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[3 New Ways That Medicare Is Supporting Family Caregivers](#)

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Family members, often thrust into caregiving with little notice, also must navigate a complex medical system without any training or guidance.

“I feel like I’ve learned all the things on the fly,” says Jessica Guthrie of Fredericksburg, Virginia, who has been caring for her mother for the past 10 years. Guthrie was part of a May 20 panel discussion at Arlington’s VHC Health, formerly Virginia Hospital Center, with the head of the Centers for Medicare & Medicaid Services, a health care provider, and AARP’s chief advocacy and engagement officer.

President Joe Biden signed [an executive order](#) April 18, 2023, to support the country’s 48 million family caregivers. It included more than 50 directives to federal agencies to find ways to better support caregivers, who provide what [AARP estimated in 2021](#) to be more than \$600 billion each year in unpaid labor to take care of family and friends.

The order, which AARP supports, included several proposals to change Medicare rules to help family caregivers with training and resources.

“Caregivers are a vital part of our health care system in doing things like helping with medication management, transportation to appointments, food shopping, bathing and dressing, and getting around the house,” says Chiquita Brooks-LaSure, administrator of the Centers for Medicare & Medicaid Services. “So often caregivers are often unseen and unsung heroes. We at CMS have tried to make sure that in fulfilling our mission to deliver better health and better health care to all people, that we strengthen our support for caregivers.”

Three changes have already begun to help family caregivers:

1. Providers get paid to train family caregivers

Under a rule that took effect Jan. 1, doctors, clinical psychologists, nurse practitioners, physical therapists and other health care providers can bill Medicare for time spent training family caregivers.

Family members who are helping aging relatives with tasks such as giving injections, managing medications and changing bandages no longer need to worry about spending too much time asking medical providers questions about the steps they need to know.

“When you reach the stage of incontinence, no one actually tells you how to change an adult brief,” says Guthrie, who moved from Texas to Virginia to live with her mom, Constance, as Alzheimer’s decreased her mother’s ability to care for herself. “No one shares with you how to roll someone effectively in a hospital bed to change them with dignity and respect.”

Before the rule, physicians and other health care providers did help caregivers learn the tasks that needed to be done, says Genesis Brown, a certified adult gerontology nurse practitioner and AARP volunteer. They just spent personal time during the day to do so.

At first, Guthrie didn’t realize that she could ask her mother’s primary care physician to arrange for physical or occupational therapy, for help to make a home safe, for instructions to get her mother out of the bed without injuring either one of them, or for a demonstration of wound care.

“It’s a little bit of everything, but you don’t know that you need it until you’re in that chapter,” she says. “I learned what to expect by asking people who were already on the journey.”

2. Patients with serious conditions get extra education

The same rule also allows Medicare to pay for what it calls principal illness navigation services to help patients and their family caregivers with high-risk illnesses such as cancer, dementia and HIV/AIDS understand their diagnosis and decide on their health care.

“It’s so easy to shut down or have no idea what to do because you’re suddenly confronted with a whole new set of people you need to see and providers,” Brooks-

LaSure says. “Not only for cancer but other serious illnesses, Medicare will pay for more of these services.

“This is intended for people who are in that category where their needs are going to be much more severe. They’re at high risk for hospitalization — everything from chronic obstructive pulmonary disease, heart disease, cancer, congestive heart failure, AIDS, dementia and severe mental illness — to make sure that people have assistance when they are trying to navigate the health care system, which we know is more complex than we’d all like it to be.”

Brown says she would discharge patients from a hospital’s intensive care unit, asking family members what they needed to know. But they had no idea what they needed.

3. Pilot project begins for dementia patients’ caregivers

A test program for caregivers whose loved ones have dementia is starting this year. Called Guiding an Improved Dementia Experience (GUIDE), it includes 24/7 access to a support line, care coordination, caregiver training and at-home or adult day-care respite services.

“It’s never been Alzheimer’s disease that’s been difficult about the journey,” Guthrie says. “It’s been navigating the health care system that’s been difficult.”

The goal is to improve the quality of life for both people with dementia and their unpaid caregivers and help those with dementia remain in their homes longer. The pilot program isn’t accepting additional applicants but could be expanded if successful.

More than 6.7 million Americans were [living with dementia](#) in 2023, according to the National Institutes of Health. Without any breakthroughs to curb the condition, cases could grow to 13.8 million by 2060.

People with dementia and their caregivers are assigned to a care navigator who helps them access medical services as well as services such as meals and transportation through community-based organizations.

“Caregiving is an unpaid job that does not discriminate by gender, race, age or any other demographic,” says Nancy LeaMond, an AARP executive vice president and its

chief advocacy and engagement officer. She and her two sons took care of her husband, Steve, at home for six years before he died in 2019 of amyotrophic lateral sclerosis (ALS), also known as [Lou Gehrig's disease](#).

"I always felt like I was on the sidelines with all the ... discussions," she says. "But these steps that talk about how you integrate the care the family caregiver is providing is so important. We hope this will lead to models for other disease."

----- Written by Kimberly Lankford, AARP, May 23, 2024

AARP was founded in 1958 and has over 38 million members. It is a nonprofit, nonpartisan organization for people over the age of 50. AARP is well-known for its advocacy efforts, providing its members with important information, products and services that enhance quality of life as they age. They also promote community service and keep members and the public informed on issues relating to the over 50 age group.

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