

'Financial ruin is baked into the system': Readers on the costs of long-term care

December 27 2023, by Jordan Rau and Reed Abelson, KFF Health News



Credit: RDNE Stock project from Pexels

Thousands of readers reacted to the articles in the "Dying Broke" series about the financial burden of long-term care in the United States. They offered their assessments for the government and market failures that

have drained the lifetime savings of so many American families. And some offered possible solutions.

In more than 4,200 comments, readers shared their struggles in caring for spouses, [older parents](#), and grandparents. They expressed anxieties about getting older themselves and needing help to stay at home or in institutions like nursing homes or assisted living facilities.

Many suggested changes to U.S. policy, like expanding the government's payments for care and allowing more immigrants to stay in the country to help meet the demand for workers. Some even said they would rather end their lives than become a financial burden to their children.

Many readers blamed the predominantly for-profit nature of American medicine and the long-term care industry for depleting the financial resources of [older people](#), leaving the federal-state Medicaid programs to take care of them once they were destitute.

"It is incorrect to say the money isn't there to pay for elder care," Jim Castrone, 72, a retired financial controller in Placitas, New Mexico, commented. "It's there, in the form of profits that accrue to the owners of these facilities."

"It is a system of wealth transference from the [middle class](#) and the poor to the owners of for-profit [medical care](#), including hospitals and the [long-term care facilities](#) outlined in this article, underwritten by the government," he added.

Other readers pointed to insurance policies that, despite limitations, had helped them pay for services. And some relayed their concerns that Americans were not saving enough and were unprepared to take care of themselves as they aged.

What Other Nations Provide

Other countries' treatment of their older citizens was repeatedly mentioned. Readers contrasted the care they observed older people receiving in foreign countries with the treatment in the United States, which spends less on long-term care as a portion of its gross domestic product than do most wealthy nations.

Marsha Moyer, 75, a retired teaching assistant in Memphis, Tennessee, said she spent 12 years as a caregiver for her parents in San Diego County and an additional six for her husband. While they had advantages many don't, Moyer said, "it was a long, lonely job, a sad job, an uphill climb."

By contrast, her sister-in-law's mother lived to 103 in a "fully funded, lovely elder care home" in Denmark during her last five years. "My sister-in-law didn't have to choose between her own life, her career, and helping her healthy but very old mother," Moyer said. "She could have both. I had to choose."

Birgit Rosenberg, 58, a software developer in Southampton, Pennsylvania, said her mother had end-stage dementia and had been in a nursing home in Germany for more than two years. "The cost for her absolutely excellent care in a cheerful, clean facility is her pittance of Social Security, about \$180 a month," she said. "A friend recently had to put her mother into a nursing home here in the U.S. Twice, when visiting, she has found her mother on the floor in her room, where she had been for who knows how long."

Brad and Carol Burns moved from Fort Worth, Texas, in 2019 to Chapala, Jalisco, in Mexico, dumping their \$650-a-month long-term care policy because care is so much more affordable south of the border. Brad, 63, a retired pharmaceutical researcher, said his mother lived just

a few miles away in a memory care facility that costs \$2,050 a month, which she can afford with her Social Security payments and an annuity. She is receiving "amazing" care, he said.

"As a reminder, most people in Mexico cannot afford the care we find affordable and that makes me sad," he said. "But their care for us is amazing, all health care, here, actually. At her home, they address her as Mom or Barbarita, little Barbara."

Insurance Policies Debated

Many, many readers said they could relate to problems with long-term care insurance policies, and their soaring costs. Some who hold such policies said they provided comfort for a possible [worst-case scenario](#) while others castigated insurers for making it difficult to access benefits.

"They really make you work for the money, and you'd better have someone available who can call them and work on the endless and ever-changing paperwork," said Janet Blanding, 62, a technical writer in Fancy Gap, Virginia.

Derek Sippel, 47, a [registered nurse](#) in Naples, Florida, cited the \$11,000 monthly cost of his mother's nursing home care for dementia as the reason he bought a policy. He pays about \$195 a month with a lifetime benefit of \$350,000. "I may never need to use the benefit[s], but it makes me feel better knowing that I have it if I need it," he said in his comment. He said he could not make that kind of money by investing on his own.

"It's the risk you take with any kind of insurance," he said. "I don't want to be a burden on anyone."

Pleas for More Immigrant Workers

One solution that readers proposed was to increase the number of immigrants allowed into the country to help address the chronic shortage of long-term care workers. Larry Cretan, 73, a retired bank executive in Woodside, California, said that over time, his parents had six caretakers who were immigrants. "There is no magic bullet," he said, "but one obvious step—hello, people—we need more immigrants! Who do you think does most of this work?"

Victoria Raab, 67, a retired copy editor in New York, said that many older Americans must use paid help because their grown children live far away. Her parents and some of their peers rely on immigrants from the Philippines and Eritrea, she said, "working loosely within the margins of labor regulations."

"These exemplary populations should be able to fill caretaker roles transparently in exchange for citizenship because they are an obvious and invaluable asset to a difficult profession that lacks American workers of their skill and positive cultural attitudes toward the elderly," Raab said.

Federal Fixes Sought

Other readers called for the federal government to create a comprehensive, national long-term care system, as some other countries have. In the United States, federal and state programs that finance long-term care are mainly available only to the very poor. For middle-class families, sustained subsidies for home care, for example, are fairly nonexistent.

"I am a geriatric nurse practitioner in New York and have seen this story

time and time again," Sarah Romanelli, 31, said. "My patients are shocked when we review the options and its costs. Medicaid can't be the only option to pay for long-term care. Congress needs to act to establish a better system for middle-class Americans to finance long-term care."

John Reeder, 76, a retired federal economist in Arlington, Virginia, called for a federal single-payer system "from birth to senior care in which we all pay and profit-making [is] removed."

Other readers, however, argued that people needed to take more responsibility by preparing for the expense of old age.

Mark Dennen, 69, in West Harwich, Massachusetts, said people should save more rather than expect taxpayers to bail them out. "For too many, the answer is, 'How can we hide assets and make the government pay?' That is just another way of saying, 'How can I make somebody else pay my bills?'" he said, adding, "We don't need the latest phone/car/clothes, but we will need long-term care. Choices."

Questioning the Value of Life-Prolonging Procedures

A number of readers condemned the country's medical culture for pushing expensive surgeries and other procedures that do little to improve the quality of people's few remaining years.

Thomas Thuene, 60, a consultant in Boston's Roslindale neighborhood, described how a friend's mother who had heart failure was repeatedly sent from the elder care facility where she lived to the hospital and back, via ambulance. "There was no arguing with the care facility," he said. "However, the moment all her money was gone, the facility gently nudged my friend to think of end-of-life care for his mother. It seems the financial ruin is baked into the system."

Joan Chambers, 69, an architectural draftsman in Southold, New York, said that during a hospitalization on a cardiac unit she observed many fellow patients "bedridden with empty eyes," awaiting implants of stents and pacemakers.

"I realized then and there that we are not patients, we are commodities," she said. "Most of us will die from heart failure. It will take courage for a family member to refuse a 'simple' procedure that will keep a loved one's heart beating for a few more years, but we have to stop this cruelty.

"We have to remember that even though we are grateful to our health care professionals, they are not our friends. They are our employees and we can say no."

One physician, James Sullivan, 64, in Cataumet, a neighborhood of Bourne, Massachusetts, said he planned to refuse hospitalization and other extraordinary measures if he suffered from dementia. "We spend billions of dollars, and a lot of heartache, treating demented people for pneumonia, urinary tract infections, cancers, things that are going to kill them sooner or later, for no meaningful benefit," Sullivan said. "I would not want my son to spend his good years, and money, helping to maintain me alive if I don't even know what's going on," he said.

Considering 'Assisted Dying'

Others went further, declaring they would rather arrange for their own deaths than suffer in greatly diminished capacity. "My long-term care plan is simple," said Karen Clodfelter, 54, a library assistant in St. Louis. "When the money runs out, I will take myself out of the picture." Clodfelter said she helped care for her mother until her death at 101. "I've seen extreme old age," she said, "and I'm not interested in going there."

Some suggested that medically assisted death should be a more widely available option in a country that takes such poor care of its elderly. Meridee Wendell, 76, of Sunnyvale, California, said, "If we can't manage to provide assisted living to our fellow Americans, could we at least offer assisted dying? At least some of us would see it as a desirable solution."

©2023 KFF Health News. Distributed by Tribune Content Agency, LLC.

Citation: 'Financial ruin is baked into the system': Readers on the costs of long-term care (2023, December 27) retrieved 29 April 2024 from <https://medicalxpress.com/news/2023-12-financial-readers-long-term.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.