



## Materials for Health Care Professionals

### FAQs

For many health care professionals in primary care or specialty care it is difficult to raise the topic of hospice palliative care with patients and their caregivers. Yet research shows that for those patients who've been diagnosed with a life-limiting illness, hospice palliative care can help. Indeed, an overall palliative approach to care can be beneficial. We hope this fact sheet helps you to start the conversation, and distinguish between *palliative care*<sup>1</sup> (also referred to as 'hospice palliative care') and the *palliative approach* to care.

#### 1. What is palliative care?

Palliative care, sometimes known as hospice palliative care, is care that aims to relieve suffering, while improving the quality of living and dying. Many health care professionals think of palliative care<sup>2</sup> as only applying to end-of-life, but we consider it a broader term that includes improving the quality of life until the end-of-life.



Philippa H. Hawley, "The Bow Tie Model of 21st Century Palliative Care," *Journal of Pain and Symptom Management* 47, no. 1 (January 2014): 2-5.

<sup>1</sup> Hospice palliative care is the accepted phrase used by the hospice palliative care community. However, we recognize that many health care professionals distinguish hospice from palliative. For simplicity, we will use the phrase "palliative care" in this document to mean "improving the quality of life until the end of life."

<sup>2</sup> See footnote 1



## 2. How is the palliative approach to care different from palliative care?

Medical advances, and the different trajectories of chronic diseases and aging, make it difficult to predict when people will die. Patients who are aging or frail, or those with serious illnesses, such as heart, lung, Alzheimer's or Parkinson's disease, can live for many months or years – and then die suddenly. Many people with serious life-limiting illnesses are never offered palliative care services such as advance care planning, pain and symptom management, psychosocial counseling and spiritual support because they are not designated as 'dying' or within the last months or weeks of life. The palliative approach to care means offering these services to patients early in the course of a disease (i.e. soon after diagnosis) and throughout the person's illness trajectory.

### a. What are the basic principles of the palliative approach to care?

- The goal is to lessen suffering, loneliness and grief for those living with chronic and life-limiting illnesses.
- A palliative approach to care is part of providing comprehensive primary care and can be augmented, if required, by palliative care professionals.
- The palliative approach to care should be available in all settings of care (home care, long-term care, primary care, in hospitals) and should include access to specialized palliative care teams when necessary.
- The palliative approach to care should be part of the skills and competencies of all health care practitioners, who care for patients with serious life limiting illnesses.

## 3. Won't raising the topic of palliative care rob my patients of hope?

A patient does not have to be designated 'palliative' to benefit from palliative care. You can start a discussion about protecting their quality of life as long as possible, which could include clinical interventions but also means understanding what's important to that patient. Findings published in *The New England Journal of Medicine* shed new light on the effects of this approach. Patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis not only were happier, more mobile and in less pain as the end neared – but they also lived nearly three months longer. Palliative care can enhance the lives of individuals and their caregivers, give them a greater sense of control and enable them to make informed decisions. In addition, in Canada some disease-oriented treatments can still be offered alongside palliative care.

## 4. Since the health care system has established methods of determining if a patient would benefit from palliative care, how does the palliative approach to care relate to the care I provide?

The palliative approach to care means offering service to patients early in the course of a disease (i.e. soon after diagnosis) and throughout the person's illness trajectory. It recognizes that although we have treatments for many life-limiting illnesses, a cure isn't always possible. With illness progression, what people need and want changes—a palliative approach to care is one that focuses on an individual's need at any given point in time. It can be provided in a hospital, residential hospice, at home, in long-term care homes or in another community setting. The patient's personal values, wishes and desires should be considered along with the choices for medical treatments or interventions. Advance care planning, a discussion about individual care plans, is an important part of a palliative approach to care as it can help determine a person's values and wishes, and how these change over time.

## 5. What is advance care planning?

Advance care planning is a process of reflection and communication, a time for individuals to reflect on their values and wishes, and to let others know their future health and personal care preferences in the event that they become incapable of consenting to or refusing treatment or other care.

- Advance care planning means having a discussion with family and friends, especially with a Substitute Decision Maker – the person who will speak for the sick or ill person when that person cannot speak for themselves.
- It could also include writing down wishes, and may even involve talking with healthcare providers and financial and legal professionals.
- Advance care planning is appropriate for all individuals regardless of their health status including those who are not ill.
- A discussion about advance care planning can be started by a healthcare professional with encouragement for the person to think about what's important to them.
- You can also visit <http://advancecareplanning.ca/> for more information.



**6. Is raising the subject of advance care planning with patients really that important?**

Ask yourself this question when wondering if you should raise advance care planning with a patient: *Would you be surprised if this patient died within 6-12 months?* If you answered yes, then raising the subject with patient is really that important. Consider this:

- Canadians who do have an advance care plan are more engaged in the health care system – 90% of them have a family physician or regular place of care.
- About six in ten Canadians believe that it's extremely important to talk to someone about their end-of-life care preferences – but only 45% have done so.<sup>4</sup>
- Canadians overwhelmingly want their health care provider to give them information about advance care planning.

<sup>4</sup>2013 Harris/Decima poll

**7. OK, I understand that discussing advance care planning with my patients is important ... any ideas on how to begin?**

First, it's a good idea to introduce the topic of advance care planning to all patients over 50 years of age and to those diagnosed with a chronic or life-limiting illness. You may also want to provide your patients with a workbook/tool to help them work through their values and wishes and to decide on their Substitute Decision maker. (You can find workbooks at <http://advancecareplanning.ca/>). You may also suggest a second appointment to discuss this in more detail. You can ask your patient to bring their Substitute Decision Maker to that appointment. It's important to allow time for your patient to reflect and have conversations with their loved ones at home. You can help them learn about the health issues and possible treatments/interventions that they can consider. And here are a few ideas to help you start the conversation:

- You are well now, but it is good to plan for the future. What if you suddenly became ill or had an accident – and couldn't speak for yourself?
- The best time to think about advance care planning is when you are well and are able to make decisions in a calm state of mind.
- If you were to get very sick and could not speak for yourself, who would you trust to make medical decisions for you?
- I'd like to talk to you about your wishes for care in case you get very sick. That might not happen, but if it does and you can't communicate, it would be important to know who would speak for you and about your wishes for care.
- Advance care planning is similar to writing your will. It is good to be prepared and let your wishes be known.
- I want to give you the best care possible. Talking about your wishes will help me do that.

**8. Really, what difference will a palliative approach to care make?**

The palliative approach to care means that patients can make informed decisions about their own care, including managing pain and symptoms. Through important conversations and planning that the palliative approach to care encourages, patients can be more engaged and have a better quality of life and caregivers will better understand their goals for care.

**9. What next?**

If you would like more information about hospice palliative care services in your area, or help in starting a conversation about hospice palliative care, please visit [www.chpca.ca](http://www.chpca.ca). The website for the Canadian Hospice Palliative Care Association offers valuable resources and links.