

Dementia Takes a Heavy Financial Toll

HEALTH
GINA KOLATA

Patients need constant care, and the bills can add up for years.

Three diseases, leading killers of Americans, often involve long periods of decline before death. Two of them — heart disease and cancer — usually require expensive drugs, surgeries and hospitalizations. The third, dementia, has no treatments to slow its course.

So when a group of researchers asked which of these diseases involved the greatest health care costs in the last five years of life, the answer they found might seem surprising. The most expensive, by far, was dementia.

The study looked at patients on Medicare. The average total cost of care for a person with dementia over those five years was \$287,038. For a patient who died of heart disease it was \$175,136. For a cancer patient it was \$173,383. Medicare paid almost the same amount for patients with each of those diseases — close to \$100,000 — but dementia patients had many more expenses that were not covered.

On average, the out-of-pocket cost for a patient with dementia was \$61,522 — more than 80 percent higher than the cost for heart disease or cancer. The reason is that dementia patients need caregivers to watch them, help with basic activities like eating, dressing and bathing, and provide constant supervision to make sure they do not wander off or harm themselves. None of those costs were covered by Medicare.

For many families, the cost of caring for a dementia patient often “consumed almost their entire household wealth,” said Dr. Amy S. Kelley, a geriatrician at Icahn School of Medicine at Mount Sinai



PHOTOGRAPHS BY SAM HODGSON FOR THE NEW YORK TIMES

in New York and the lead author of the paper, published in the Annals of Internal Medicine.

Dr. Diane E. Meier, a professor of geriatrics and palliative care at Mount Sinai Hospital, said most families are unprepared for the financial burden of dementia, assuming Medicare will pick up most costs.

“What patients and their families don’t realize is that they are on their own,” Dr. Meier said.

Everything gets complicated when a person has dementia, noted Dr. Christine K. Cassel, a geriatrician and chief executive of the National Quality Forum.

She described a familiar situation: If a dementia patient in a nursing home gets a fever, the staff members say, “I can’t handle it” and call 911, she said. The patient lands in the hospital. There, patients with dementia tend to have complications — they get delirious and con-



A HELPING HAND Naomi Wallace receives care from Alicia Joseph, a home health aide in New York. Left, Ms. Wallace’s son-in-law John Rakis looks over notes detailing her care.

fused, fall out of bed and break a bone, or they choke on their food. Medical costs soar.

To obtain cost estimates, Dr. Kelley and her colleagues used data from the Health and Retirement Survey, a federally funded study that conducts detailed interviews every two years with a nationally representative sample of older people, getting an average response

rate of 86 percent. It collects data on participants’ incomes, health and needs for care. It includes data on subjects’ cognitive functioning and the likelihood that they are demented, and on their total out-of-pocket spending.

The reason for the big disparities in out-of-pocket costs for the three diseases, Dr. Kelley said, is that Medicare covers discrete medical

Problems In Pricing A Funeral

YOUR MONEY
ANN CARRNS

Comparison shopping for funeral services is usually the last thing on someone’s mind when a family member dies. And a lack of easily available pricing information from funeral homes doesn’t help matters, a new report finds.

An analysis of 10 markets by two nonprofit advocacy groups, the Funeral Consumers Alliance and the Consumer Federation of America, found that funeral pricing information is often hard to obtain — and that when it is available, prices vary widely.

Even after the advent of the Internet, consumers may still have to work hard to obtain pricing information, said Josh Slocum, the alliance’s executive director.

For the new analysis, the alliance and its affiliates examined pricing information from 150 funeral homes in 10 markets.

Just a quarter of the funeral homes in the study fully disclosed prices on their websites, while another 58 percent provided them after researchers sent emails or made phone calls. But 16 percent failed to disclose the information even after researchers followed up by email or phone.

In some cases, the researchers

Q & A

¶ How can consumers avoid overpaying for a funeral?
Do not use the first funeral home you contact, and do not simply walk into the same funeral home your family may have used for years, Mr. Slocum said. While you may not feel like making telephone calls if someone close to you dies, checking with just a handful of local operators will probably be fruitful, he said: “Calling just three or four will find a substantial price variation.”

¶ What if a relative dies out of state, and I must make a quick decision about services?
If a person dies in a hospital, you can sometimes request that the body be held in the hospital’s

morgue for several days, Mr. Slocum said. That may give you extra time to gather information and make a decision. Nursing homes generally do not have extensive morgue space so that may not be an option in that case, he said.

¶ Where can I complain if I was not given required pricing information?
You can complain to the Federal Trade Commission, which provides advice about purchasing funeral services on its website, and to the Funeral Consumers Alliance, Mr. Slocum said. Also, most states have boards that regulate funeral homes or cemetery operations.

had to visit the funeral home in person to obtain the information. The Federal Trade Commission requires funeral homes to make pricing information available by telephone and in person. But its rules predate widespread use of the Internet, so they do not address online disclosure.

Researchers sought information about three separate services: cremation without a ceremony; immediate burial without a ceremony or the cost of a coffin; and a full-service funeral. The cost for the same service varied widely.

For instance, in Seattle, cremation ranged from about \$500 to \$3,400.

In Atlanta, a simple burial ranged from \$1,200 to \$5,200. And in Washington, a full-service funeral ranged from \$3,800 to \$14,000.

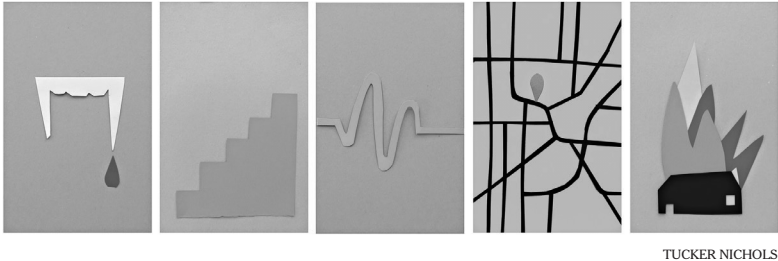
Stephen Brobeck, executive di-

rector of the consumer federation, said the findings suggested that a lack of disclosure insulated the industry from comparison shopping by consumers.

The National Funeral Directors Association, in an emailed statement, said, “Many factors contribute to the final determination of how an individual funeral home prices its goods and services, including the firm’s business philosophy and the market in which it operates.”

Mr. Slocum and Mr. Brobeck said they were asking the F.T.C. to update its rules to require funeral homes that use websites to provide price lists online.

The F.T.C. currently has a review of its “funeral rule” scheduled for 2018, an agency spokesman, Frank Dorman, said in an email.



TUCKER NICHOLS

Health Assistance From Your Phone

TECHNOLOGY
JENNIFER JOLLY

A doctor friend once told me the best thing I could do for my health was to turn off my cellphone. But that was before smartphone makers began building health and safety features into their phones. Here are five healthful tricks your phone can do.

MEDICAL ID: Apple’s Medical ID turns any iPhone 4s or newer model into a mobile medical alert bracelet. Tap on your phone’s Health app icon (it’s the white square with a red heart) to find it. Setting up your phone’s medical ID allows doctors or emergency workers to tap and hold the Emergency button on your home screen — even when it’s locked — to access medical conditions, allergies, emergency contacts, blood type and other potentially lifesaving information.

FITNESS TRACKING: Smartphones now come equipped with motion sensors that measure steps, distance traveled and even stairs climbed. To find this feature on an iPhone, head back to the Health app. Click on the dashboard and panes open up with steps, walking and running distance, and flights climbed. It shows your daily, weekly, monthly and yearly totals. No setup is required, but to get the most accurate count, it helps to carry your phone in your hand, jacket, or jeans pocket.

Samsung Galaxy S3 phones and newer come with the option to use a preloaded health app called S Health, which performs a similar tracking of steps and movement as well as calories burned, but you’ll have to take a few minutes to set it up the first time you use it.

HEART MONITORS: Samsung’s S Health app also has a place to measure your heart rate. Tap the orange heart, then edit your profile. Tap “save” and it takes you back to an orange screen. Touch “measure,” then place your finger on the infrared sensor next to the camera on the back of the device. When it’s done getting a reading, it shows whether you’re within a healthy range. Over time you can use this

services like office visits and acute care such as hospitalization and surgery. Expenses for cancer patients and heart patients tend to be of that sort. The patients often do not need full-time home or nursing home care until the very end of their life, if at all, so do not have that continuing cost. Dementia patients, in contrast, need constant care for years. They may not be sick enough for a nursing home but cannot be left alone.

When they are sick enough for a nursing home, that cost is not covered by health insurance. More than half of patients with dementia — and three-quarters of those from racial minorities — spend down, using savings to pay for the nursing home until nothing is left. Then Medicaid, the federal-state program for low-income people, takes over.

John Rakis, a consultant in New York, spent more than \$189,000 in less than two years for caregivers and other expenses for his mother-in-law, Naomi Wallace, 92, who has dementia and lives in a housing project in Manhattan. He promised his wife, who died in January 2013, that he would take care of her mother. She left a portion of her life insurance and death benefit money to her mother, and Mr. Rakis spent it on her care. Until it was gone.

“The money ran out in June,” Mr. Rakis said. “I was losing sleep.”

Then he discovered a Medicaid program that covers home health care for disabled people living at the poverty level.

Mr. Rakis remains actively involved in his mother-in-law’s care, overseeing her needs, including going with her when she ends up in an emergency room. He speaks regularly to doctors, nurses and social workers from Mount Sinai’s Visiting Doctors Program who make house calls. He has what amounts to a second job taking care of her, despite the full-time home health care aides he pays for.

“We were fortunate,” he said. “The money was there. But it went pretty quickly.”

Trying to Let Go of Irrational Fears

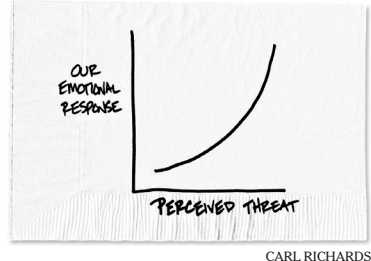
SKETCH GUY
CARL RICHARDS

When we talk about the chances of something bad happening, people tend to fall into three groups.

■ The Numbers Don’t Matter: No matter the odds, this group dismisses the statistics. People insist they can trust their gut. I suspect this group buys lottery tickets.

■ The Odds Look Great: This group focuses on the good news. It prefers to focus on things other than the chance a bad thing might happen. People in this group will buy plane tickets even after a plane crash because they realize it’s still safer than driving a car.

■ We’re Doomed: No matter how low the risk, this group focuses on it. It plans for the 10 percent chance that something bad will happen. People in this group worried about dying from Ebola.



CARL RICHARDS

I want to focus on this last group. To be sure, today’s world can be a scary one. In some ways, I’m surprised we don’t all walk around thinking, “We’re doomed!” It feels like the chances of something bad happening at any time are huge.

We do something similar with our money fears. Over the last few years, I’ve lost track of how many people have told me about their plans to avoid the next financial catastrophe. “Great,” I tell them, “but how do you

know what will happen next time?”

They all begin answering my question in roughly the same way. “Well, the last time ...” Do you know how small the probability is that the next financial crisis will look like the last one? They’re focused on the tiny possibility that what happened last time will predict what happens the next time.

Whether we’re talking about our money, our health or our safety, we’ve got to get past that fear of the thing with a tiny chance of happening. Once we’ve done everything we can do to be safe, we let go of the rest.

In life, the chance of something bad happening will never be zero. But Calvin Coolidge got it right when he said, “If you see 10 troubles coming down the road, you can be sure that nine will run into the ditch before they reach you.” Let’s see what happens if we save our worry for that 10th trouble and let the rest run into the ditch.