

Setting personal goals for dementia care

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Dementia is a health condition that affects your memory in ways that can make it difficult to carry out your usual daily tasks. The most common cause of dementia is Alzheimer's disease, which causes abnormal changes that kill brain cells. However, there are many other types of dementia. Overall, dementia is a long-term illness, and most people live from four to 10 years after being diagnosed.

When you are first diagnosed with dementia, your goals may be to preserve your ability to perform your daily activities. But as the disease progresses, your goals may shift and your preferences for your care may shift with them. Eventually, you may wish to make sure that your preferences and expectations are known, particularly for end-of-life care. You may also want to be sure those wishes can be put into action by those who might make decisions for you when you don't feel comfortable or are no longer able to make them on your own.

Healthcare providers can use a tool called "goal attainment scaling" (GAS) to help you set your personal health goals and measure whether you're meeting them. Researchers have been using GAS for decades to measure the effects of mental health and rehabilitation efforts.

In a new study, researchers used GAS when caring for people with dementia to learn more about these individuals' personalized goals for care. Their study was published in the *Journal of the American Geriatrics Society*.

Participants were recruited from the UCLA Alzheimer's and Dementia Care (ADC) program, a dementia care management program. The program uses nurse practitioners partnered with primary care providers and community-based organizations. It addresses the complex care needs not only of people living with dementia but also of their caregivers.

The study participants were required to have a diagnosis of dementia, and to have a family

member or friend serving as a <u>caregiver</u> who also was willing to participate in the study.

The researchers developed a process for using GAS to set goals and to measure whether participants reached those goals. In a first phase of the study, they tested goal setting with 32 people who had dementia and their caregivers. Caregivers were spouses or children, and most lived with the patient. The researchers also trained five nurse practitioner dementia care managers (DCMs) in using GAS.

In the next phase, the dementia care managers helped an additional 101 people with dementia and their caregivers set care goals. The research team used a scale to measure how well the participants achieved their goals 6 and 12 months after setting them. The researchers then conducted interviews with the patient-caregiver teams as well as with the DCMs to explore goal setting and measurement.

The researchers learned that 84 percent of goals set by patient or caregivers were non-medical, meaning they didn't address healthcare treatments specifically. Most often, the goals focused on improving quality of life for the person with dementia, followed by caregiver support goals (goals that help reduce caregiver stress or make caregiving as easy as possible).

Some commonly chosen goals for the person with dementia included:

- Maintaining physical safety
- Continuing to live at home
- · Receiving medical care related to dementia
- · Avoiding hospitalization
- Maintaining mental stimulation
- · Remaining physically active

Commonly chosen caregiver goals included:

- Maintaining the caregiver's own health
- Managing stress
- · Minimizing family conflict related to



dementia caregiving

The researchers concluded that <u>goal</u>-setting measures could be useful in caring for people with dementia, but that more research is needed.

The researchers concluded that GAS can be used in clinical care to help people with dementia and their caregivers set and achieve personalized health goals. Goal setting may help people with dementia work with healthcare professionals and caregivers to identify and achieve realistic goals that are most important to them.

More information: Lee A. Jennings et al, Personalized Goal Attainment in Dementia Care: Measuring What Persons with Dementia and Their Caregivers Want, *Journal of the American Geriatrics Society* (2018). DOI: 10.1111/jgs.15541

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