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Yale School of Medicine to study mental health of caregivers for people with dementia



Christopher Capozziello/The New York Times

Dr. Terri R. Fried, section chief of Geriatrics at Yale School of Medicine, will lead the research to develop advance care planning tools.



By **MARCIA SIMON**

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[The Yale School of Medicine](#) has been awarded \$250,000 from the [Humana Foundation](#) to study mental health among primary caregivers for people living with dementia.

The goals are to determine whether advance care planning makes a positive impact on both caregivers and patients, and to develop tools to facilitate meaningful communication to make this happen.

[Dr. Terri R. Fried, section chief of Geriatrics at Yale School of Medicine](#), will lead the research to develop advance care planning tools to help prevent depression, anxiety and post-traumatic stress disorder among full-time caregivers for senior adults, most often an elderly spouse or parent, experiencing dementia.

Fried has focused on helping older adults plan for the future when they can no longer make their own health decisions, but said the situation is very different when dementia is involved.



“The current model of advanced care planning asks people to think about a trajectory where they get very ill and face high-tech kinds of decisions about whether or not to use a treatment. But for patients with dementia, their caregivers or surrogates responsible for decision-making have to make decisions over a much longer time period and about a much broader array of different kinds of decisions,” Fried said, adding that these decisions need to be consistent with how the patient has led his or her whole life up until that point.

Fried cites an example — you can say something when you are cognitively intact, such as “I would never want you to keep me alive if I can’t recognize my grandchildren. Then the dementia progresses and the individual no longer recognizes their grandchildren, but the person seems happy watching these children play.

“Does the caregiver listen to what the person said when they were able to speak for themselves? Or do you consider who the person is now?”

Fried ponders this, as well as issues for families who don’t do advance planning until the dementia progresses. She asks, “How do we help a person who has developed some degree of impairment to verbalize the kinds of things that are important to them that caregivers can use when they have to make decisions?”

Another issue to be studied through this grant addresses culturally tailored communication. Some religious beliefs, for example, lead to advanced care planning at lower rates and, therefore, create disparities for families who dismiss opportunities to think through end-of-life decisions.

Working toward health equity across all populations to include patients with dementia and their caregivers, Fried is pulling together a group of national experts in the fields of medicine, nursing, ethics and geriatrics to wrestle with fundamental concepts and come up with guidelines to address these types of issues for healthcare surrogates and caregivers.

“Our goal is to educate caregivers and early-stage patients on how they can be thinking about particularly tricky issues related to dementia, and to create tools to help facilitate conversations so that the patient can express meaningful things they would want the caregiver to keep in mind when making decisions down the road,” said Fried.

Ultimately, she and her team plan to measure depression, anxiety and PTSD to see if improved communication reduces mental health problems among caregivers, she said. The second phase in Fried’s studies will be to create groups for caregivers in the New Haven area that measure the impact of social interaction on depression, anxiety, loneliness and isolation, which are common among full-time caregivers.

Yale School of Medicine is one of three academic partners to receive the Humana Foundation’s first-ever research grants in service of the foundation’s health equity strategy. In addition to the Yale study on dementia and caregiver mental health, the [University of Texas Health Science Center at Houston’s School of Public Health](#) was awarded a grant to examine the impact of a 32-week nutritious produce prescription program on the mental and physical health of children who are overweight or obese, living primarily in low-income families experiencing food insecurity.

The [University of North Carolina at Chapel Hill's Gillings School of Global Public Health](#) will study the benefits of healthful, home-delivered meals and social connectedness programs for seniors with low incomes. The 12-week intervention is designed to address both food insecurity and loneliness. Chapel Hill's School of Social Work will research the potential for racially and ethnically diverse high school peer leaders to improve suicide prevention programs.

The [Humana Foundation](#) was established in 1981 as the philanthropic arm of Humana Inc. It is focused on health equity, working to eliminate unjust, avoidable and unnecessary barriers in health and health care, it says. The foundation works to foster evidence-based collaborations and investments to help people in underserved communities live connected, healthy lives.

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