Caring for elders often a costly quagmire

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People with dementia — especially those with Alzheimer's disease — often live for years after reaching the point where they need 24-hour care, leaving families in an emotional, financial and logistical quagmire.

Randy and Mary Kaump of Hamden, Conn., know this all too well.

Randy's mother, Janis, just marked her 97th birthday in her $13,000-per-month nursing home room. She was diagnosed with senile dementia about four years ago, and her varied types of care since then have totaled about $400,000, which depleted her savings and about $100,000 of the couple's.

"You feel like you're responsible because they raised you, so you owe it to them to take care of them in old age," said Randy Kaump, an obstetrician/gynecologist. "But it can be hard to deal with when we have our own kids and careers."
Baby boomers are increasingly faced with supporting both their children and their parents or at least helping to figure out how their parents can best help themselves.

Senior citizens with heart disease and cancers that were once a death sentence are now living far longer. And as Randy Kaump noted, "Almost everyone becomes demented if they live long enough."

For some, while the brain is deteriorating, the rest of the body is often fairly healthy, said Bari Lewis, director of community outreach for the Kentucky and Southern Indiana chapter of the Alzheimer's Association.

Once they can no longer be trusted to handle their medications or meals on their own, some outside care is needed, but Lewis said round-the-clock care can be necessary for five to eight years. At a median annual cost of $91,250 for a private nursing home room, according to Genworth Financial's 2015 Cost of Care study, that can add up to $456,250 for five years and $730,000 for eight.

In fact, long-term care of all sorts could break almost anyone's bank.
Genworth's study says median annual costs nationally total $80,300 for a semi-private room in a nursing home, $45,760 for a home health aide, $43,200 for a stay in an assisted-living facility and $17,904 for adult day health care.

Annual costs are similar in this region, the study says. The median cost for a semi-private room in a nursing home, for example, is $75,920 in Kentucky and $78,475 in Indiana. For a year in an assisted-living facility, it's $40,200 in Kentucky and $44,310 in Indiana.

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Medicare doesn't pay for long-term nursing home care, and even short-term rehab stays are often cut short long before they should be, said Judy Stein, founder and executive director of the Center for Medicare Advocacy. She blames both nursing homes that rush patients out — saying they aren't progressing with physical therapy, for example — and the independent contractors who handle coverage decisions for Medicare.

"If you have any relatively long-term care needs, Medicare contractors regularly deny coverage," Stein said.

Long-term care insurance can ease some of the financial burden. But experts say this type of insurance often doesn't cover what patients need.

That leaves many families turning to Medicaid to pay for in-home and long-term nursing home care. Experts say most states' Medicaid programs allow the patient's spouse to keep their house and one car.

But coverage varies by state.

Indiana's Medicaid program covers assisted living, while Kentucky's does not forcing some patients to move. That's the kind of distinction that Stein thinks is nonsensical since the goal is to keep people in their homes.

It can pay to fight coverage denials. Medicare's home care benefit, for example, is often wrongly refused for people who are home-bound, even if they aren't bed-bound, Stein said. Her elderly uncle won an appeal of such a decision — but his family was notified days after he died.
One key to dealing with the often mind-boggling rules and costs, experts say, is planning early.

Sandy Markwood, CEO of the National Association of Area Agencies on Aging, is one of several experts who advise families to start thinking about how to get and pay for 24-hour care as soon as a loved one is diagnosed with dementia.

That way, parents can have a say in their care when they are lucid enough to do so, and family members can know the patient's wishes. They can also start thinking about ways to arrange caregiving among siblings, find the supportive services they need, adapt the parent's home and ensure that there is safe transportation to and from doctor's appointments.

"We've heard horror stories from the field from people who didn't plan ahead," Markwood said.

Pre-planning may even let families protect more of the patient's assets, said Kelly Gannott, a partner at Kentucky ElderLaw in Louisville.

"Eldercare attorneys do far more crisis planning than preplanning," she said, adding that about 75 percent of her firm's work is crisis planning. "If there's an inkling there's dementia, don't think that means you can no longer do planning. That is precisely the time you need to do the planning."

One reason is that middle-aged caregivers are also planning for their children's futures.

The Kaumps, for example, had one child in college and another in medical school for part of the time they cared for Janis. At one point, she had a live-in health aide and was able to stay in an apartment. But when her dementia worsened, they had to move her into the nursing home.

The nursing home's financial counselor advised Mary on everything she'd need to do to file for Medicaid, seeing Janis' money would soon run out. Mary spent nearly eight months gathering all of the paperwork, and Janis was approved about a month after the application was submitted. Mary thinks that's a testament to how thorough her record gathering was. The documents filled two large boxes; the bank costs for making check copies totaled about $200 alone.

Mary, a former emergency room nurse, stopped working two years ago in part to help with Janis and her own mother, who was also having health issues in Maryland. It's an option the couple recognizes many people don't have.
"I was very fortunate I had Mary, who could do all this," said Randy Kaump. "I would not have had the time, nor do I have the temperament to deal with it."

It could overwhelm anyone. Lewis suggests that people seek advice from eldercare attorneys, who can help navigate the financial morass, sort out power-of-attorney issues and help patients write living wills.

Area agencies on aging or non-profits like the Alzheimer's Association can also help, as can geriatric care managers — although many of these consultants charge a fee, and those who don't are often associated with specific nursing homes. Word of mouth is one of the best ways to find experts who can help with your caregiving search, but there are many other resources that exist to help people navigate the health care system.

But even with help, it's an immense challenge to find and pay for best senior care.

"It's a really difficult place to be," Lewis said, "...a really tough road."

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**Costs**

**Nursing Home**

$80,300 — National annual median cost for semi-private room in a nursing home.

$75,920 — Kentucky annual median cost for semi-private room in a nursing home.

$78,475 — Indiana annual median cost for a semi-private room in nursing home.

**Assisted living**

$43,200 — National annual median cost for semi-private room assisted-living facility

$40,200 — Kentucky annual median for a semi-private room in Kentucky assisted-living facility.
$44,310 — Annual median for a semi-private room in Indiana assisted-living facility.

— Genworth Financial’s 2015 Cost of Care study

**Here is what the Alzheimer's Association suggests asking of potential providers:**

- Do they offer specific services the person with dementia needs?
- Is family involved with creating and reviewing care plans?
- Is the staff trained in dementia care or have experience in working with someone with dementia? Are those credentials verified?
- Does the agency, service provider or care facility conduct background checks on all staff?
- What is the procedure if the care provider is sick, on vacation or quits?
- Could they provide at least three families that you can call as references? Contact the families and ask about their experiences, the care the patients received and any concerns they had.
- For adult day/respite care providers or residential care, arrange a meeting with staff and take time to look around. Are individuals involved in activities? What is your overall feeling about the environment?
- For in-home help, ask if the care provider can come to your home to meet you and the person with Alzheimer's. Pay special attention to how well the care provider interacts and communicates with the person with Alzheimer's.

**RESOURCES**

The National Clearinghouse for Long-Term Care Information has information to help families plan for future long-term care needs at [healthinaging.org](http://healthinaging.org).

[Eldercare.gov](http://Eldercare.gov), a service of the federal government run by Markwood's organization, connects people to services, including legal and financial, for seniors and their families. The services on this site are vetted, as is the information in the clearinghouse.

Search for "Nursing Home Compare" at the Centers for Medicare and Medicaid Services' [Medicare.gov](http://Medicare.gov) to help choose a highly rated nursing home.