THE REST OF YOUR LIFE

The Challenges of Caring for an Aging Parent

Now in his fifth year of dementia, 86-year-old Leonard Winakur doesn't know what day it is. If he's not sleeping when his son, Dr. Jerald Winakur, drops by for a visit (as Dr. Winakur does nearly every day), sometimes he'll engage his son in superficial conversation. Other times he's abrasive and says things like "You ought to come around more often" or "You're not my son."

"As my brother Michael says, he thinks it's always a good visit when he can get my father to laugh," said Dr. Winakur, who practices internal medicine and geriatrics in San Antonio. "We're able to do that on occasion."

Even though Leonard's dementia and physical health continue to worsen, Dr. Winakur and his brother do what they can to keep their father at home with his wife, Frances. That includes sharing the $1,500/month cost of assistance from two home health aides.

"My brother and I are my parents' only real social activity, so we feel we need to go over there frequently, not only to check on them but also to spend time with them," said Dr. Winakur. "My brother does that task on the weekends when I'm off from my doctoring life, and I try to spend time with my wife. During the week, I'll generally go by my parents' house every day, usually after work. My wife helps me a lot. My mother's big outing every week is to go to the beauty shop, something she's done for 50 years, probably. My brother or I will take her in the morning to her appointment, and my wife will pick her up and take her out to lunch."

To complicate the caregiving situation, Frances has developed severe macular degeneration and is unable to perform some activities of daily living.

"I'm running kind of a mini two-bed nursing home in their house," said Dr. Winakur, who is on the faculty at the Center for Medical Humanities and Ethics at the University of Texas, San Antonio. "I've had many conversations with my mother about maybe moving her into an assisted-living situation where there might be a dementia unit on the same campus. But she won't consider that—at least not now. They're most comfortable in their own home. Even though I as a medical professional know there are 'other levels of care' available for them, keeping them home is what will make them most comfortable now."

The circumstances frustrate him in the sense that "you don't want to watch this [decline] happening to them, but it is happening," he said.

Though he shares caregiving duties with his brother, Dr. Winakur noted that his mother carries the bulk of burden. She lives with Leonard's erratic behavior 24 hours a day, 7 days a week. "Every year we try to get her to go away for a week and visit relatives back east. One of us—usually my brother—will take her, and I will stay with my father. It should be more [often] than that, but she won't go. She knows my father gets agitated when she isn't there. He can't remember that she's gone away for a visit. He thinks something's wrong. It's a trying time for him. My mother knows it is, which is one of the reasons that keeps her from going," he says.

He was quick to note that it takes "great effort" to keep his parents at home. It is expensive, frustrating, and depleting, "but it can be done. We've been doing it for 4 years." Dr. Winakur knows something will disrupt the current balance of care. His father might become acutely ill or break a hip. "That will necessitate a change," he said. "What will happen then is that my father will most likely end up in some sort of long-term–care facility. And my mother will probably need ongoing help if she elects to stay at home. Then I'll have one parent in a long-term–care facility and one parent at home."

For him, the events have underscored the importance of discussing end-of-life issues with parents long before an actual crisis arises. "I read a statistic that 75% of Americans haven't had the kind of in-depth conversation with their siblings and their parents about end-of-life issues," Dr. Winakur noted. "[These discussions] need to be had. As doctors, we need to take the initiative with our elderly parents."

Dr. Robert Kane said his mother's great-

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est fear was losing her independence. That fear was realized in 1999 when Ruth Kane suffered a stroke at the age of 84 in her Florida condominium. A stepwise decline in health led to her death in a nursing home 3 years later, despite the best efforts of Dr. Kane, an international expert in long-term care, and his sister, Joan C. West, to "get the system to perform the way it should."

First, there was a brief hospitalization in Florida and a move to a rehabilitation hospital near Ms. West in Long Island, N.Y., where Ruth was able to regain her ability to perform most activities of daily living.

Then, Ruth was moved into an assisted living facility, where she was hospitalized several times for heart failure and her overall physical and mental health began to decline. From there, she was moved into another assisted-living facility in the area known for its special dementia care. Nine months later, she entered a nursing home, where she died after a 3-month stay.

" I had a good network of people who could find geriatricians to care for my mother in the various places she was," said Dr. Kane, who holds the endowed chair in long-term care and aging at the University of Minnesota School of Public Health, Minneapolis. "But that didn't make the care good. For example, the geriatrician who was caring for her did not necessarily have admitting privileges in the hospital they would take her to when she fell down in assisted living."

Although Dr. Kane and his sister discussed having Ruth move in with one of them when she completed her rehabilitation, they determined that would not work. "The only reasonable approach would have been to set her up in an apartment and bring in 24-hour care," Dr. Kane said. "She was so hard on people who took care of her that it would have been a constant battle just keeping the roster full."

Dr. Kane and Ms. West cowrote a book about the frustrations they experienced trying to arrange long-term care for Ruth, called "It Shouldn't Be This Way: The Failure of Long-Term Care" (Nashville: Vanderbilt University Press, 2005). Three key lessons he learned from the ordeal were:

► **Be wary about whom you trust.** "Discharge planners are not your advocates," he said. "Their job is to move people out of hospitals. If you're looking for a doctor to take care of your mother, I would probably start with the American Geriatrics Society. If you're looking for an assisted-living facility, I would try and find somebody I trust in the area who can tell me where the good places are."

► **Choose your battles carefully.** It's easy to fall into an unequal negotiating position when arranging for the care of a loved one, even if you know more than the people who are delivering the care. "You can't afford to either antagonize them or to push them to a point where they say, 'We just can't do the job,' " Dr. Kane said.

► **Assume a leadership role.** Dr. Kane said he draws inspiration from the Howard Beale character portrayed by Peter Finch in the 1976 film "Network," who got people to shout, "I'm mad as hell, and I'm not going to take it anymore!" Physicians "ought to be advocates for major reform in the way health care is delivered, to recognize that we live in a world of chronic disease and that the acute care fixation that we have in our current health care system is never going to do the job," he said.

To help bring about such reform, Dr. Kane founded Professionals with Personal Experience in Chronic Care, a group of more than 700 physicians, nurses, and other health care workers whose main purpose is to advocate for improvements in the way long-term care is delivered. (For information, visit www.ppecc.org.) ■

By Doug Brunk, San Diego Bureau

Book Selections For Caregivers

"Caregiving at Home," by Dr. William Leahy and the editors of Hartman Publishing (Albuquerque: Hartman Publishing, 2005).

"How to Care for Aging Parents," by Virginia Morris (New York: Workman Publishing, 2004).

"It Shouldn't Be This Way: The Failure of Long-Term Care," by Dr. Robert L. Kane and Joan C. West (Nashville, Tenn.: Vanderbilt University Press, 2005).

"Meeting the Challenges of Chronic Illness," by Dr. Robert L. Kane, Reinhard Priester, J.D., and Annette M. Totten, Ph.D. (Baltimore: The Johns Hopkins University Press, 2005).

"Our Parents, Ourselves: How American Health Care Imperils Middle Age and Beyond," by Judith Steinberg Turiel (Berkeley: University of California Press, 2005).