

## It's up to us to begin the conversation

**A**dvance care planning is a communication process between the patient, his or her family, and health care providers to determine preferences for care should the patient become incapable of making health care decisions. In a 2004 Ipsos-Reid survey, 49% of respondents felt it was important for them to discuss end-of-life care with their physicians, but only 9% said they had actually done that.<sup>1</sup> A 2001 study of patients with chronic illness showed that the greatest predictor of patient satisfaction with their office visit was having a discussion of preferences for their care.<sup>2</sup> It seems it is up to physicians to begin this dialogue.

However, these conversations often have underlying assumptions that we rarely discuss with patients. For example, an older woman I saw during a palliative care consult still had a nasogastric feeding tube inserted despite the recurrence of her pancreatic tumor 2 months after surgery. When she expressed exasperation and discomfort with the tube I asked her why she was putting up with it. "When I saw the surgeon I committed to having the surgery and having aggressive treatment. So here I am," she said. Making her aware of her ability to stop or withdraw from treatment resulted in immediate removal of the tube, and a patient who now understands that she does have some control over what happens to her.

Many older adults, and patients from more traditional cultures, are not aware of their "abilities" as a patient in Canada. Abilities such as:

- Having as much information about their care and being involved in decision-making to the extent that they desire.
- Determining who has information about their condition.

- Refusing treatment—even if suggested by the physician.
- Withdrawing from treatment even if they had previously agreed to it.
- Complaining or speaking their mind without fear of reprisal or compromise of care.
- The right to have all efforts made to control symptoms and relieve suffering—physical, psychosocial, or spiritual—throughout their disease.

In a study published in 2000,<sup>3</sup> researchers interviewed 728 patients with chronic disease who were attending an outpatient medical clinic. Only 69% knew it was their right to refuse treatment, and just 46% were aware that they were able to withdraw from a treatment once it was started. While the level of the patient's education or being a decision-maker for another patient correlated with having greater knowledge on this topic, having an advance directive did not. Another study of 214 patients with advanced cancer, COPD, and CHF were surveyed along with their attending physician to determine if a discussion about prognosis and survival had occurred. In 46% of the cases the clinician said the conversation had occurred while the patient said it had not.<sup>4</sup> Only 20% of the time did both agree that the conversation had occurred.

So how can physicians educate their patient as well as determine their treatment preference? Just by beginning the conversation you indicate its importance and your willingness to listen. There are a few key phrases that help you do both.

As an opening statement: *I'd like to be able to respect your decisions about treatment even if you were unable to tell me. Can we take some time to discuss this?*

If they agree ask them: *Are you the kind of person who likes to know all*

*the details about your illness or not? Or how much information would you like to know about your illness?*

If they do not wish to know any details, ask: *Who can I share this information with? Who would you like involved in decision-making?*

If they wish to have limited or full information about their illness, then it is best to begin by asking: *Can you tell me what you understand about your illness?*

When you understand their view of the illness, fill in the information gaps using similar words and phrases to those used by the patient. Understanding the illness from the patient's perspective is key to understanding their preference for care.

Discuss the person's goals for treatment: *What do you hope for in the future? What would be a good outcome for you? What is important to you right now in your life?*

You may also ask about fears and concerns: *What are your concerns or fears about the future or about your medical care?*

Assure them of ongoing care throughout their illness as many people mistake a DNAR decision as no treatment as well as no resuscitation: *No matter how we decide to treat your illness we will always work hard to keep you comfortable and support you.*

At the end of the discussion ensure all involved know that the decisions can be discussed again any time.

Using key phrases and steps in the discussion should teach your patient what their "abilities" are as a patient, prevent common communication errors, and make them feel truly cared for.

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4. Fried T, Bradley E, O'Leary J. J Am Geriatrics Soc 2003 Oct;51(10):1398-1403.

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care. STI Clinic staff at the BC Centre for Disease Control follow up on all positive syphilis test results and are available by telephone at 604 660-6161 to answer questions regarding the interpretation of syphilis serology results and further management of infectious syphilis cases in pregnancy.

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**Further reading**

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- BC Centre for Disease Control British Columbia Treatment Guidelines: Sexually Transmitted Infections in Adolescents and Adults 2007. [www.bccdc.org/division.php?item=3#Reports](http://www.bccdc.org/division.php?item=3#Reports) (accessed 20 December 2007).

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