

# National Public Radio

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**Morning Edition**

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## **Analysis: Getting quality health care for your elderly relatives**

RENEE MONTAGNE, host:

This is MORNING EDITION from NPR News. I'm Renee Montagne.

STEVE INSKEEP, host:

And I'm Steve Inskeep.

Many Americans are overwhelmed by the challenge of finding health care for an aging parent. You have to make decisions quickly, often with little information. Doctors disagree on what to do and it's not always clear what insurance covers. The system is so frustrating that even doctors have trouble making it work for their own parents. Now doctors, nurses and other health-care experts are telling their own stories in hopes of improving the system. NPR's Joseph Shapiro reports.

JOSEPH SHAPIRO reporting:

Robert Kane is one of the country's top researchers on aging. He's an expert on medical care for the elderly, on nursing homes and assisted living. Kane sits in his large office on the campus of the University of Minnesota. He's reading the titles of some of his research papers.

Dr. ROBERT KANE (Researcher; University of Minnesota): 'Older adult satisfaction with integrated and capitated care and long-term care. The effect of an innovative Medicare, managed-care program on the quality...

SHAPIRO: He's written almost 500 articles, books, book chapters, all on aging. (Soundbite of page being turned)

Dr. KANE: 'Clinical challenges in the care of frail, older persons. Geriatrics as a paradigm for good chronic care.'

SHAPIRO: A few years ago, Kane cared for his own elderly mother. She'd had a stroke. With all of his expertise, Robert Kane couldn't get things to work just right.

Dr. KANE: My mother was hospitalized at one point almost every week. She would fall down. Her congestive heart failure would get worse. She'd develop an infection. And every time she went to the hospital, her condition deteriorated because she changed her environment. She was confused. She got agitated. They put her on psychoactive drugs. I mean, it was just a repeated cycle of bad events that happened that are, what we call in the trade, iatrogenic. They were produced by the treatment.

SHAPIRO: Problems that should have been treatable only got worse or led to new problems. Kane is also a physician. He could figure out some solutions, but he couldn't convince his mother's expensive assisted-living facility or sometimes even her doctors to take responsibility.

Dr. KANE: I was livid. I mean, I was spitting nails. I mean, I knew what needed to be done.

SHAPIRO: After a couple years of decline, Kane's mother died and Kane was left feeling frustrated and angry.

Mr. KANE: Thirty years of practice and research wasn't worth a damn. Basically, knowing people, being able to have direct contact, being able to seek out the best and the brightest in the field didn't make the system work. If somebody with my experience and my knowledge couldn't make the system work, I mean, what chance does the ordinary person who comes into this for the first time?

SHAPIRO: Kane placed letters in journals read by doctors and other experts in care for the elderly. He asked if they'd had the same experiences and if they wanted to help him start a group. He called it Professionals with Personal Experience in Chronic Care. That was less than a year ago. More than 200 doctors, nurses and other medical professionals wrote back.

Unidentified Woman #1: OK. Got him. Lift his walker.

Unidentified Woman #2: I know. I know. His vision isn't very good.

Unidentified Woman #3: No.

Unidentified Woman #1: Lift your feet up over the cord.

(Soundbite of patient being helped into wheelchair)

Unidentified Woman #1: OK. Go straight ahead.

SHAPIRO: At a nursing home near St. Paul, Dr. Tom von Sternberg visits some of his patients. Von Sternberg works for one of Minnesota's biggest health-care companies. He's a geriatrician, a specialist in medicine for the elderly. One of his hardest cases wasn't one of his patients, it was his own 82-year-old mother in Ohio.

Dr. TOM VON STERNBERG (Geriatrician): She was falling in increasing frequency throughout the house, in the yard, when shopping, in parking lots. And literally she could be falling anywhere between two to five times per day.

SHAPIRO: Von Sternberg was alarmed. His mother was alarmed. But when she went to see her doctor, the physician shrugged.

Dr. VON STERNBERG: His message to her was, 'There's nothing we can do. And I'm not going to refer you anywhere else. You're going to have to just deal with it.' She simply said, 'Isn't there some therapy I could have? Isn't there an evaluation I could have? Aren't there tests that could be done?' And again his response was, No.

SHAPIRO: Von Sternberg jumped on a plane to Cleveland. He was shocked to find his mother in much worse shape than he'd imagined, more than she'd let on.

Dr. VON STERNBERG: When I flew home, it was quite a surprise because what I had been hearing over the phone didn't come close to the intensity of the decline that she'd experienced over the preceding two months. When I got home, I looked at a woman who was unable to take more than two or three steps and those steps took her five minutes to take. She would be unable to walk from the bedroom to the living room in less than 20 minutes, with a walker. Each step for her was an extreme effort.

SHAPIRO: Von Sternberg found a new doctor for his mother, a geriatrician. The new doctor checked her into a hospital right away. A neurologist ran tests and came up with a cause for her falls. She had fluid building up on her brain. It was a condition that could be treated with surgery. But at that hospital, there were no surgeons who could do the operation. So an ambulance took her to a bigger hospital. The geriatrician and the neurologist did not have privileges to practice at the big hospital, so she got a whole new team of doctors. And these doctors disagreed with the first set of doctors.

Dr. VON STERNBERG: My dad called me to say--and this is now, again, over the phone. I'm back in Minneapolis. He calls me to say, 'Well, the surgeon team doesn't feel they are going to proceed with what we thought. They're thinking of a whole new, different process.

SHAPIRO: These doctors diagnosed a different problem and recommended a different kind of surgery, only this one was much more invasive and the doctors wanted to operate soon. At this point, Dr. von Sternberg stepped in. He got the two teams of doctors to talk to each other. In the end, they agreed that the first diagnosis was correct but not until his mother had gone through a second, somewhat painful four-hour spinal tap. She had the surgery and was moved back to the first hospital for physical therapy and rehabilitation. Then there was a complication from the surgery. That required a second operation. And this one caused some bruising on her brain tissue which left her weak on one side of her body, as if she'd had a mild stroke. That was 10 months ago. Today, Tom von Sternberg keeps watch over his mother by telephone.

(Soundbite of phone conversation)

Mrs. JEANNE VON STERNBERG: Hello?

Dr. VON STERNBERG: Hello, Mom.

Mrs. STERNBERG: Hi, Tom.

Dr. VON STERNBERG: How are you today?

Mrs. STERNBERG: I'm just fine.

Dr. VON STERNBERG: I thought I would call you again just to check in and see how things are going.

SHAPIRO: Jeanne von Sternberg is making a strong recovery.

(Soundbite of phone conversation)

Mrs. VON STERNBERG: Things are going beautifully.

Dr. VON STERNBERG: And your balance continues to be good?

Mrs. VON STERNBERG: Yes, it does. I was just out walking in the garden. Can you imagine?

Dr. VON STERNBERG: Well, it's a big change. That's for sure.

Mrs. VON STERNBERG: And pulling weeds, Tom.

Dr. VON STERNBERG: Oh, that's great.

Mrs. VON STERNBERG: So it is amazing. It's amazing to me, too. Thanks to you.

Dr. VON STERNBERG: Well, actually it's thanks to a lot of people.

Mrs. VON STERNBERG: Oh, I know that. You know, I was going to ask you a question.

Dr. VON STERNBERG: OK.

Mrs. VON STERNBERG: Do you think I ought to call Dr. Baker and...

SHAPIRO: Tom von Sternberg has been a doctor for 20 years, but he says he never realized just how hard it was to follow a case all the way through. He spends more time with his own patients now telling them what they can expect on each step through an illness. For researcher Robert Kane, there's one conclusion from stories like these, the system of caring for the elderly needs fixing and fast.

Dr. KANE: I don't know how it's going to play out in the future. But I know right now we've got a mess on our hands. I mean, we have a system that frankly is broke and is costing us a lot of money and it isn't producing the results that we really would like to see for ourselves or our parents.

SHAPIRO: Kane thinks experts in health care can best make the case for change. His new group, Professionals With Personal Experience in Chronic Care, has set up a Web site that's got a newsletter. People like Kane and Tom von Sternberg are sharing their stories. Kane hopes his group will come up with solutions for changing health care. Even though Kane's mother died a few years ago, he's living through the care problem all over again, this time with his wife's parents. Kane's wife Rosalie too is a well-known researcher on aging. On this day, she's had to fly out of town in a hurry. She's gone to the home of her elderly parents to help arrange for their care.

Joseph Shapiro, NPR News.

INSKEEP: You can find more doctors' personal stories about challenges they've faced with care for their parents by going to our Web site, [npr.org](http://npr.org). It's 11 minutes before the hour.