

November 10, 2005

When Experts Need Experts

By [JANE GROSS](#)

MINNEAPOLIS — Between them, Robert and Rosalie Kane, he a physician and she a social worker, have devoted 60 years to the study of aging, written scores of books and hundreds of journal articles about long-term care and are widely considered among the world's leading experts.

Presumably, that would make them better prepared than most of us to care for frail elderly parents, a rite of passage that most of America's 77 million baby boomers will eventually experience, if they haven't already, with all its heartache and hardship.

But expertise is no match for the harsh particulars of old age, and what the Kanes and other experts consider a broken long-term care system. Thus the couple, both professors at the University of Minnesota School of Public Health, were just as flummoxed as the next person when confronted with the day-to-day reality of tending to their own parents: Ruth Kane, who died in 2002 at the age of 87 of complications following a stroke; Pearl Smolkin, who died a year ago at 89 after a slow descent into dementia; and Max Smolkin, 97, who soldiers on despite blindness and kidney disease.

"The epiphany for us is that all this theory doesn't work, and being prepared doesn't matter," Dr. Kane said during a recent conversation at their sprawling lakeside Tudor home, full of family photographs going back generations. "It's technically complex, emotionally taxing, there's not much help out there and panic is the normal reaction. If Rosalie and I can't do it, what chance does the average person have?"

Inspired by their own experience, the Kanes want to share what they call "take home points" with other consumers of long-term care and also galvanize policy makers to overhaul a system designed to treat acute illness rather than chronic conditions, which account for 95 percent of the health care dollars spent on those 65 and over.

To that end, Dr. Kane and his sister, Joan West, a retired schoolteacher on Long Island, wrote "It Shouldn't Be This Way: The Failure of Long-Term Care" (Vanderbilt University Press, 2005), a common-sense book that is part memoir, part guidebook and part call to arms.

In addition, the Kanes have formed an organization of more than 600 professionals, including doctors, nurses, educators and even employees of the federal Centers for Medicare & Medicaid Services who have also been daunted caring for their own relatives. This nascent organization, called Professionals With Personal Experience in Chronic Care, aims to lobby for change in the form and financing of long-term care.

The couple also have culled some trade secrets, if you will, from time spent in emergency rooms and intensive care units that agitate the elderly, acute care hospitals that often misunderstand their inter-related conditions, assisted living centers that may promise more than they can deliver, nursing homes

where care is often better but at the expense of privacy and quality of life, and private homes where reliable aides can be hard to find and supervise.

Dr. Kane's primary piece of advice for adult children is to hew to a structured and deliberate process of decision-making, especially when they are catapulted into a medical crisis, like his mother's 1999 stroke when she was a widow living in Florida. He suggests dividing the process into two parts, first settling on the kind of care - for example, an assisted living center versus a nursing home - and then choosing a vendor, often based on cost and location.

Dr. Kane warns that hospital discharge planners have a stake in pressuring families to make quick decisions because of the way they are reimbursed by Medicare. If possible, he suggests hiring an outside advocate, perhaps from among the growing number of geriatric case managers, to help gather information, consider options and resist the time urgency.

This is especially important, Dr. Kane said, when relocations are involved, for instance the decision to sell his mother's Florida condominium, move her to a rehabilitation center near his sister on Long Island and later to two different assisted living communities and finally a nursing home.

"You can burn bridges and lose options with each choice," Dr. Kane said, noting that some families, although not his own, regret selling a home where a parent might have stayed on, despite disease or disability, with adequate assistance.

Rosalie Kane's primary suggestion is to seek a multidisciplinary geriatric consultation rather than relying on the advice of a trusted family doctor or a specialist like a cardiologist or oncologist. While not all hospitals have departments of gerontology, those that do pull together doctors, physical and occupational therapists, dieticians, social workers and other professionals who better understand how to manage the cascade of ailments that can overtake a frail elderly person.

Ms. Kane's parents, each with an array of medical problems in addition to Mrs. Smolkin's Alzheimer's disease and Mr. Smolkin's blindness, had muddled along in their apartment in Ottawa without such a workup until the final few months of her mother's life. By then, Mrs. Smolkin had lost all interest in eating and drinking, and required hospitalization for dehydration.

During that crisis, a team of gerontologists figured out that a treatable problem, an obstructed bile duct, was responsible for Mrs. Smolkin's loss of appetite. But during the two-month hospitalization that followed, she broke a hip, wound up with a bed sore, was put on a catheter because she could not take herself to the bathroom and developed a series of infections associated with being bedridden. Her deterioration required a transfer to a nursing home, where she died after five days. "An old person is a fragile ecosystem," Ms. Kane said. "That calls for being vigilant, assuming nothing and being more sensitive to the side effects of care."

The Kanes, both 65 years old, with three grown daughters and seven grandchildren, began collaborating early in their nomadic academic careers. Together or separately, they have edited scholarly journals for gerontologists, founded departments of geriatrics in medical schools where none existed, studied nursing homes in various countries and evaluated experimental forms of assisted living.

Both were long-distance caregivers, with siblings more immediately on the scene; in Dr. Kane's case his sister, Joan, 60, and in Ms. Kane's case one of her two brothers, Robert, 62, a retired real estate

lawyer who lives in Canada. Dr. Kane's mother spent the last three years of her life in institutional settings because she no longer had her own home and, Dr. Kane said, "it would have done in my sister" to take her in. The Smolkins, by contrast, remained in their own apartment, with many relatives nearby to assist them. Now that Mr. Smolkin is widowed, he has live-in help.

Dr. Kane's situation was more tumultuous, since his mother had always been a temperamental woman, he said, and her stroke led to an aggressive form of dementia. Over Dr. Kane's objections, her caretakers at an assisted living center used sedation and restraints, insisted the family hire round-the-clock private duty help and later suggested that the family seek another place for Mrs. Kane to live.

"We were cobbling together the best care we could and we were always a battle behind," Dr. Kane said.

In his experience, assisted living is "the grayest of options, neither fish nor fowl" and tends to be "inflexible and unimaginative" about tailoring care to individual needs. In addition, in Dr. Kane's view, residents are rushed off in ambulances for minor ailments and accidents because the staff is not medically qualified and afraid of liability. In his mother's case, Dr. Kane said, "each hospitalization made things worse," forcing her eventual transfer to a nursing home.

One remedy for traumatic hospitalizations, Dr. Kane said, is something called a negotiated risk contract, which he offered to sign, thus absolving the center of responsibility. "Safety is not necessarily the paramount virtue," for people in his mother's situation, Dr. Kane said, yet such contracts, while legal, remain a rarity. The people in charge at the two assisted living centers where his mother lived declined to enter into such a contract.

Ms. Kane agrees that fear of a fall or other accident should not drive decision-making for the frail elderly and said that she has endured criticism from some friends and relatives for being too relaxed about her parents' safety during the decade they were in failing health yet still living on their own. Now the same critics worry that Ms. Kane has chosen "unorthodox home care" for her father rather than a more typical cast of agency employees.

She concedes the risks. Her father's first live-in companion was "Marilyn Monroe meets Mary Poppins," Ms. Kane said, a woman whom the old man adored. Then a drinking problem landed her in jail on a D.W.I. charge. She has been replaced with a man who used to be the Smolkins' driver. So far, so good, Ms. Kane said, "but it's very tricky, hard not to get too involved and not unlike dealing with nannies."

The key to her decision-making, Ms. Kane said, is trying to honor the individuality of her parents. Her mother, she said, was an anxious woman who would never have felt safe at home without her solicitous, protective mate. Her father, by contrast, is bold enough to continue taking walks in the park and navigating the supermarket by memory even though he is now totally blind.

"My brother and I are dedicated to the idea that it's their lives and they can take the risks they want," she said. "That means you have to be fatalistic sometimes."