

Study highlights financial burden of dementia on older adults, families

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A new study that provides details on out-of-pocket expenses for people with dementia finds that costs for long-term care create a financial burden that can easily consume nearly all their income.

A team of researchers from the Georgia State University School of Public Health, the University of Washington School of Pharmacy and the University of California San Francisco analyzed data from a national sample of more than 4,500 adults aged 70 and older to arrive at what are thought to be the first comparisons of out-of-pocket expenses by dementia status and care setting.

The researchers found that the median adult with dementia in residential facilities such as assisted living centers spent 97% of their monthly income on long-term care. People with dementia in nursing homes spent nearly 83% of their monthly income on long-term care.

The findings were recently [published](#) in the *Journal of the American Medical Directors Association*.

"Because dementia is such an expensive illness, it really is in a category of its own when we start to think about funding for long-term care," said senior author Jalayne Arias, associate professor in the GSU School of Public Health. "Our study shows that if you compare people with dementia to their age-matched counterparts, they experience costs that are untenable to manage."

Jing Li, lead author and assistant professor of health economics at the University of Washington School of Pharmacy, noted that the new study emphasizes the [financial burden](#) dementia care places on individuals and their families rather than highlighting aggregate costs to funders like Medicaid, which is the more common approach.

"It's really striking to see that the median individual with dementia is basically putting nearly all of their income toward long-term care," Li said. "We hear about this anecdotally, but to get confirmation of that from the data is really concerning."

The average monthly out-of-pocket facility payment was \$3,090 for those in non-nursing home residential care such as assisted living facilities and \$3,849 for people with dementia in nursing homes. For older adults without dementia, those figures are \$2,801 for adults in non-nursing home residential care and \$2,176 for nursing home residents.

Regardless of their residential status, more than three-quarters of people with dementia hired helpers to assist with activities of daily living such as dressing and bathing, as well for doing laundry, shopping for groceries and other errands. More than half (56%) of the people with dementia in the study paid an average of \$1,000 per month to helpers.

Policy Implications

The researchers noted that their findings can inform policy in an era in which the percentage of older Americans is expected to rise significantly in the coming years.

Washington State, for example, passed legislation in 2019 to establish the WA Cares Fund, the nation's first public long-term care insurance program. Benefits are capped at \$36,500 adjusted for inflation, which the researchers note covers just two years of out-of-pocket expenses for the median person with dementia living in a nursing home or a single year for a person with dementia living in an assisted living facility.

The federal Program of All-Inclusive Care for the Elderly, better known as PACE, provides long-term care services to nursing home-eligible seniors in the community. It is only offered in 32 states and the District of Columbia, however, and its premium puts it out of reach for the vast majority of Medicare-only (non dual-eligible) beneficiaries.

"Given the costs associated with residential care facilities like nursing homes and assisted living centers, increasing funding for home- and

community-based care is a promising way to reduce the financial burden that [long-term care](#) places on older adults, particularly those with [dementia](#)," the authors noted.

More information: Jing Li et al, Out-of-Pocket Expenses for Long-Term Care by Dementia Status and Residential Setting among US Older Adults, *Journal of the American Medical Directors Association* (2023).
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