

**State of Palliative Care in Canada:
End of Life Care**

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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.

We thank Senator Carstairs for permission to reproduce this abstract of her Cardinal Ambrozic Lecture for the CCBI, March 3, 2006. We also thank her for her commitment to securing adequate palliative care for all Canadians at the end of life, and help for their caregivers.

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.