators from across the country had the opportunity to network and share information and ideas on this issue.

Inventory of Performance Measures

The SWG supported an extensive literature review on ways to measure the performance of PEOLC programs and services. This resulted in an inventory of performance measures which palliative program administrators can use to assess the quality of their services. The inventory and its accompanying methods report are available from the author: Konrad.Fassbender@ualberta.ca

Pilot Project on Standardized Patient Data

In collaboration with 16 palliative care programs across the country, and following a planning meeting held in March 2002, the SWG pilot-tested a method for collecting standardized information on PEOLC patients. This innovative pilot project resulted in information that may one day be used to ensure that quality PEOLC is delivered in a consistent manner across different care settings and jurisdictions.

Partnership Meetings

Representatives from Health Canada, the Public Health Agency of Canada, Statistics Canada, and the Canadian Institute for Health Information held several meetings in the Fall of 2005 to discuss ways of working together to address surveillance issues in PEOLC. In order to maximize communication and coordination of efforts, and to leverage change to achieve common goals, these stakeholders participated in the SWG.

Data Needs Assessment

A two-day meeting was held in March 2007 in Ottawa. The purpose of this meeting was to discuss the informational requirements to inform policy and planning for PEOLC. Examples of such needs include: identification of the minimum data to describe the need for and supply of palliative care services; the sources, method and implications of collection and utilization; and identification of key stakeholders for each jurisdictional level. Accordingly, representatives of federal, provincial and territorial government departments responsible for PEOLC, as well as PEOLC surveillance experts and program administrators, participated in this event.

CONCLUSION

The Coordinating Committee of the Canadian Strategy on Palliative and End-of-Life Care is proud to impart the valuable contribution this initiative has made to the Canadian health care system. Over the past five years, through significant collaborative effort, the working groups have laid the foundation for continued work to enhance Canada's capacity for quality and accessible PEOLC.

Health Canada will continue to address palliative care and will engage palliative care stakeholders in this important work. All parties look forward to experiencing new and dynamic forms of engagement.

Although challenges still remain, as shifting demographics translate into growing needs for all areas of the health care system, the accomplishments of this Strategy provide a positive example of the successes to be gained from teamwork.

APPENDIX A

Members of the Coordinating Committee and Working Groups

The following list includes all community members who have served on one of the five working groups and/or the Coordinating Committee of the Canadian Strategy on Palliative and End-of-Life Care. This list is in alphabetical order and includes all individuals who contributed at any point over the lifespan of the Strategy. The workplace that is indicated for each individual on this list reflects their position and place of employment at the time they participated in the Strategy.

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APPENDIX B

Links and Resources

Links

The Canadian Council of Health Services Accreditation
www.cchsa.ca

The Canadian Hospice Palliative Care Association
www.chpca.net

Educating Future Physicians in Palliative and End-of-Life Care
www.efppecc.ca

Canadian Virtual Hospice
www.virtualhospice.ca

Resources

National Action Planning Workshop on End-of-Life Care
http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2002-nat-plan-palliat/index_e.html

CHCPA's *A Model Guide to Hospice Palliative Care: Based on National Principles and Norms of Practice* (2002)
http://www.chpca.net/marketplace/national_norms/national_norms_of_practice.htm#download

CHPCA's *Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice* (2006)
http://www.chpca.net/marketplace/pediatric_norms/pediatric_norms.htm#download

Hospice Palliative Care – Public Awareness Raising Framework
http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-palliat-public/index_e.html

The information needs of informal caregivers involved in providing support to a critically ill loved one
http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2005-info-caregiver-aidant/index_e.html

Advance Care Planning – The Glossary Project
http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index_e.html