

# Many Americans facing financial ruin as costs soar for elder care

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Margaret Newcomb, 69, a retired French teacher, is desperately trying to protect her retirement savings by caring for her 82-year-old husband,

who has severe dementia, at home in Seattle. She used to fear his disease-induced paranoia, but now he's so frail and confused that he wanders away with no idea of how to find his way home. He gets lost so often that she attaches a tag to his shoelace with her phone number.

Feylyn Lewis, 35, sacrificed a promising career as a research director in England to return home to Nashville after her mother had a debilitating stroke. They ran up \$15,000 in medical and credit card debt while she took on the role of caretaker.

Sheila Littleton, 30, brought her grandfather with dementia to her [family home](#) in Houston, then spent months fruitlessly trying to place him in a nursing home with Medicaid coverage. She eventually abandoned him at a psychiatric hospital to force the system to act.

Millions of families are facing such daunting life choices—and potential financial ruin—as the escalating costs of in-home care, assisted living facilities, and nursing homes devour the savings and incomes of older Americans and their relatives.

"People are exposed to the possibility of depleting almost all their wealth," said Richard Johnson, director of the program on retirement policy at the Urban Institute.

The prospect of dying broke looms as an imminent threat for the boomer generation, which vastly expanded the middle class and looked hopefully toward a comfortable retirement on the backbone of 401(k)s and pensions. Roughly 10,000 of them will turn 65 every day until 2030, expecting to live into their 80s and 90s as the price tag for [long-term care](#) explodes, outpacing inflation and reaching a half-trillion dollars a year, according to federal researchers.

The challenges will only grow. By 2050, the population of Americans 65

and older is projected to increase by more than 50%, to 86 million, according to census estimates. The number of people 85 or older will nearly triple to 19 million.

The United States has no coherent system of long-term care, mostly a patchwork. The private market, where a minuscule portion of families buy long-term care insurance, has shriveled, reduced over years of giant rate hikes by insurers that had underestimated how much care people would actually use.

Labor shortages have left families searching for workers willing to care for their elders in the home. And the cost of a spot in an assisted living facility has soared to an unaffordable level for most middle-class Americans. They have to run out of money to qualify for nursing home care paid for by the government.

For an examination of the crisis in long-term care, The New York Times and KFF Health News interviewed families across the nation as they struggled to obtain care; examined companies that provide it; and analyzed data from the federally funded Health and Retirement Study, the most authoritative national survey of older people about their long-term care needs and financial resources.

About 8 million people 65 and older reported that they had dementia or difficulty with basic daily tasks like bathing and feeding themselves—and nearly 3 million of them had no assistance at all, according to an analysis of the survey data. Most people relied on spouses, children, grandchildren, or friends.

The United States devotes a smaller share of its gross domestic product to long-term care than do most other wealthy countries, including Britain, France, Canada, Germany, Sweden, and Japan, according to the Organization for Economic Cooperation and Development. The United

States lags its international peers in another way: It dedicates far less of its overall health spending toward long-term care.

"We just don't value elders the way that other countries and other cultures do," said Rachel Werner, executive director of the Leonard Davis Institute of Health Economics at the University of Pennsylvania. "We don't have a financing and insurance system for long-term care," she said. "There isn't the political will to spend that much money."

Despite medical advances that have added years to the average life span and allowed people to survive decades more after getting cancer or suffering from heart disease or strokes, federal long-term care for older people has not fundamentally changed in the decades since President Lyndon Johnson signed Medicare and Medicaid into law in 1965. From 1960 to 2021, the number of Americans age 85 and older increased at more than six times the rate of the general population, according to census records.

Medicare, the federal health insurance program for Americans 65 and older, covers the costs of medical care, but generally pays for a home aide or a stay in a nursing home only for a limited time during a recovery from a surgery or a fall or for short-term rehabilitation.

Medicaid, the federal-state program, covers long-term care, usually in a nursing home, but only for the poor. Middle-class people must exhaust their assets to qualify, forcing them to sell much of their property and to empty their bank accounts. If they go into a nursing home, they are permitted to keep a pittance of their retirement income: \$50 or less a month in a majority of states. And spouses can hold onto only a modest amount of income and assets, often leaving their children and grandchildren to shoulder some of the financial burden.

"You basically want people to destitute themselves and then you take

everything else that they have," said Gay Glenn, whose mother lived in a nursing home in Kansas until she died in October at age 96.

Her mother, Betty Mae Glenn, had to spend down her savings, paying the home more than \$10,000 a month, until she qualified for Medicaid. Glenn, 61, relocated from Chicago to Topeka more than four years ago, moving into one of her mother's two rental properties and overseeing her care and finances.

Under the state Medicaid program's byzantine rules, she had to pay rent to her mother, and that income went toward her mother's care. Glenn sold the family's house just before her mother's death in October. Her lawyer told her the estate had to pay Medicaid back about \$20,000 from the proceeds.

A play she wrote about her relationship with her mother, titled "If You See Panic in My Eyes," was read this year at a theater festival.

At any given time, skilled nursing homes house roughly 630,000 older residents whose average age is about 77, according to recent estimates. A long-term resident's care can easily cost more than \$100,000 a year without Medicaid coverage at these institutions, which are supposed to provide round-the-clock nursing coverage.

Nine in 10 people said it would be impossible or very difficult to pay that much, according to a KFF public opinion poll conducted during the pandemic.

Efforts to create a national long-term care system have repeatedly collapsed. Democrats have argued that the federal government needs to take a much stronger hand in subsidizing care. The Biden administration sought to improve wages and working conditions for paid caregivers. But a \$150 billion proposal in the Build Back Better Act for in-home and



community-based services under Medicaid was dropped to lower the price tag of the final legislation.

"This is an issue that's coming to the front door of members of Congress," said Sen. Bob Casey, a Pennsylvania Democrat and chair of the Senate Special Committee on Aging. "No matter where you're representing—if you're representing a blue state or red state—families are not going to settle for just having one option," he said, referring to nursing homes funded under Medicaid. "The federal government has got to do its part, which it hasn't."

But leading Republicans in Congress say the federal government cannot be expected to step in more than it already does. Americans need to save for when they will inevitably need care, said Sen. Mike Braun of Indiana, the ranking Republican on the aging committee.

"So often people just think it's just going to work out," he said. "Too many people get to the point where they're 65 and then say, 'I don't have that much there.'"

## **Private companies' prices have skyrocketed**

The boomer generation is jogging and cycling into retirement, equipped with hip and knee replacements that have slowed their aging. And they are loath to enter the institutional setting of a nursing home.

But they face major expenses for the in-between years: falling along a spectrum between good health and needing round-the-clock care in a nursing home.

That has led them to assisted living centers run by for-profit companies and private equity funds enjoying robust profits in this growing market. Some 850,000 people age 65 or older now live in these facilities that are

largely ineligible for federal funds and run the gamut, with some providing only basics like help getting dressed and taking medication and others offering luxury amenities like day trips, gourmet meals, yoga, and spas.

The bills can be staggering.

Half of the nation's assisted living facilities cost at least \$54,000 a year, according to Genworth, a long-term care insurer. That rises substantially in many metropolitan areas with lofty real estate prices. Specialized settings, like locked memory care units for those with dementia, can cost twice as much.

Home care is costly, too. Agencies charge about \$27 an hour for a home health aide, according to Genworth. Hiring someone who spends six or seven hours a day cleaning and helping an older person get out of bed or take medications can add up to \$60,000 a year.

As Americans live longer, the number who develop dementia, a condition of aging, has soared, as have their needs. Five million to 7 million Americans age 65 and up have dementia, and their ranks are projected to grow to nearly 12 million by 2040. The condition robs people of their memories, mars the ability to speak and understand, and can alter their personalities.

In Seattle, Margaret and Tim Newcomb sleep on separate floors of their two-story cottage, with Margaret ever mindful that her husband, who has dementia, can hallucinate and become aggressive if medication fails to tame his symptoms.

"The anger has diminished from the early days," she said last year.

But earlier on, she had resorted to calling the police when he acted

erratically.

"He was hating me and angry, and I didn't feel safe," she said.

She considered memory care units, but the least expensive option cost around \$8,000 a month and some could reach nearly twice that amount. The couple's monthly income, with his pension from Seattle City Light, the utility company, and their combined Social Security, is \$6,000.

Placing her husband in such a place would have gutted the \$500,000 they had saved before she retired from 35 years teaching art and French at a parochial school.

"I'll let go of everything if I have to, but it's a very unfair system," she said. "If you didn't see ahead or didn't have the right type of job that provides for you, it's tough luck."

In the last year, medication has quelled Tim's anger, but his health has declined so much that he no longer poses a physical threat. Margaret said she's reconciled to caring for him as long as she can.

"When I see him sitting out on the porch and appreciating the sun coming on his face, it's really sweet," she said.

The financial threat posed by dementia also weighs heavily on adult children who have become guardians of aged parents and have watched their slow, expensive declines.

Claudia Morrell, 64, of Parkville, Maryland, estimated her mother, Regine Hayes, spent more than \$1 million during the eight years she needed residential care for dementia. That was possible only because her mother had two pensions, one from her husband's military service and another from his job at an insurance company, plus savings and Social



Security.

Morrell paid legal fees required as her mother's guardian, as well as \$6,000 on a special bed so her mother wouldn't fall out and on private aides after she suffered repeated small strokes. Her mother died last December at age 87.

"I will never have those kinds of resources," Morrell, an education consultant, said. "My children will never have those kinds of resources. We didn't inherit enough or aren't going to earn enough to have the quality of care she got. You certainly can't live that way on Social Security."

## **Women bear the burden of care**

For seven years, Annie Reid abandoned her life in Colorado to sleep in her childhood bedroom in Maryland, living out of her suitcase and caring for her mother, Frances Sampogna, who had dementia. "No one else in my family was able to do this," she said.

"It just dawned on me, I have to actually unpack and live here," Reid, 61, remembered thinking. "And how long? There's no timeline on it."

After Sampogna died at the end of September 2022, her daughter returned to Colorado and started a furniture redesign business, a craft she taught herself in her mother's basement. Reid recently had her knee replaced, something she could not do in Maryland because her insurance didn't cover doctors there.

"It's amazing how much time went by," she said. "I'm so grateful to be back in my life again."

Studies are now calculating the toll of caregiving on children, especially

women. The median lost wages for women providing intensive care for their mothers is \$24,500 over two years, according to a study led by Norma Coe, an associate professor at the Perelman School of Medicine at the University of Pennsylvania.

Lewis moved back from England to Nashville to care for her mother, a former nurse who had a stroke that put her in a wheelchair.

"I was thrust back into a caregiving role full time," she said. She gave up a post as a research director for a nonprofit organization. She is also tending to her 87-year-old grandfather, ill with prostate cancer and kidney disease.

Making up for lost income seems daunting while she continues to support her mother.

But she is regaining hope: She was promoted to assistant dean for student affairs at Vanderbilt School of Nursing and was recently married. She and her husband plan to stay in the same apartment with her mother until they can save enough to move into a larger place.

## **Government solutions are elusive**

Over the years, lawmakers in Congress and government officials have sought to ease the financial burdens on individuals, but little has been achieved.

The CLASS Act, part of the Obamacare legislation of 2010, was supposed to give people the option of paying into a long-term insurance program. It was repealed two years later amid compelling evidence that it would never be economically viable.

Two years ago, another proposal, called the WISH Act, outlined a long-

term care trust fund, but it never gained traction.

On the home care front, the scarcity of workers has led to a flurry of attempts to improve wages and working conditions for paid caregivers. A provision in the Build Back Better Act to provide more funding for home care under Medicaid was not included in the final Inflation Reduction Act, a less costly version of the original bill that Democrats sought to pass last year.

The labor shortages are largely attributed to low wages for difficult work. In the Medicaid program, demand has clearly outstripped supply, according to a recent analysis. While the number of home aides in the Medicaid program has increased to 1.4 million in 2019 from 840,000 in 2008, the number of aides per 100 people who qualify for home or community care has declined nearly 12%.

In April, President Joe Biden signed an executive order calling for changes to government programs that would improve conditions for workers and encourage initiatives that would relieve some of the burdens on families providing care.

## **Turning to Medicaid, a shredded safety net**

The only true safety net for many Americans is Medicaid, which represents, by far, the largest single source of funding for long-term care.

More than four in five middle-class people 65 or older who need long-term care for five years or more will eventually enroll, according to an analysis for the federal government by the Urban Institute. Almost half of upper-[middle-class](#) couples with lifetime earnings of more than \$4.75 million will also end up on Medicaid.

But gaps in Medicaid coverage leave many people without care. Under federal law, the program is obliged to offer nursing home care in every state. In-home care, which is not guaranteed, is provided under state waivers, and the number of participants is limited. Many states have long waiting lists, and it can be extremely difficult to find aides willing to work at the low-paying Medicaid rate.

Qualifying for a slot in a nursing home paid by Medicaid can be formidable, with many families spending thousands of dollars on lawyers and consultants to navigate state rules. Homes may be sold or couples may contemplate divorce to become eligible.

And recipients and their spouses may still have to contribute significant sums. After Stan Markowitz, a former history professor in Baltimore with Parkinson's disease, and his wife, Dottie Burt, 78, exhausted their savings on his two-year stay in an assisted living facility, he qualified for Medicaid and moved into a nursing home.

He was required to contribute \$2,700 a month, which ate up 45% of the couple's retirement income. Burt, who was a racial justice consultant for nonprofits, rented a modest apartment near the home, all she could afford on what was left of their income.

Markowitz died in September at age 86, easing the financial pressure on her. "I won't be having to pay the nursing home," she said.

Even finding a place willing to take someone can be a struggle. Harold Murray, Sheila Littleton's grandfather, could no longer live safely in rural North Carolina because his worsening dementia led him to wander. She brought him to Houston in November 2020, then spent months trying to enroll him in the state's Medicaid program so he could be in a locked unit at a nursing home.

She felt she was getting the runaround. Nursing home after nursing home told her there were no beds, or quibbled over when and how he would be eligible for a bed under Medicaid. In desperation, she left him at a psychiatric hospital so it would find him a spot.

"I had to refuse to take him back home," she said. "They had no choice but to place him."

He was finally approved for coverage in early 2022, at age 83.

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