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New guidelines urge doctors to start end-of-life discussions sooner

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"One of the worst things you can hear as an oncologist is when someone says, 'I wish I had known I could die so soon,' " says Dr. Robert J. Green.

So Green, with the Palm Beach Cancer Institute, works hard to have "the talk" reviewing how the patient wants to live at the closing of his or her life.

Statistics indicate that nationally, only 40 percent of cancer patients recall having that conversation.

Also, fewer than 45 percent of cancer patients enroll in hospice, and of those who do, about a third arrive in the last week of their lives.

Thus the quality of many patients' lives suffers inexcusably, as does their health, according to the American Society of Clinical Oncology.

In January, the group issued a new policy statement urging physicians to initiate "candid discussions about the full range of palliative care and treatment options soon after patients' diagnosis with advanced cancer," defined as incurable disease.

"At 3 a.m. in the back of the ambulance on the way to the intensive care unit is not the time to ask Mr. Jones what would you like for care should your condition deteriorate very quickly," said Dr. Allen Lichter, chief executive of ASCO.

The society has posted a patient guide to end-of-life discussions on its website. The group intends to issue more detailed guidelines for physicians this summer.

But a variety of factors stymie what is often the most difficult conversation a physician can have with a patient.

When attorneys have an end-of-life planning discussion with their clients, they bill for the hour and most clients are happy to pay for it, Lichter said.

But when it is suggested that physicians be required to have the conversation and be reimbursed for it, it's often deemed "inappropriate" at best and devolves into debates about "death panels," he said.

Even when the conversations take place, not everyone hears the same thing, says Mary Jean Houlahan, a nurse whose job it is to sit in on those chats as the oncology patient navigator at Good Samaritan Medical Center in West Palm Beach.

"Sometimes they don't hear everything the doctor intended them to hear," she said. "Sometimes it's hard to comprehend all the nuances and hospital-speak."

That's where Houlahan's role is vital. She continues to check in with the patient and family, and fields follow-up

questions they may be afraid to ask the doctor.

"Having someone that's outside this very intense patient-oncologist relationship who can be objective and trained in these areas can be quite beneficial," Lichter said.

Houlahan's job is not unique, but it's not common at for-profit hospitals, she said.

Houlahan says she welcomes ASCO's push to put this discussion in the public eye and demand doctors do more.

"This statement gives permission to have this conversation from the medical side," she said. "It also addresses tacitly the humanity of doctors. It says we're addressing your humanity when we talk about these issues. We're behind you."

That may be necessary for a field that does not typically get training on how to have these discussions.

"It's a big problem that traditionally there has not been formal training," said the Palm Beach Cancer Institute's Green, who completed his oncology fellowship in 1999.

"I think I do a very good job at this," he said. "I also think I'm much better than I was 10 years ago, and it didn't have to be that way."

One thing doctors must learn is how to address so many patients who perceive palliative care or hospice care as giving up, Green and others agree.

Some don't realize palliative care, which addresses making a patient comfortable, can occur alongside aggressive treatment. And even end-of-life hospice care isn't about giving up.

Lichter points to an ASCO-sponsored trial that showed advanced lung cancer patients who received chemotherapy and palliative care immediately after diagnosis lived nearly three months longer than those treated with chemotherapy alone.

"People need to know not to be afraid of talking about it," Houlahan said . "I have never, ever, ever had a family say to me we did this too soon. I have had families say I wish we did this sooner."

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