



Health
Canada Santé
Canada

Health Canada Secretariat on Palliative and End-of-life Care

National Action Planning Workshop on End-of-life Care

Workshop Report

March 2-4, 2002
Winnipeg, Manitoba

*Strachan Tomlinson
March 26, 2002*

Contents

Acknowledgements	iv
Introduction	1
National Action Plan on End-of-Life Care	5
#1: Availability and Access to Services	7
#2: Education for Healthcare Providers	11
#3: Ethical, Cultural and Spiritual Considerations	13
#4: Public Education and Awareness	17
#5: Research	19
#6: Support: Family, Caregiver and Significant Others	21
#7: Surveillance	23
Implementation Challenges	25
Structure	27
Next Steps	27
Closing Remarks	27
Appendix #1: Acronyms and Key Terms	29
Appendix #2: Key National Events: A Chronology	33
Appendix #3: Presentation Slides - Dr. Neil Hagen	35
Appendix #4: Presentation Slides - Ms. Ceal Tournier and Ms. Gaye Hanson	39
Appendix #5: Definitional Issues ñ National Action Planning Workshop	41
Appendix #6: Organizations	45
Appendix #7: Participants	54

Acknowledgements

Sincere thanks to the volunteer Steering Committee Members and Working Group Co-Chairs who helped to organize the workshop.

Dr. Pierre Allard

Mr. Barry Ashpole

Ms. Sharon Baxter

Dr. Fred Burge

Dr. Harvey Chochinov

Dr. Robin Cohen

Ms. Kirstin Doull

Dr. Michael Downing

Mr. Eugene Dufour

Rev. Dr. Neil Elford

Dr. Robin Fainsinger

Dr. Neil Hagen

Dr. Laura Hawryluck

Ms. Lorna Hillman

Ms. Laurianne Jodouin

Ms. Rosella Kinoshameg

Dr. Francis Lau

Dr. Larry Librach

Dr. Sue Morrison

Dr. Neil MacDonald

Ms. Patricia Russell

Ms. Judy Simpson

Note: This report reflects the work and discussion of the Working Groups formed for this workshop and does not reflect the official policy of Health Canada unless this is clearly stated.

Introduction

Quality palliative and end-of-life care involves not only professional health care providers, but also family and other volunteer caregivers. It encompasses not only the physical, but also the spiritual, social, psychosocial, cultural and emotional dimensions of patient care. It is sustained by research and surveillance and it involves different levels of government.

Canada has the opportunity to take an international leadership role in establishing what we think should be priorities for end-of-life care. We can forge a new component to our health care policy that reflects our values on life, so that it is truly comprehensive, from cradle to grave.

This workshop is an important first step—and a catalyst to further action—in developing a national, five-year action plan for end-of-life care.

Senator Sharon Carstairs, Minister with Special Responsibility for Palliative Care

The Elders taught us to look at the whole picture. That's why we're here nationally today. We are the roadbuilders for the youngsters. We have to build it well so that they will respect us.

Ken Saddleback, Cultural Advisor, Kiwetahk Cultural Society, Alberta

Unfortunately, in end-of-life care, we do not have a vocal constituency: the dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.

Dr. Harvey Chochinov, Professor, Department of Psychiatry, University of Manitoba

The National Action Planning Workshop on End-of-life Care¹ took place in Winnipeg, Manitoba on March 2-4, 2002. Over 150 participants attended the workshop, representing a broad spectrum of stakeholders across the continuum of palliative and end-of-life care, including healthcare providers², representatives of federal and provincial/territorial governments, consumers, Aboriginal peoples, researchers, delegates from health charities, professional associations, advocacy groups and non-government organizations.

The purpose of this workshop was to launch the development of a national action plan to ensure that all Canadians have access to quality end-of-life care. The conclusions in this report consolidate and follow through on the considerable work already in place in

¹ See Appendix #2 for a chronology of events leading up to the workshop.

² For the purposes of this workshop, 'healthcare provider' was defined in the broadest sense possible and included all individuals involved in formal caregiving, e.g., physicians, nurses, specialists, community workers, volunteers, etc.

INTRODUCTION

Canada and other countries on implementing change related to end-of-life care. This workshop focused on the following seven areas:

- Availability and Access to Services
- Education for Healthcare Providers
- Ethical, Cultural and Spiritual Considerations
- Public Education and Awareness
- Research
- Support: Family, Caregiver and Significant Others
- Surveillance.

This workshop was the first step in launching the development of a national action plan. The next step involves collaborative work between the Health Canada Secretariat on Palliative and End-of-Life care and the project Steering Committee as they follow through on this report. As one participant put it, “the time is now”, reflecting the belief that, based on the significant work already completed in this area and the political will behind the initiative, there is an unprecedented opportunity to move forward and make important progress in quality palliative and end-of-life care.



OPENING SESSIONS

The workshop opened with a powerful demonstration of Aboriginal dances by First Nations Drummers and Dancers. George Bear, the dancers' spokesperson, emphasized that, regardless of age, dancing and singing are regarded in his culture as important to healing.

Participants were welcomed by Ms. Abby Hoffmann, Director General, Health Care Strategies and Policy Directorate, Health Canada. The Honourable David Chomiak, Minister of Health, Manitoba and His Worship Mayor Glen Murray, City of Winnipeg also extended their welcome to participants and thanked Minister Carstairs for acting as a champion of palliative and end-of-life care in Canada.

The Honourable Sharon Carstairs, P.C., Leader of the Government in the Senate and Minister with Special Responsibility for Palliative Care, provided opening remarks. The Minister shared her personal experiences of how death has touched her life. She expressed her deep commitment to improving palliative and end-of-life care in Canada and her profound appreciation of the contribution made by workshop participants in this area.

Dr. Neil Hagen, Head, Division of Palliative Medicine, University of Calgary, gave the keynote presentation on quality end-of-life care, describing progress made to date. He framed the challenge of developing a national action plan using three questions:

- Can it work?
- Does it work?
- Will it make a difference?

Dr. Hagen's presentation slides are included in Appendix #3.

Ms. Ceal Tournier, National Aboriginal Health Organization (NAHO), and Ms. Gaye Hanson, Hanson Consulting, provided an overview of the Aboriginal Peoples' perspectives on end-of-life care. Their presentation slides are included in Appendix #4.

NORMS FOR WORKING TOGETHER

Participants agreed on the following norms for working together during their discussions at the Workshop.

1. Create something you can be proud of in 5 years' time.
2. Be clear and concise.
3. Collaborate to reach agreement.
4. Think strategic and national.
5. Share the air time.
6. Look for solutions that are simple and elegant.

Participants also recognized the importance of treating each other with respect and being mindful of cultural differences.

INTRODUCTION

National Action Plan on End-of-Life Care

There is no magic answer. ...We want to stay focused on developing an action plan – on determining what we can do, not what we can't do.

Minister Sharon Carstairs

Participants worked in groups to provide feedback on the Discussion Paper prepared for the workshop and develop priorities and actions related to the following seven key areas (alphabetical order):

1. Availability and Access to Services
2. Education for Health Care Providers
3. Ethical, Cultural and Spiritual Considerations
4. Public Education and Awareness
5. Research
6. Support: Family, Caregiver and Significant Others
7. Surveillance.

The conclusions of these seven groups are outlined in this report; they vary in format and depth, reflecting the current situation in each area.

The National Aboriginal Health Organization (NAHO) also prepared a draft discussion paper on quality end-of-life care, palliative care, and home and community care for Aboriginal peoples. Aboriginal delegates met during the workshop to share their perspectives on discussions. In a post-workshop meeting, Aboriginal delegates explored their understanding of a national action plan and identified next steps after the workshop, including dissemination of their final discussion paper.

This report launches the implementation phase of this project. As such, the plan is meant to be iterative, with regular updates and revisions that reflect the current situation in each area. The role of the Working Group chairs for the seven areas in this report is to support dissemination and implementation and enable monitoring of results. Follow-up will happen as soon as possible in each area.



#1: Availability and Access to Services

The challenge is to describe the availability and access to services for palliative and end-of-life care that presently exist across Canada, define clear goals for comprehensive access and availability, and develop a strategy to provide quality palliative and end-of-life care for all Canadians irrespective of their type of life threatening illness.³

VISION 2010

Palliative and end-of-life services – structured along a continuum of specialization from primary healthcare to services whose core activity is limited to the provision of palliative care – are available and accessible to all Canadians. Achieving this vision improves systemic performance within the healthcare system and enhances system capacity. Business cases provide both the health care and economic rationale for this approach. Both best practices and working, funded models are being diffused across the country.

PRIORITY #1.1:

Make available integrated, accessible and adequately funded palliative and end-of-life care to all Canadians.

	Action	By Whom	By When
1.1.1	<p>Direct Federal and Provincial/Territorial (P/T) Health Ministers to support collaborative work focused on ensuring that quality palliative and end-of-life care is available across Canada. Expanded and properly funded end-of-life home care services should include financial coverage for drugs; both professional and non-professional care services; access to community day programs; 24-hour pain and symptom management teams; support for families such as respite care and bereavement follow-up. Key characteristics:</p> <ul style="list-style-type: none"> - public accountability/reporting for what each province/territory is doing regarding palliative and end-of-life care - responsibility centre in each province/territory - provincial/territorial/regional accountability - address particular needs of individuals from specific groups: urban, rural, remote, aboriginal, pediatrics and others - services need to be developed within the context of an improved home and continuing care sector and primary health care sector. 	TBD based on structure for this initiative	Before August Premiers' meeting, provide advice on core components of end-of-life and palliative care to ensure that Premiers identify palliative and end-of-life care as a priority in home and community care.

³ The Working Group accepted the above statement **in principle**. For the purposes of this Workshop, the group wanted to focus on the need for a strategy.

#1: AVAILABILITY AND ACCESS TO SERVICES

1.1.2	Establish and adopt norms for palliative and end-of-life care across federal/provincial/territorial areas of jurisdiction.	TBD based on structure for this initiative	December, 2003
1.1.3	Ensure that advocacy/accountability is undertaken at the local, regional, provincial/ territorial and national levels to support this federal/provincial/territorial initiative.	TBD based on structure for this initiative	December, 2002
1.1.4	Ensure that health care delivery at end-of-life is adequately funded.	Federal/ Provincial/ Territorial (F/P/T) Health Ministers	

PRIORITY #1.2:

Make available integrated, accessible, adequately funded palliative and end-of-life care in varied institutional and home settings in rural and urban communities.

	Action	By Whom	By When
1.2.1	Support the cost of drugs for end-of-life care to assure that patients can afford to be out of the acute care sector and in their home communities.	P/T Ministers of Health	December, 2004
1.2.2	Provide support for caregivers, such as families, e.g., income security, job protection, tax benefit for loss of salary, no loss of seniority, drug benefit plan.	P/T Premiers and Ministers of Health	December, 2004
1.2.3	Promote/support end-of-life care to meet the particular needs of Aboriginal communities, i.e., community based and culturally sensitive. Promote action at the federal level (regarding populations it serves directly) as a demonstration of leadership by example.	TBD based on structure for this initiative	
1.2.4	Establish and implement standards for community based end-of-life care.	TBD based on structure for this initiative	
1.2.5	Ensure that health care professionals receive adequate funding through the primary care model of health care delivery involved in palliative and end-of-life care. Palliative and end-of-life care should be part of overall provincial-territorial strategies for primary health care renewal.	Professional Associations and P/T Deputy Ministers of Health	
1.2.6	Develop programs at the federal and provincial/territorial levels aiming at development and capacity building of the voluntary sector in each community.	Canada's Voluntary Sector Initiative (VSI)	2003

PRIORITY #1.3

Formalize accountability mechanisms in each jurisdiction (federal, provincial/ territorial, regional, First Nations, Métis and Inuit) to ensure accessible and equitable palliative and end-of-life services throughout Canada.

	Action	By Whom	By When
1.3.1	Identify an individual (senior) to be responsible for comprehensive policy development in palliative and end-of-life care in order to address the vision for palliative/end-of-life care.	P/T Premiers	2002
1.3.2	Develop specific standards for palliative and end-of-life care across all care settings, including a mechanism to ensure rigorous application, e.g., through quality improvement indicators.	Canadian Council on Health Services Accreditation (CCHSA)	December, 2004

#2: Education for Healthcare Providers

The challenge is to develop accessible and effective strategies for educating healthcare providers to provide holistic, interdisciplinary and quality end-of-life care for Canadians.

PRIORITIES

Participants in this group identified the following three priorities and identified the same action areas for each priority.

PRIORITY #2.1:

Develop an effective and relevant national education framework for service delivery at all levels based on standards.

PRIORITY #2.2:

Develop a National Framework for Entry-to-practice education for healthcare providers.

PRIORITY #2.3:

Develop a National Framework For Continuous Learning and Competency for generalists and specialists.

Each of these priorities require action in the following five areas:

1. Surveillance and Data
2. Funding/resources
3. Standards
4. Key methods/tactics
5. Key partners.

Members of this group had wide ranging discussions focused on each of these five areas for action. More specific action steps will be developed as part of following through on this work.





#3: Ethical, Cultural and Spiritual Considerations

The challenges are to:

- i equip public and healthcare providers with the abilities to have discussions about ethical decisions throughout the process of dying*
- enable culturally-specific practices and relationships that support the dying process and provide meaning for patient and family and assist healthcare providers with cross cultural sensitivity*
- develop broader understanding and use of spirituality to support and respect the diversity of meanings and practices of the dying process to the person, family, and healthcare providers.*

PRIORITY #3.1: ADVOCACY

	Action	By Whom	By When
3.1.1	Advocate for the inclusion of ethical, spiritual and cultural dimensions in all aspects of end-of-life care.	Health Canada (HC), Social Sciences and Humanities Research Council (SSHRC), Canadian Institutes of Health Research (CIHR) in partnership with professional organizations, across jurisdictions, provincial ministries of health, Inter-Faith groups, cultural groups, Aboriginal Elders	March, 2003
3.1.2	Develop a vision, set of values and competencies based on existing research and knowledge on ethical, spiritual, and cultural dimensions of end-of-life care and death.	Canadian Bioethics Society (CBS), Canadian Association of Pastoral Practice and Education (CAPPE)	March, 2003
3.1.3	Coordinate the legislation regarding advance care planning across the provinces and across care jurisdictions to ensure values, beliefs and culture are consistently respected.	Federal Government to coordinate with Canadian Bar Association, P/T Ministries of Health	March, 2005

PRIORITY #3.2: EDUCATION

	Action	By Whom	By When
3.2.1	Develop and ensure implementation of ethical, cultural and spiritual curricula for all those concerned in end-of-life care, including adult and pediatric perspectives.	Professional colleges, MCC, CHPCA, CBS, Ethics Educators, Ethics Centres, Ian Anderson Program, Aboriginal Elders, CAPPE and cultural groups	March, 2003

#3: ETHICAL, CULTURAL AND SPIRITUAL CONSIDERATIONS

3.2.2	Teach respect for diversity and individual interpretations of spirituality and culture.	Spiritual Leaders, Community Leaders, Canadian Council of Churches, Federal Department of Canadian Heritage, Canadian Race Relations Association, clinical educators , spiritual care providers in health care agencies/ organizations, Aboriginal Elders, cultural groups, professional associations, Victorian Order of Nurses (VON)	March, 2005
3.2.3	Enable public discussion about the search for and the benefits of spirituality, values, beliefs and meanings at the end-of-life.	Provincial Palliative Care Associations, CHPCA, Associations of Churches, hospitals, professional associations, ethics centres, Local Council of Churches, Catholic Health Association of Canada, CAPPE, Elder and cultural groups, VON	March, 2005
3.2.4	In a culturally sensitive manner, develop education for the public on advance care planning that enables them to understand what to expect in the decision-making process and the implications of decisions.	Universities, Colleges, Clinical Ethical Centres, professional associations, Provincial Association of Gerontology, Canadian Association of Gerontology, Aboriginal Elders and cultural groups, Working-Group on Public Education and Awareness	March, 2004

PRIORITY #3.3: RESEARCH

	Action	By Whom	By When
3.3.1	Promote interdisciplinary research in ethical, cultural and spiritual dimensions of end-of-life experience and appropriate care.	CIHR, SSHRC, Canadian Association of Social Workers (CASW), Rural and Remote Health Interdepartmental Committee (CRP), various religious organizations, Aboriginal Elders and cultural groups, working-group on research	March, 2004

PRIORITY #3.4: PRACTICE

	Action	By Whom	By When
3.4.1	Develop strategies to support (including financially) the dying person and his or her family in their cultural and spiritual beliefs at the end-of-life, e.g., dying in place of choice.	Professional associations such as CASW, CAPPE, Canadian Chamber of Commerce, Canadian Bar Association, Institute of Chartered Accountants, Canadian Home Care Association (CHCA), Ethics Centres, CIHR, SSHRC, VON, professional societies, Aboriginal Elders and cultural groups	March, 2004
3.4.2	Develop guidelines and standards for (a) the provision of treatment for the purpose of alleviating suffering where that may shorten life; (b) practice of the total sedation of patients; and (c) to govern the withholding and withdrawal of life-sustaining treatment.	Health Canada in collaboration with the provinces, territories, and national associations of health care professionals	March, 2004

#4: Public Education and Awareness

The challenges are to:

- a. *have every Canadian accept dying as a natural process of life, and*
- b. *ensure/enable/help/educate every community, family and individual to know how to work together with the community and health care system to access quality end-of-life care.*

PRIORITY #4.1

Create a national public education campaign to address the two points in the challenge statement. The campaign would include the following elements:

- *consistent messages and terminology used by everyone at all levels across the country*
- *multimedia, i.e., look at ways to reach different targets and groups of people*
- *in conjunction with current initiatives if possible.*

	Action	By Whom	By When
4.1.1	Develop key campaign messages.	CHPCA in partnership with others, e.g., Health Canada, provincial organizations, QEOLCC, private sector and provincial governments	Immediately
4.1.2	Develop the campaign.	Contractor	To be determined
4.1.3	Develop awareness tools.	Contractor	To be determined

PRIORITY #4.2

Develop multiple information sources of quality, credible information on hospice/palliative care and end-of-life care that are targeted to specific audiences and use a variety of methods.

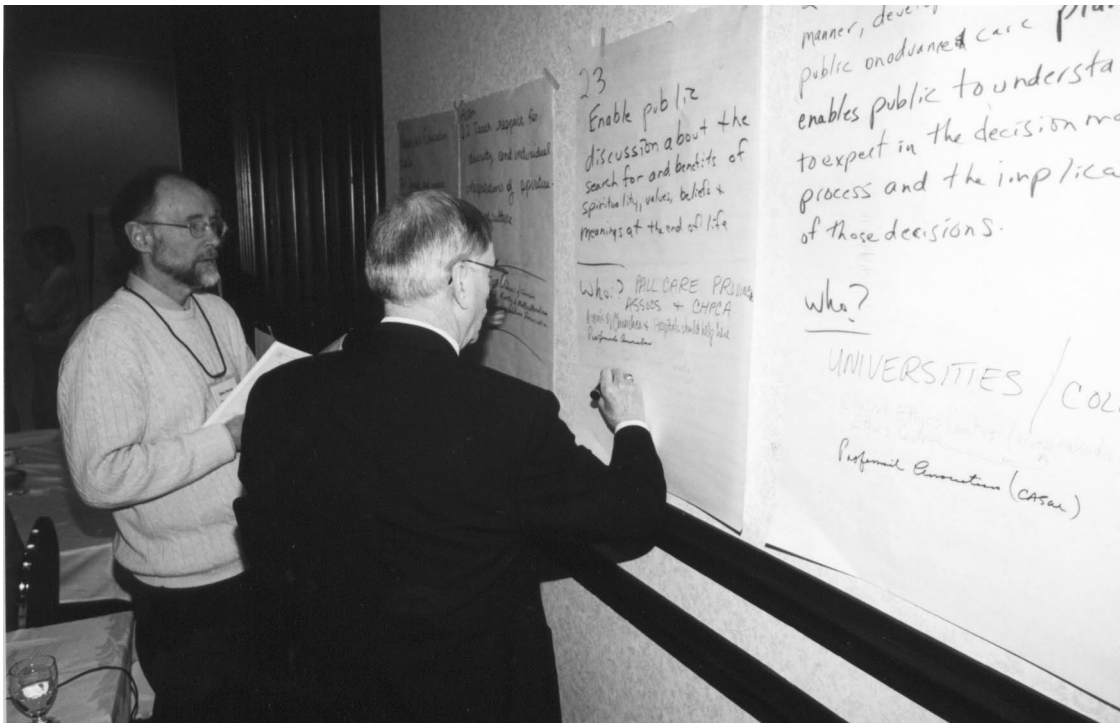
	Action	By Whom	By When
4.2.1	Continue to support the development, implementation and expansion of the Canadian Virtual Hospice.	Health Canada, CVH, private sector and others	Immediately and evaluate in two years
4.2.2	Create and/or verify and disseminate education and skills-based resources for the local level.	To be determined based on structure for this initiative	To be determined based on structure for this initiative

#4: PUBLIC EDUCATION AND AWARENESS

PRIORITY #4.3:

Encourage Canadians to plan for the ends of their lives.

	Action	By Whom	By When
4.3.1	Develop an inventory of tools for providers, individuals and families.	Health Canada in partnership with CAG, QEOLCC, CHPCA, provincial governments, CHA and others	Start immediately
4.3.2	Develop standards for health care settings admissions to ensure that physicians or other health care practitioners ask every patient or decision maker about their goals regarding end-of-life care. (Follow example of long term care sector.)	Provincial Ministries of Health Hospital Accreditation (CCHSA) Canadian Medical Association (CMA)	2 years, followed by evaluation



#5: Research

The challenge is to create an infrastructure (e.g., structure and process) with a critical mass of interdisciplinary investigator research teams to support all types of palliative care and end-of-life⁴ research (basic science, clinical, health services, population-based, psychosocial, ethics and cultural) that will help prevent suffering and provide optimal palliative and end-of-life care and allow monitoring and dissemination to ensure the uptake of research findings.

PRIORITY #5.1: HUMAN RESOURCE CAPACITY BUILDING

	Action	By Whom	By When
5.1.1	Create capacity through multi-level training programs, senior and junior scientist awards, clinician scientists, buy-back salary, studentships and career awards, summer institutes and undergraduate education.	Health Canada Secretariat to assemble a coordinating group that includes representation from national planning research group participants, governmental and non-governmental national granting agencies, universities, and private research foundations	Group assembled by April 2002 Programs in place by March, 2003

PRIORITY #5.2: INFRASTRUCTURE

	Action	By Whom	By When
5.2.1	Develop a national network with central coordination capacity and the ability to identify and organize specific streams of activity with a view to creating centres of excellence. (Responsibilities and function to be defined.)	Health Canada Secretariat to assemble a coordinating group that includes representation from national planning research group participants, governmental and non-governmental national granting agencies, universities, and private research foundations	Group assembled by April, 2002 Proposal: June, 2002 Network: November, 2002 Meeting in October, 2002 in Montréal at International PC Congress

⁴ Participants in this Working Group noted concerns around definitions of palliative and end-of-life care, i.e., the terminology must mean more than cancer care.

#5: RESEARCH

5.2.2	Creation of thematic centres of excellence supported by the national palliative care community and universities, with emphasis on national mentoring.	National Network created in 5.2.1	June, 2003
5.2.3	Develop a funding strategy to find resources for research, capacity building and leadership development, e.g., inventory of sources and terms of reference including private, public, non-governmental and other partnership/leveraging opportunities e.g., chronic diseases, stroke, Canadian Palliative Care Research Initiative; Regional Partnership Program for palliative care; Millenium Chair; CIHR.	To be determined based on structure for carrying forward this action plan	March, 2003

PRIORITY #5.3: INFORMED PEER AND ETHICAL REVIEW

Actions for this priority will be developed later in the process.

#6: Support: Family, Caregiver and Significant Others

The challenge is to ensure access and availability to universal, quality and appropriate support for caregivers and other family members.

PRIORITY #6.1:

Put forward a family caregiver agenda to develop National Caregiver Legislation.

	Action	By Whom	By When
6.1.1	Develop a national caregiver action plan on end-of-life care.	CCC-CCAN, CHPCA, CAPPE, QEOLCC and others	September, 2003
6.1.2	Advocate for implementation of the national caregiver action plan with strategic processes at all levels, e.g. the primary health care initiative.	CCC-CCAN, CHPCA, CAPPE, QEOLCC, and others	2007

PRIORITY #6.2:

Promote a multisectoral approach to reduce or alleviate the financial burden for families.

	Action	By Whom	By When
6.2.1	Introduce paid leave similar to parental leave.	Human Resources Development Canada	March, 2004
6.2.2	Amend current legislation for job protection in the Canada Labour Code and provincial labour codes (The federal government should provide the above for their employees in the next collective agreement.)	F/P/T governments	March, 2004
6.2.3	Extend and increase the existing tax credit for caregivers.	Canadian Customs and Revenue Agency (CCRA) and Ministry of Finance	March, 2004
6.2.4	Ensure equitable access to out-of-pocket expense reimbursement for end-of-life care e.g., medications, equipment, respite care, transportation.	F/P/T governments	March, 2004

#6: SUPPORT: FAMILY, CAREGIVER AND SIGNIFICANT OTHERS

PRIORITY #6.3:

Provide a variety of options for and approaches to care, including psychosocial, cultural and spiritual support at home and in institutions before and after death.

	Action	By Whom	By When
6.3.1	Establish a caregiver Bill of Rights, e.g., UK model.	CHPCA, CACC, CCC-CCAN, and others	March, 2003
6.3.2	Create community-based hospice residential beds.	CHPCA (standard), Provincial Associations; Operating funds - Health Authorities CCHSA, F/P/T governments and Aboriginal, Inuit and Métis leaders	March, 2003
6.3.3	Implement palliative, population-focused spiritual and cultural support.	CAPPE, CHPCA, CCHSA, F/P/T, Health Authorities, Aboriginal, Inuit and Métis leaders	March, 2003
6.3.4	Implement bereavement programs as a component of HPC programs in service contracts with Hospice Societies and appropriate community partners.	CHPCA, Health Authorities, Provincial Hospice associations and Aboriginal, Inuit and Métis leaders	March, 2003
6.3.5	Implement palliative, population-focused psychosocial care for communities, respecting all cultures.	WHO-CCHSA, CHPCA, Provinces, Associations, Health Authorities; Aboriginal, Inuit and Métis leaders	March, 2004

#7: Surveillance

The challenge is to build, within the broad scope of palliative/end-of-life care for all diseases, all ages and all locations, an effective, national, population-based surveillance system to improve quality care at end-of-life. This system will facilitate: i) health service planning, program and policy development, ii) clinical and outcomes measurement, and iii) social and population research.

PRIORITY #7.1:

Establish an accountable governance structure.

	Action	By Whom	By When
7.1.1	Mandate a national Palliative Surveillance Workgroup to lead the surveillance initiative, including development of a business plan (see Action 7.3.3). Build on earlier work such as CaPDN and Canadian Virtual Hospice.	National Steering Committee supported by the Secretariat and Population and Public Health Branch, Health Canada.	May, 2002

PRIORITY #7.2:

Establish common palliative definitions, indicators and data set.

	Action	By Whom	By When
7.2.1	Conduct consensus building exercise to reach agreement on core indicators and a data set for palliative care.	National Palliative Surveillance Workgroup	March, 2003 and ongoing
7.2.2	Implement a pilot project on core indicators and data set.	To be determined, with reporting to National Palliative Surveillance Workgroup	December, 2003
7.2.3	Develop a population-based palliative data set and comprehensive indicators.	National Palliative Surveillance Workgroup	December, 2005

#7: SURVEILLANCE

7.2.4	Implement a population-based palliative data set and comprehensive indicators.	National Palliative Surveillance Workgroup	December, 2007
-------	--	--	----------------

PRIORITY #7.3:

Secure funds to establish national palliative data surveillance.

	Action	By Whom	By When
7.3.1	Secure sustainable funds to support the national palliative surveillance working group and to contract a consulting group to develop a business plan.	Steering Committee and Secretariat	April, 2002
7.3.2	Secure funds to a) develop the business case, including identification of existing databases and resources with palliative related information, and b) carry out Priority #7.2.	Steering Committee and Secretariat	October, 2002
7.3.3	Develop a business plan to fully detail the structures, policies and funding resources required.	Contracted consulting group reporting to the Palliative Surveillance Workgroup	September, 2002

Implementation Challenges

Participants worked in plenary and small groups to identify implementation challenges related to the national action plan. Following is a synthesis of these challenges for consideration during next steps.

a. Attitudes

The attitudes of Canadians towards issues related to death and dying vary depending on a host of factors such as background, culture, religion, spirituality, ethnicity, education, values and ethics. The action plan needs to take these attitudes into consideration when designing educational materials, programs and processes focused on enabling changes in perspectives and attitudes.

b. Champions

Leaders are required in each jurisdiction and key issue area to advocate for the ideas, visions, supports and resources required to implement the plan and to enable buy-in of programs and services in the action plan.

c. Coordination

The end-of-life care area lacks a mechanism for moving forward in a coordinated and strategic manner. There is limited organizational capacity and capability for basic activities such as information sharing, priority setting and operationalizing the plan.

Effective coordinating structures require a built-in capacity to “think outside the box”, e.g., system design, knowledge application, models of care.

d. Definitions

For the purposes of this workshop, key terms were defined in the background discussion paper. However, while developing action plans in the seven working group areas, participants recognized the need to come to agreement at a national level – for implementation purposes – on key terms such as palliative care and end-of-life care. To clarify this issue, a small group of volunteers described three different perspectives outlined in Appendix #5.

Other definitions required include: “good” end-of-life care, surveillance system, outcomes, indicators, caregiver, volunteer, healthcare provider, etc.

e. Inclusion

An effective national plan must be sensitive to and include a variety of health care providers, volunteers, disciplines, organizations, associations, cultures, ethnic groups and perspectives. The perspectives of Aboriginal populations must be integrated. Sometimes, in the interests of a national approach, the unique richness of a variety of perspectives can be lost.

f. Managing Complexity

The situation in end-of-life care is complex, with several levels of initiatives – local, regional, provincial, national – to be addressed, as well as ethical issues such as privacy legislation and security. Research demands are also complex, e.g., given the number of Institutes at CIHR that need to address research on end-of-life care, a special advisor model may be required for coordination purposes.

Political environments are not fixed, e.g., changes of governments may lead to discontinuities in policy. There are challenges in the relationships between provincial and federal governments and Aboriginal/Inuit/Métis leadership.

g. Monitoring and Evaluation

The plan needs to be monitored on a regular basis and evaluated based on benchmarks for success.

h. Resources

Existing resources are insufficient to address changing demographics in relation to the demand for end-of-life care. Targeted funding is required to implement the action plan, e.g., to develop business plans and a marketing strategy, to free up clinicians for time to do research, to support recommended programs such as surveillance.

For resources to flow to palliative and end-of-life care, this area needs to be valued by those who have influence and positional power in relation to resources.

i. Vision

Although previous reports and recommendations have developed national visions for palliative and end-of-life care, each issue area also needs its own vision that is part of a clear, national vision.

Structure

Following the identification of implementation challenges, participants discussed structural models for implementation of the action plan and created possible structures for consideration by the Health Canada Secretariat on Palliative and End-of-Life care. This activity involved lively discussions and the development of a wide range of options.

At a meeting of Steering Committee members and Working Group Co-Chairs following the workshop, a small sub-group of volunteers was created to review the draft structures, and distill them into two or three choices. These choices will be forwarded to the Secretariat for a decision on how to move forward. The sub-group will be meeting shortly to do its work.

Next Steps

The Steering Committee and Working Group Co-Chairs will meet before the end of May, 2002 to recommend a structure, decide on next steps, and develop a strategy for operationalizing the plan. The focus will be on an early success in each of the seven action areas and a realistic plan for longer term implementation.

Closing Remarks



In closing, Minister Carstairs thanked participants for their contribution and reminded them of the importance of collaboration in making the action plan a reality in the day-to-day lives of Canadians. She reaffirmed her commitment to palliative care and end-of-life care issues and will continue to act as a strong supporter and facilitator of this initiative.

Ms. Abby Hoffman, Director General, Health Care Strategies and Policy Directorate, Health Canada, remarked on the team effort and hard work of participants during sessions. She also recognized that more work is required to finalize the National Action Plan and that she appreciated the contributions of Steering Committee members,

Working Group Chairs and the Secretariat in this regard. Health Canada will do its best to champion the plan while recognizing that future resource and policy decisions cannot be pre-judged. She noted that Health Canada is only one of the partners in this initiative, and that she is looking forward to collaborating with other stakeholders in ensuring the success of this initiative.

Mr. Eugene Dufour, President, Canadian Hospice Palliative Care Association, thanked participants on behalf of the CHPCA and asked people to keep in mind that it is the little successes that will help to move this initiative forward.

The workshop closed with a song and prayer offered by Mr. Ken Saddleback, Cultural Advisor, Kiwetahk Cultural Society, Alberta and Mr. Bob Cardinal, Aboriginal Cultural Helper, Royal Alexandra Hospital, Alberta.

Appendix #1: Acronyms and Key Terms

AFN	Assembly of First Nations
CACC	Canadian Association for Community Care
CACL	Canadian Association for Community Living
CAD	Canadian Association of the Deaf
CAG	Canadian Association of Gerontology
CAPC	Centre to Advance Palliative Care
CAPCA	Canadian Association of Provincial Cancer Agencies
CaPDN	Canadian Palliative Data Network
CAPO	Canadian Association of Psychosocial Oncology
CAPPE	Canadian Association for Pastoral Practice and Education
CAR	Canadian Association of Radiologists
CARA	Community Academic Research Award (California)
CARO	Canadian Association of Radiation Oncologists
CARP	Canadian Association of Retired Persons
CAS	Canadian AIDS Society
CASW	Canadian Association of Social Workers
CBCN	Canadian Breast Cancer Network
CBS	Canadian Bioethics Society
CCC	Canadian Coalition of Churches
CCC – CCAN	Canadian Caregiver Coalition
CCHSA	Canadian Council on Health Services Accreditation
CCRA	Canadian Customs and Revenue Agency
CCS	Canadian Cancer Society or Canadian Cardiovascular Society
CCCS	Canadian Critical Care Society
CFPC	College of Family Physicians of Canada
CHAC	Catholic Health Association of Canada
CHCA	Canadian Home Care Association
CHPCA	Canadian Hospice Palliative Care Association
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes of Health Research
CMA	Canadian Medical Association
CME	Continuing Medical Education
CMHA	Canadian Mental Health Association
CNA	Canadian Nurses Association
CPhA	Canadian Pharmacists Association

APPENDIX #1: ACRONYMS AND KEY TERMS

CPHA	Canadian Public Health Association
CSN	Canadian Society of Nephrology
CSPCP	Canadian Society of Palliative Care Physicians
CSCC	Canadian Strategy for Cancer Control
CVH	Canadian Virtual Hospice
F/P/T	Federal/Provincial/Territorial
HC	Health Canada
HCCC	Health Charities Council of Canada
NACA	National Advisory Council on Aging
NAHO	National Aboriginal Health Organization
NCI	National Cancer Institute (US)
NCIC	National Cancer Institute of Canada
NCPB	National Cancer Policy Board
NCWC	National Council of Women of Canada
NGO	Non-government Organization
NHS	National Health Service (UK)
NIH	National Institutes of Health (US)
NVO	National Voluntary Organizations (Coalition of)
ORPCC	Ottawa Regional Palliative Care Centre
PHCTF	Primary Health Care Transition Fund
P/T	Provincial/Territorial
QEOLCC	Quality End-of-Life Care Coalition
RCPSC	Royal College of Physicians and Surgeons of Canada
RPCP	Regional Palliative Care Program
RPHCP	Rural Palliative Home Care Project
SSHRC	Social Sciences and Humanities Research Council
ST	Systemic Therapy
VON	Victoria Order of Nurses
WHO	World Health Organization

Key Terms

COLLABORATION⁵

is a process through which parties who see different aspects of a problem can constructively explore their differences and search for solutions that go beyond their own limited visions of what is possible. Collaboration involves joint problem solving and/or decision making among key stakeholders in a problem or issue.

Interactivity Continuum

Coordination

Cooperation

Collaboration

Five features are critical to the process:

- (1) the stakeholders are interdependent
- (2) solutions emerge by dealing constructively with differences
- (3) joint ownership of decisions is involved
- (4) stakeholders assume collective responsibility for the future direction of the domain, and
- (5) collaboration is an emergent process.

NATURE OF COLLABORATIVE PROBLEMS

- disparity of power and/or resources
- problems complex, not well defined, scientific uncertainty
- stakeholders not clear, unorganized
- differing perspectives may lead to adversarial relationships
- incremental or unilateral efforts unsatisfactory
- existing approaches and processes insufficient.

⁵ Barbara Gray. *Collaborating: Finding Common Ground for Multiparty Problems*. Jossey-Bass Publishers, London, 1989, 5.

CONSENSUS

Most dictionary definitions equate “consensus” with “unanimity”, but at this workshop, the word will have its more popular meaning, “substantial agreement”.

We will measure the degree of consensus that has been achieved by asking participants to express one of the following positions:

- I agree with the proposal;
- I can live with the proposal;
- I disagree, or remain undecided.

PRIORITIES

- ✓ are applied recommendations
- ✓ describe a major area of responsibility and commitment in a challenge area
- ✓ require collaboration among stakeholders to be successful.

ACTIONS

- ✓ are measurable statements that define each priority
- ✓ describe clearly what is going to be done
- ✓ enable you to fulfill your priority
- ✓ provide a realistic stretch, i.e., they plan for success
- ✓ enable buy-in from key stakeholders.

STAKEHOLDERS

- ✓ are organizations or individuals who have a strong interest in the success of the National Action Plan on End-of-Life Care, e.g., non-government organizations, patients and their families, caregivers, healthcare providers, Health Canada and other organizations.

VISION

- ✓ is a statement describing a preferred future for end-of-life care in Canada
- ✓ looks five years ahead
- ✓ provides a realistic stretch
- ✓ enrolls others through its focus and appeal.

Appendix #2: Key National Events: A Chronology

1984	<i>Chronic Pain: A Monograph on the Management of Cancer Pain</i> , Report of the Health Canada Advisory Group on the Management of Severe Chronic Pain
June 1995	<i>Of Life and Death</i> , Report of the Special Senate Committee on Euthanasia and Assisted Suicide
June 2000	<i>Quality End-of-Life Care: The Right of Every Canadian</i> , Subcommittee to Update <i>Of Life and Death</i> of the Standing Senate Committee on Social Affairs, Science and Technology
December 2000	<i>Blueprint for Action</i> by the National Stakeholders/Quality End-of-Life Care Coalition
February 2001	Canadian Strategy for Cancer Control Consultation Conference (Working Group on Palliative Care)
March 2001	Senator Sharon Carstairs becomes Minister with Special Responsibility for Palliative Care and advisor to the Minister of Health on palliative care
June 2001	Secretariat on End-of-Life and Palliative Care established in Health Canada
January 2002	Steering Committee Meeting for National Action Plan on End-of-Life Care Workshop
March 2002	Invitational Workshop: National Action Planning Workshop on End-of-Life Care, March 2-4, Winnipeg
March 2002	Implementation begins: Action Plan and Next Steps

Appendix #3: Presentation Slides - Dr. Neil Hagen

END OF LIFE CARE: A NATIONAL ACTION PLAN

THE CHALLENGE

- construct an action plan to assure that there is **quality end of life care** for all Canadians

INTRODUCTION

- Can it work?
- Does it work?
- Will it make a difference?

THE ETHICAL IMPERATIVE

- to relieve suffering
- to set health priorities to achieve primacy in relief of correctable suffering

DEFINITIONS: MEETING PATIENTS' NEEDS

- Palliative Care
- End of life Care
- Supportive Care
- Psychosocial Oncology

ELEMENTS OF THE PROBLEM

- the medical model (science driving change)
- silos of care
- primary care services
- medical education
- supporting the care providers
- research and research capacity
- funding ethos: funding items vs. governance of health care delivery

THE ROOT PROBLEM:

System performance:

Why doesn't our health care system work as well as it should?

DIFFUSION OF INNOVATION: EXAMPLES

- Controlling scurvy in the British Navy
- Technology run wild: proliferation of CT scans in the 1970's
- promotion of condom use in San Francisco

DIFFUSION OF INNOVATIONS

- Diffusion is the process by which innovation is communicated through certain channels over time, among the members of a social system. Everett M. Rogers 1995
- "What do we know about adoption of innovation?" Jocelyn Lockyer. *J Cont Educ in the Health Professions* 1992;12:33-38.
- "Organizational aspects of health communication campaigns: what works?" Thomas E. Backer, Everett M. Rogers eds.

DIFFUSION OF INNOVATION AND CHANGE MANAGEMENT

- Identify the poor outcome and the desired outcome to be attained through the innovation
- identify all stakeholders and powerbrokers
- identify barriers to change
- set up strategies to effect measurable change through consensus and developing a demand for the innovation
- measure the change and reassess the outcome

NATIONAL EFFORTS TO ADDRESS THE PROBLEM: USA

- NCI - designated cancer centres should play a central role as agents of national policy in palliative care
- NCI should promote research in Palliative Care and promote capacity building in Palliative Care research
- enhance data systems to evaluate the quality of care delivered
- improve education in end-of-life care at the undergraduate and post graduate levels

CANADIAN NATIONAL INITIATIVES 1985-2002

- Report on the needs of people living with cancer in Canada B. Adair, J Loveridge et al. 1986-1990
- pain was prevalent
- patients with pain often or usually were receiving no medication
- of those receiving analgesics, they often did not work well
- Canadian national initiatives 1985-2002

CANCER 2000

- October 1988: The CCS and Health and Welfare Canada co-hosted a national conference: “Cancer control in Canada: the challenge to coordinate”.
- October 1989: the Cancer 2000 Task Force first meets. Establishes nine expert panels, 80 submissions from national organizations.
- Result: 62 Goals in 15 broad areas, including palliative care, research and education.
117 recommendations in palliative care

CANADIAN NATIONAL INITIATIVES 1985-2002

- NCIC workshop 1994: Diffusion of Standards of Care for Cancer Pain
Hagen NA, Young J, Macdonald N. CMAJ 1995
- Tertiary cancer centres should routinely screen for pain and should have expert multidisciplinary pain clinics
- Faculties of Medicine should regard expertise in pain and symptom control as core undergraduate and post graduate curricular material
- Research funding agencies should establish processes to promote research in symptom control

CANADIAN NATIONAL INITIATIVES: 1985-2002

- 1995 Senate Report: Of Life and Death
- Canadian national initiatives: 1985-2002
- 2000 Senate Report “Quality End-of-Life care: The Right of Every Canadian”

CANADIAN NATIONAL INITIATIVES: 1985-2002

Canadian Hospice and Palliative Care Association

- National Consensus-based Model to Guide Hospice Palliative Care
(to be released March 11, 2002)
- Quality End-of-Life Care Coalition
- a group of 25 national stakeholders
- created the “Blueprint for Action” (December 2000)

CANADIAN NATIONAL INITIATIVES 1985-2002

Canadian Strategy for Cancer Control

- purpose
- who

CANADIAN NATIONAL INITIATIVES 1985-2002

Canadian Strategy for Cancer control: progress to date

- 12 working groups, extensive consultation
- Integration report
- Governance and Action Workshop

NATIONAL EFFORTS TO IMPROVE END-OF-LIFE CARE: WHAT HAS BEEN LEARNED?

- Health care delivery, and the public policy that supports health care delivery, change direction slowly
- not all ideas that ought to work, do work
- some positive change has occurred

CANADIAN NATIONAL INITIATIVES 1985-2002

SUCCESSES TO DATE:

- research support in palliative care
 - clinical trials-NCIC
 - CIHR
 - palliative care program development
 - Canadian Society of Palliative Care Physicians
 - Palliative Medicine: a Case-Based Manual
 - experience in national action plans

THE CHALLENGE

- construct an action plan to assure that there is **quality end of life care** for all Canadians

INTRODUCTION

- Can it work?
- Does it work?
- Will it make a difference?

Appendix #4: Presentation Slides - Ms. Ceal Tournier and Ms. Gaye Hanson

A BACKGROUND AND DISCUSSION ON: QUALITY OF END OF LIFE CARE PALIATIVE CARE AND HOME AND COMMUNITY CARE FOR ABORIGINAL PEOPLES

UNIQUE CHARACTERISTICS OF ABORIGINAL PEOPLES AND COMMUNITIES

- **Demographics:** fast growing, young Aboriginal population
- **Location** - Non-isolated, semi-isolated, isolated and remote
- **Housing** – Affordability and Quality

UNIQUE CHARACTERISTICS OF ABORIGINAL PEOPLES AND COMMUNITIES CONT'D

- Jurisdiction, Responsibility and Self-Government
- Local Access to Health Care
- Cost of Service Delivery

CULTURAL AND SPIRITUAL CONSIDERATIONS

- Diverse belief systems = need to demonstrate sensitivity to individual cultural/spiritual beliefs and practices
- Experience of death and traditions, beliefs and culture surrounding it need to be fully supported

PLANNING ISSUES

- Cultural and Spiritual Considerations – are different among Aboriginal groups
- Increasing Aboriginal Research Capacity vital to assuming control over research and health
- Ethics, Values and Policy Related Challenges - Complex
- Health Care Delivery Models for new innovative health care models

SUPPORT: FAMILY, CAREGIVERS AND SIGNIFICANT OTHERS

- Health and safety concerns
- Lack of local expertise, adequate space and equipment
- Respite and personal support for caregivers

SURVEILLANCE: GENERAL POPULATION

- Increased demand for services
- Decreased supply of informal caregivers
- Increased devolution of health care
- Emphasis on consumer-directed and self-managed care

SUMMARY OF RESPONSES TO INTERVIEWS AND QUESTIONNAIRES

- Priorities
- Basic requirements
- Care at home
- Respect and support for all religious, spiritual and cultural beliefs

ACTION

- Aboriginal participation in:
 - Identifying issues of Aboriginal peoples in palliative/end-of-life care
 - Based on that information, develop new delivery models for Aboriginal Peoples
 - Documenting delivery models which are best practices
- Conduct research to identify models for Aboriginal Peoples palliative care

ACTION CONT'D

- Do needs assessments to include urban Aboriginal peoples
- Identify jurisdictional barriers and create a coordination mechanism to eliminate these

ACTION CONT'D

- Educate and train an appropriate number of health workers to work with Aboriginal Peoples, regardless of residence or location
- Provide supervisory and professional development for health workers in Aboriginal communities

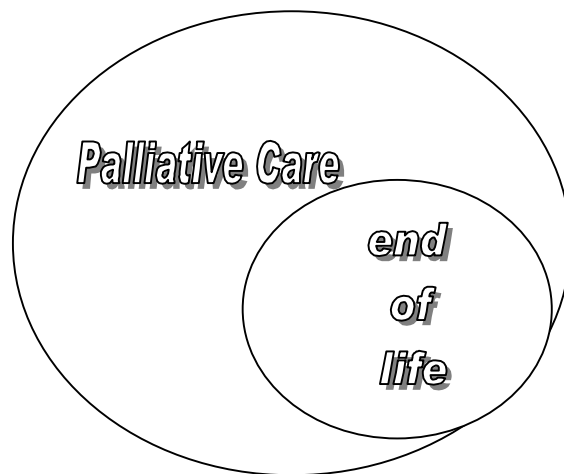
Appendix #5: Definitional Issues - National Action Planning Workshop

While the National Action Planning Workshop began with instructions that we were not to address the specific word-smithing of definitions, the issue of definitions became an issue for the workshop. The goals of clear vision and clear communication of the issues to the public and policy makers require a clear definition of the core issue being addressed.

It became apparent during the workshop that there were at least two fundamentally different conceptions of the core issue.

MODEL #1: PALLIATIVE CARE

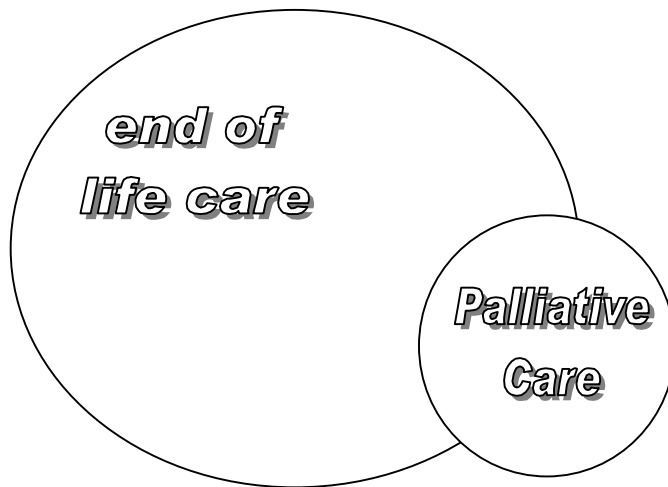
The first conception understands palliative care as the overarching issue. Here, end-of-life care is a concept within palliative care and the focus of the workshop and the national strategy is the promotion of palliative care services and the philosophy of palliative care. It might be visualized as:



This understanding emphasizes the inter-disciplinary focus and holistic approach of palliative care as the context for end-of-life-care. It is unclear, however, how to distinguish between palliative care as a philosophy practiced by many in end-of-life care and palliative care as a specialty practice. During the workshop both palliative care as practice and palliative care as a philosophy were apparent.

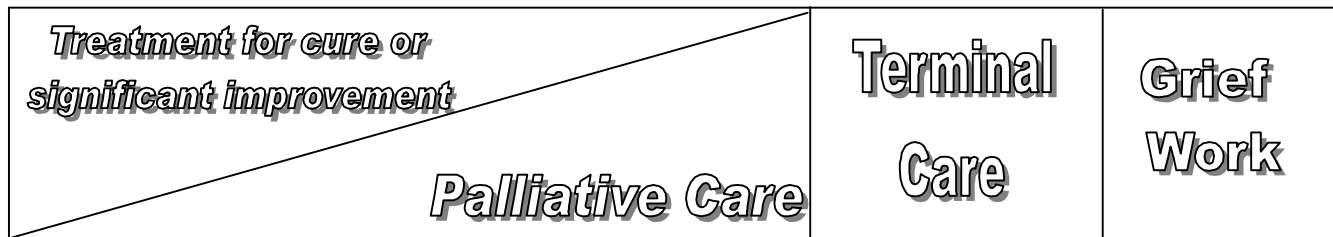
MODEL #2: END-OF-LIFE CARE

The second conception has end-of-life care as the central issue. Here, palliative care is a component of end-of-life care. Palliative care focuses on issues beyond end-of-life care, such as care for those with chronic illness and potentially life-threatening illness in remission. In addition, end-of-life care focuses on a number of issues beyond the scope of palliative care, such as advance care planning (which could/should be undertaken even by healthy and young persons who may experience an unanticipated, acute, life-threatening event such as an accident). This conception can be visualized as:



MODEL #3: GOALS OF CARE

In another conception the relationship of palliative care to end-of-life care is captured over time:



This conception seems to focus on the goals of care over time.

SUMMARY

It seems clear that the National Action Planning Workshop needs agreement on the focus in order for the vision and messages to be clear. Some questions need to be addressed:

- Is there agreement that the urgent need is to focus on improving end-of-life care?
- Is the urgent issue to promote the philosophy of palliative care generally?
- Is palliative care a philosophy or a specialty practice?
- In a desire to promote the expansive and inclusive philosophy of palliative care, might the National Action Planning Workshop diffuse the issues and fail to focus on improved care of dying?

Following presentation of these models, participants were asked to indicate by a show of hands which of Models #1 and #2 they used in their work. A majority chose Model #2, but a significant minority chose #1, thus illustrating the challenge regarding development of a definition that can be used by all stakeholders.

Appendix #6: Organizations

Following is a brief overview of organizations that are either represented on the Steering Committee for this initiative or involved with palliative and end-of-life care in Canada.

- ï **Aboriginal Health Institute (AHI)** was established to increase the ability of Inuit to communicate and share information and expertise with other Inuit across the north, reducing the isolation felt by many health workers, communities and individuals. (www.tapirisat.ca)
- ï **ALS Society of Canada (ALS)** is small, voluntary national health organization committed to providing care and finding a cure for ALS. (www.als.ca)
- ï **Arthritis Society** is a national, non-profit organization devoted to funding and promoting research into the underlying causes and subsequent cures for arthritis, and to promoting the best possible care and treatment for people with arthritis. (www.arthritis.ca)
- ï **Assembly of First Nations (AFN)** is the national representative/lobby organization of the First Nations in Canada. There are over 630 First Nation's communities in Canada. The AFN Secretariat is designed to present the views of the various First Nations through their leaders in areas such as: Aboriginal and Treaty Rights, Economic Development, Education, Languages and Literacy, Health, Housing, Social Development, Justice, Taxation, Land Claims, Environment, and a whole array of issues that are of common concern and arise from time to time. (www.afn.ca)
- ï **Association of Canadian Medical Colleges (ACMC)**: ACMC provides the national voice for academic medicine in Canada, contributing to improving the health of all Canadians through medical education and biomedical and health research. (www.acmc.ca)
- ï **Association des hôpitaux du Québec (AHQ)** is an umbrella organization offering short-term care, rehabilitation, residential and long-term care services to Quebec residents. The Association and its members believe in the importance of developing and maintaining accessibility to high-quality care and service for everyone. (www.ahq.org/apropos)
- ï **Association québécoise de soins palliatifs** operates within Québec to provide a multidisciplinary approach to palliative care. It also promotes education in the community and training of personnel. (www.aqsp.org)

APPENDIX #6: ORGANIZATIONS

- ï **BC Centre for Excellence in HIV/AIDS** is fully supported by the BC Ministry of Health, provides education to healthcare providers, conducts natural history and observational studies, develops innovative laboratory tests, and carries out clinical trials. Its drug program is at the core of the Centre's activities. (cfeweb.hivnet.ubc.ca)
- ï **Canada's Association for the Fifty-Plus/Canadian Association of Retired Persons (CARP)** is a non-profit organization whose mandate is to promote the rights and quality of life of mature Canadians. (www.50plus.com)
- ï **Canadian AIDS Society (CAS)** is a coalition of community-based AIDS organizations. CAS advocates on behalf of people and communities affected by HIV/AIDS, facilitates the development of programs, services and resources for member groups, and provides a national framework for community-based participation in Canada's response to AIDS. (www.cdnaids.ca)
- ï **Canadian Association for Community Living (CACL)** is a national association dedicated to promoting the participation of people with intellectual disabilities in all aspects community life. (www.cacl.ca)
- ï **Canadian Association for Community Care (CACC)** promotes the development of high-quality, flexible, responsive and accessible community care services in Canada. It also supports research, education and training on issues related to community care. (www.cacc-acssc.com)
- ï **Canadian Association for Pastoral Practice and Education (CAPPE)** is committed to the professional education, certification and support of those endorsed by their faith communities in ministries of pastoral care, counseling and education. (www.cappe.org)
- ï **Canadian Association of Provincial Cancer Agencies (CAPCA)** is a national organization consisting primarily of provincial cancer agencies. It is committed to making a significant contribution to Canada's overall cancer control effort by reducing the incidence of cancer, the mortality from cancer, and by improving the quality of life of those living with cancer. (www.hc-sc.gc.ca/hpb/lcdc/publicat)
- ï **Canadian Association of Psychosocial Oncology (CAPO)** is the oldest interdisciplinary professional association in North America dedicated to helping people to cope with cancer by encouraging interdisciplinary excellence in psychosocial research, education, and clinical practice in oncology. (www.capo.ca)
- ï **Canadian Association of Retired Persons (CARP):** *see Canada's Association for the Fifty-Plus.*

- ii Canadian Association of Social Workers (CASW)** provides a national leadership role in strengthening and advancing the social work profession in Canada. It promotes social justice and well-being for all Canadian residents and furthers the interests of social work internationally. (www.casw-acts.ca/AboutCASW.htm)
- ii Canadian Association of the Deaf (CAD)** is the national, non-profit consumer organization of the Deaf people of Canada. It combines the purposes of a research and information centre, an advisory council, a representative body, a self-help society, and a community action organization. (www.cad.ca)
- ii Canadian Association on Gerontology (CAG)** is a national association which provides leadership in matters relating to the aging population in Canada. It helps to foster research, education, and policy aimed at improving the quality of life of the elderly in Canada. (www.cagacg.ca)
- ii Canadian Bioethics Society (CBS)** seeks to bring together persons and organizations concerned and involved with the ethical and humane dimensions of health care. (www.bioethics.ca/english)
- ii Canadian Breast Cancer Network (CBN)** is funded by Health Canada and acts as a link between breast cancer groups across Canada to broaden their resources, provide educational activities, and share information. (www.cbcn.ca)
- ii Canadian Cancer Society (CCS)** is a national, community-based organization of volunteers, whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. Their work is focused in five areas: (i) funding cancer research through their research partner the National Cancer Institute of Canada (NCIC), (ii) providing leadership in the fight against cancer, e.g., through the Canadian Strategy for Cancer Control (CSCC), (iii) helping Canadians prevent cancer, (iv) keeping Canadians informed about cancer, and (v) helping Canadians who live with cancer. (www.cancer.ca)
- ii Canadian Cardiovascular Society (CCS)** is a non-profit medical society that represents over 1,000 cardiologists, cardiac surgeons, and cardiac researchers working to advance the cardiovascular health and care of Canadians through leadership in professional development, advocacy, and the promotion and dissemination of research. (www.ccs.ca)
- ii Canadian Caregiver Coalition (CCC-CCAN)** is a bilingual alliance composed of individuals, groups, and organizations working to influence policy and to promote awareness and action on care giving issues in healthcare policy. (www.ccc-ccan.ca)

APPENDIX #6: ORGANIZATIONS

- ii **Canadian Council of Churches** (CCC-CCE) encourages ecumenical understanding and action throughout Canada and relates to the World Council of Churches and to other agencies serving the world-wide ecumenical movement. From time to time, the Council undertakes special projects and initiatives. (www.ccc-cce.ca/english)
- ii **Canadian Council on Health Services Accreditation** (CCHSA) is a non-profit, non-governmental organization with approximately 1,800 organizations voluntarily participating in an accreditation program based on national standards. (www.cchsa.ca/english/indexeng.html)
- ii **Canadian Critical Care Society** (CCCS) represents Adult and Paediatric Critical Care Medicine physicians in Canada. It espouses the philosophy of collaborative multidisciplinary practice to promote research, education and patient care in Critical Care Medicine. (critcare.lhsc.on.ca/cc/index.html)
- ii **Canadian Healthcare Association** (CHA) is the federation of provincial and territorial hospital and health organizations, representing a broad continuum of care across Canada. It is committed to improve the delivery of publicly funded health services in Canada through policy development, advocacy and leadership. (www.canadian-healthcare.org)
- ii **Canadian Home Care Association** (CHCA) is a national organization which influences the development of national policy regarding the role of home care and community support as an integral and mandatory component of the health system. (www.cdnhomecare.on.ca)
- ii **Canadian Hospice Palliative Care Association** (CHPCA) is the national association providing leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened. The Association aims to increase awareness, develop national standards of practice and support research on hospice palliative care in Canada. (www.cPCA.net)
- ii **Canadian Institutes of Health Research** (CIHR): is Canada's premier federal agency for health research. Its objective is to excel in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened healthcare system. (www.cihr.ca)
- ii **Canadian Medical Association** (CMA) is a national voluntary professional organization representing more than 50,000 physicians across the country. It has developed a Code of Ethics to guide physicians in areas of traditional medical ethics, as well as in human rights and recent bioethical discussions. (www.cma.ca/cma/)

- ii **Canadian Mental Health Association (CMHA)** exists to promote the mental health of all people and to serve mental health consumers, their families and friends through the combined efforts of volunteers and staff in locally run organizations throughout Canada. (www.cmha.ca/english)
- ii **Canadian Nurses Association (CAN)** is a federation of 11 provincial and territorial nursing associations representing more than 110,000 registered nurses. It promotes high standards of practice, education, research and administration in order to advance the quality of nursing in the interest of the public. (http://www.cna-nurses.ca/_frames/aboutcna/aboutusframe.html)
- ii **Canadian Pharmacists Association (CphA)** is the national voluntary organization of pharmacists committed to establishing the pharmacist as the health professional whose practice ensures optimal patient outcomes. (<http://www.cdnpharm.ca/cphanew/about/abframe.htm>)
- ii **Canadian Public Health Association (CPHA)** is the national, independent, not-for-profit, voluntary association that represents public health in Canada and links to the international public health community. CPHA's members believe in universal and equitable access to the basic conditions which are necessary to achieve health for all Canadians. (www.cpha.ca)
- ii **Canadian Society of Nephrology (CSN)** promotes the highest quality of care for patients with renal diseases by setting high standards for medical training, education and research to increase the knowledge, skills and attitudes of nephrologists. (csn.medical.org)
- ii **Canadian Society of Palliative Care Physicians (CSPCP)** has more than 160 members: the major issues of interest are the CHPCA Norms of Practice and palliative care education for physicians at all levels.
- ii **Canadian Virtual Hospice** is a Government of Canada web-based initiative, announced in November 2001, that is designed to be of benefit to palliative care patients and their families, healthcare providers and researchers across Canada. (www.hc-sc.gc.ca/english/media/releases/2001/2001_121e.htm)
- ii **Caregiver Network Inc.** was created to help caregivers of the elderly and ill, by providing information on the Internet, in a newsletter, in a TV/video series, and through seminars. (www.caregiver.on.ca)
- ii **Catholic Health Association of Canada (CHAC)** is a national Christian community committed to healthcare in the tradition of the Catholic Church. It is concerned with health in all its aspects: physical, emotional, spiritual, and social. (www.chac.ca)

APPENDIX #6: ORGANIZATIONS

- ii **Childhood Cancer Foundation ~ Candlelighters Canada** is a national volunteer charitable organization that works with professional and volunteer organizations and is dedicated to improving the quality of life for families experiencing the effects of childhood cancer through the provision of resources, parent support and the promotion of research. (www.candlelighters.ca)
- ii **Coalition of National Voluntary Organizations (NVO)** is an umbrella, not-for-profit coalition comprised of over 130 national voluntary charities active in health and social services, the environment, justice, education and international development. (www.nvo-onb.ca)
- ii **College of Family Physicians of Canada (CFPC)** is a national voluntary organization which promotes high standards of medical education and care in family practice. (www.cfpc.ca/about_us/mission.asp)
- ii **Community Hospice Association of Ontario (CHAO)** promotes, represents and assists the development and enhancement of community hospice services including those services for children. These services include respite care, grief counseling and friendly visiting. (www.pogo.on.ca/guide/organ_details)
- ii **Federal/Provincial/Territorial Health Ministers' Meeting** at St. John's, September 26, 2001: agreement and progress on a number of initiatives were announced on behalf of federal, provincial and territorial Health Ministers. Ministers viewed a presentation on palliative care and discussed current pressures and directions that are being pursued to ensure Canadians have access to high quality end-of-life care and support. (www.hc-sc.gc.ca/english/feature/fpt2001)
- ii **Frost Health Care Foundation** is an organization dedicated to providing patients, patients' organizations and health charities with a more unified voice in the ongoing healthcare reform discussions in Canada. The Foundation's main objective is to ensure that the needs and values of patients continue to be the first priority in health care. (www.fondationfrost.ca)
- ii **GlaxoSmithKline Foundation (GSK)** matches personal contributions of eligible employees and retirees of GSK to qualifying educational institutions, health and human service organisations, and arts and cultural organisations in the United States. (www.gsk.com)
- ii **Health Charities Council of Canada (HCCC)** represents national health charities which bring together a wealth of knowledge, expertise, experience and resources, to improve the health of Canadians and strengthen Canada's health system. (www.healthcharities.ca)

- ii Heart and Stroke Foundation of Canada** (HSFC) is a Federation of Provincial and National Foundations led and supported by more than 250,000 volunteers. The Foundation receives no core operational funding from government sources and is dedicated to improving the health of Canadians by preventing and reducing disability and death from heart disease and stroke through research, health promotion and advocacy. (www.heartandstroke.ca)
- ii Huntington Society of Canada** (HSC) is a national network of volunteers and professionals committed to finding new treatments and ultimately a cure for Huntington disease (HD), and to improve the quality of life for people with HD and their families. (www.hsc-ca.org/)
- ii Inuit Tapirisat** (ITC), was established in 1971 as the national voice for the Inuit of Canada. One of their objectives is to take measures at the national level, along with other national Inuit organizations, to protect and promote Inuit culture, language, values, health, education, justice and any other matter that impacts upon the ability of Inuit to shape the future of their society within Canada. (www.tapirisat.ca)
- ii Kidney Foundation of Canada** (KFOC) consists of volunteers, patients, donors and staff members working together to help Canadians suffering from kidney failure and related disorders. (www.kidney.ca)
- ii National Aboriginal Health Organization** (NAHO) is an Aboriginal designed and controlled body dedicated to improving the physical, mental, emotional, social and spiritual health of Aboriginal peoples. It is their fundamental belief that the advancement and sharing of knowledge in the field of Aboriginal health is a key to empowering Aboriginal peoples.
(www.aboriginalcanada.gc.ca/abdt/interface/interface2.nsf/engdoc/1.html)
- ii National Advisory Council on Aging** (NACA) consists of up to 18 members from all parts of Canada and all walks of life, who assist and advise the Minister of Health on all matters related to the aging of the Canadian population and the quality of life of seniors. A team of federal public service employees located in Ottawa provides support for the Council's operations. (www.hc-sc.gc.ca/seniors-aines/seniors/english/naca)
- ii National Council of Women of Canada** (NCWC) is national, non-partisan federation of voluntary organizations working to improve conditions for women, families and communities through education, empowerment and community involvement. (www.ncwc.ca)
- ii National Cancer Institute of Canada** (NCIC) with its partner the Canadian Cancer Society, and with the Terry Fox Foundation, undertakes and supports cancer research and related programs in Canada that will lead to reduction of the incidence, morbidity and mortality from cancer. (www.ncic.cancer.ca)

APPENDIX #6: ORGANIZATIONS

ii **Quality End-of-Life Care Coalition (QEOLCC)** represents a broad cross-section of stakeholders who wish to be part of the process of creating a national strategy for end-of-life care in Canada. Members include:

- ALS Society of Canada
- Arthritis Society
- Canadian AIDS Society
- Canadian Association for Community Care
- Canadian Association of Social Workers
- Canadian Association of the Deaf
- Canadian Association on Gerontology
- Canadian Breast Cancer Network
- Canadian Cancer Society
- Canadian Healthcare Association
- Canadian Home Care Association
- Canadian Hospice Palliative Care Association
- Canadian Pharmacists Association
- Caregiver Network Inc.
- CARP: Canada's Association for the Fifty-Plus
- Childhood Cancer Foundation (Candlelighters)
- Coalition of National Voluntary Organizations
- Frosst Health Care Foundation
- GlaxoSmithKline Foundation
- Heart and Stroke Foundation of Canada
- Huntington Society of Canada
- National Advisory Council on Aging
- National Council of Women of Canada
- VON Canada

ii **Regional Health Authority-Central Manitoba Inc (RHA)** provides leadership in implementing a quality community needs-based health system through education, consultation and the allocation of resources to improve health in the Central Region of Manitoba. (www.rha-central.mb.ca)

ii **Royal College of Physicians and Surgeons of Canada (RCPSC)** is a national, private, nonprofit organization of medical specialists dedicated to ensuring the highest standards and quality of health care. (rcpsc.medical.org/english)

ii **St. John Ambulance Canada** is a world-wide, non-denominational charitable organization dedicated to enabling Canadians to improve their health, safety and quality of life by providing training and community service. (www.sja.ca/english)

- ii **Victorian Order of Nurses for Canada** (VON) is a national healthcare charity that cares for the lives and well being of Canadians in their homes and local communities while contributing to the development of health and social policy in Canada. (www.von.ca)

- ii **Veterans Affairs Canada** (VAC) offers a variety of services to veterans, including a Pastoral Care program and *Between Friends* support groups.

- ii **Volunteer Canada** is a national organization committed to supporting volunteerism and civic participation through ongoing programs and special projects. Its board members, partners and members represent hundreds of different communities across Canada. (www.volunteer.ca)

Appendix #7: Participants

Name	Affiliation	Prov	Tel
Ms. Deborah Adams	Program Manager, The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital	ON	416-586-4800, x 6776
Mr. Michael Aherne	Associate, Institute for Professional Development/ Pallium Project Consultant	AB	780-413-8195
Dr. Pierre Allard,	Director, Institute of Palliative Care, Elizabeth Bruyère Centre	ON	613-562-6301
Mr. Barry Ashpole	Chair, Communications and Public Policy, Ontario Palliative Care Association	ON	905-309-6208
Ms. Heather Balfour	District Management Consultant, Saskatchewan Health	SK	306-787-3216
Ms. Sharon Baxter	Executive Director, Canadian Hospice Palliative Care Association	ON	613-241-3663, x227
Ms. Mary Anne Bourque	Chaplain, SCO Health Services	ON	613-562-0050, x1674
Dr. Michel Brazeau	CEO, Royal College of Physicians & Surgeons	ON	613-730-6205
Ms. Carleen Brenneis	Program Director, Regional Palliative Care Program, Capital Health	AB	780-450-7767
Ms. Pam Brown	Director, Regional Palliative Care Service, Calgary Health Region	AB	403-943-0252
Dr. Fred Burge	Research Director and Associate Professor, Dalhousie University, Department of Family Medicine	NS	902-473-4742
Mr. Brian Burnett	Facilitator	MB	204-261-5322
Mr. Robert Cardinal	Aboriginal Cultural Helper, Royal Alexandra Hospital	AB	780-477-4425
Ms. Donalda Carson	Executive Director, Prince George Hospice Society	BC	250-563-2551
The Honourable Senator Sharon Carstairs	P.C., Leader of the Government in the Senate and Minister with Special Responsibility for Palliative Care	ON	613-949-7123
Ms. Janet Carver	Palliative Care Coordinator, Lunenburg and Queens Counties	NS	902-521-0081
Ms. Andrea Challis	Research Coordinator, Health Canada	ON	613-957-7774
Ms. Cheryl Chapman	Health Canada	ON	
Mr. David Cheperdak	Executive Director, Victoria Hospice Society	BC	250-370-8725
Ms. Gail Chester	Social Worker, Yukon Home Care Program	YT	867-667-3624
Dr. Paula Chidwick	Clinical Ethics Fellow, University of Toronto Joint Centre for Bioethics	ON	416-978-1898
Dr. Harvey Chochinov	Professor, Department of Psychiatry, University of Manitoba/ Cancer Care Manitoba	MB	204-787-3380
Mrs. Velda Clark	Director, Palliative Care Services, Regina Health District	SK	306-766-2665
Mrs. Margaret E. Clarke	Executive Director, Hospice & Palliative Care Manitoba	MB	204-889-8525
Dr. Robin Cohen	Research Director, Palliative Care, McGill University	QC	514-934-1934, x35158
Mr. Duncan Conrad	Program Consultant, Health Promotion and Rehabilitation Directorate, Veterans Affairs Canada	PEI	902-566-8111
Dr. Marlyn Cook	Physician, IFNA Physician Services	ON	807-737-3030
Ms. Shelly Cory	Senator Carstairs' Office	ON	613-949-7123

APPENDIX #7: PARTICIPANTS

Dr. Michael Coughlin	Ethics Consultant, St. Joseph's Healthcare, Hamilton	ON	905-522-1155, x3099
Ms. Stephanie Craig	Senator Carstairs' Office	ON	613-949-7123
Dr. Patrick Critchley	Palliative Care Physician, QEII HSC & Dalhousie University	NS	902-473-2878
Ms. Lynn Cummings	Nurse Manager, Victoria Hospice Society	BC	250-370-8848
Ms. Eleanor Davies	Past President, Chair of Advocacy, Active Volunteer, Hospice Palliative Care Association, PEI	PEI	902-569-1670
Dr. Mervyn Dean	Regional Medical Director, Palliative Care, Western Health Care Corporation	NF	709-637-5000, x5414
Ms. Jo Ann Derrickson	Administrator, Pine Acres Home	BC	250-768-7676
Ms. Linda Doody	Manager, Seniors Programs, Department of Health and Community Services	NF	709-729-5246
Ms. Kirstin Doull	Senator Carstairs' Office	ON	613-949-7123
Dr. Michael Downing	Medical Director, Victoria Hospice Society	BC	250-370-8715
Dr. Deborah Dudgeon	Director of Palliative Care Medicine Queen's University	ON	613-533-6000, x77694
Mr. Eugene Dufour	President, Canadian Hospice Palliative Care Association	ON	519-272-8210, x2621
Dr. Serge Dumont	Professor, School of Social Work, Laval University	QC	418-656-2131
Ms. Janet Dunbrack	Consultant	QC	514-932-1253
Rev. Dr. Neil Elford	Manager, Supportive Care Services, Royal Alexandra Hospital	AB	780-477-4195
Dr. Robin Fainsinger	Director, Division of Palliative Care Medicine, Dept. of Oncology, University of Alberta/ Clinical Director, Regional Palliative Care Program	AB	780-477 4038
Mr. Brian Falck	Consultant, Manitoba Health	MB	204-788-6637
Mme. Justine Farley	Medecin, Association québécoise des soins palliatifs	QC	514-345-3511, x3395
Dr. Konrad Fassbender	Senior Research Associate, Alberta Cancer Board Palliative Care Research Initiative	AB	780-450-7525
Ms. Alma Favel-King	National Coordinator, Home & Community Care Assembly of First Nations	ON	613-241-6789
Dr. Margaret Fitch	Coordinator Supportive Care/Head Oncology Nursing, Cancer Care Ontario	ON	416-480-5891
Dr. Gerri Frager	Medical Director, Pediatric Palliative Care, IWK Health Centre/Dalhousie University	NS	902-470-7262
Dr. Gillian Fyles	Medical Leader, Pain & Symptom Management/Palliative Care Program, Centre for the Sourthern Interior, BC Cancer Agency	BC	250-712-3994
Dr. Pierre Gagnon	Psychiatre, professeur, Maison Michel Sarrazin, CHUQ, Université Laval	QC	418-691-5075
Dr. Romyne Gallagher	Director, Division of Palliative Care, University of British Columbia	BC	604-822-1603
Ms. Leslie Gaudette	Acting Chief, Treatment and Outcomes Surveillance, Health Canada, Cancer Division	ON	613-946-5159
Mr. Gary Goldsand	Coordinator, Clinical Ethics Services, Royal Alexandra Hospital	AB	780-491-5330

APPENDIX #7: PARTICIPANTS

Mr. Trent Gow	Director, Hospice Association of Ontario	ON	416-777-0449, x28
Ms. Avis Gray	Facilitator	MB	204-453-5102
Ms. Roda Grey	Senior Health Policy Analyst, FNIB, Health Canada	ON	613-954-0757
Dr. Neil Hagen	Head, Division of Palliative Medicine, University of Calgary	AB	403-670-2304
Ms. Mary Elizabeth Harriman	Director, Policy Coordination and External Relations, Heart and Stroke Foundation of Canada	ON	613-569-4361
Dr. Laura Hawryluck	Physician Leader, Ian Anderson Continuing Education Program in End of Life Care/ Assistant Professor Critical Care Medicine, University of Toronto	ON	416-946-7899
Ms. Karen Henderson	Founder, Caregiver Network/How to Care	ON	416-323-1090
Ms. Lorna Hillman	President, Canadian Caregiver Coalition / La coalition canadienne de aidantes et aidants naturels	ON	250-384-0408
Ms. Mary Hitchman	Provincial President, New Brunswick Palliative Care Association/Representative, CHPCA	NB	506-623-3406
Ms. Abby Hoffman	Director General, Health Care Strategies and Policy Directorate, Health Canada	ON	613-946-1791
Rev. Glen Horst	Coordinator of Pastoral Care Services, Riverview Health Centre	MB	204-478-6281
Dr. Mary Anne Huggins	Director, Palliative Care Program, Princess Margaret Hospital / University Health Network	ON	416-946-2135
Ms. Mary Hughes Power	Director, Acute and Continuing Care, Department of Health and Social Services, Government of PEI	PEI	902-368-6132
Ms. Kendra Hunter	Policy Analyst, Primary Health Care Division, Health Canada	ON	613-957-3053
Ms. Denise Hycha	Palliative Care Program Coordinator David Thompson Health Region	AB	403-341-2168
Ms. Janina Jaw	Community Living Worker	NU	867-897-8877
Ms. Laurianne Jodouin	Program Manager, Palliative Benefits Program, Home and Community Care Specialist, BC Ministry of Health Services	BC	250-952-1174
Ms. Sandy Johnson	Executive Director, Hospice Saint John	NB	506-632-5723
Rev. Dr. Dale Johnson	Clinical Coordinator, Spiritual Care, Vancouver Hospital & Health Sciences Centre	BC	604-875-4643
Dr. Nuala Kenny	Chair, Department of Bioethics, Dalhousie University	NS	902-494-3801
Ms. Rosella Kinoshameg	Vice President, Aboriginal Nurses Association of Canada	ON	705-859-2594
Ms. Barbara Korabek	Director Home Care, Calgary Health Region, Canadian Home Care Association	AB	403-943-1640
Ms. Vivien Lai	Senior Policy Advisor, Alberta Health & Wellness	AB	780-415-2850
Dr. Bernard J. Lapointe	Directeur, Division des soins palliatifs, Hopital general juif Sir Mortimer B. Davis	QC	514-340-8222
M. Jacques Lapointe	Chef du service de pastorale du (CHUM) Centre Hospitalier de l'Université de Montréal/ Association Canadienne pour la pratique et l'éducation pastorales	QC	514-890-8000, x25021
Dr. Francis Lau	Director and Associate Professor, Health Information Science, University of Victoria	BC	250-721-8576

APPENDIX #7: PARTICIPANTS

Dr. Neil Lazar	Critical Care Medicine, University Health Network & University of Toronto	ON	416-340-3438
Ms. Janis Leiterman	Director, Clinical Services, Victorian Order of Nurses for Canada	ON	613-233-5694
Dr. S. Lawrence Librach	Director, The Temmy Latner Centre for Palliative Care, Mt. Sinai Hospital/ Director, Palliative Care, Sunnybrook & Women's College Health Science Centre	ON	416-586-4800, x6773
Ms. Liliane Locke	Program Director, Palliative Care, SCO Health Service	ON	613-562-0050, x1294
Ms. Emmie Luther-Hiltz	Coordinator, Cancer Patient Family Network, Cancer Care Nova Scotia	NS	902-473-2637
Mr. Jay Lynch	Project Coordinator, University of Ottawa Institute of Palliative Care	ON	613-562-0050
Ms. Catherine MacDonald	Senator Carstairs' Office	ON	613-949-7123
Ms. Michelle MacDonald	Senator Carstairs' Office	ON	613-949-7123
Ms. Nancy MacDonald	Baffin Regional Occupational Therapist, Department of Health & Social Services	NU	867-975-4808
Dr. Neil MacDonald	Bioethics Programme, Clinical Research Institute of Montreal	QC	514-987-5620
Mr. Chris MacDonald	Department of Philosophy, Dalhousie University	NS	902-429-5771
Dr. Joan MacIsaac	Director, Palliative Care Services, Queens Health Region	PEI	902-368-4781
Ms. Sandra MacLeod	Policy Analyst, Health Services Division, Health Canada	ON	613-941-5217
Mr. Vincent MacNeil	Senator Carstairs' Office	ON	613-949-7123
Mr. Michael Martin	Senior Policy Analyst, National Aboriginal Health Organization	ON	613-237-9462
Ms. Debbie Mayer	Registered Nurse, Mohawk Council of Akwesane Home Care Programs	ON	613-575-2341
Rev. Dr. Don Mayne	Chair, North American Interfaith Network	AB	780-466-2757
Ms. Ann McKim	Project Manager, Rural Palliative Home Care Project	NS	902-893-5554, x2149
Ms. Lorena McManus	Program Director, Palliative Care Sub Program, Winnipeg Regional Health Authority	MB	204-237-2371
Ms. Lynne Mitchell-Pedersen	Facilitator	MB	204-786-5502
Dr. R. Sue Morrison	Manager, Palliative and End-of-Life Care Unit, Health Canada	ON	613-946-9851
Rev. Gary Myatt	Staff Chaplain, Queen Elizabeth II Health Sciences Centre	NS	902-473-2400
Mr. Cyril Nair	Chief, Health and Outcome Statistics, Statistics Canada	ON	613-951-8387
Dr. Murray Nixon	Provincial Medical Advisor, Continuing Care Branch, Department of Health, Province of Nova Scotia	NS	902-424-3726
Ms. Marlene Nosé	Senior Policy Analyst, Health Programs Support, Health Canada	ON	613-954-6848
Ms. Laurie Ann O'Brien	Manager, Palliative Care Consultative Services/ President, Newfoundland & Labrador Palliative Care Association, Health Care Corporation of St. John's	NF	709-777-5742
Ms. Dale Orychock	Director, Palliative Care, Cape Breton District Health Authority	NS	902-567-7870
Ms. Barbara Ouellet	Director, Health Services Division, Health Canada	ON	613-954-1930
Ms. Deborah Palumbo	Senator Carstairs' Office	ON	613-949-7123

APPENDIX #7: PARTICIPANTS

Ms. Edna Parrott	President, Saskatchewan Palliative Care Association	SK	306-542-3386
Ms. Anne Patenaude	Policy Analyst, Office of Rural Health, Health Canada	ON	613-946-2615
Mr. Jose Pereira	Alberta Cancer Foundation Professorship in Palliative Medicine, University of Calgary	AB	403-670-2307
Ms. Marian Perrett	Facilitator	MB	204-837-4718
Dr. Rhéa Plouffe	Manager of Pastoral Care & Counseling Dept., Cross Cancer Institute	AB	780-432-8545
Ms. Pat Porterfield	Clinical Nurse Specialist, Palliative Care, Vancouver Hospital & Health Science Centre	BC	604-875-4715
Ms. Simone Powell	Research Analyst, Knowledge Development Section, Health Canada	ON	613-952-7605
Dr. Daryl Pullman	Associate Professor of Medical Ethics, Memorial University of Newfoundland	NF	709-777-6220
Ms. Joanne Purvis	Facilitator	MB	204-477-6890
Ms. Della Roberts	Hospice Palliative Care Coordinator, Delta Hospital, South Fraser Health Region, Fraser Health Authority	BC	604-946-1121
Dr. Paddy Rodney	Assistant Professor, University of Victoria School of Nursing/ Research Associate, Providence Health Care Ethics Services	BC	604-323-5923
Ms. Corinne Rowswell	Palliative Care Coordinator, East Prince Health	PEI	902-888-8038
Ms. Patricia Russell	Senior Policy Analyst, Palliative and End-of-Life Care Unit, Health Canada	ON	613-941-9309
Mr. Ken Saddleback	Cultural Advisor, Kiwetahk Cultural Society	AB	780-585-3793
Ms. Vivian Sandberg	Regional Health Systems Analyst, Health Canada	MB	204-984-0548
Ms. Sheila Scaravelli	Vice President, Patient Services, Pictou County District Health Authority	NS	902-752-8311
Dr. Brent Schacter	President & CEO, Cancer Care Manitoba	MB	204-787-2241
Ms. Kendra Shaw	Policy Analyst, Employment Insurance Analysis, Human Resources and Development Canada	QC	819-997-5675
Mr. Russ Simmons	Facilitator	MB	204-885-3740
Dr. Trevor Smith	Assistant Professor, Health Studies & Gerontology University of Waterloo	ON	519-888-4567, x5879
Dr. Kelli Stajduhar	CIHR/MSFHR Post Doctoral Fellow, Centre on Aging, University of Victoria/ Research Associate, Vancouver Island Health Region	BC	250-721-7487
M. Jean-François St-Denis	Deputy Director, Programs Branch, Canadian Institutes of Health Research	ON	613-954-7224
Ms. Anita Stern	Graduate Student, McMaster University	ON	905-525-9140, x22293
Ms. Ann Syme	Leader, Pain and Symptom Management, BC Cancer Agency	BC	250-519-5608
Ms. Carolyn Tayler	Director, Palliative Care, Simon Fraser Health Area	BC	604-517-8644
Dr. Mary Van Soeren	Acute Care Nurse Practitioner, Consultant	ON	519-780-0447
Ms. Roberte Vautier	Health Care Consultant, Extra Mural Program, Department of Health and Wellness	NB	506-457-6927
Ms. Wendy Wainwright	President, BC Hospice Palliative Care Association/ Manager, Counselling Services, Victoria Hospice	BC	250-370-8715
Ms. Gail Watson	Facilitator	MB	204-889-9024

APPENDIX #7: PARTICIPANTS

Ms. Heather Watson	Special Assistant to Minister McLellan, Health Canada	ON	613-954-1328
Dr. Robin Weir	Professor, School of Nursing, McMaster University	ON	905-525-9140
Ms. Dona Whalen	Social Worker, Nova Scotia Association of Social Workers	NS	902-473-8691
Dr. Keith Wilson	Psychologist, The Rehabilitation Centre	ON	613-737-7350, x5608
Dr. Cornelius Woelk	Medical Director of Palliative Care, Rural Health Authority - Central Manitoba	MB	204-325-4312
Ms. Roberta Wraith	Manager – Health, Metis Nation of Ontario	ON	416-977-9881
Ms. Lynn Yetman	Coordinator, Volunteer Services / Palliative Care, Colchester East Hants Health Authority	NS	902-893-4321