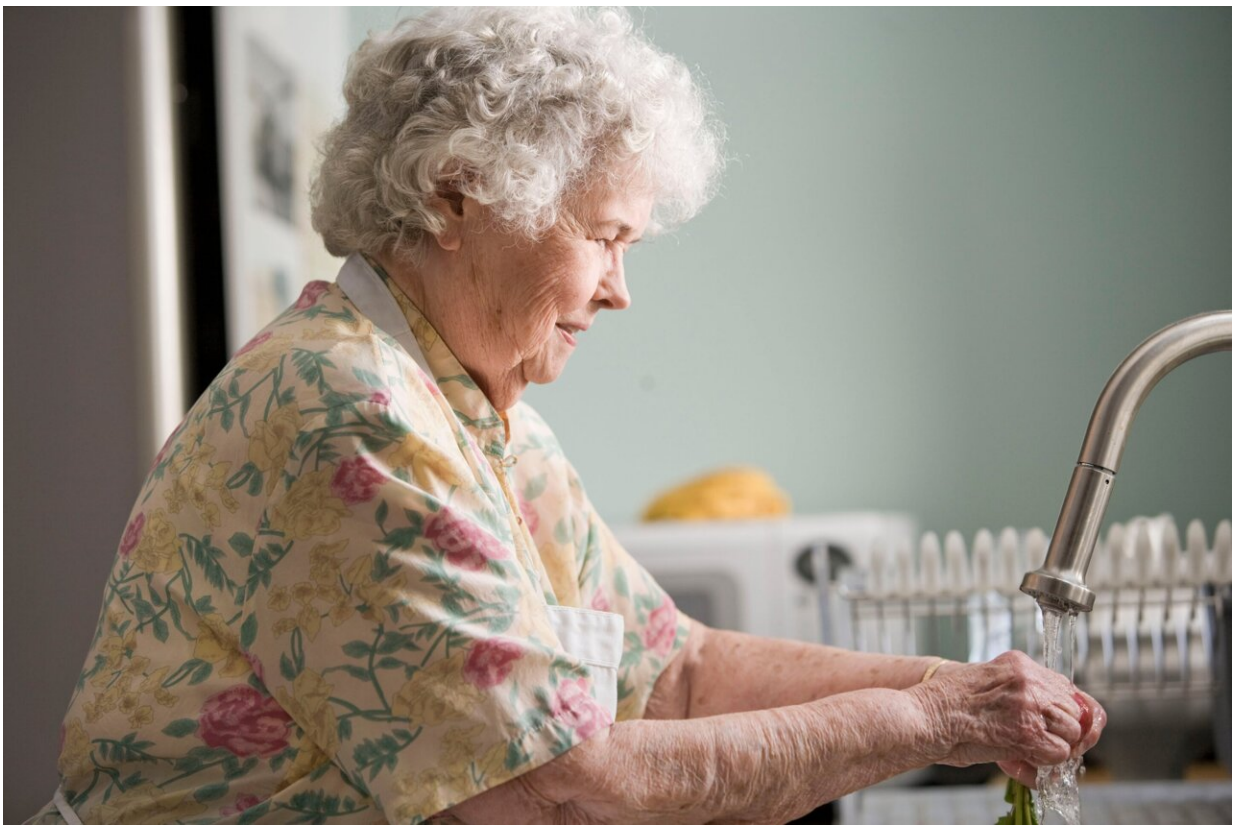


Alzheimer's report highlights immense caregiver burden—and potential ways forward

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Some 7 million Americans live with Alzheimer's, and about 11 million provide unpaid care for them.

Dementia caregiving can present unique challenges, including financial burdens and [time constraints](#), as well as [health complications](#).

A report this year from the Alzheimer's Association demonstrates the true cost of caregiving for those with the disease and calls to establish dementia care navigation throughout the U.S. to lift this burden.

Not only is the estimated value of unpaid care near \$14 billion in Pennsylvania alone, the report also revealed emotional and physical tolls. Nearly 77% of Alzheimer's caregivers in the commonwealth reported a [chronic health condition](#) and a third reported depression.

Alzheimer's was the fifth-leading cause of death in the U.S. in 2021. Prior to death, years are spent with health challenges and progressive deterioration from the disease.

"Most caregivers do fairly well in their role and report high levels of reward, but there is a small selection that experience adverse effects," said Jennifer Wolff, a professor in the Department of Health Policy and Management at Johns Hopkins Bloomberg School of Public Health, specializing in older adult and caregiver quality of life. Those with issues tend to be providing high levels of care, she said. Wolff was not involved in the research.

"These results raise a number of challenges," said Wolff. "We currently do not have system-level solutions."

The report pulled data from dozens of databases and thousands of journal articles about dementia, caregiving, health, and economic costs. It examined metrics related to caregiver well-being and Alzheimer's disease projections over time, as well as solutions moving forward to address the crisis, namely bolstering dementia care navigation and easing access to resources. It encouraged private insurers and health systems to

directly address dementia and dementia caregiving and called for better financial incentives for caregiving to expand the workforce.

More than half of caregivers reported "high" or "very high" emotional stress due to their roles.

"Dementia caregiving as a whole is very stressful and taxing," said Wolff. It can involve bearing witness to an array of behavioral changes and inconsistencies, including wandering, agitation, combativeness and, of course, memory lapses.

These caregivers help with more daily activities compared to other kinds of caregivers—including dealing with incontinence, bathing and feeding. More than other caregivers, they leave work early, take off work or quit their jobs entirely. And dementia caregivers are more likely to have had a stroke, heart disease, diabetes and cancer compared to other caregivers.

Some physical ailments could be due to growing older themselves: A third of dementia caregivers are 65 or older, per the report.

"There is evidence that they're in that age group where chronic conditions may (emerge)," said Karen Roberto, executive director of the Institute for Society, Culture and Environment and a senior fellow at the Virginia Tech Center for Gerontology, and who was not involved in the research. "They're dealing with their own issues."

But these caregivers also report high physical stress from their roles.

"The repetition and forgetting can grate on a caregiver," Roberto said. "This can trigger the stress of caregiving."

Clay Jacobs, executive director of the Alzheimer's Association of

Greater Pittsburgh, said the results about chronic health issues with dementia caregivers were particularly concerning.

"We don't see that same level of challenge with other diseases," he said. "Most people take care of their loved ones at home as long as they can. Certainly, it has a tremendous impact."

These burdens are not equally distributed, either. Although Black and Hispanic Americans are more likely than whites to develop Alzheimer's, they're less likely to be diagnosed.

Two-thirds of unpaid caregivers were white, per the report; 10% were Black.

While Black American caregivers are more likely to experience a lack of resources from systemic health inequities, there's evidence that some report less of a sense of burden compared to other races. This could be because, in certain cultures, caregiving is seen as a family responsibility as opposed to something they should receive money or additional resources for, said Roberto.

"If you have means, you have a leg up," she said. "You have opportunities. That doesn't always mean you're going to get the services you need, because there's a limited amount of services available."

And even if they had access to services, Wolff said caregivers don't always want them or can't take time away to attend [support groups](#). Roberto said her research suggests some caregivers actually report higher levels of stress when utilizing services, and the Alzheimer's Association report supports this. Unpaid caregivers cite additional work, burden and confusion involved in seeking out resources, coordinating and managing care, leading to nearly one in five stating the experience is "very stressful."

The Alzheimer's Association report also estimates that 1 million additional care professionals will be needed by 2031 to manage the growing number of adults with dementia and Alzheimer's—the most workers needed than in any other occupation in the U.S.

And federal social security monies to support the older population could deplete as soon as 2035 unless Congress acts, according to an annual report from the U.S. Social Security Office, meaning patients and caregivers may not have the funds to hire in-home care.

The Centers for Medicare and Medicaid Services created the Guiding an Improved Dementia Experience (GUIDE) model last year to fund dementia care and support patients and caregivers longer term. The pilot program is expected to launch in July and run for eight years. It includes a 24/7 helpline and increased support for care coordination, in an effort to improve patient and caregiver quality of life and the dementia care navigation system overall.

Experts say it's a first step toward structural changes for dementia caregivers. The model is, for the first time, testing out built-in support for unpaid caregivers, and time will tell how it rolls out, said Wolff.

"I'm excited for the new era we're entering in," Jacobs said. "My hope is that when a caregiver does decide to reach out, there's no shortage of ways for them to do so."

Wolff is also researching how using the digital sphere can help support the dementia [caregiver](#) network. This might involve easier navigation of the patient portal or telehealth appointments for caregivers who can't leave their patients unsupervised. Or it could mean establishing support within the primary care model and dementia clinics, so resources can be deployed in-house during regular doctor's visits.

Taking advantage of the digital sphere could be huge, said Carol Schramke, the director of behavioral neurology at Allegheny General Hospital and chair of the Ethics Committee for AGH and Allegheny Health Network. But it's important to note that many older adults aren't tech savvy, and symptoms can be improved with behavioral changes, she said.

Healthy eating, regular exercise, social experiences and adequate sleep can all lower the risk of developing [dementia](#). Taking a preventive approach may proactively chip away at the millions expected to develop the disease in the coming decades.

And if you're going to help someone else, you should make sure you're taking care of yourself, said Schramke.

"It's important to remember that helping other people is good for us," she said. "Especially if you're not completely at your wit's end, being able to provide care for someone who needs your help can be very rewarding. It's just about trying not to put the burden on one person."

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