

**CARE OF THE DYING PERSON**  
**“Is Quality Care the Luck of the Draw?”**

The Catholic Health Association of Canada

Brief to the  
Senate Social Affairs Subcommittee to Update “On Life and Death”

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Catholic Health Association of Canada  
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**The  
Catholic  
Health  
Association  
of Canada**

The Catholic Health Association of Canada (CHAC) is a national Christian association supportive of health care in the tradition of the Roman Catholic Church. As the national voice for Catholic health care, we actively promote health in all its aspects: physical, emotional, spiritual and social. Because we see health as a condition for full human development, our association encourages all activities designed to promote wellness, prevent disease, and cure sickness. Our membership comprises eight provincial/regional health associations; 34 sponsors/owners of health care organizations; 127 hospitals and homes; health care professionals; and affiliate organizations and individuals.

The Catholic Health Association of Canada is committed to advocating with and on behalf of the most marginalized members of our society, most particularly those who are sick, suffering and dying. Many of CHAC's member hospitals and homes are actively involved in the care of those who are dying and offer palliative care services. The association has actively promoted palliative care and improved pain control through education and advocacy activities, and has articulated ethical norms for care of the dying person. The association appeared before the Special Senate Committee on Euthanasia and Assisted Suicide in 1994.

We appreciate the opportunity to appear before The Senate Social Affairs Subcommittee to Update "Of Life and Death."

**Introductory  
Comments**

Advances in science and technology are dramatically improving our ability to cure illness, ease suffering and prolong life. At the same time, these advances also raise new ethical questions concerning end-of-life care, particularly around life-sustaining treatment. There are occasions when prolonging life by artificial means places onerous burdens on dying persons and their families. In the face of such issues the CHAC emphasizes the necessity to maintain a balance between two important obligations. We are obliged not to intentionally kill someone; as a result, assisted suicide and euthanasia are not acceptable options. At the same time, we are not obliged to use life-sustaining procedures which would impose burdens out of proportion with the benefits to be gained from such procedures.

**Palliative  
Care: A  
Best Case  
Scenario**

To illustrate what is at stake in palliative care, it might help to explore a case scenario:

Ms. J.H., age 63 years, has end stage heart failure. She is admitted with severe breathing problems to a large urban teaching hospital. Her cardiologist knows her well. He applies all available treatment measures but these are ineffective because of the advanced state of illness. She continues to suffer breathing difficulty. Although she is going to die, Ms. J.H. and her family have several factors in their favour:

1. Her cardiologist recognizes the palliative nature of her illness. He speaks with her and the family in a caring way and they agree on goals of comfort care and no aggressive life support measures (CPR, ventilation, etc.). He orders a small, effective dose of regular morphine for her breathing.
2. The hospital has a commitment to providing palliative care and has funded a fully staffed palliative care team (physicians, nurses, social workers, chaplains and volunteers). The cardiologist often consults and works collaboratively with this team and they are called in to care for Ms. J.H. Her symptoms are relieved with medications and she and her family are provided supportive counselling. She would like to go home and to die there, if she can be comfortable and if it isn't too hard on her family.
3. Ms. J.H.'s "luck" continues to hold. Her community home care services are "palliative care aware," and they have not suffered too many funding cuts in recent downsizing and health care restructuring. Her community also has a regionalized palliative care program with a palliative care physician-nurse team to come to her home, and a palliative care unit/ hospice of sufficient size that it can readily admit her if a crisis arises. Her family doctor is knowledgeable in palliative care. She will see Ms. J.H. at home on a regular basis and welcomes the input of the home-based palliative care team, home care nurses and the potential role of the in-patient unit.
4. Ms. J.H. goes home and is cared for there for three weeks. Her breathing difficulties begin to increase and she becomes somewhat restless and delirious. She is admitted to the palliative care unit where these are again brought under control with medications. Although she is somewhat sleepy, she does recognize her family and is able to speak with them. She dies peacefully with family at her side four days later.

## **Key Components Surrounding the “Luck of the Draw”**

From the perspective of patient & family, the quality of care received when seriously ill and dying in Canada will vary greatly. It still depends, to a large and unacceptable degree, on the “luck of the draw.” The key components that vary include:

### **1. Nature of the Illness**

Palliative care is presently associated mainly with cancer patients. Patients dying of other illnesses (heart & lung disease, stroke, pneumonia, etc.) are less likely to be identified as being in a palliative phase of their illness and are less likely to receive the skills of an interdisciplinary palliative care team.

### **2. Primary Attending Health Care Teams**

These teams may be surgeons, internists, cardiologists, family physicians and others. They play a key role in identifying an illness as palliative and in referring patients to palliative care services. Since many such teams do not have an awareness of palliative care, or lack palliative care skills, patients and families will suffer unrelieved symptoms and will not receive the services that they require.

### **3. The Setting for Care & Availability of Specialist Palliative Care Services**

A hospital’s failure to provide palliative care services will greatly impact care. All hospitals (acute, chronic care and long-term care) should have palliative care services. Patients in the community, at home, require palliative care nursing, physician care and other services (home-making, physiotherapy, occupational therapy, nutrition etc.).

### **4. Palliative Care Programs**

Such programs should exist in all communities, large & small, urban & rural (refer to Appendix 2: OMA Colloquium on care of the dying patient). Components include hospital teams, home care services, palliative care unit and/or hospice, and home visiting specialized teams, bereavement services, and voluntary support services. Palliative care consultant physicians are key members of teams in all settings.

### **5. A Responsible Physician**

A responsible physician is required to assume the ongoing care of patient and family at home and in hospital. This physician needs educational preparation, clinical skills and the willingness to provide palliative care. This physician also requires the presence of palliative care services, and services that provide spiritual and religious care, upon which to call for assistance in caring for palliative care patients.

**Applying the  
Key  
Components  
to our  
Scenario**

In the case scenario that we have outlined today, the application of the key components of Ms. J.H.'s "luck" are applied in the following manner:

1. She has physicians who are knowledgeable about effective palliative care, are willing to refer to palliative care services, are willing and educationally prepared to care for her, and who are not afraid to order symptom control medications like morphine. They are also compassionate and have effective communication skills to establish goals of care and to provide ongoing supportive counselling.
2. The hospital where she is admitted has made an overt commitment to insuring that seriously ill and dying patients will receive the care they need. It has included in its mission, the mandate to relieve suffering, as well as to cure disease. To implement this mission statement, the hospital has financially supported a fully-staffed palliative care service and participates in the regional palliative care program to insure that there are coordinated services available. The hospital regularly sponsors educational events for nursing and other staff to insure that all staff are prepared to provide palliative care, recognizing that this is everyone's role. Staff are recognized for providing compassionate end-of-life palliative care.
3. The local home care program is similarly aware and can provide skilled nurses and other team members in sufficient hours to meet Ms. J.H.'s needs. The resources (financial and human) are sufficient for effective palliative care.
4. The region where Ms. J.H. lives has collaborated to develop a coordinated range of services for palliative care. A full palliative care program is in place so that she can receive the care required.
5. Her family physician makes house-calls and participates in an on-call group

**A Radically  
Different  
Scenario**

that shares her philosophy and skills in palliative care. She has taken courses in palliative care in a project funded through the provincial health ministry.

Were any of these components of care absent or ineffective, Ms. J.H.'s options would be severely limited and a radically different scenario would be described. For example, were her breathing difficulty not controlled, she might not be able to go home. If at home, she might need to come back to the emergency room for help rather than having house call support and admission to a palliative care unit. She and her family would be recipients of disruptive and ineffective end-of-life palliative care. Palliative care is either excellent or falls apart because of the central role of the physician. Even though other health care professionals play major roles in the provision of palliative care, access to care and the provision of total patient care depend on the involvement of skilled and aware physicians who can and will provide symptom control and supportive, compassionate overall care.



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**CARE FOR PATIENTS AND FAMILIES**

**Current Status**

- ↪ Although 75% of Canadians die in hospitals or long-term care facilities, palliative care services in these institutions are still grossly lacking, or at best, unevenly provided and available. There can be a tendency to want those who are dying to leave the hospital because of the pressures on hospitals to vacate beds for other needs.
- ↪ The effects of restructuring and downsizing on health services across Canada are also affecting palliative care. There is decreased home care availability and decreased hospital resources. Hospital physicians, surgeons and programs are urgently seeking palliative care services so that dying patients can receive the care they require in a setting that matches their needs and wishes. The availability of such programs would relieve congestion on hospital in-patient beds and programs.
- ↪ Coordinated and effective palliative care programs in communities are still quite rare. Such programs provide a range of services in all settings (the patient's home, clinics, hospitals, long-term care facilities) and they work together to provide a "seamless" integrated program of care for patients and families.
- ↪ No province in Canada has a policy regarding the provision of palliative care services, and no province funds palliative care services directly. Palliative care services, funded through constrained global budgets, find themselves in the position of competing with other programs and services.
- ↪ Partial palliative care may exist. This occurs when key components of a system do not exist (e.g. home care team, palliative care unit/hospice) or when only partial services are available. For example, a hospital may have a nurse clinician or social worker who is identified as a palliative care provider, but there may be no palliative care consultant physician. This may lead to inadequate symptom control and stress for the current care providers.

**Recommendations for Action**

1. That provinces move toward the formation of a policy for palliative care services, and provide the adequate funding required to insure uniform quality end-of-life care.
2. That the establishment of palliative care programs of services be made a priority and that communities make palliative care services available in all settings (hospital, home, long-term, and palliative care unit/hospice) with sufficient resources to meet patient and family needs.
3. That the *National Palliative Care Standards* being finalized by the Canadian Palliative Care Association (CPCA) be embraced and supported

**2****EDUCATION**

- by ministries of health, health care planners, hospitals and community care programs. These standards should become a mandatory part of the accreditation process for hospitals and long-term care facilities.
4. That obstacles to effective palliative care be identified and addressed. Obstacles will vary from community to community and may include lack of referral, lack of services, attitudes and beliefs of health professionals.

**Current Status**

- ↪ There is considerable education in palliative care in Canada with national conferences and education in communities. Ontario has been funding a ministry initiative since 1994 that would serve as a model for all provinces. Outcomes from such education include the following:
  - ↪ Health professionals who are educated feel constrained by the lack of service programs to implement their new knowledge.
  - ↪ Health professionals who are not directly connected to palliative care (e.g., staff in intensive care units, surgery) have not yet received sufficient education. Yet they, too, care for dying patients on a regular basis.
  - ↪ There is no minimum expectation or standard for health professional education at the undergraduate, postgraduate or practicing professional level.
  - ↪ Physicians are key players in the health care system. Education of all physicians (those in training and those in practice) is lacking. Similarly, nursing programs provide insufficient education in palliative care.

**Recommendations for Action**

5. That the 16 medical schools in Canada integrate palliative care education into their curricula immediately and that sufficient time in the curriculum and funding be provided for such courses. *The Canadian Palliative Care Curriculum* and *Case-Based Text* that are already available can form the basis for implementing the curriculum.
6. That nursing schools and other health and social service professions adopt similar measures as a part of their education.
7. That residency training of physicians incorporate palliative care objectives and education as part of the program.
8. That the national colleges (Royal College of Physicians and Surgeons and the Canadian College of Family Physicians) take leadership in defining and endorsing a standard of professional expectations regarding the provision of pain and symptom control, the relief of emotional and spiritual suffering, and ethical care at the end-of-life. All physicians, related to their knowledge and practice of pain and symptom control (including the relief of emotional and spiritual suffering), and their practice of palliative end-of-life care, would be expected to meet a certain standard of professional care.

9. That the corresponding licensing body for nurses adopt a similar approach in developing expected standards of knowledge and practice.

**3**

### **RESEARCH**

#### **Current Status**

- ↳ Research in the areas of symptom control, psychosocial support and effective models of care delivery is needed.
- ↳ Research flows out of effective clinical care service programs since programs are interwoven with education and research.

#### **Recommendations for Action**

10. That palliative end-of-life care be embraced as a worthy area of health care research, with the goal of improving patient and family care. Research is urgently needed in all areas of palliative care (pain and symptom control which includes the relief of the emotional and spiritual suffering of the patient, family and staff).
11. That research funding bodies (both government and private) be encouraged to support research in palliative care.

**4**

### **ADVANCE HEALTH CARE DIRECTIVES**

#### **Current Status**

- ↳ Advance health care directives enable a person to communicate their directions concerning the type of treatment they desire should they lose their decision-making capacity. Persons are encouraged to discuss these directives with their family and care providers, and, if appropriate, to appoint a proxy before crisis situations arise. A statement of philosophy or beliefs, when included as part of a written advance health care directive, assists family and care providers to carry out the wishes of the person receiving care.
- ↳ Directives are not a “panacea” for good care and they cannot replace compassionate and effective communication with patient and family.

#### **Recommendations for Action**

12. That public education about the role of advance health care directives be continued and expanded throughout Canada.
13. That a key component of the public education campaign on advance health care directives be to provide families and patients with tools to help them communicate with one another and their health care team. It is vital to communicate their wishes, needs and preferences concerning end-of-life care.

**5****WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT****Current Status**

- ↪ Health care professionals engage in regular discussions with patients and families about decisions concerning treatment.
- ↪ The nature of the discussions and decisions made is unique to each situation because the patient's illness as well as needs, wishes and preferences are also unique.
- ↪ Decision-making in this area is a complex process that requires time and great sensitivity on the part of the health care team.

**Recommendations for Action**

14. That a process of decision-making in this area be developed and that health professionals be encouraged to use this process. An approach to the decision-making process must be systematic and ethical in nature, while remaining sensitive to the patient's needs, wishes and preferences.
15. That the complexity of making end-of-life decisions be recognized as unique to each individual situation. There are no easy solutions to expediting this process.
16. That education programs and practice expectations include skills in compassionate and effective interpersonal communication.
17. That withholding and withdrawing of treatment be recognized as just one part of palliative care. They must be implemented together with effective symptom control and on-going supportive care of patient and family.

**6****SEDATION PRACTICES IN PALLIATIVE END-OF-LIFE CARE****Current Status**

- ↪ Patients often require sedation near the end of life. Sedation is ordered to provide relief from physical symptoms like intractable pain, suffocation or agitated delirium and restlessness.
- ↪ The goal of such sedation is to provide a calm restful state for the patient and relief of their symptoms. This forms a part of palliative care practice.
- ↪ Not all physicians have sufficient expertise in symptom control, thus its proper use is often uneven and inadequate.

**Recommendations for Action**

18. That the management of end stage intractable symptoms become an integral part of education for all physicians in palliative end-of-life care.
19. That pain and symptom control form a significant section of the curriculum of such education.
20. That emotional and spiritual suffering be recognized as forming a large component of the distress of patients and families. All health care professionals should be required to receive appropriate education in clinical

practice for the relief of suffering and collaborate with those in charge of spiritual and religious care to help patients, families and staff in situations of distress.

21. That the relationship between expert pain and symptom control, and the relief of suffering, and a fully staffed palliative care service be recognized and that such services be available in an integrated manner throughout the health care system.
22. That ethics and the components of ethical practice in palliative end-of-life care form an integral part of the education programs and the clinical care of patients and families.

## Concluding Remarks

In conclusion, the Catholic Health Association of Canada would again strongly affirm the vision of care of the dying set out in the recommendations on palliative care, pain control and sedation practices, withholding and withdrawing of life-sustaining treatment, and advance directives, contained in the report *Of Life and Death*. Our brief has noted, however, that, although some progress has been made since 1995 in implementing these recommendations, much still needs to be done.

## A Model of Care

Palliative care cannot remain an “add-on” to health care but should be a high-profile integral component in all patient care settings. The challenge of end-of-life care is that very few situations are alike. Individuals, families and circumstances of illness vary. People need time to accept information concerning an impending death and time to make decisions with which they are at peace. When palliative care becomes part of an integrated health care system, it is a short term investment that provides a long term gain. Palliative care, as an example of compassionate care, creates a model of care for the whole health care system.

Canada has enjoyed a reputation as a nation that promotes respect for every person and encourages compassionate care of those in need. We believe that Canada must continue its role as a global leader in humanitarian causes by committing itself to quality care of those who are dying. If Canadian health care providers can institute effective palliative care practices that promote care-in-dying, not only will we be caring well for the dying members of our communities, we will be giving to the global community a model of health care that values healing and compassion without apology. The values and human rights upon which Canadian society is founded makes it imperative that we promote and establish *care-in-dying* as our duty and as our statement to the world.

The Catholic Health Association of Canada strongly urges the *Senate Social Affairs Subcommittee to Update Of Life and Death* to recommend action that would complete the vision enunciated five years ago. The Catholic Health Association of Canada will gladly participate in any action that will make this vision a reality.

## Annotated Bibliography

CHA, CMA, CNA, CHAC, *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*, 1999.

The needs, values and preferences of the person receiving care should be the primary consideration in the provision of quality health care. The statement addresses those situations when disagreements arise between health care providers and persons receiving care.

CHA, CMA, CNA, CHAC, *Joint Statement on Resuscitative Interventions, Update, 1995*.

The joint statement is intended to provide guidance for the development of policies regarding appropriate use of cardiopulmonary resuscitation (CPR); CPR as a treatment option; competence; the treatment decision; its communication, implementation and review; and palliative care.

Chater, Susan, et al., "Sedation for Intractable distress in the dying – a survey of experts," *Palliative Medicine*: Vol. 12, pages 255-269.

A discussion of "terminal sedation," a phrase that appeared in palliative care literature in the past few years but with no clear definition or any agreement on the frequency with which the technique is used. The article discusses the results of a survey of 61 selected palliative care experts and it concludes that the term "terminal sedation" should be abandoned and replaced by "sedation of intractable distress in the dying."

Chochinov, Harvey Max, et al., "Desire for Death in the Terminally Ill," *American Journal of Psychiatry*, Vol. 152, no. 8, pages 1185-1191.

The study investigates the prevalence of the desire for death in terminally ill patients, the stability of this desire over time, and its association with psychiatric disorders. It concludes that the desire for death in terminally ill patients is closely associated with clinical depression - a potentially treatable condition - and can also decrease over time. Informed debate about euthanasia should recognize the importance of psychiatric considerations, as well as the inherent transience of many patients' expressed desire to die.

Chochinov, Harvey Max, et al., "Will to Live in the Terminally Ill," *The Lancet*, Vol. 354, September 4, 1999, pages 816-819.

Complex biomedical and psychosocial considerations figure prominently in the debate about euthanasia and assisted suicide. This study seeks to examine the extent to which a dying patient's "will to live" fluctuates as death approaches. Four main predictor variables of "will to live" were identified: depression, anxiety, shortness of breath and sense of well-being, with the prominence of these variables changing over time. The ability of clinicians and researchers to understand and track "will to live" as an outcome measure in this vulnerable population will no doubt lead to better palliative care for patients approaching death.

Ferris, Frank D., Cummings, Ina (editors) *Palliative Care: Towards a Consensus in Standardized Principles of Practice*, Canadian Palliative Care Association, 1995.

This working document is the first step in developing a consensus on the definition, philosophy and principles of palliative care or the principles of practice that are necessary to provide effective palliative care. The Canadian Palliative Care Association is currently in the process of finalizing these standards.

Latimer, Elizabeth, "Ethical Care at the End of Life," *Canadian Medical Association Journal*, Vol. 158, No. 13 (June 30, 1998) pages 1741-1747.

In treating dying patients, who by virtue of their physical and emotional situation are frail and vulnerable, physicians must meet a high standard of professional, ethical care. Such a standard is based upon a philosophy of care that recognizes the patients' inherent worth and uniqueness as human beings. The ethical physician will not act with the intention of bringing about the death of the patient, whether by ordering medication in excess of that required for symptom control, administering a lethal injection or any other means.

Latimer, Elizabeth, et al., "Towards the provision of effective palliative care in Ontario: Excerpts from the OMA Colloquium on Care of the Dying Patient," *Ontario Medical Review*, July/August, 1998, pages 22-28.

This article provides a summary of the resource guide for health care providers and communities in building an integrated approach to patient and family care.

Roche, James W. *Facing Death, Discovering Life*. Catholic Health Association of Canada, 2000, Ottawa.

This book explores the seeming paradox between facing death and discovering life. Facing death and entering into the anguish and suffering that accompany it can be an experience in discovering life. Death, that we will all live one day, is not an encounter with meaninglessness; it is a fulfilment of life. Facing death allows the dying person and their family to embark on a journey, one in which they will be taught more powerful lessons about life than about death.

Seely, John F. & Mount, Balfour M., "Palliative Medicine and Modern Technology," *Canadian Medical Association Journal*, Vol. 161, No. 9 (November 2, 1999) pages 1120-1121.

When a patient is dying, therapeutic impotence frequently leads to therapeutic excess. As a profession, physicians appear to assign disproportionate importance to technology and its practitioners, and thus may distance themselves from the patient. Attention must be given to those aspects of the patient that cannot be measured, irrespective of the clinical setting. The central goal of all medical practice includes improving quality of life and relieving suffering.