

## LET'S TALK ABOUT HOSPICE PALLIATIVE CARE FIRST



DECISIONS









Canadian Hospice Palliative Care Association Association canadienne de soins palliatifs

## LET'S TALK ABOUT HOSPICE PALLIATIVE CARE FIRST



For more information on hospice palliative care, please visit www.chpca.net

### Let's talk about dying in Canada...

What will I want or need at the end of life?

Will I suffer pain and need medication to manage my symptoms?

How can I let my family and friends know my wishes and preferences for end of life care?

What help is available to me?

If I am ill, will I be a burden to others?

What decisions will I have to make?

Many Canadians find themselves asking these questions as they near end of life. They are unsure what to expect, leading them to ask how they want to die, and whether they should have more control over their dying. Recently, this has led to a focus on controversial issues, such as euthanasia and physician assisted suicide rather than a focus on accessible and quality end of life care.

The Canadian Hospice Palliative Care Association (CHPCA) believes it's time focus on the right to high quality hospice palliative care for all Canadians at the end of life.

We need to talk about hospice palliative care first.



Hospice Palliative Care strives to help patients and families cope with end of life issues with dignity and compassion.



For more information on hospice palliative care, please visit www.chpca.net

# Q & A

#### 1. What is hospice palliative care?

Hospice palliative care aims to relieve suffering and improve the quality of living and dying. It strives to help patients and families:

- deal with important physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears as these occur;
- promote opportunities for meaningful experiences and personal and spiritual growth as they prepare for dying and death; and
- cope with loss and grief.

Hospice palliative care is appropriate for any patient and/or family living with a progressive life-threatening illness due to any diagnosis, with any prognosis, regardless of age. It may co-exist with and enhance therapy of the disease or it may become the total focus of care.

Hospice palliative care is most effectively delivered by a team of skilled healthcare providers who are both knowledgeable and skilled in all aspects of hospice palliative care.

# Euthanasia, physician assisted dying or assisted suicide are not considered a part of the practice of hospice palliative care.<sup>i</sup>

#### 2. What is advance care planning?

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;
- Learning about medical procedures that can be offered at the end of life;
- Talking to health care providers, family and friends about future health care wishes; (cont'd on next page)





Hospice palliative care is most effectively delivered by an interdisciplinary team of healthcare providers.

- Choosing a person would like to speak for them, when they cannot speak for themselves; and
- Recording goals and wishes.

Advance Directive – advance care planning may result in preparing an advance directive, which is 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. Provinces and territories have their own legislation regarding the preparation of advance directives.

For more information on either of these tools and for more on the CHPCA's *Speak Up: Start the conversation about end-of-life care* campaign, please go to **www.advancecareplanning.ca**.

#### 3. What is physician assisted death or euthanasia?

**Euthanasia** – Ending the patient's life on request. It is defined as a doctor intentionally ending a person's life through the administration of specific drugs, at the person's voluntary and competent request.

Assistance in suicide – Knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.

**Physician Assisted Dying** – A doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request.



Advance care planning is a process of reflection and communication.

#### 4. What leads a patient to ask for assisted suicide?

Hospice palliative care providers have observed – and these observations are confirmed by research evidence<sup>iiii</sup>, – that the desire for euthanasia or physician-assisted suicide usually stems from one or more of the following factors:

- a desire not to be a burden on others;
- the individual's need for control over the illness and his or her body/life, his/her autonomy;
- depression and psychological distress often associated with illness;
- fear of pain and suffering that may accompany terminal illnesses.

Comprehensive hospice palliative care can help alleviate many of the factors that may cause people to consider physician assisted suicide, particularly the burden on loved ones, depression and pain and symptom management.

#### 5. What can you do?

Whether you are an individual wanting to advocate for your personal or familial needs, a professional, or an organization, here are some ways you can get involved!

- Write a letter to the editor, your MP, or your MLA.
- Speak to your health care professional, your local health authority or your hospital.
- Print out some of our downloadable materials and post them in your office.
- Find out what services are available in your community.

You can familiarize yourself further with the current situation and key messages by going to **www.chpca.net/hpcfirst**. Together we can ensure that all Canadians have access to high quality end-of-life care.





FACTS about Access to Hospice Palliative Care in Canada

Only 16% to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services – regardless of where they live in Canada.<sup>iv</sup> Even fewer receive grief and bereavement services.

The 2005 Senate Report *Still Not There: Quality End-of-Life Care: A Progress Report*, reported that despite a number of significant advancements at the federal level in palliative and end-of-life care since 2000, significant disparities across Canada remained with respect to access to end-of-life care, quality of care and out-of-pocket costs to the patient.

When asked, most people have indicated that they would prefer to die at home in the presence of loved ones<sup>v</sup>, yet almost 70% of Canadian deaths occur in a hospital.

#### END NOTES:

<sup>1</sup>Canadian Hospice Palliative Care Association, A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Canada: 2002.

<sup>iii</sup> 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.

<sup>III</sup> Allard P, Chary S, Chochinov HM, Clinch JJ, De Luca M, Fainsinger R, Gagnon PR, Karam AM, Kuhl D, Macmillan K, McPherson CJ, O'Shea F, Skirko MG, Wilson KG. Desire for Euthanasia or Physician-Assisted Suicide in Palliative Cancer Care. Health Psychology, Vol. 26, No. 3, 314–323.

<sup>iv</sup> Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada*, Ottawa, CIHI, 2007.

<sup>v</sup>Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada*, Ottawa, CIHI, 2007, p. 22.

© 2012, Canadian Hospice Palliative Care Association www.chpca.net, info@chpca.net toll free: 1-800-668-2785 Charitable business number: 13760 4195 RR0001

