

Let's Talk about the Right to Hospice Palliative Care Instead

(October 19, 2009 - Winnipeg, Manitoba) After a five year battle with cancer, Robert was told he had three months to live. He and his wife were unsure what to expect, and their 23 year-old child had not yet accepted his father's impending death. They asked for advice from a neighbour who worked in hospice palliative care. Her first question was "What do you want your last month of life to look like?" No one had ever asked Robert that question so he found it hard to answer.

What would he want or need at the end of life? Would he suffer pain and need medication to manage his symptoms? Would he and his wife need help at home? What did he want to do with those days? What decisions would he have to make?

Like Robert, many Canadians are unsure what to expect at the end-of-life. This uncertainty often leads people to question how they want to die, and whether they should have more control over their dying. In our society, it can lead to a focus on controversial issues, such as euthanasia and physician assisted suicide.

The Canadian Hospice Palliative Care Association (CHPCA), the Canadian Society of Palliative Care Physicians and the Alzheimer Society of Canada believes it's time to refocus the debate on the right to have high quality hospice palliative care for all Canadians at the end of life.

What is high quality hospice palliative care? It is care that aims to relieve suffering and improve the quality of living and dying. It strives to help patients and families meet all their physical, psychological, social, spiritual and practical needs at the end of life, and cope with loss and grief. High quality hospice palliative care includes treatment for conditions that can be treated, care to prevent people from developing other health problems, and opportunities for meaning and spiritual growth.

High quality hospice palliative care can give people a greater sense of meaning and control over their lives. It helps people plan for end of life, and gives them choices about when and for how long they want treatment, medications, food or ventilator support. It recognizes that people have the right to refuse treatment and that loss of appetite is a normal stage in dying. Hospice palliative care also offers many ways to control and manage pain and other symptoms. It provides psychological and spiritual support to address the suffering of patients and their families.

The Quality End-of-Life Care Coalition of Canada (QELCCC) believes that all Canadians have a right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice.

We also believe that every health care provider should have basic competency in providing end-of-life care and that every health care institution should ensure quality at the end of life for all of those who will die in institutions. We believe that the option of staying at home as long as is possible, and perhaps dying at home as most Canadians

wish, needs to be supported with increased resources and specialized hospice palliative care resources.

Each year, more than 259,000 Canadians die[2] and, with our aging population, that number will grow. By 2026, 330,000 will die each year. By 2036, more than 425,000 will die.

Will all those Canadians receive high quality hospice palliative care? Right now, only 16% of Canadians who die have access to or receive hospice palliative, and quality end-of-life care services. Too many Canadians die with suffering that could be addressed in a more effective manner.

The Canadian Hospice Palliative Care Association (CHPCA) believes it is time to shift the focus to the right to high quality hospice palliative care at the end of life before we enter into the debate around the contentious issue of euthanasia and physician assisted suicide.

Please refer to the attached list of definitions should you wish clarification on various terms.

Join us for a discussion of hospice palliative care as a human right -- nationally and internationally -- at the closing plenary during the 2009 Canadian Hospice Palliative Care Conference, to be held in Winnipeg, Manitoba, October 18-21 2009.

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Lexicon of Commonly Used Terms

Advance Care Plan - Advance care planning is a process of reflection and communication in which a person who is capable, makes decisions about future health and personal care in the event that they become incapable of giving informed consent. It involves:

- Thinking about what gives life meaning
- Talking to health care providers, family and friends about future health care wishes
- Thinking about who a person would like to speak for them, when they cannot speak for themselves
- Recording goals and wishes

Advance Directive - a verbal or written statement of the person's future desires in the event that he or she should be unable to communicate his or her intentions in the future.

Allow Natural Death (AND) - "refers to decisions that can be made NOT to have any treatment or procedure that will only delay the moment of death and applies only where death is about to happen from natural causes"[1]

Caregiver - Anyone who provides care.[2]

Formal caregivers are members of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers. They are sometimes called "providers."

Informal caregivers are not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice. They may be family members or friends.

Do Not Resuscitate (DNR) - an order given by a patient or family, directing medical staff not to start CPR if a person's heart stops beating. It does not mean "do not treat." Until the point when the heart stops beating, aggressive medical interventions may still be used. This also is not a form of assisted dying; the definition is included here only for reference.

Family - Those closest to the patient in knowledge, care and affection. May include:

- the biological family
- the family of acquisition (related by marriage/contract)
- the family of choice and friends (including pets)

Health - "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."[3]

Hospice Palliative Care - Hospice Palliative care aims to relieve suffering and improve the quality of living and dying.[4]

Hospice palliative care strives to help patients and families:
address physical, psychological, social, spiritual and practical issues, and their associated

expectations, needs, hopes and fears prepare for and manage self-determined life closure and the dying process. Cope with loss and grief during the illness and bereavement. Hospice palliative care aims to: treat all active issues prevent new issues from occurring promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Pain - An individual, subjective, unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage, or both (Adapted from the International Association for the Study of Pain - see <http://www.iasp-pain.org/dict.html#RTFTtoC25>).[5]

Proxy - A person or agency of substitute recognized by law to act for, and in the best interest of the patient.

Quality of Life - "meaningful and valuable experiences" and "the capacity to have such experiences." [6]

Suffering - A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping.[7]

Total pain - Suffering related to, and the result of, the person's physical, psychological, social, spiritual, and practical state.[8]

[1]

<http://www.fraserhealth.ca/Services/HomeandCommunityCare/AdvanceCarePlanning/Pages/Definitions.aspx>

[2] Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

[3] World Health Organization (WHO) Definition of Health, <http://www.who.int/aboutwho/en/definition.html>.

[4] Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

[5] Ibid.

[6] Ibid.

[7] Ibid.

[8] Ibid.