

Dementia care programs help, if caregivers can find them

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There's no cure, yet, for Alzheimer's disease. But dozens of programs developed in the past 20 years can improve the lives of both people

living with dementia and their caregivers.

Unlike support groups, these programs teach caregivers concrete skills such as how to cope with stress, make home environments safe, communicate effectively with someone who's confused, or solve problems that arise as this devastating illness progresses.

Some of these programs, known as "comprehensive dementia care," also employ coaches or navigators who help assess patients' and caregivers' needs, develop individualized care plans, connect families to community resources, coordinate medical and social services, and offer ongoing practical and emotional support.

Unfortunately, despite a significant body of research documenting their effectiveness, these programs aren't broadly available or widely known. Only a small fraction of families coping with dementia participate, even in the face of pervasive unmet care needs. And funding is scant, compared with the amount of money that has flooded into the decades-long, headline-grabbing quest for pharmaceutical therapies.

"It's distressing that the public conversation about dementia is dominated by [drug development](#), as if all that's needed were a magic pill," said Laura Gitlin, a prominent dementia researcher and dean of the College of Nursing and Health Professions at Drexel University in Philadelphia.

"We need a much more comprehensive approach that recognizes the prolonged, degenerative nature of this illness and the fact that dementia is a family affair," she said.

In the U.S., more than 11 million unpaid and largely untrained family members and friends provide more than 80% of care to people with dementia, supplying assistance worth \$272 billion in 2021, according to the Alzheimer's Association. (This excludes patients living in nursing

homes and other institutions.) Research shows these "informal" caretakers devote longer hours to tending to those with dementia and have a higher burden of psychological and physical distress than other caregivers.

Despite those contributions, Medicare expected to spend \$146 billion on people with Alzheimer's disease or other types of dementia in 2022, while Medicaid, which pays for nursing home care for people with low incomes or disabilities, expected to spend about \$61 billion.

One might think such enormous spending ensures high-quality [medical care](#) and adequate support services. But quite the opposite is true. Medical care for people with Alzheimer's and other types of dementia in the U.S.—an estimated 7.2 million individuals, most of them seniors—is widely acknowledged to be fragmented, incomplete, poorly coordinated, and insensitive to the essential role that family caregivers play. And support services are few and far between.

"What we offer people, for the most part, is entirely inadequate," said Carolyn Clevenger, associate dean for transformative clinical practice at Emory University's Nell Hodgson Woodruff School of Nursing.

Clevenger helped create the Integrated Memory Care program at Emory, a primary care practice run by [nurse practitioners](#) with expertise in dementia. Like other comprehensive care programs, they pay considerable attention to caregivers' as well as patients' needs. "We spent a great deal of time answering all kinds of questions and coaching," she told me. This year, Clevenger said, she hopes three additional sites will open across the country.

Expansion is a goal shared by other comprehensive care programs at UCLA (the Alzheimer's and Dementia Care Program, now available at 18 sites), Eskenazi Health in Indianapolis, the University of California-

San Francisco (Care Ecosystem, 26 sites), Johns Hopkins University (Maximizing Independence at Home), and the Benjamin Rose Institute on Aging in Cleveland (BRI Care Consultation, 35 sites).

Over the past decade, a growing body of research has shown these programs improve the quality of life for people with dementia; alleviate troublesome symptoms; help avoid unnecessary emergency room visits or hospitalizations; and delay nursing home placement, while also reducing depression symptoms, physical and emotional strain, and overall stress for caregivers.

In an important development in 2021, an expert panel organized by the National Academies of Sciences, Engineering, and Medicine said there was sufficient evidence of benefit to recommend that comprehensive dementia care programs be broadly implemented.

Now, leaders of these programs and dementia advocates are lobbying Medicare to launch a pilot project to test a new model to pay for comprehensive dementia care. They have been meeting with staff at the Center for Medicare and Medicaid Innovation and "CMMI has expressed a considerable amount of interest in this," according to Dr. David Reuben, chief of geriatric medicine at UCLA and a leader of its dementia care program.

"I'm very optimistic that something will happen" later this year, said Dr. Malaz Boustani, a professor at Indiana University who helped develop Eskenazi Health's Aging Brain Care program and who has been part of the discussions with the Centers for Medicare & Medicaid Services.

The Alzheimer's Association also advocates for a pilot project of this kind, which could be adopted "Medicare-wide" if it's shown to be beneficial and cost-effective, said Matthew Baumgart, the association's vice president of [health policy](#). Under a model proposed by the

association, comprehensive dementia care programs would receive between \$175 and \$225 per month for each patient in addition to what Medicare pays for other types of care.

A study commissioned by the association estimates that implementing a comprehensive care dementia model could save Medicare and Medicaid \$21 billion over 10 years, largely by reducing patients' use of intensive health care services.

Several challenges await, even if Medicare experiments with ways to support comprehensive dementia care. There aren't enough health care professionals trained in dementia care, especially in rural areas and low-income urban areas. Moving programs into clinical settings, including primary care practices and medical clinics, may be challenging given the extent of dementia patients' needs. And training needs for program staff members are significant.

Even if families receive some assistance, they may not be able to afford necessary help in the home or other services such as adult day care. And many families coping with dementia may remain at a loss to find help.

To address that, the Benjamin Rose Institute on Aging later this year plans to publish an online consumer directory of evidence-based programs for dementia caregivers. For the first time, people will be able to search, by ZIP code, for assistance available near them. "We want to get the word out to caregivers that help is available," said David Bass, a senior vice president at the Benjamin Rose Institute who's leading that effort.

Generally, programs for dementia caregivers are financed by grants or government funding and free to families. Often, they're available through Area Agencies on Aging—organizations that families should consult if they're looking for help. Some examples:

- Savvy Caregiver, delivered over six weeks to small groups in person or over Zoom. Each week, a group leader (often a social worker) gives a mini-lecture, discusses useful strategies, and guides group members through exercises designed to help them manage issues associated with dementia. Now offered in 20 states, Savvy Caregiver recently introduced an online, seven-session version of the program that caregivers can follow on their schedule.
- REACH Community, a streamlined version of a program recommended in the 2021 National Academy of Sciences report. In four hour-long sessions in person or over the phone, a coach teaches caregivers about dementia, problem-solving strategies, and managing symptoms, moods, stress, and safety. A similar program, REACH VA, is available across the country through the Department of Veterans Affairs.
- Tailored Activity Program. In up to eight in-home sessions over four months, an occupational therapist assesses the interests, functional abilities, and home environment of a person living with dementia. Activities that can keep the individual meaningfully engaged are suggested, along with advice on how to carry them out and tips for simplifying the activities as [dementia](#) progresses. The program is being rolled out across health care settings in Australia and is being reviewed as a possible component of geriatric home-based care by the VA, Gitlin said.

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