

STILL NOT THERE
Quality End-of-Life Care: A Progress Report

June 2005

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Executive Summary

The 1995 report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled *Of Life and Death* and the 2000 report of the Senate Subcommittee to Update "Of Life and Death", entitled *Quality End-of-Life Care: The Right of Every Canadian* were important in focussing national attention on the need for palliative and end-of-life care and in raising public awareness of the issue. Each of these reports had the effect of giving voice to those concerned with end-of-life care and strengthened the sense of identity of the discipline. As June 2005 marks the 10th anniversary since the tabling of the first report and the fifth anniversary of the tabling of the second report, it is time to reflect on what progress has been made in implementing the 1995 and 2000 recommendations.

The Canadian population is ageing. By 2026, 8 million Canadians will be over the age of 65 – approximately 20% of the population. Seniors account for 75% of deaths each year. It is estimated that there will be 40% more deaths every year by 2020. This will amplify demand for increased capacity and improved access to quality end-of-life care in every province and territory.

The aim of care focussed on dying individuals is to achieve the best possible quality of life for both the person who is dying and for their family by addressing their physical, psychological, social, spiritual, and practical expectations and needs. Patients of all ages suffering from all life-threatening illnesses can benefit from access to palliative and end-of-life care. However, palliative care is still largely cancer based and volunteer delivered.

Since 2000 there have been a number of significant advancements at the federal level in palliative and end-of-life care. However, the combination of the relative newness of end-of-life care with the variety of health care jurisdictions and a strong locally-based volunteer movement has resulted in significant disparities across Canada with respect to access to end-of-life care, quality of care and out-of-pocket costs to the patient. Although there are in excess of 430 programs and services listed by the Canadian Hospice Palliative Care Association, most of those working in the field still estimate that no more than 15% of Canadians have access to hospice palliative care. For children, that figure falls to 3.3% according to a recent Canadian Institutes of Health Research project. Hospice palliative care programs and services need to be integrated into the health care system and not be an additional program that may or may not be available in the community.

The current Canadian Strategy on Palliative and End-of-Life Care is essential to ensuring quality end-of-life care for all Canadians; however, the current Strategy is not sustainable in the long term. The Canadian Strategy has been incompletely implemented and has not met its original objectives. Without federal leadership there will continue to be a patchwork of services available to Canadians as no single province is equipped to provide the necessary leadership.

There is a need to standardize greater access to quality end-of-life care across the country. There is a need for ongoing education and training of health care professionals. There is a need for continued research and its dissemination, including socio-economic research, and the development and dissemination of best practices. There is a need for support for family caregivers who are assuming a greater portion of the responsibility for health care as more care is delivered in the home and community. There is a need to inform patients and caregivers of supports and services available to them. There is a need for coordination and support across care settings as patients move from home to hospital to long-term care facilities and to hospices.

The report makes 10 new recommendations in five areas: National Strategy; Patient and Caregiver Support; Training and Education for Formal and Informal Health Care Providers; Government and Citizens Working Together; and Planning for the Future.

Summary of Recommendations

National Strategy

- 1. Health Canada provide long-term, sustainable funding for the further development of a Canadian Strategy on Palliative and End-of-Life Care which is cross-departmental and cross-jurisdictional, and meets the needs of Canadians.**
- 2. Federal, Provincial and Territorial governments make palliative and end-of-life care programs a top priority in the restructuring of the health care system through:**
 - **implementing consistent norms of practice to eliminate disparities between different jurisdictions;**
 - **integrating services to make the transitions between all health care settings (including hospital, long-term care, home and hospice) seamless; and**
 - **enhancing homecare and pharmacare, including the provision of respite care.**

Patient and Caregiver Support

- 3. The federal government amend the Compassionate Care Leave Benefit under the Employment Insurance Program to improve Canadians' access and eligibility under the Benefit by:**
 - **extending the leave from 8 weeks to 16 weeks, including a two week waiting period;**
 - **allowing the patient to determine the best person to be their caregiver, be it a family member or a friend;**
 - **not limiting the benefit to the last six months of life, especially for children; and**
 - **mounting a public education campaign designed to inform Canadians about the benefit.**
- 4. The federal government and the Provinces and Territories amend their respective Labour Code provisions to reflect these changes to the compassionate care leave benefit.**

Training and Education for Formal and Informal Health Care Providers

- 5. The federal government support the development of multi-disciplinary education and training with respect to palliative and end-of-life care and support an integrated and coordinated approach to palliative and end-of-life care across care settings.**

6. Health care providers be educated on the practice of providing treatment for the purpose of alleviating suffering that may have the unintended effect of shortening life and the circumstances in which the withholding and withdrawal of life-sustaining treatment is legally acceptable.

Government and Citizens Working Together

7. Those territories that do not have advance directive legislation adopt such legislation, and all provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

8. Health Canada, in cooperation with the provinces and territories and the hospice palliative care community, sponsor a national campaign designed to inform the public about end-of-life care, including information on:

- **palliative and end-of-life care services available in their region;**
- **advance directives and end-of-life care planning;**
- **the compassionate care leave benefit and how to apply for it;**
- **their legal rights with respect to the withdrawal and withholding of life-sustaining treatment; and**
- **caring for the dying as an informal caregiver.**

Planning for the Future

9. That the Canadian Institute for Health Information be encouraged to develop indicators for quality end-of-life care.

10. That the Canadian Institutes of Health Research undertake research into the socio-economic issues of palliative and end-of-life care, including the physical, mental and economic impact on informal caregivers.

Introduction

In June 1995, the Special Senate Committee on Euthanasia and Assisted Suicide tabled its final report in the Senate, entitled *Of Life and Death*. Although the Committee was not unanimous in its recommendations concerning euthanasia and assisted suicide, it was unanimous in its recommendations concerning palliative care. In June 2000, the Senate Standing Committee on Social Affairs, Science and Technology created a Subcommittee to Update “Of Life and Death”. This report, entitled *Quality End-of-Life Care: The Right of Every Canadian*, was a five-year update on the status of the unanimous recommendations from the 1995 report concerning palliative care. It also included 14 new recommendations regarding quality end-of-life care.

The 2000 report found that very little progress had been made since the tabling of the report in 1995. However, since the 2000 report, there have been some significant developments, including the appointment of a federal Cabinet Minister responsible for palliative care from 2001 to 2003 and the establishment of a Secretariat on Palliative and End-of-Life Care within Health Canada.

As June 2005 marks the 10th anniversary since the tabling of the first report, and five years since the second report, it is time to reflect on what progress has been made in implementing the 1995 and 2000 recommendations.

In the fall of 2004, letters were sent to over 100 federal, provincial and territorial associations, non-governmental organizations and professional associations with an interest in palliative and end-of-life care. Witnesses who had appeared before the Senate Subcommittee in 2000 were asked to review their testimony and make any necessary changes. The letters posed the following questions:

1. What progress has been made in implementing the 14 recommendations from the 2000 report?
2. What progress has been made in implementing the unanimous recommendations in the 1995 report?
3. Are the recommendations still valid?
4. Are the Appendices from the 2000 report up to date?
5. Where is palliative care headed in Canada? Internationally?

The responses received from these letters form the basis of the information included in the Status section of this report. Information was also collected from one-on-one conversations, research, conferences and reviewed materials.

I. Palliative and End-of-Life Care in Canada 2000-2005

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.

(Harvey Chochinov, testimony before the Subcommittee to Update “Of Life and Death” of the Standing Senate Committee on Social Affairs, Science and Technology, February 28, 2000)

Background

The two Senate of Canada reports in 1995 and 2000 on palliative and end-of-life care were important in focussing national attention on the need for end-of-life care and in raising public awareness of the issue. Each of these reports had the effect of giving voice to those concerned with end-of-life care and strengthened the sense of identity of the discipline.

This sense of identity was further strengthened with the creation of the Quality End-of-Life Care Coalition of Canada in December 2000. For the first time, the Canadian Hospice Palliative Care Association (CHPCA) was joined by approximately 20 national organizations to lobby as one voice for better end-of-life care for Canadians. The Quality End-of-Life Care Coalition of Canada now has over 30 member organizations.

The 2000 Senate report, *Quality End-of-Life Care: The Right of Every Canadian*, not only acted as a catalyst for creating a strong community voice for hospice palliative care, it also acted as a catalyst for government action. One of the 14 recommendations in the 2000 report was that the federal government, in collaboration with the provinces, develop a national strategy for end-of-life care.

The first step towards that was the appointment in March 2001 of the Honourable Senator Sharon Carstairs, P.C. as Minister with Special Responsibility for Palliative Care. This gave the issue of palliative care a designated voice at the Cabinet table for the first time. In June of 2001 the Secretariat on Palliative and End-of-Life Care was created within the department of Health Canada to support the Minister with Special Responsibility for Palliative Care and to provide leadership and cross-sectoral co-ordination and collaboration in the development of a national strategy on end-of-life care.

In March 2002, the Secretariat hosted the National Action Planning Workshop on End-of-Life Care in Winnipeg, a meeting of over 150 stakeholders, F/P/T representatives and researchers. At this meeting, seven priority areas were identified for action: availability and access to services; ethical, cultural and spiritual consideration; support for caregivers; research; surveillance; public education and awareness; and education for health care providers. This was followed with an

Aide Memoire to Cabinet in June 2002 outlining the Canadian Strategy on Palliative and End-of-Life Care with five priorities: best practices; research; public information and awareness; surveillance; and education for professional health care providers.

Canadian Strategy

The Canadian Strategy has three components: community, federal and F/P/T. The community component is the most developed part of the Strategy. In the Fall of 2002, the community component of the strategy began when the Secretariat established five working groups to address the priorities identified at the 2002 Action Planning Workshop: best practices and quality care; education for formal caregivers; public information and awareness; research; and surveillance. Coordination across these groups occurs through a Coordinating Committee consisting of the co-chairs of the five working groups, Aboriginal and Quality End-of-Life Care Coalition of Canada representation, and Health Canada as co-chair. The initiatives of the five working groups have formed the bulk of the Strategy as supported by the Secretariat for the past two years.

Community Component

The working groups have provided excellent opportunities for networking, building cooperative partnerships and sharing best practices. Here is a sampling of some of the initiatives undertaken by each Working Group.

The **Best Practices and Quality Care Working Group** has been working with the Canadian Council on Health Care Service Accreditation (CCHSA) to influence hospice palliative care accreditation across Canada. This partnership will implement standards for hospice palliative care in all existing accreditation programs by 2006. This includes national hospice palliative care accreditation standards, an accreditation program for free-standing hospice and volunteer programs, as well as a set of national indicators to access care. Practices employed by the Canuck Children's Place in Vancouver and the Toronto Hospital for Sick Children have aided in the establishing of national paediatric standards.

Following an environmental scan of palliative care education of undergraduate and post-graduate physician, nursing, social work, pharmacy and chaplaincy training programs, the **Education for Formal Caregivers Working Group** established core discipline competencies for formal caregivers. They were able to achieve national consensus through a Professional Competencies Consensus Survey. This Working Group was also able to secure \$1.25 million over five years to develop palliative and end-of-life care training for future medical students. The goal of this project is to bring palliative and end-of-life care medical education to all undergraduate students at Canada's seventeen medical schools.

The **Public Information and Awareness Working Group** has completed two phases of a three-

phase project to develop a framework for a national public awareness raising initiative on palliative and end-of-life care. Working with a representative of the Research Working Group, in partnership with the CHPCA and the GlaxoSmithKline Foundation, the Public Information and Awareness Working Group has established benchmarks of Canada's awareness and understanding of hospice palliative care. The Ipsos-Reid Canadian Omnibus poll conducted from December 9th -11th, 2003, provided valuable information, and will help facilitate future assessments of the Working Group. Furthermore, the Public Information and Awareness Working Group identified and addressed the informational needs of informal caregivers, the results of which will inform future action to ensure that primary caregivers have access to appropriate information.

The **Research Working Group** has established a business plan to support the creation of a palliative care research infrastructure in Canada. This infrastructure would provide support, interaction and application of research findings to improve practices, education and policy. Establishing an interactive database was the first step in establishing this network. Thirteen experts were then interviewed and an environmental scan of knowledge translation for palliative care was undertaken. The results will be summarized in a report that will be made available from Health Canada. The Research Working Group also facilitates protocol development meetings for researchers in palliative and end-of-life care. The first protocol development meeting was held in Toronto in October 2003. The Research Working Group has also partnered with the Canadian Institutes of Health Research in the development of a Strategic Initiative for Palliative Care Research.

The **Surveillance Working Group** has completed a study and pilot project to develop a core data set and method for data collection. In order to describe and assess the characteristics of palliative admissions, a core set of data must be collected. This will also be used to provide a baseline and comparative data for surveillance purposes at all levels of governance. A set of core national indicators is under development to help address the lack of standards in accessing the quality of palliative care service delivery. These indicators will serve as the basis of program evaluation and comparisons.

Federal Component

The federal component of the Strategy has not been as well developed as the community component. The federal component was envisaged as a cross-departmental approach to end-of-life care in recognition of the federal government's role in service delivery to certain populations in addition to its leadership and coordination role at the national level.

A number of federal departments have a direct service delivery role to certain populations within Canada. Health Canada's First Nations and Inuit Health Branch supports the delivery of health services on-reserve and in Inuit communities. Veterans Affairs Canada is responsible for delivering pensions and health care and social and economic support for war veterans and

Canadian Forces veterans. National Defence Canada is responsible for the delivery of health care services to members of the Canadian Forces. The Department of Public Safety and Emergency Preparedness is responsible for the RCMP who has responsibility for delivering health care services to its members. Citizenship and Immigration Canada administers the Interim Federal Health Program to cover emergency and essential health services for needy refugee claimants and those refugees not yet eligible for provincial health coverage. Finally, Correctional Services Canada is responsible for providing in-house health services for inmates in federal institutions.

There are a number of other departments which have a role to play in end-of-life care issues. Health Canada has overall responsibility for coordination and leadership in health policy within Canada. Justice Canada has a role to play in the harmonization of advance care directives and the clarification of the law as it pertains to the withholding and withdrawal of life sustaining medical treatments and the administration of medication to alleviate pain. Industry Canada has played a role in supporting new technologies, such as the creation of a virtual hospice on the World Wide Web. Finance Canada, Status of Women Canada, Human Resources Skills Development and Social Development (including Families and Caregivers) all have a role to play in supporting caregivers.

Due to the number of federal departments who have a responsibility and role to play surrounding issues of palliative and end-of-life care, a cross-departmental approach is essential. A federal Interdepartmental Working Group was created under the Strategy. It met inconsistently and largely was a vehicle for sharing information between different federal government departments with an interest in end-of-life care.

There have been some important federal initiatives in end-of-life care which must be recognized:

- The Compassionate Care Benefit, an initiative of Human Resources Skills Development Canada, provides up to 6 weeks of paid leave through Employment Insurance for a person to care for a terminally ill parent, spouse or child;
- The Canadian Virtual Hospice, funded largely by Industry Canada, has created a virtual hospice on the web which can be accessed by health care professionals and patients alike;
- The Canadian Institutes for Health Research have also made palliative care a research priority with over \$16.5 Million over five years for palliative care research;
- Veterans Affairs Canada created a set of guidelines for palliative care for veterans; and
- Correctional Services Canada has done some pioneering work creating palliative care programs for life inmates in federal correctional institutions.

Many of the accomplishments under the federal component to date were kick started at the political level through the work of the Minister with Special Responsibility for Palliative Care in collaboration with her Cabinet colleagues and have not necessarily been achieved as part of a cohesive cross-departmental Strategy on Palliative and End-of-Life Care. Better coordination is

needed to ensure a more effective and more balanced policy development process in the palliative care area.

Federal/Provincial/Territorial Component

The third component of the Strategy, F/P/T collaboration, recognized that end-of-life care is not only a cross-departmental issue, but a cross-jurisdictional issue as well. Although there is a direct service delivery role and a leadership and coordination role for the federal government, it is the provinces who deliver health care, including end-of-life care, in Canada.

Palliative care was on the agenda at the F/P/T meeting of the Ministers of Health in June 2001. This was followed by a series of informal bi-lateral meetings between the Minister with Special Responsibility for Palliative Care and provincial Ministers of Health in the Fall of 2001 and the Winter and Spring of 2002. The purpose of these informal bilateral meetings was two-fold: to inform provincial Ministers of Health of the Canadian Strategy; and to get the name of a provincial contact person within each province for further follow up and information sharing with Health Canada's Secretariat on Palliative and End-of-Life Care.

Many provinces sent representatives to the March 2002 Action Planning Meeting in Winnipeg. However, when the Canadian Strategy was introduced in June 2002 the decision was made not to pursue the F/P/T component of the Strategy as the Romanow Commission¹ was underway. Soon after the Romanow report was tabled, the federal government entered negotiations on the 2003 Health Accord and again, the decision was made not to proceed with this component. However, palliative care has been mentioned in the 2003 and 2004 health accords and a base level of hospice palliative care services has been agreed to by all provinces, although the definition of publically funded services has not been completed by F/P/T partners.

To date the development and implementation of the Canadian Strategy has focussed on the initiatives of the five working groups and a collection of federal departmental actions. Health Canada has recently undertaken a review of the Strategy with the intention of revitalizing the Strategy in order to better incorporate all three components into the Strategy.

2004 Health Plan

¹ *Building on Values: The Future of Health Care in Canada*, Commission on the Future of Health Care in Canada, headed by Roy Romanow. <http://www.hc-sc.gc.ca/english/care/romanow/index1.html>

The 2004 Health Action Plan² agreed to by First Ministers in September 2004 promises \$41 billion in additional federal money for health care over the next 10 years. Under this Plan, provinces have agreed to provide by the end of 2006 first dollar coverage, based on assessed need, for a base level of home palliative care services, including: case management; nursing; palliative care specific pharmaceuticals; and personal care at end of life.

At the senior F/P/T levels the current priorities are the ones laid out in the Plan: health human resources, wait times, and pharmaceuticals. However, there are linkages that can be made between hospice palliative care and all three of these priorities.

Health human resources is an area of concern for end-of-life care. In particular, basic palliative care training for health professionals varies a great deal from province to province. This issue is one where F/P/T collaboration on developing best practices guidelines and uniform training standards could lead to significant improvements in the system with a minimal outlay of funding.

With respect to wait times, palliative care patients are as much in need as any in the health care system. End-of-life care is not specifically identified as a priority for reducing wait times in the 2004 Plan. However, in the absence of initiatives to address end-of-life care, the rapidly increasing client base could lead to a significant increase in wait times. Given that palliative care patients are near death, time is of the essence.

End-of-life care has a significant pharmaceutical component. This is illustrated by the fact that in the 2004 Plan, First Ministers agreed to provide first dollar coverage by 2006 for palliative-specific pharmaceuticals in the context of home care.

International

The modern palliative care movement began in the United Kingdom in the 1960s and for many years the UK was seen as a leader in palliative care. As the modern palliative care movement spread across the world countries like Australia, Ireland, Spain and the United Kingdom have all adopted national palliative care strategies. Although the Canadian Strategy of Palliative and End-of-Life Care has not been fully implemented, Canada is now seen as a leader by many in the international community with respect to palliative and end-of-life care strategy development and implementation. In particular, countries like the United Kingdom and Portugal look to our community model of the Quality End-of-Life Care Coalition of Canada and to initiatives such as the compassionate care benefit under Employment Insurance as examples of international excellence.

²A 10-year plan to strengthen health care, Government of Canada, <http://www.hc-sc.gc.ca/english/hca2003/fmm/index.html>

II. Status 2005

A. National Strategy

1995 Recommendations

- **Governments make palliative care programs a top priority in the restructuring of the health care system.**
- **There be an integrated approach to palliative care. The delivery of care, whether in the home, in hospices or in institutions, with the support of volunteers, must be coordinated to maximize effectiveness. The provision of respite services is an essential component.**

2000 Recommendations

- **That the federal government, in collaboration with the provinces, develop a national strategy for end-of-life care.**
- **That the federal government, in collaboration with the provinces, establish a five-year plan for implementing this national strategy.**
- **That the federal government prepare an annual progress report on implementing this national strategy.**
- **That the federal Minister of Health work with other relevant federal ministers to develop an interdepartmental strategy on end-of-life care.**
- **That the federal Minister of Health discuss the establishment of a federal, provincial, and territorial strategy on end-of-life care with provincial and territorial counterparts at the next meeting of the Ministers of Health.**
- **That the federal Minister of Health discuss with provincial and territorial counterparts appropriate measures for funding of end-of-life initiatives.**
- **That the federal government, in collaboration with the provinces, develop a five-year plan for implementing the 1995 unanimous recommendations.**

That the federal government prepare an annual progress report on the implementation of the unanimous recommendations.

The Secretariat on Palliative and End-of-Life Care was established in June 2001 by Health Canada to coordinate the development of a national strategy. In March 2002, the Secretariat conducted a three day National Action Planning Workshop on Palliative Care in Winnipeg intended to lead to creating a Canadian strategy for end-of-life care. An Aide Memoire was presented to Cabinet June 2002 which outlined a Canadian Strategy on Palliative and End-of-Life Care with three components: federal; F/P/T and community. Based on the recommendations made at the National Action Planning Workshop in March 2002, the Secretariat on Palliative and End-of-Life Care established in the fall of 2002 five working groups in order to advance end-of-life care issues: Best Practices and Quality Care; Public Information and Awareness; Education for Formal Caregivers; Research; and Surveillance. These working groups representing the community component of the Strategy have formed the core of the Canadian Strategy on Palliative and End-Of-Life Care.

The federal component has never been fully implemented. An interdepartmental committee was struck but to date the impact is unclear. As well, there have been a number of federal initiatives in palliative and end-of-life care which support the Strategy. However, a more comprehensive interdepartmental strategy on end-of-life care would acknowledge the end-of-life care is an issue which impacts on many federal departments.

The F/P/T component of the Strategy has never been implemented; however, there has been some peripheral work on palliative care as part of the First Ministers' 2003 Health Accord and 2004 Health Plan. In February 2003, the First Ministers agreed to the Accord on Health Care Renewal which identified home care including end-of-life care as a priority. Federal investment in health care occurred through the Health Reform Fund, which supported the 2003 First Ministers Accord. At that time \$16B in federal funding was announced to support home care, primary health care and catastrophic drug coverage.

At the September 2004 First Ministers' Meeting, the Prime Minister and his counterparts agreed to *A 10 Year Plan to Strengthen Health Care*. This plan specifies first dollar coverage for home palliative care for case management, nursing, palliative-specific pharmaceuticals and personal care services. To support this agreement, the Government of Canada committed more than \$41.2B of new federal investments in health over the next ten years.

Also, the Primary Health Care Transition Fund (PHCTF) is providing \$800 million dollars to support efforts of provinces and territories and key stakeholders to develop and implement transitional primary health care reform initiatives.

Since 2002, the federal government has allocated just over \$1M each year to support the activities of the working groups and of the Secretariat. Progress on developing and implementing the current work and planning for future activities under the Strategy is limited

due to the inadequate budget and the uncertainty of continued resources as current funding is neither long term nor sustainable. Ad hoc funding does not provide for adequate resources or the stability needed to develop a strong program.

As the Canadian Strategy is not well formed, a five year plan for implementing this strategy has not been developed to date. Since the five year plan was never developed nor implemented, the annual progress report was never produced. Health Canada did release a report which was an update of the community component of the Strategy between 2002 and 2004. As a result of the 2003 First Ministers Meeting, the Health Council of Canada was created in December 2003 with a mandate to monitor the health care system performance and to make annual public reports on the implementation of the Accord. In its first report in January 2005, the Health Council did include palliative and end-of-life care.

The one major recommendation that still needs to be addressed from the 1995 unanimous recommendations and is not covered in the 2000 recommendations is that the federal government make palliative care programs a top priority in the restructuring of the health care system.

Currently the care one receives for a life threatening illness is variable across the country and much is left up to chance. To date, palliative care programs are largely grass roots and voluntary in nature with a high proportion of unpredictable charitable funding, resulting in an uneven distribution of end-of-life programs across Canada, considerable differences in services provided, and unmet care needs. It is not a guarantee that a Canadian who can benefit from palliative care will receive it. The Canadian Hospice Palliative Care Association estimates that less than 15% of Canadians have access to integrated palliative care services. For children that figure falls to 3.3% according to a recent survey funded by the Canadian Institutes of Health Research. The engagement of provincial/territorial governments in a meaningful and collaborative manner is essential as services are overwhelmingly delivered at the provincial level.

B. Education and Training

1995 Recommendations

- **The training of health care professionals in all aspects of palliative care be increased.**
- **Education and training with respect to pain control be expanded and improved for all health care professionals.**
- **The Federal Ministry of Health, in cooperation with the provinces and territories,**

sponsor a national campaign designed to inform the public as to their rights with respect to the refusal of life-sustaining treatment.

2000 Recommendations

That the federal government, working in collaboration with the provinces and the educational community, explore ways to increase multi disciplinary training and education of professionals involved in end-of-life care.

In 2003, the Government of Canada created a Health Human Resources Strategy to initiate improvements in health human resource planning, inter-professional education for collaborative patient-centered practice, and recruitment of health professionals. As a result of the work of the Canadian Strategy of Palliative and End-of-Life Care Working Group on Education for Formal Caregivers, federal funding has been approved for the project *Educating Future Physicians in Palliative and End-of-Life Care*, sponsored by the Association of Faculties of Medicine of Canada and the Canadian Hospice Palliative Care Association. The goal of this project is to ensure that by 2008, all undergraduate medical students and clinical post graduate trainees in Canada's medical schools will receive education in palliative and end-of-life care. Similar proposals have been submitted for the fields of nursing and social work.

In November 2003, the *Pallium Integrated Care Capacity Building Initiative* was awarded \$4.3 million from the Primary Health Care Transition Fund through Health Canada. Activities proposed by Pallium include: to develop and enhance provider skill; the development of learning resources for adoption on a pan-Canadian basis; establishing learning centers in provinces and territories; implementation of outreach education and professional development supported by peer mentors; and to initiate collaborative development between the health care delivery system, voluntary sector and citizens.

As part of its education mandate for family medicine in Canada, an important responsibility of the College of Family Physicians of Canada (CFPC) is to create and consistently apply accreditation standards in evaluating family medicine programs at the sixteen Canadian medical schools. Recently, the CFPC's Ethics and Palliative Care Committees recommended changes to the family medicine accreditation guidelines specifically relating to death and dying and end-of-life care. The recommendations were reviewed and the official guidelines were amended under palliative and end-of-life care as follows:

Residents must learn the skills, knowledge, and attitudes related to the management of physical, psychological, social and spiritual needs of dying patients and their families. Residents must be familiar with medical and societal attitudes towards death and dying.

The CFPC and the Royal College of Physicians and Surgeons of Canada conjointly accredit one-year palliative medicine programs and therefore create and approve the standards applied to palliative care medical education.

SCO Health Service, Ottawa have implemented the first inter-professional course at the Faculty of Medicine of the University of Ottawa, *Death Made Visible: An Inter professional Exploration of Death and Dying in Literature*, which uses literature to examine issues of death and dying.

The Canadian Hospice Palliative Care Association (CHPCA) has created a palliative care training manual. A number of organizations and provinces were asked to pilot it. The model enabled transfer of knowledge to a high number of workers with positive client outcomes, yet, it appears that there has been no continued uptake by the provinces in any formal way. The GlaxoSmithKline Foundation in partnership with the CHPCA have created the Living Lessons®, initiative, a public awareness campaign designed to provide resources to patients, caregivers, volunteers and medical professionals. The partnership has also developed and provided resources aimed at policy makers and the public-at-large.

The Ian Anderson Continuing Education Program in End-of-Life Care is a joint initiative of the Continuing Education Department in the Faculty of Medicine at the University of Toronto, the Joint Centre for Bioethics at the University of Toronto and the Temmy Latner Centre for Palliative Care at Mount Sinai Hospital in Toronto. The Program was established with a \$1 million donation to the University of Toronto from Mrs. Margaret Anderson in memory of her husband and has the aim of educating 10,000 primary care physicians and specialists across Canada over a five-year period to deal with issues surrounding death and dying. As an accredited national continuing education program, the education program is tailored to the needs of both family physicians and specialists and uses small group problem-based learning, case-based teaching and distance learning to deliver 13 learning modules. The Program is currently in its fifth year.

University teaching hospitals often drive palliative care practices, but are funded at the federal level. Service delivery funding is at the provincial level. Education and training, however may be done at a school, research or organizational level. There seems to be limited integration of the three.

There has been no federal education campaign designed to inform the public as to their rights with respect to the refusal of life-sustaining treatment and the administration of medications to control pain. One issue is the myth that morphine and other pain killers shorten life. Physicians also indicate fear of sanction by their provincial Colleges of Physician and Surgeons who can remove the prescribing license of those who they deem to be prescribing inappropriately. Some physicians hide their lack of knowledge behind regulatory scrutiny. An educational campaign could also help to dispel the great fear and resistance that our society has built up around death

and dying, which is a barrier to patients and professionals learning more about palliative care and what it has to offer to those who could benefit from its service.

C. Research

1995 Recommendations

- **Research into palliative care, especially pain control and symptom relief, be expanded and improved.**
- **The federal government, in cooperation with the provinces and territories, undertake a study in order to determine the frequency and conditions under which total sedation is practiced.**
- **Research be conducted in order to determine the frequency with which and conditions under which life-sustaining treatment is withheld or withdrawn under the recommended legislation and guidelines.**
- **Research be undertaken into how many are requesting euthanasia, why it is being requested, and whether there are any alternatives that might be acceptable to those who are making the requests.**

2000 Recommendations

- **That the Canadian Institutes of Health Research be encouraged to establish an institute that focuses on end-of-life issues facing Canadians of all ages with all medical conditions.**
- **That the Canadian Institute for Health Information be encouraged to develop indicators for quality end-of-life care.**
- **That the federal Minister of Health coordinate and implement a multi-dimensional agenda for end-of-life research that involves relevant departments, agencies, and other levels of government.**

Canadian Institutes of Health Research (CIHR) is the major arms length federal agency responsible for funding health research in Canada. It aims to excel in the creation of new health knowledge, and to translate that knowledge from the research setting into real world applications. CIHR was created in 2000 to replace the Medical Research Council. CIHR consists of 13 "virtual" institutes, each headed by a Scientific Director and assisted by an Institute Advisory Board. They work together to shape a national health research agenda for

Canada. The institutes bring together researchers, health professionals and policy-makers from voluntary health organizations, provincial government agencies, international research organizations and industry and patient groups from across the country with a shared interest in improving the health of Canadians.

In 2001, CIHR created the Institute of Cancer Research (ICR) as one of CIHR's virtual institutes. A separate institute for end-of-life issues was not created within CIHR as it was felt that issues regarding end-of-life care crossed over into several CIHR institutes. Instead, CIHR institutes identified a strategy to focus on palliative end-of-life care research in collaboration with government departments and external organizations.

Through a broad-based consultation process in the initial year of ICR's operation, six research priorities were identified, the first of which was palliative end-of-life care. Although traditionally associated with cancer care, palliative end-of-life care also intersects with other clinical disciplines such as cardiology, respiratory medicine, critical care, nephrology, pediatrics and neurology.

In June of 2003, the first Strategic Initiative for Palliative Care Research was launched by eight of CIHR's 13 Institutes along with Health Canada and other non-governmental health organizations. In recognition of the cross cutting nature of palliative and end-of-life care, there are currently nine of the CIHR institutes involved in palliative care research initiatives related to end-of-life care: Institute of Cancer Research; Institute of Population and Public Health; Institute of Aboriginal Peoples' Health; Institute of Aging; Institute of Circulatory and Respiratory Health; Institute of Gender and Health; Institute of Health Services and Policy Research; Institute of Human Development, Child and Youth Health; and the Institute of Neurosciences, Mental Health and Addiction. Support for this initiative is being shared by Health Canada, the National Ovarian Cancer Association, and the Canadian Breast Cancer Research Alliance.

The Strategic Initiative for Palliative Care Research included three components: one-year pilot project grants intended to support innovative, high risk, pilot, or feasibility research; one-year Career Transition Awards to attract new researchers to the field to facilitate rigorous training outside a primary research area; and 50 New Emerging Team (NET) grants to build research capacity through the creation of multi-disciplinary teams and training of new investigators.

On September 21, 2004, the Honorable Tony Ianno, Minister of State (Families and Caregivers) and Dr. Alan Bernstein, President of CIHR, officially announced the first wave of projects (\$16.5 million over five years) under the CIHR Palliative and End-of-Life Care Initiative. In total, 19 Pilot Projects, 1 Career Transition Award, 10 New Emerging Team Grants, and 1 Strategic Training Initiative in Health Research Grants were funded.

Partly in response to the success of the Strategic Initiative announced in June 2004, the CIHR created a review committee specific to applications for funding palliative and end-of-life care research. They will review operating grants submitted for the September 2005 competition.

Co-chaired by the CIHR and Health Canada, a National Working Group on Palliative Care Research was created in 2004, expanding the scope of the previous CIHR-led working group on palliative care research.

A Canadian Network of Palliative and End-of-Life Care Beyond Cancer is in the process of being developed. Its objective is to bring together scientists researching palliative and end-of-life care research in the non-cancer patient population across Canada. There are relatively few researchers who focus on patients with a non-cancer terminal illness and the development of a network would optimize a sharing of information, collaborative research, and serve as a channel for the promulgation of best practices, and knowledge transfer.

The announcement of the CIHR joint initiative of \$16.5 million is an important first step, but the research needs to be broadened to include end-of-life care for a spectrum of diseases and populations. Sustaining research initiatives in this area will be difficult without a sustaining long-term strategy acting as a framework.

In regards to indicators, the Canadian Institute for Health Information does not currently include end-of-life care in their health indicators.

D. Guidelines and Standards

1995 Recommendations

- **The development and implementation of national guidelines and standards be continued (palliative care)**
- **The division of Health Canada responsible for health protection and promotion, in cooperation with the provinces, territories and the national associations of health care professionals, develop guidelines and standards for the provision of treatment for the purpose of alleviating suffering where that may shorten life.**
- **The division of Health Canada responsible for health protection and promotion, in cooperation with the provinces, territories and the national associations of health care professionals, develop guidelines and standards for the practice of the total sedation of patients.**

- **The division of Health Canada responsible for health protection and promotion, in consultation with the provinces and territories and the relevant professional associations, establish guidelines to govern the withholding and withdrawal of life-sustaining treatment.**
- **Professional guidelines be amended so that they are consistent with these recommendations, the amended Criminal Code, and the national guidelines (withholding and withdrawal).**

2000 Recommendations

- **That the federal government , in collaboration with the provinces, develop a five-year plan for implementing the 1995 unanimous recommendations.**

In March 2002 in a consensus-building process funded by Health Canada and led by the Standards Committee of the Canadian Hospice Palliative Care Association, organizations and consumers joined to share their experiences and develop a clear vision for hospice palliative care standards that everyone could use. The result is the CHPCA's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. The resulting model represents more than 10 years of collaboration by individuals, committees, associations and governments across Canada and is based on the nationally accepted principles and norms of practice. The *Model* has been endorsed by many professional associations and by many provincial governments.

The Canadian Council on Health Services Accreditation (CCHSA) in conjunction with the Secretariat on Palliative and End-of-Life Care, the Strategy's Best Practices and Quality Care and Surveillance Working Groups, is working to develop a national set of accreditation standards based on the CHPCA's *Norms of Practice*.

The pilot project of the Volunteer Task Group (under the Strategy's Best Practices and Quality Care Working Group) is sponsored by the Sisters of Charity (Ottawa Health Services). Its goal is to build a wider community of hospice palliative care volunteers and Volunteer Service Managers and Trainers, as well as to affirm a commitment to quality and evidence based practices. Once the Standards of practice are set, indicators to measure and evaluate these standards and norms can be created.

E. Advance Directives

1995 Recommendations

- **Those provinces and territories that do not have advance directive legislation adopt such legislation.**
- **The provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.**

2000 Recommendations

- **That the federal government, in collaboration with the provinces, develop a five-year plan for implementing the 1995 unanimous recommendations.**

Since 2000, Prince Edward Island has brought its legislation into force; New Brunswick has enacted and brought into force new legislation; and the Yukon has enacted new legislation which is not yet in force. The Northwest Territories, and Nunavut are the only jurisdictions without legislation, and a renewed call should be made for the Northwest Territories and Nunavut to put in place advance directives legislation.

British Columbia, Saskatchewan, Manitoba, Ontario and Prince Edward Island have enacted legislation which allows for reciprocity to some extent, meaning that these jurisdictions will respect advance directives completed in other jurisdictions as long as they meet the requirements of those jurisdictions. The Yukon has a provision for reciprocity; however, it is not yet in force. These arrangements should be made between all provinces and territories.

F. Legislative Initiatives

1995 Recommendations

- **The Criminal Code be amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life.**
- **The Criminal Code be amended and necessary legislation be enacted in order to explicitly recognize and to clarify the circumstances in which the withholding and withdrawal of life-sustaining treatment is legally acceptable.**

2000 Recommendations

· **That the federal government, in collaboration with the provinces, develop a five-year plan for implementing the 1995 unanimous recommendations.**

Since 2000 there have been a number of attempts to introduce legislation to clarify the Criminal Code on these matters, but none have been adopted by Parliament.

In 2003, the Supreme Court of Canada released its decision in *Starson v. Swaze*. While this case involved refusal of treatment for mental illness, it reinforced the belief that competent adults have the legal right to refuse treatment even if the treatment is potentially life-sustaining.

Although the issues of the withholding and withdrawal of life sustaining medical treatments and the administration of pain medication to alleviate suffering have been explored in numerous court cases and now form part of our common law, there is still some confusion on the part of physicians about the law. The need for clarification still exists. Efforts are being made within education and training initiatives to clarify for practitioners their rights and responsibilities under the law. Ongoing education and training is essential to ensure that patients receive the best possible care according to their needs and wishes.

G. Caregiver Support

1995 Recommendations

There were no recommendations made on caregiver support in 1995.

2000 Recommendations

· **That the federal government immediately implement income security and job protection for family members who care for the dying.**

The federal government implemented income security in June of 2003 with the adoption of Bill C-28 by Parliament which created a compassionate care leave program under the *Employment Insurance Act*. This federal benefit provides for a two week waiting period and then up to six weeks of paid leave through Employment Insurance for a person to care for a terminally ill parent, spouse or child who is at risk of dying within 26 weeks. A positive feature of this benefit is that it can be shared among family members who are eligible. If the benefit is shared, only one waiting week needs to be served. The Compassionate Care Leave Benefit was implemented on January 4, 2004.

Labour laws are largely provincial responsibility and when the compassionate care leave benefit was announced all provinces promised to amend their legislation to provide job protection for

compassionate leave. However, not all provinces in Canada have amended their provincial Labour Codes. The chart below outlines the status of job protection in each province.

Provincial Legislation Regarding Compassionate Care

British Columbia	As of October 31, 2004, no amendments made.
Alberta	As of October 31, 2004, no amendments made.
Saskatchewan	<i>Labour Standards Act</i> Amended, June 2004 to provide for up to 12 weeks unpaid compassionate leave (and up to 16 weeks where provincial and federal statutes apply jointly).
Manitoba	<i>Employment Standards Code</i> Amended, December 2003, up to 8 weeks unpaid compassionate leave.
Ontario	<i>Employment Standards Act</i> Amended, June 2004, up to 8 weeks unpaid family medical leave.
Quebec	Legislation existed prior to federal amendment. Up to 12 weeks unpaid compassionate leave permitted in cases where employee has at least 3 months of uninterrupted service.
New Brunswick	<i>Employment Standards Act</i> Amended, December 2003, up to 8 weeks unpaid compassionate leave.
Nova Scotia	<i>Labour Standards Code</i> Amended, May 2004, up to 8 weeks unpaid compassionate leave.
Prince Edward Island	<i>Employment Standards Act</i> Amended, December 2003, up to 8 weeks unpaid compassionate leave.
Newfoundland and Labrador	<i>Labour Standards Act</i> Amended December 2004, up to 8 weeks unpaid compassionate leave.
Yukon	<i>Employment Standards Act</i> Amended, November 2003, up to 8 weeks unpaid compassionate leave.

Northwest Territories	As of October 31, 2004, no amendments made, but the Department of Justice has stated in a consultation paper on the <i>Labor Standards Act</i> that the Department recommends an amendment to provide for up to 8 weeks of unpaid compassionate leave.
Nunavut	<i>Labour Standards Code</i> Amended, November 2003, up to 8 weeks unpaid compassionate leave.

When the Compassionate Care Leave Benefit was implemented in 2004 it was expected 275,000 Canadians would benefit from this policy. Media reports indicate that less than 5000 people actually qualified to receive the benefit last year. This year the budget for compassionate care leave was cut.

Although the Compassionate Care Leave Benefit was an important and necessary step in providing income and job protection for family caregivers, there are some significant deficiencies which have been identified with the current provisions. At eight weeks, the length of the benefit is considered too short and does not allow flexibility for the unpredictability of the dying process. The eligibility provisions are considered too narrow and rigid and do not take into account the reality of the Canadian family as the benefit does not allow a sibling, aunt or uncle, in-law, grandchild or friend to access the benefit.

Furthermore, the provision which requires a doctor to sign a note stating that the patient is likely to die within six months makes it very difficult for people to access the benefit. Many doctors and patients alike are unwilling to accept that cure is not an option. This is especially true for parents of terminally ill children where parents have difficulty accepting that their child may die and the medical profession is even more reluctant to put a time limit on a child's life.

A number of provinces did not reform their labor standards legislation to provide necessary job protection when these benefits and the changes in the Canada Labor Code were introduced. This leads to inequality of access across the country.

Many women are excluded as a result of their over-representation in part-time, temporary, seasonal and contract work since Employment Insurance rules exclude individuals without the required number of work hours. This is significant as most informal caregivers are women. The inequalities in eligibility of who can care for a loved one and the length of time of compensation require review.

There are currently two reviews of the first year of operation of this benefit underway, an internal departmental review and an external review. Eligibility and accessibility will be some of the issues discussed in the reviews.

There are a number of other developments surrounding caregiver support to note.

The Honourable Tony Ianno, Minister of State for Families and Caregivers, is developing a national strategy on caregiving. A number of departments are engaged in this process, including Health Canada. One of the goals of Health Canada in developing this strategy is to ensure that the interests of those individuals caring for terminally ill friends and family members are reflected in the strategy.

Veterans Affairs will be field testing the Caregiver Assessment Tool in various sites. Health Canada will have access to these results. The Home and Continuing Care Unit (HCCU) continues to work with VON Canada in the area of respite policy. The HCCU has undertaken some preliminary work in tele-home care and the impact it has on family caregivers.

In the 2005 Federal Budget, the government moved to update the list of expenses eligible for the Medical Expense Tax Credit (METC). The METC recognizes the impact of above-average medical and disability-related expenses on an individual's ability to pay income tax. The list of expenses eligible for the credit is regularly reviewed and updated in light of new technologies and other disability-specific or medically related developments. In order to improve the recognition of medically necessary expenses, Budget 2005 proposes to update the list of expenses eligible for the METC. These changes will be effective for the 2005 and subsequent taxation years and, collectively, are estimated to reduce federal revenues by \$5 million annually.

Earlier this year, the CHPCA and the Order of St. Lazarus jointly published *A Caregivers Guide: A handbook about end-of-life care*. This resource is a revised national edition of a handbook that was originally developed and published in Alberta in 2000 by the Palliative Care Association of Alberta and the Order of St. Lazarus. The handbook is available to informal and family caregivers free of charge. The Living Lessons® guidebook for informal caregivers, a joint CHPCA-GSK Foundation venture, is also widely used. It is available free on the Living Lessons® website³.

H. Homecare / Pharmacare

1995 Recommendations

There were no recommendations made in 1995 regarding homecare / pharmacare.

³Website: <http://www.living-lessons.org/>

2000 Recommendations

- **That the federal government immediately assess the need for home care and pharmacare for the dying and establish, in collaboration with the provinces, the funding required for these programs.**

Currently, over a million Canadians use home care services every year. This number is expected to rise as the population ages and technological advances enable people to stay at home. In many cases, the amount of funded home care given to an individual client may fall short of reported needs. Private palliative home care support is extremely expensive for families. Private insurance may cover the costs of nursing services, but rarely covers the costs of home care support workers.

In both the Kirby⁴ and Romanow reports, the home was considered to be a key health delivery setting and consequently, both referred to the availability of home care resources for specified periods of time prior to the end-of-life. Support for informal caregivers was also identified as an area of major concern, given the need for the family members of many dying patients to stay home to care for loved ones as their palliative care becomes more acute and complicated.

In February 2003, the First Ministers agreed to the Accord on Health Care Renewal and the Government of Canada established a \$16 billion Health Reform Transfer to provide the provinces and territories with funding for three initiatives, one of which was short-term home care including end-of-life care. The Accord promised to identify a basket of home care services by September 2003. In the September 2004 Health Plan, the First Ministers agreed to provide first dollar coverage by 2006 for certain home care services, based on assessed need. This will include case management, nursing, palliative-specific pharmaceuticals and personal care at the end-of-life.

As directed by the First Ministers in the 2004 Plan, Health Ministers in October 2004 established a Ministerial Task Force to develop and implement a national pharmaceutical strategy and report on progress by June 30, 2006.

Some provinces and territories, such as British Columbia, Ontario, Alberta, Saskatchewan, Manitoba, Yukon, Northwest Territories and Nunavut, have introduced drug and equipment plans to cover the cost of providing pharmaceuticals and equipment at home to varying degrees; however, these programs are inconsistent across the country.

⁴ In October 2002 the Senate Standing Committee on Social Affairs, Science and Technology, chaired by Senator Michael Kirby, published a study on the future of the health care system.

<http://www.parl.gc.ca/37/2/parlbus/commbus/senate/com-e/soci-e/rep-e/repoct02vol6-e.htm>

III. Recommendations

The Canadian population is ageing. According to Statistics Canada, the proportion of the population over 65 years of age has been steadily growing throughout Canada's history. Immediately after the Second World War, the percentage of the population over 65 was in the range of 7%. In 1996, that figure surpassed 12%. The "Baby Boom" generation will begin to turn 65 in 2011. By 2026, 8 million Canadians will be over the age of 65 – approximately 20% of the population. Seniors account for 75% of deaths each year. It is estimated that there will be 40% more deaths every year by 2020. This will amplify demand for increased capacity and improved access to quality end-of-life care in every province and territory. Given that care in the last months of life engenders the highest costs to the health system, end-of-life care is an issue which requires cost effective measures to ensure access in a responsive manner to appropriate care.

The aim of care focussed on dying individuals is to achieve the best possible quality of life for both the person who is dying and for their family by addressing their physical, psychological, social, spiritual, and practical expectations and needs. Patients of all ages suffering from all life threatening illnesses can benefit from access to palliative and end-of-life care. However, palliative care is still largely cancer based and volunteer delivered.

Since 2000 there have been a number of significant advancements at the federal level in palliative and end-of-life care. However, the combination of the relative newness of end-of-life care with the variety of health care jurisdictions and a strong locally-based volunteer movement has resulted in significant disparities across Canada with respect to access to end-of-life care, quality of care and out-of-pocket costs to the patient. Although there are more than 430 hospice palliative care programs and services listed by the Canadian Hospice Palliative Care Association⁵, most of those working in the field still estimate that no more than 15% of Canadians have access to hospice palliative care. For children, that figure falls to 3.3% according to a recent CIHR project. Hospice palliative care programs and services need to be integrated into the health care system and not be an additional program that may or may not be available in the community.

Canadians are becoming increasingly aware of palliative care as an end-of-life care model for all ages, including children, and are demanding it. Polls show that in 1997, only 30 % of Canadians were familiar with palliative care. An Ipsos-Reid poll, commissioned by The GlaxoSmithKline Foundation and CHPCA, in December 2003 showed that 75% of Canadians were familiar with palliative care and 25% of those surveyed reported that they or someone in their family had used hospice palliative care services. These results demonstrate a dramatic shift in the awareness of hospice palliative care among Canadians.

⁵ Canadian Hospice Palliative Care Association website, www.chpca.net

Without federal leadership there will continue to be a patchwork of services available to Canadians as no single province is equipped to provide the necessary leadership. The current working groups have achieved some successes under the Strategy; however, much of the work which still needs to be done requires provincial/territorial cooperation. Only the federal government can bring together a collaborative partnership between the private, public and volunteer sectors to generate and disseminate a body of knowledge which positively impacts on access to quality end-of-life care services.

In the September 2004 Health Plan, the First Ministers agreed to provide first dollar coverage by 2006 for certain home care services, based on assessed need, including case management, nursing, palliative-specific pharmaceuticals and personal care at the end-of-life. However, new palliative and end-of-life care programs need to be part of a comprehensive, integrated, coordinated and well funded plan where care is offered in all settings - acute care, long-term care, hospice and the home.

There is a need to standardize greater access to quality end-of-life care across the country. There is a need for ongoing education and training of health care professionals. There is a need for continued research and its dissemination, including socio-economic research, and the development and dissemination of best practices. There is a need for support for family caregivers who are assuming a greater portion of the responsibility for health care as more care is delivered in the home and community. There is a need to inform patients and caregivers of supports and services available to them. There is a need for coordination and support across care settings as patients move from home to hospital to long-term care facilities and to hospices.

There is a need for sustainable, secure funding for a fully developed and implemented national strategy on end-of-life care. The current Canadian Strategy on Palliative and End-of-Life Care is essential to ensuring quality end-of-life care for all Canadians; however, the current Strategy is not sustainable in the long term. The Canadian Strategy has been incompletely implemented and has not met its original objectives.

Therefore, it is recommended that:

National Strategy

1. Health Canada provide long-term, sustainable funding for the further development of a Canadian Strategy on Palliative and End-of-Life Care which is cross-departmental and cross-jurisdictional, and meets the needs of Canadians.

2. Federal, Provincial and Territorial governments make palliative and end-of-life care programs a top priority in the restructuring of the health care system through:

- **implementing consistent norms of practice to eliminate disparities between different jurisdictions;**
- **integrating services to make the transitions between all health care settings (including hospital, long-term care, home and hospice) seamless; and**
- **enhancing homecare and pharmacare, including the provision of respite care.**

Patient and Caregiver Support

3. The federal government amend the Compassionate Care Leave Benefit under the Employment Insurance Program to improve Canadians' access and eligibility under the Benefit by:

- **extending the leave from 8 weeks to 16 weeks, including a two week waiting period;**
- **allowing the patient to determine the best person to be their caregiver, be it a family member or a friend;**
- **not limiting the benefit to the last six months of life, especially for children; and**
- **mounting a public education campaign designed to inform Canadians about the benefit.**

4. The federal government and the Provinces and Territories amend their respective Labour Code provisions to reflect these changes to the compassionate care leave benefit.

Training and Education for Formal and Informal Health Care Providers

5. The federal government support the development of multi-disciplinary education and training with respect to palliative and end-of-life care and support an integrated and coordinated approach to palliative and end-of-life care across care settings.

6. Health care providers be educated on the practice of providing treatment for the purpose of alleviating suffering that may have the unintended effect of shortening life and the circumstances in which the withholding and withdrawal of life-sustaining treatment is legally acceptable.

Government and Citizens Working Together

7. Those territories that do not have advance directive legislation adopt such legislation, and all provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

8. Health Canada, in cooperation with the provinces and territories and the hospice palliative care community, sponsor a national campaign designed to inform the public about end-of-life care, including information on:

- palliative and end-of-life care services available in their region;
- advance directives and end-of-life care planning;
- the compassionate care leave benefit and how to apply for it;
- their legal rights with respect to the withdrawal and withholding of life-sustaining treatment; and
- caring for the dying as an informal caregiver.

Planning for the Future

9. That the Canadian Institute for Health Information be encouraged to develop indicators for quality end-of-life care.

10. That the Canadian Institutes of Health Research undertake research into the socio-economic issues of palliative and end-of-life care, including the physical, mental and economic impact on informal caregivers.

Appendix I: Update 2005

A. Palliative Care in Canada

Government of Canada Initiatives Through Federal Departments Offering Health Services to Specific Groups

A. Overview

The federal government has responsibility for the delivery of health care, including palliative care services, to six specific groups in Canada: First Nations and Inuit; Canadian Forces personnel, veterans, Royal Canadian Mounted Police, inmates in federal penitentiaries, and refugee claimants. Each federal department or agency has a different authority for its health program. Overall, the authority is derived primarily from explicit constitutional authority with respect to the client population but in some cases, it is the result of policy evolution.

In 2001, the Mission in Ottawa opened a residential hospice to help the homeless who have a terminal illness, the first palliative care home linked to a shelter for the homeless. This project has been partially funded by the federal Homelessness Strategy.

In 2002, the federal government reported that it is "the fifth largest provider of health services." At this time it served approximately 950,000 clients at a cost of \$3.4 billion annually.⁶ Two years later, it declared that it served approximately 990,000 people at a cost of almost \$4.0 billion.⁷ Although the information is not currently available, part of this cost was presumably attributable to palliative care.

A portion of the \$4.0 billion in federal health care spending was on medications. The Auditor General of Canada in November 2004 estimated that about one million Canadians were eligible for federal drug benefits at a cost of \$438 million.⁸ This places the federal government as the fourth largest payer of drug benefits in Canada, after Ontario, Quebec, and British Columbia. Once again, some of these drug costs were related to palliative care but the exact amount is not

⁶ Health Canada, *Healthy Canadians - A Federal Report on Comparable Health Indicators 2002*, Ottawa, September 2002, <http://www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/accountability/indicators.html>.

⁷ Health Canada, *Healthy Canadians: A Federal Report on Comparable Indicators 2004*, Ottawa, November 2004, http://www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/datadevelop/health_indicators_e.pdf.

⁸ Auditor General of Canada, Chapter 4 - Management of Federal Drug Benefit Programs, November 2004, <http://www.oag-bvg.gc.ca/domino/reports.nsf/html/20041104ce.html>.

indicated.

B. Health Canada and First Nations and Inuit

1. Organization

The First Nations and Inuit Health Branch supports the delivery of health services on-reserve and in Inuit communities, where there are no provincial services readily available. It provides urgent care, short-term in-patient care and primary care in nursing stations and health centres staffed by community health nurses, Community Health Representatives with physicians providing services on a visiting basis. Limited hospital services are provided in three facilities in small northern towns staffed by several doctors, nurses, and community health workers. It also provides health services - considered to be medically necessary but outside of private or provincial/territorial health plans - offered through the Non-Insured Health Benefits Program such as drugs, counselling, transport, and medical supplies and equipment to eligible First Nations and Inuit clients regardless of residence.

First Nations and Inuit Health Branch regional offices are located in every province, except in the Atlantic provinces, which are represented by the Atlantic Regional Office in Halifax, Nova Scotia. The Northern Secretariat, located in Ottawa, includes the Yukon, the Northwest Territories, and the Nunavut Territories.

2. Services

Palliative care can be delivered through any of the organized services in any region but, at present, there are no clear mechanisms for reporting on palliative, end-of-life and hospice care delivered to First Nations and Inuit populations.

The Community Programs Directorate works in partnership with First Nations and Inuit to deliver a wide range of programs in key community health sectors. As many as 48% of First Nations and Inuit communities have assumed greater control over their own health services through negotiated transfer agreements. These agreements could encompass community-based services such as palliative care.

After the federal budget of February 1999 announcing a National First Nations and Inuit Home and Community Care Program, there was a move to develop programs in each First Nations and Inuit community based on community needs and priorities, the existing infrastructure and availability of resources. The Home and Community Care Program was to include supportive elements such as home-based palliative care.

3. Post-2000 Initiatives

By 2003, the First Nations and Inuit Home and Community Care Program had provided funds to 96% of eligible communities. However, gaps remained in extended forms of care such as residential and palliative care. Various concerns included lack of clarification of roles and responsibilities of all levels of government; gaps in services available on- and off-reserve; lack of culturally-relevant service delivery and facility standards; lack of ongoing education and training for service providers; and the overall inadequacies for infrastructure development in First Nations communities to facilitate service delivery.⁹

C. Veterans Affairs Canada and Veterans

1. Organization

The Veterans Services Branch is responsible for delivering pensions and health care, and for providing social and economic support to war and Canadian Forces veterans and qualified civilians in all regions of Canada. Health care is provided to eligible veterans in the departmental hospital at Ste-Anne-de-Bellevue, Québec, in contract hospital beds, in veterans' homes, and in hospitals of choice.

Eligible veterans and other qualified clients are entitled to health care benefits under the *Veterans Health Care Regulations*. These benefits include medical care, home adaptations, supplementary benefits such as travel costs for examinations or treatment and other community health care services and benefits.

2. Services

The Health Care Program is designed to provide a continuum of care for war and Canadian Forces veterans who meet service, income and other requirements. Palliative and respite care may be provided along with other community health care services and benefits. Treatment benefits including prescription drugs and supplies may be provided to disability pensioners and other clients when these are not covered by a provincial health plan.

The Veterans Independence Program assists clients in their own homes or communities by offering a variety of services to those who meet the eligibility requirements. The program includes care for clients in long term care facilities; support to family caregivers; and coordinated palliative care assistance to enable veterans to "die with dignity" in their own homes, surrounded by family and friends.

⁹ Lemchuk-Favel, Laurel, *Integration of Continuing Care in First Nations Communities: A Draft Model for Discussion*, Ottawa, Health Canada, 2003.

Institutional health care is provided to eligible veterans in the departmental hospital at Ste-Anne-de-Bellevue, Québec, in contract hospital beds, in veterans' homes, and in hospitals of choice. Through its Residential Care Strategy announced in 2004, Veterans Affairs Canada (VAC) encourages its larger contract facilities to move in the direction of specialized care including provision of palliative and respite care to respond to the needs of veterans.

At Ste. Anne's Hospital, end-of-life care is intended to complement curative care and encompasses palliative care. End-of-life care requires an active approach as well as supportive care and attention with regards to treatments, alleviation of pain and support for those suffering from progressive or chronic diseases that pose a short or long term threat to a patient's life. Various institutional facilities across the country have support from federal funds based on agreements between Veterans Affairs Canada and the provincial governments to provide palliative care for veterans. Some examples include: Camp Hill Veterans' Memorial Building in Halifax, Nova Scotia housing about 175 veterans and offering a formalized palliative care program; Veterans Health Unit at Dr. Everett Chalmers Regional Hospital with 47 beds, including palliative care in Fredericton, New Brunswick; expanded and upgraded Ridgewood Veterans Wing of the Atlantic Health Sciences Corporation with palliative care rooms in Saint John, New Brunswick. Many facilities such as the Perley and Rideau Veterans' Health Care Centre in Ottawa, Ontario offer palliative care volunteer training programs covering clinical, spiritual, pastoral and ethical perspectives on death and dying.

VAC participates in interdepartmental policy discussions and national policy development in areas such as support for persons with disabilities, seniors and aging, health promotion, home care and telehospice services, long-term care, palliative/end-of-life care.

3. Post-2000 Initiatives

In November 2002, VAC sponsored the second annual National Long-Term Care Meeting, in Victoria, British Columbia, to share best practices and advances in elder care in the areas of dementia, palliative and respite care.

Since April 2000, Ste. Anne's Hospital is a member of the International Association "Partners Against Pain."

In 2004, the Minister of Veterans Affairs announced the Residential Care Strategy covering dementia care, palliative care, and respite care. This strategy provides a framework for long-term care quality assurance across the country. It involves national accreditation, monitoring of VAC outcomes through client satisfaction and facility questionnaires, and the involvement of provincial care monitoring staff. It also provides for specialized services for dementia and palliative care in large contract facilities where veterans reside.

D. Correctional Services Canada and Federal Inmates

1. Organization

Correctional Services Canada (CSC) is headed by the Commissioner of Corrections, who reports to the Minister of Public Safety and Emergency Preparedness. The national headquarters in Ottawa performs overall planning and policy development for the Service, while each of the five regional offices implements CSC activities in facilities within the region.

The Commissioner's Directive on Health Services has as its objective "to ensure that inmates have access to essential medical, dental and mental health services in keeping with generally accepted community practices."

CSC provides in-house health care services for individuals sentenced to prison for two years or more and sent to federal correctional institutions offering minimum, medium, maximum levels of security through three settings:

- Health care units at its 53 penitentiaries where nurses and general practitioners provide primary health care. Specialists provide secondary healthcare through institutional visits or from outside.
- Regional hospitals in four of the five regions (except the Prairie Region) to provide in-patient care at the tertiary level. In the Prairie region, patients are placed in the chronic care wing of the in-patient psychiatric facility.
- Six regional psychiatric treatment centres with diverse programs. Additional tertiary care (specialist, diagnostic and hospital services) in the community are used as required.

Once inmates are released on parole into the general population, CSC is not responsible for their health services. If an offender is on conditional release in one of the 17 community facilities operated by CSC, the CSC continues to pay for essential services.

2. Services

The Commissioner's Directive on Health Services with respect to terminal or chronic illness states that:

If an inmate is terminally or seriously chronically ill, the Service shall consult with the National Parole Board to determine eligibility for parole. This would include those inmate-patients with incapacitating illness, who are chronically sick and have impairments which have one or more of the following characteristics: are residual; leave residual disability; are caused by

*non-reversible pathological alteration; and require a long period of supervision, observation or care.*¹⁰

Various advocates have identified the need for the development of guidelines for the provision of palliative care in the prisons. The department is moving toward a set of uniform practices and approaches to that care and to the professional training of those who provide this specialized area of health care across the country.

3. Post-2000 Initiatives

The CSC Report on Plan and Priorities 2003-2004 indicates under its plans for 2003 to 2006 that the department aims to provide support services for chronically ill offenders and those requiring palliative care.¹¹

E. National Defence Canada and Canadian Forces Members

1. Organization

The *National Defence Act* gives the Minister of National Defence management and direction of the Canadian Forces. The Minister in turn gives management and direction of the Medical and Dental Services to the Canadian Forces.

The Medical and Dental Services provide health care services for Canadian Forces members whether at home or abroad through 51 Canadian Forces' Health Care Clinics located throughout Canada where staff provide mainly primary health care services and by purchasing services from the provinces, most tertiary care services are available.

2. Services

There is no information on palliative care services for the members of the Canadian Forces.

¹⁰ Correctional Services Canada, *Commissioner's Directive*, Health Services, Number 800, 30 September 2004, <http://www.csc-scc.gc.ca/text/plcy/doc/800-cd.pdf>.

¹¹ CSC, *RPP 2003-2004*, Strategic Outcome: Care, section 4.1.1, http://www.tbs-sct.gc.ca/est-pre/20032004/CSC-SCC/CSC-SCCr34_e.asp.

F. Royal Canadian Mounted Police and RCMP Members

1. Organization

The Royal Canadian Mounted Police Regulations 1988 made pursuant to the *Royal Canadian Mounted Police Act* specify that medical and dental treatment programs for a regular member or special constable member are subject to approval by the Commissioner.

The Royal Canadian Mounted Police (RCMP) provides comprehensive health services to ensure that members are emotionally and medically fit to perform duties; and payment for personal health care provided to members from providers that meet specified RCMP criteria. When a serving member of the RCMP uses provincial services, they present their client registration number and ensure that authorization is obtained from a Health Services Officer of RCMP. The provincial service then bills the RCMP for services.

2. Services

No information on palliative care services for RCMP members is available.

G. Citizenship and Immigration Canada and Refugee Claimants

1. Organization

Citizenship and Immigration Canada administers the Interim Federal Health Program to cover emergency and essential health services for needy refugee claimants and those refugees in Canada who are not yet eligible for provincial health care. Benefits are limited to essential health services for such things as the treatment of serious medical conditions and for essential prescription medications.

While refugee claimants are eligible to be residents of a province for health insurance purposes, they may have to wait for three months before they are considered an insured person with eligibility for or entitlement to provincial services.

2. Services

No information is available about palliative care for claimants under this federal plan.

B. Major Canadian Developments in Palliative and End-of-Life Care Since June 2000

December 2000 - Creation of the Quality End-of-Life Care Coalition. The Canadian Hospice Palliative Care Association joined with over 30 national organizations to lobby as one voice for better palliative and end-of-life care for Canadians.

January 2001 - The Government of Canada, in the Speech From The Throne, committed to work towards enabling parents to provide care for a gravely ill child, without the fear of sudden income or job loss.

February 2001 - The report of the Canadian Strategy for Cancer Control Palliative Care Working Group was accepted after consultation with stakeholders, and resulted in palliative and end-of-life care being chosen as one of the five areas for immediate action. The report affirmed palliative care as a fundamental component of cancer control and it recommended improving the integration of palliative care delivery within existing cancer care and other health care delivery systems.

March 2001 - The Honourable Senator Sharon Carstairs, P.C. was named Minister with Special Responsibility for Palliative Care, giving the issue of palliative care a voice at the Cabinet table until December 2003.

June 2001 - The Secretariat on Palliative and End-of-Life Care was created within the Department of Health Canada in order to support the Minister and to provide leadership and coordination in the creation of a national strategy.

June 2001 - Intra-departmental Working Group is established within Health Canada to bring together divisions within Health Canada with responsibility for palliative care.

June 2001 - Palliative care is on the agenda at the F/P/T meeting of the Ministers of Health. Minister Carstairs and Health Minister Allan Rock lead a discussion on issue of palliative care.

November 2001 - Interdepartmental Working Group is established within the federal government to bring together federal departments with responsibility for palliative care.

Fall 2001 and early 2002 - Minister Carstairs meets with provincial Health Ministers.

March 2002 - The Secretariat hosted the National Action Planning Workshop in Winnipeg, a meeting of stakeholders, some F/P/T representatives and researchers. At this meeting, five priority areas were identified for action.

March 2002 - *A Model to Guide Hospice Palliative Care* is released. This document is the end result of a national consensus building process aimed at developing norms of practice in hospice palliative care.

April 2002 - The online Canadian Directory of Hospice Palliative Care Services was launched. This directory provides information on hospice palliative care programs and services available throughout Canada.

June 2002 - A presentation is made to Cabinet by Minister Carstairs and Health Minister Anne McLellan outlining the Canadian Strategy on Palliative and End-of-Life Care. The Canadian Strategy has three components: community, federal and F/P/T.

July 2002 - Human Resources Development Canada established a policy to streamline the application process for clients whose medical condition is considered “terminal.”

Fall 2002 - The community component of the strategy began when the Secretariat established five working groups to address the following issue areas: best practices and quality care; education for formal caregivers; public information and awareness; research; and surveillance. Coordination across these groups occurs through a Coordinating Committee consisting of the co-chairs of the five working groups, Aboriginal and Quality End-of-Life Care Coalition representation, and Health Canada as co-chair. The five working groups reflect the areas identified for action at the 2002 National Action Planning Workshop.

September 2002 - The Speech From the Throne included a commitment to ensure that “Canadians can provide compassionate care to a gravely ill or dying child, spouse, or parent without at risk their incomes or jobs.”

October 2002 - Senator Michael Kirby tables Senate report on the Future of Health care in Canada. Report calls for a national palliative care program, homecare, pharmacare and a compassionate care benefit.

November 2002 - Industry Canada announces funding for Canadian Virtual Hospice and for the first ever research chair in palliative care at the University of Manitoba.

November 2002 - Roy Romanow tables final report of the Royal Commission on the Future of Health Care in Canada. The report makes a number of recommendations concerning palliative care and home care.

January 2003 - The proposal identifying the educational needs of physicians in palliative and end-of-life care was funded in the amount of \$1.25 million over four years by the Health Human Resources Strategies Division of Health Canada.

February 2003 - Health Accord reached between First Ministers.

June 2003- Bill C-28 is passed which creates a compassionate care leave program under the *Employment Insurance Act*. The benefit provides up to 6 weeks of paid leave through

Employment Insurance for a person to care for a terminally ill parent, spouse or child.

June 2003 - The Canadian Institutes of Health Research (CIHR) and partner organizations announced the first Strategic Research Initiative specific to palliative and end-of-life care.

September 2003 - The Primary Health Care Transition Fund, created by the Government of Canada in September 2000, allocated \$6,463,707 over 37 months to Prince Edward Island to ensure the sustainability of the health care system.

December 2003 - As a result of the 2003 First Ministers Meeting, the Health Council of Canada was created, whose mandate is to monitor the health care system performance and to make annual public reports on the implementation of the Accord.

December 2003 - The Primary Health Care Transition Fund allocated \$4,317,000 to the Alberta Cancer Board for the creation of the Pallium Integrated Care Capacity Building Initiative.

January 4, 2004- Compassionate Care Leave Benefit is implemented.

February 2004 - The Canadian Virtual Hospice was launched. The Canadian Virtual Hospice is an interactive network on the World Wide Web designed to facilitate information exchange, communication, and mutual support between and among patients, their friends and family, health care providers, and palliative care volunteers.

June 2004 - The Canadian Institutes of Health Research (CIHR) announced the allocation of \$16.5 million over five years for the Palliative and End-of-Life Care Strategic Research Initiative.

July 2004 - The Honourable Tony Ianno was appointed Minister of State (Families and Caregivers) by The Right Honourable Paul Martin, Prime Minister. Families and caregivers play an important role in palliative and end-of-life care, therefore, Health Canada plans to work in collaboration with this ministry.

September 2004- Provinces agree to a Ten-Year Plan for Health Renewal.

November 2004 - Health Canada hosted a Palliative Care Forum in Calgary, Alberta.

January 2005 - Health Canada began a policy development and a consultation process aimed at revitalizing the Canadian Strategy on Palliative and End-of-Life Care.

February 2005 - CIHR announced its intentions to create a peer-review panel for palliative and end-of-life care research, to review applications for operational funding in their regular competitions.

C. Legislation Proposals Introduced in Parliament in Response to the 2000 Recommendations.

Bill C-219 Peter Stoffer, M.P.

An Act to amend the Employment Insurance Act (persons who leave employment to be care-givers to family members)

Introduced and read a first time- February 5, 2001

Bill C-206 Peter Stoffer, M.P.

An Act to amend the Employment Insurance Act (persons who leave employment to be care-givers to family members)

Introduced and read a first time - October 3, 2002

Defeated at second reading March 25, 2003

Bill C-28 Minister of Finance

An Act to implement certain provisions of the Budget (Compassionate Care Leave Benefit) tabled in Parliament on February 18, 2003.

Passed June 2003

Implemented January 4, 2004

D. Advance Directives Legislation in Canada

In the past five years, Prince Edward Island has brought its legislation into force; New Brunswick has enacted and brought into force new legislation; and the Yukon has enacted new legislation which is not yet in force.

Citations

British Columbia

Health Care (Consent) and Care Facility (Admission) Act, RSBC (Revised Statutes of British Columbia) 1996, chapter 181.

Representation Agreement Act, RSBC 1996, chapter 405.

Alberta

Personal Directives Act, RSA (Revised Statutes of Alberta) 2000, chapter P-6.

Saskatchewan

The Health Care Directives and Substitute Health Care Decision Makers Act, SS (Statutes of Saskatchewan) 1997, chapter H-0.001.

Manitoba

The Health Care Directives Act, CCSM (Continuing Consolidation of the Statutes of Manitoba), chapter H27.

Ontario	<i>Health Care Consent Act</i> , 1996, SO (Statutes of Ontario) 1996, chapter 2, Schedule A. <i>Substitute Decisions Act</i> , 1992, SO 1992, chapter 30.
Quebec	<i>Civil Code of Quebec</i> , S.Q. (Statutes of Quebec) 1991, chapter 64. Articles 10-25 (Integrity of the Person/Care), articles 2130-2185 (Mandate/power of attorney).
New Brunswick	<i>Infirm Persons Act</i> , RSNB (Revised Statutes of New Brunswick) chapter I-8, as amended by S.N.B.2000, c.45.
Nova Scotia	<i>Medical Consent Act</i> , RSNS (Revised Statutes of Nova Scotia) 1989, chapter 279.
Prince Edward Island	<i>Consent to Treatment and Health Care Directives Act</i> , RSPEI (Revised Statutes of Prince Edward Island), chapter C-17.2
Newfoundland and Labrador	<i>Advance Health Care Directives Act</i> , SNL (Statutes of Newfoundland) 1995, chapter A-4.1.
Yukon Territory	<i>Health Act</i> , RSY2002 (Revised Statutes of the Yukon, 2002), chapter 106. In December, 2003, The Yukon legislature passed the <i>Decision Making, Support and Protection to Adults Act</i> , SY 2003, c. 21. Schedule B consists of a new <i>Care Consent Act</i> . However, the Act has been brought into force.
Northwest Territories	No specific legislation, although it has been suggested that the <i>Powers of Attorney Act</i> , SNWT (Statutes of the Northwest Territories) 2001, chapter 15 might be used to create the equivalent of a living will.
Nunavut	No legislation.

Sources for Sample Directives

The End of Life Project at the Health Law Institute, Dalhousie University, has a useful website that deals with province-by province information on advance directives as well as frequently asked questions.

Reciprocity Between Provinces

When dealing with advance directives, “reciprocity” between provinces or territories refers to provisions that allow advance directives to be implemented in a given province or territory even though they were executed in a different jurisdiction. The following provinces have enacted legislation which allows for reciprocity to some extent: British Columbia, Saskatchewan,

Manitoba, Ontario, and Prince Edward Island. The Yukon Territory enacted legislation in 2003 which would allow for reciprocity in certain situations, but the act is not yet in force.

Appendix II: Terminology

For the purpose of this report, the definition of the Canadian Hospice Palliative Care Association is used: *Hospice palliative care is aimed at the relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved.*¹²

The term “end-of-life care” in this report is considered to be all forms of care provided for the dying, including hospice palliative care.

For the purposes of this report the same terminology as defined in the 1995 Report is used. The following are the relevant definitions:

"Total sedation" is the practice of rendering a person totally unconscious through the administration of drugs without potentially shortening life.

"Treatment aimed at the alleviation of suffering that may shorten life" is the administration of sufficient amounts of drugs to control suffering even though this may shorten life.

"Withholding of life-sustaining treatment" is not starting treatment that has the potential to sustain the life of a patient.

"Withdrawal of life-sustaining treatment" is stopping treatment that has the potential to sustain the life of a patient.

"Advance directive", referred to as mandate in the Quebec Civil Code, and also commonly known as a living will, is a document executed by a competent individual concerning health care decisions to be made in the event that the individual becomes incompetent to make such decisions. Advance directives can be divided into two categories - instruction directives and proxy directives. The latter are also known as durable powers of attorney for health care. In an instruction directive, an individual sets out what or how health care decisions are to be made in the event that he or she becomes incompetent. In a proxy directive, an individual sets out who is to make health care decisions in the event that he or she becomes incompetent. A valid advance directive is one completed according to the requirements set out in the relevant legislation. Throughout this report, when the expression advance directive is used, validity is assumed unless otherwise indicated.

"Futile Treatment" is treatment that in the opinion of the health care team will be completely ineffective. This term does not include treatment that may be effective but whose results are deemed undesirable.

¹² For a more fully operational definition of hospice palliative care, see *A Model to Guide Hospice Palliative Care*, Canadian Hospice Palliative Care Association, 2002.

"Free and informed consent" means the voluntary agreement by a person who in the possession and exercise of sufficient mental capacity, as defined by an appropriate medical professional, makes an intelligent choice as to treatment options. It supposes knowledge about the consequences of having or not having the treatment and about possible alternatives. The consent must be free from coercion, duress and mistake.

Appendix III: International Experiences

United Kingdom

Dame Cicely Saunders is widely recognized as the originator of the modern hospice movement through her work in establishing St. Christopher's Hospice in London in 1967. By the year 2000, there existed 172 adult inpatient units, 27 children's units, and 264 home care teams throughout the country.

A 1999 Palliative Care survey documented that one third of Health Authorities within the United Kingdom had not developed palliative care strategies. The survey also revealed major regional variations in access to palliative care. Before 2000, 75% of palliative care for patients was provided by the voluntary sector. From 2001-2004, an initiative to train community nurses in palliative care was undertaken to support people in their choice of place in which to live and die, as well as to reduce inappropriate hospital admissions.

The National Partnership Group was established in July of 2002, by Ministers to ensure that the £50m cancer plan commitment was delivered. In January 2003, guidelines and allocations were published. Preliminary data from 2003-2004 shows that 54% of the allocated funding has gone to the voluntary sector.

More than 40% of cancer patients in the UK are estimated to have access to hospice palliative care, with access by non-cancer patients being much lower. Under the terms of the *Regulation of Care Act 2001*, separate registration of care at home services provided by voluntary hospices was required by June of 2004. In 2003, the Welsh Assembly Government announced that £10 million would be made available over a three-year period for Hospices in Wales. The Treasury of England has indicated that by 2006 voluntary organizations must be paid the full costs of providing public services.

The National Institute for Clinical Excellence (NICE), which supports the National Health Service in the UK, developed guidelines on palliative care in 2004 that guide the national palliative care strategy. *Improving Supportive and Palliative Care for Adults with Cancer*, outlined these guidelines, which applied to England and Wales. Palliative care policy is determined within the national cancer strategy, including an exploration of non-palliative care within the national strategy. A National Partnership group consisting of key voluntary sector partners and senior officials of the National Health Service was created to guide policy and planning.

In 2004, the British House of Commons issued a report which recommended a coordinated national approach to palliative care. This report cited Canada's Compassionate Care Benefit and the Quality End-of-Life Care Coalition as models for reference. The priorities for the National Plan include: improving patient care; building partnerships to provide seamless care;

performance (common standards); prevention and inequality; as well as making better use of professionals.

In January 2004, the NHS Quality Improvement Scotland published the first ever national review of specialist palliative care services in Scotland. Performance of 13 adult voluntary hospices, seven NHS specialist palliative care services and one voluntary children's hospice was reviewed in 2003. The review found that staff were well trained and had a high level of awareness of the needs of patients. Areas needing improvement was the fact that many units and specialist teams were reaching capacity, as well as the need for further research to determine the most effective form of service configuration.

The Scottish Executive Health Department issued a letter in April of 2003 to NHS Boards in Scotland outlining the expectation that by 2006-2007, at the very latest, they would fund 50% of the annual running costs of voluntary hospices providing specialist palliative care for adults.

Ireland

The National Advisory Committee on Palliative Care was established by the Minister for Health and Children in 1999. In 2001, this Advisory Committee published an in-depth report which discussed a number of topics including the need for specialist palliative care, patients and caregivers' perceptions, specialist services and palliative care units, bereavement support, education, standards, funding and planning. Among the many recommendations made in this report, was the need for at least one specialist palliative care inpatient unit in each health board area, academic departments of palliative medicine be established in universities, and that all acute general hospitals have a specialist palliative care service,. The Committee also stated the implementation of the report's recommendations should occur within a five year period.

This year the Irish Hospice has been chosen as Tesco's *Charity of the Year*. Throughout 2005 Tesco staff across Ireland are pledging to support local hospice care through a range of fund-raising events and activities. All the money raised will go to support local hospice care

Australia

Published in 2002, *The National Palliative Care Strategy* guides palliative care policy and development in Australia. This national strategy includes priorities for access to pharmaceuticals, assistance for informal care givers, access to professional education, and research capacity building. Unlike the UK, palliative care policies in Australia are included under policies to support the aged, rather than being disease specific.

The Australian Health Care Agreements represent the commitment from the Australian Government to the enhancement of palliative care. The Australian government has committed

approximately CDN \$185 million from 2003-2008, to implement initiatives under the priorities of their national palliative care program.

The goals and objectives of Australia's National Strategy are threefold:

- Awareness and understanding to improve community and professional awareness, understanding of, and professional commitment to the role of palliative care practices;
- Quality and effectiveness of all palliative care service delivery across Australia; and
- Partnerships in care, to promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, as well as to support the delivery of high quality, effective care across all settings.

The six priorities of the Australian National Palliative Care Program:

- Provision of an expanded range of medications for palliative care in the community.
- Assistance for families and increased support to other networks.
- Education, training and support for the primary care workforce.
- Increasing the range and support of palliative care services.
- Capacity building in the palliative care research community.
- Performance information development.

United States

Initiated in 1983, the major federal program in the United States is the Medicare Hospice Program. This program pays for services through Medicare-certified hospices for those aged 65 and over who are expected to live six months or less. Although Medicare benefits are similar in all fifty states, end-of-life care is supported through policies for the aged and disabled rather than being disease-specific.

The Medicare Hospice Benefit also offers support for the family and loved ones of the patient with the allowance for two, ninety day periods of care, with a total of six months, succeeded with an unlimited number of 60-day periods. Many Americans, however, do not benefit from the Medicare hospice services as many are unwilling to choose hospice care, and prefer the curative care approach.

Health Care is considered to be a for-profit industry in the US, and the Hospice Association of America an industry representative association. In comparison with Canada, the UK and Australia, there is generally less federal leadership in areas such as research and professional education.

The National Board for Certification of Hospice and Palliative Nurses has partnered with the American Nurses Credentialing Center to offer an advanced practice certification for nurses educated at a Master level or higher. The American Nurses Association in collaboration with the

Hospice and Palliative Nurses Association has published *Scope and Standards of Hospice and Palliative Nursing Practice*. The *Scope and Standards* covers both the generalist and the advanced practice nurses standards.

In April 2004, the National Consensus Project on Quality Palliative Care, Essential Elements and Best Practices, released clinical practice guidelines for palliative care programs for healthcare institutions.

The *Lifespan Respite Care Act* (S. 538) was passed in the Senate in 2004 and incorporated into the caregiver supports section of both the House and the Senate bills. The *Act* seeks to assist family caregivers in accessing affordable and high-quality respite care and authorize funding for the development of lifetime respite programs at the state and local levels. The *Act* also provides for the recruitment and training of respite care workers and volunteers, as well as training for caregivers to help them make informed decisions about respite services.

The *Pain Care Policy Act* (H.R.1020) was re-introduced into the House of Representatives in March of 2005 by representative Mike Rogers. This legislation was introduced to recognize pain as a priority health problem in the United States. The *National Pain Care Policy Act* calls for the establishment of a National Center for Pain and Palliative Care Research at the National Institutes of Health and the development and implementation of six regional pain research centers throughout the country. The legislation would provide for a White House Conference on pain care, education and training programs for health care professionals, and the development and implementation of a national outreach and awareness campaign to educate consumers. It would also require development and implementation of a pain care initiative in all military health care facilities and pain care standards in military plans and Medicare Choice plans.

Appendix IV: Sources for Update

Submissions were received from:

Amyotrophic Lateral Sclerosis Society of Canada
Canadian Healthcare Association
Canadian Hospice Palliative Care Association
Canadian Institutes of Health Research
Hamilton Health Services
Health Canada
Health Council of Canada
Health Law Institute, Dalhousie University
Office of the Chief Coroner of Ontario
Palliative Care and Chronic Pain
Quality End-of-Life Care Coalition of Canada
 ALS Society of Canada
 Canadian Association of Community Care
 Canadian Association of Occupational Therapists
 Canadian Association of the Deaf
 Canadian Breast Cancer Network
 Canadian Cancer Society
 Canadian Homecare Association
 Canadian Hospice Palliative Care Association
 Canadian Lung Association
 Canadian Medical Association
 Canadian Pharmacists Association
 Caregiver Network Inc.
 Catholic Health Association of Canada
 Childhood Cancer Foundation (Candlelighters)
 The GlaxoSmithKline Foundation
 Huntington Society of Canada
 National Advisory Council on Aging
 VON Canada
SCO Health Service
The College of Family Physicians of Canada
VON Canada