

Most cancer doctors avoid saying it's the end

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One look at Eileen Mulligan lying soberly on the exam table and Dr. John Marshall knew the time for the Big Talk had arrived.

He began gently. The chemotherapy is not helping. The cancer is advanced. There are no good options left to try. It would be good to look into hospice care.

"At first I was really shocked. But after, I thought it was a really good way of handling a situation like that," said Mulligan, who now is making a "bucket list" — things to do before she dies. Top priority: getting her busy sons to come for a weekend at her Washington, D.C., home.

Many people do not get such straight talk from doctors, who often think they are doing patients a favor by keeping hope alive.

New research shows they are wrong.

Only one-third of terminally ill cancer patients in a new, federally funded study said their doctors had discussed end-of-life care.

Surprisingly, patients who had these talks were no more likely to become depressed than those who did not, the study found. They were less likely to spend their final days in hospitals, tethered to machines. They avoided costly, futile care. And their loved ones were more at peace after they died.

Convinced of such benefits and that patients have a right to know, the California Assembly just passed a bill to require that health care providers give complete answers to dying patients who ask about their options. The bill now goes to the state Senate.

Some doctors' groups are fighting the bill, saying it interferes with medical practice. But at an American Society of Clinical Oncology conference in Chicago earlier this month, where the federally funded study was presented, the society's president said she was upset at its finding that most doctors were not having honest talks.

"That is distressing if it's true. It says we have a lot of homework to do," said Dr. Nancy Davidson, a cancer specialist at Johns Hopkins University in Baltimore.

Doctors mistakenly fear that frank conversations will harm patients, said Barbara Coombs Lee, president of the advocacy group Compassionate Choices.

"Boiled down, it's 'Talking about dying will kill you,'" she said. In reality, "people crave these conversations, because without a full and candid discussion of what they're up against and what their options are, they feel abandoned and forlorn, as though they have to face this alone. No one is willing to talk about it."

The new study is the first to look at what happens to patients if they are or are not asked what kind of care they'd like to receive if they were dying, said lead researcher Dr. Alexi Wright of the Dana-Farber Cancer Institute in Boston.

It involved 603 people in Massachusetts, New Hampshire, Connecticut and Texas. All had failed chemotherapy for advanced cancer and had life expectancies of less than a year. They were interviewed at the start of the study and are being followed until their deaths. Records were used to document their care.

Of the 323 who have died so far, those who had end-of-life talks were three times less likely to spend their final week in intensive care, four times less likely to be on breathing machines, and six times less likely to be resuscitated.

About 7 percent of all patients in the study developed depression. Feeling nervous or worried was no more common among those who had end-of-life talks than those who did not.

That rings true, said Marshall, who is Mulligan's doctor at Georgetown University's Lombardi Comprehensive Cancer Center. Patients often are relieved, and can plan for a "good death" and make decisions, such as do-not-resuscitate orders.

"It's sad, and it's not good news, but you can see the tension begin to fall" as soon as the patient and the family come to grips with a situation they may have suspected but were afraid to bring up, he said.

From an ethics point of view, "it's easy — patients ought to know," said Dr. Anthony Lee Back of the Fred Hutchinson Cancer Center in Seattle. "Talking about prognosis is where the rubber meets the road. It's a make-or-break moment — you earn that trust or you blow it," he told doctors at a training session at the cancer conference on how to break bad news.

People react differently, though, said Dr. James Vredenburg, a brain tumor specialist at Duke University.

"There are patients who want to talk about death and dying when I first meet them, before I ever treat them. There's other people who never will talk about it," he said.

"Most patients know in their heart" that the situation is grim, "but people have an amazing capacity to deny or just keep fighting. For a majority of patients it's a relief to know and to just be able to talk about it," he said.

Sometimes it's doctors who have trouble accepting that the end is near, or think they've failed the patient unless they keep trying to beat the disease, said Dr. Otis Brawley, chief medical officer at the American Cancer Society.

"I had seven patients die in one week once," Brawley said. "I actually had some personal regrets in some patients where I did not stop treatment and in retrospect, I think I should have."

James Rogers, 67 of Durham, N.C., wants no such regrets. Diagnosed with advanced lung cancer last October, he had only one question for the doctor who recommended treatment.

"I said 'Can you get rid of it?' She said 'no,'" and he decided to simply enjoy his final days with the help of the hospice staff at Duke.

"I like being told what my health condition is. I don't like beating around the bush," he said. "We all have to die. I've had a very good life. Death is not something that was fearful to me."