### THE REST OF YOUR LIFE

# Going Beyond the Disease

eath is not often discussed among physicians, but after Dr. Pauline W. Chen's critically acclaimed book, "Final Exam: A Surgeon's Reflections on Mortality," (New York: Knopf, 2007) hit bookstores, many physicians approached her, eager to share their own stories about caring for patients at the end of life.

Many said they felt the same way, commented Dr. Chen, a transplant surgeon who lives near Boston.

The book chronicles her transformation came preoccupied with her aunt's physical from a student taught to depersonalize death to a transplant surgeon who must be emotionally present for patients and their families during the end of life. "I'm not an end-of-life care expert, but I hope that being open about my experience helps."

In one chapter, she recalls the challenges of her Aunt Grace's kidney failure. She knew what to expect and was the person relatives turned to with questions. But she bestatus and transplant candidacy and forgot about her as a person.

Three weeks before Aunt Grace died, she called her niece on the phone. Part of the conversation involved Dr. Chen's request to include her aunt's story in an article she was writing. Aunt Grace granted permission but insisted the article mention the care and support that Dr. Chen's uncle and cousin had provided her. "They have been here for me always," Aunt Grace told her. "I owe everything to them."

That brief conversation reminded Dr. Chen of the importance of caring for the person beyond the symptoms and illness.

Despite the growing popularity of palliative medicine and hospice care, Dr. Chen said that some physicians equate patients' deaths with failure. "The metaphor for a surgeon is that you've actually got your hand in there affecting the cure. When those deaths occur, it can be devastating ... because you form relationships with your patients [and] you feel like you failed them and [your] profession.'

That sense of responsibility "can hamper our future ability to care for people and for ourselves," she said. "We worsen the situ-



After the death of her aunt, Dr. Pauline W. Chen began contemplating the importance of end-of-life care.

ation by not doing the little bit that we can, which is discussing [end-of-life care] with our patients and among ourselves. By talking about it—by being present for our patients—we can fulfill the ideals that brought us to medicine in the first place."

#### Overwhelmed by Gratitude

When San Diego-area physicians feel isolated after a patient's death, many speak with Dr. Charles F. von Gunten, a consultant in hospice and palliative medicine.

"For most doctors, caring for a dying patient is very lonely, because all the other consultants go away," said Dr. von Gunten, medical director of the Center for Palliative Studies at San Diego Hospice and Palliative Care. "If I agree they have done everything that can be done and are doing a good job, [it] helps them cope.

Such support marks one benefit of expanding palliative care and hospice programs, but medicine has yet to devote adequate training to coping with death, said Dr. von Gunten, who also is editor in chief of the Journal of Palliative Medicine. The message from the medical culture is, 'You should have no feelings about death.' [Medical training] teaches that doctors are not supposed to be upset by this.'

As an oncology fellow, Dr. von Gunten was rattled when his first patient died. He remembered what he'd learned: Send a Continued on following page

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sympathy note and attend the funeral of patients with whom you are close.

When Dr. von Gunten arrived at the funeral of one of his patients, the man's family expressed unexpected gratitude. "I couldn't make sense of how grateful the family was. With more maturity, I realized they were expressing gratitude for the sense that I had cared as a doctor, even though he didn't recover; and cared enough to stick



Unfortunately, "the message  $\dots$  is, 'You should have no feelings about death," said Dr. Charles F. von Gunten.

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with him and go to the funeral."

Recently, a retired physician Dr. von Gunten had been caring for died. He sent a note to the man's daughters, who asked him to be a pallbearer. "It was their way of saying, 'You were important to him. You're an important part of our family in the doctor role.' It reaffirmed why I wanted to be a doctor. It was a very special day," he said.

#### No One Is Immune

When two patients of Dr. Robert S. McKelvey committed suicide during his psychiatry residency in the 1970s, he was so devastated he considered leaving the field.

"I took it that I wasn't doing a good

enough job or that I wasn't cut out to be a psychiatrist," recalled Dr. McKelvey, now director of the division of child and adolescent psychiatry at Oregon Health and Science University, Portland.

Physicians' reactions to death vary, said Dr. McKelvey, author of "When a Child Dies: How Pediatric Physicians and Nurses Cope" (Seattle: University of Washington Press, 2007). Patient deaths tend to affect residents and early-career physicians the most, but no physician is immune.

"No matter how experienced you are, there are going to be situations that really affect you," said Dr. McKelvey, who interviewed about 35 pediatricians, pediatric residents, and pediatric nurses for his book.

He discovered that many coped with a dying child by focusing their energies on keeping the child comfortable, explaining the circumstances to the family, and being emotionally present for them.

One strategy is to share your feelings with someone. "Physicians usually find either someone within their own field to talk to, or a professional listener like a psychiatrist or psychologist, or their spouse. [It helps] to continue to do the job. You realize you have only a limited amount of control over what happens to patients."

By Doug Brunk, San Diego Bureau



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