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Web Exclusive: What Is a "Good Death?"

BY KATHY LATOUR

Elizabeth Paulk, MD, director of the Palliative Care Clinic at Parkland Hospital in Dallas, and Eugene Perlov, MD, a hospice physician with Visiting Nurse Service of New York, both spend their days caring for those who are facing death. In her role, Paulk works with patients who come into the hospital before ultimately transitioning to home care for those who have chosen to die at home to physicians such as Perlov, who care for the patients through hospice at home until their death or re-hospitalization.

Paulk, who began the first palliative care clinic in Texas at Parkland Hospital in 1999, says she was moved to begin working with dying patients during her internal medicine residency when a good friend died without knowing what was happening to her.

“Then I had a patient, a young woman with metastatic breast cancer who was actively dying,” Paulk says. “No one had ever taught me how to provide comfort driven medical care for a dying patient. Instead, I did what I had learned in the intensive care unit, like suctioning, breathing treatments and x-rays. I was doing all these things to try and treat her instead of making her feel better with some morphine and treatment for anxiety. I went back a few hours later and she was dead and I knew I had not done right by her.”

In response, Paulk decided there needed to be a clinic and inpatient consult service for those patients who were living with terminal illness and to teach young doctors all the things she wished someone had taught her. Today the clinic has three doctors and sees between 500 and 600 patients a year.

Perlov is one of seven doctors in the Visiting Nurses program, which served more than 3,000 patients in 2008. Perlov visits two to five patients a day who are debilitated to various degrees by advanced illness.

Paulk and Perlov agree that a good death is defined by each individual—the death that the patient wants.

“I let the patient be the expert,” Perlov says. “They will tell you what they want, and listening is what I do to help them achieve their goal. This may be the first time the family hears those wishes, and the dialogue starts, allowing them to express their feelings.”

Perlov recalls a time when he attempted to talk to a patient, who was focused on a cure, about the possibility that he was dying, only to have the family get angry. “Our job is to support patients and family as much as possible through a very difficult time. Many don’t want to talk about death or dying,” Perlov says. “That is

their choice.”

Both physicians rely on building relationships with their patients so they will feel comfortable expressing their feelings and needs. Paulk says if a patient is referred to her, she will begin by asking the patient to tell her about who they are.

“They tell me what is most important. If it’s a mother, she tells me about her children. Or someone says, ‘I have lived a good life and I am tired.’ So, what the patient tells you about is important, and it’s where you start the conversation.”

From there, Paulk tries to determine the patient’s goals for their death, and if that means treatment until they die, then Paulk honors that. She will try to encourage communication between the patient and oncologist when she feels the patient does not understand what is happening.

“I frequently see between the patient and the oncologist a collusion of hope,” Paulk says. “Both want desperately to please the other.” Paulk says this collusion results in the oncologist wanting to make the patient happy by offering some treatment and not giving bad news, while the patient wants to make the oncologist happy by getting better and staying positive—and neither wants to betray this agreement.

“Even if the oncologist thinks hospice is appropriate, they don’t want to discourage the patient by bringing it up,” Paulk says. Often the patient can help the oncologist by telling him or her what their goals are and giving them some language to let them know when death is approaching such as asking if they will make it to a graduation or holiday, she says.

The patient must tell the oncologist they want clear language and they have to know what they want. If they want to know they have two weeks left, they need to communicate to the oncologist how they want that information given.

“If they have two months left, they may want to stop treatment and go to Tahiti,” she says.

But Paulk says another clear message she gives her patients is to “do it now.” Whatever it is they want to do, go now and don’t wait until you are sick, she says. “Why wait?” Paulk asks. “And if you have someone you love who has been a good friend to you, then call them now. I tell them that I can’t even guarantee [the] sun will come up tomorrow.”

In the home, Perlov often deals with patients as they begin actively dying, and he works to keep them comfortable and at ease. For example, Perlov says the No. 1 cause of agitation in someone who is dying is a full bladder.

“Agitation can also be emotional if there is anger, guilt, or fear,” says Perlov, who also helps the family understand the stages of dying, and that it is not unusual for someone close to death to wake and begin talking quite clearly.

Paulk says one of the most challenging things in treating Judy Abernathy was her terror of being out of control or feeling foggy from pain medication.

“She wasn’t willing to ride it out and get used to it. It cut her off from a lot of options to give her a better quality of life,” Paulk says, adding that she can’t argue with what Abernathy did, but she would have liked her to be more patient with it.

“But in the end it was most important that she did things the way she wanted. It was important to her to feel in control and it was hard to watch that, knowing I could fix the problem but she wouldn’t let me. She lived her life the way she wanted and died the way she wanted, so I can’t argue with her choices.”

Paulk says her recommendations for those who are ready to think about dying include:

- 1. What are your goals? Talk to your family about what you want, and identify the person who should talk for you.
- 2. Tell your family how you feel about life.
- 3. Talk to your doctor, even if you are early in your illness. Tell them what you want.
- 4. Think about what you want to accomplish and what your goals are for treatment. For instance: “I want to live as long as I can. I want to do anything I can that will help but if we run out of options, I want you to tell me.”
- 5. Keep that communication open. If your goals are not being met, ask for a referral to another doctor or a palliative care specialist.