More Candor Urged In Care Of Dying Cancer Patients

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WASHINGTON (AP) — Patients don't want to hear that they're dying and doctors don't want to tell them. But new guidance for the nation's cancer specialists says they should be upfront and do it far sooner.

The American Society of Clinical Oncology says too often, patients aren't told about options like comfort care or even that their chemo has become futile until the bitter end.

To help families broach the topic, too, the group developed an easy-to-read booklet about those choices, from standard care to symptom relief, and advice about what to ask to maximize remaining time.

"This is not a 15-minute conversation, and it should not happen in the back of the ambulance on the way to the ICU at 3 in the morning," says ASCO chief executive Dr. Allen Lichter. "When everyone is well and has their wits about them, it's time to start the process."

The guidance and booklet — available at http://www.cancer.net [1] — mark an unusually strong push for planning end-of-life care, in a profession that earns more from attacking tumors than from lengthy, emotional discussions about when it's time to stop.

"This is a clarion call for oncologists . to take the lead in curtailing the use of ineffective therapy and ensuring a focus on palliative care and relief of symptoms throughout the course of illness," the guidance stresses.

But it's part of a slowly growing movement to deal with a subject so taboo that Congress' attempt to give such planning a nudge in 2009 degenerated into charges of "death panels."

Now consider a program in Pittsburgh named Closure. In so-called "community conversations," the program teaches families how to talk with each other and their doctors about what they want — and want to avoid — in their final days. Created by the Jewish Healthcare Foundation, sessions have spread to hospitals, religious centers and neighborhoods around the city, and a website opened last month at http://www.closure.org [2].

The sessions are frank. Doctors tell of entering hospital rooms late at night asking for resuscitation preferences should a very ill patient worsen only to find relatives

didn't know their loved one was that sick.

"There is going to be, over the next few years, a groundswell of people telling physicians, 'I don't want to go out in excruciating pain, short of breath, alone, surrounded by lights and sirens and people pounding on my chest,'" predicts Dr. Jonathan Weinkle, a primary care physician who advises the program.

"Everybody wants a good death but not a moment too soon, but they don't have the language to ask for it."

Closure participant Pearl Moore, a retired Pittsburgh oncology nurse, urges people to start planning before they're ever sick, when it's easier to discuss.

Moore's mother died of stomach cancer without health workers or family ever discussing the inevitable. Haunted, she returned to college to specialize in cancer nursing. She helped her patients discuss quality of life, "to be able to live until they died, is the way I put it," Moore says.

And years ago she prepared her own living will and other health care directives, giving copies to her daughter, Cheryl, as soon as she was grown.

"Remembering my mother, we had the discussion," says Moore.

It's not clear how often the still healthy like Moore do that kind of advance planning.

But the oncology society says it isn't happening enough with the very sick. Fewer than 40 percent of advanced cancer patients have what it calls a "realistic conversation" with their doctors about what to expect and their choices of care.

The consequences: Patients increasingly are receiving aggressive chemotherapy in the last two weeks of life. They're spending more of their last months hospitalized. They're not told that a lot of expensive, side effect-prone therapies buy at best a few more months.

They think palliative care — specialized care for pain, nausea, shortness of breath — means giving up when it should be offered with standard anti-tumor care.

And they're not referred to hospice until their final days. Lichter tells of a lung cancer patient who spent his last days on a ventilator, unable to say goodbye and incurring $25,000 in hospital bills, because his family called 911 when he became short of breath. Hospice care could have eased that symptom at home.

The society plans by summer to issue detailed guidelines to help doctors conduct those tough conversations. Meanwhile, among its advice for patients:

—Ask your doctor about pros and cons of different treatment options, and discuss your priorities, including quality of life, with the doctor and family. You can change your mind later.

—Ask about palliative care for symptom relief along with your chemo. A major study last summer found that combination helped advanced lung cancer patients live a few months longer, because people who feel better can tolerate more anti-cancer treatment.

—A living will ensures health workers and family know your choices when you cannot communicate, including whether you would want such things as a feeding tube.

—Most clinical trials for experimental treatments won't admit people who've already undergone multiple treatments, so consider that option early.

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