

2026-7-6

GTK

WSJ Print Edition



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Why a Standard Living Will May Fall Short if You Develop Dementia

A 'dementia directive' can spell out your wishes at various stages of the disease. Even if you don't have dementia, it doesn't hurt to plan.

BY CHERYL WINOKUR MUNK

SHARING YOUR

wishes for medical care and end-of-life decisions should be standard practices for people as they age. But for people with dementia, the usual advance directives—such as a living will and a durable power of attorney for healthcare—may not be detailed enough.

That's why documents called dementia directives are gaining popularity, to help people make decisions about their care if they've been diagnosed with dementia or there is a high likelihood they could be in the future. It's something for everyone to at least think about, given that there's a 42% risk of Americans developing dementia after age 55, according to a study published in Nature Medicine in January 2025.

With that in mind, here's what you need to know about dementia directives: What's in a dementia directive?

Broadly speaking, dementia directives spell out a person's wishes for care at different stages of the disease. This includes the types of medical interventions you might want if you have mild dementia, moderate dementia and severe dementia.

For instance, says Elizabeth Edgerly, senior director, community programs and services, for the Alzheimer's Association, you might want to continue your daily medications at one stage, while later, you might only want what's needed to keep you comfortable and not prolong your life with medication.

Different versions of directives are available free online, including one from Dartmouth College and another developed by Dr. Barak Gaster, a professor at the University of Washington School of Medicine. People can choose whichever works best as a framework for their wishes.

The Dartmouth version, for example, has a section on nutritional support during the stages of dementia and an option to indicate preferences for participating in research, while Gaster's document focuses more on goals for medical care for a person with mild, moderate or severe dementia. But whatever directive you use, you can also add any instructions and preferences that aren't already outlined.

The version you use is less important than having a conversation with family members about your wishes and getting them in writing, says Dr. Robert V. Brody, a physician in San Francisco who is the board president of End of Life Choices California, a nonprofit focused on helping individuals and families navigate end-of-life issues.

Are they legally binding?

Dementia directives are not legal documents. Rather, they should be used alongside documents like a living will and healthcare proxy, says Sheryl J. Dennis, partner at Fields & Dennis in Wellesley, Mass., to spark conversations among families and document a person's wishes in writing.

They allow people to be more specific about their dementia-related care than a standard advance directive, says Robert Santulli, a senior lecturer in the department of psychological and brain sciences at Dartmouth, who co-created the Dartmouth dementia directive. Attorneys can work specific language about dementia care into advance directives, but for many people, having a dementia directive as an addendum is a cost-effective option. As a primary care-doctor, Gaster has seen numerous families struggle to make decisions on behalf of loved ones with dementia. They wish they had had conversations and documented the family member's wishes before the disease took over, he says.

Unlike other life-threatening diseases, like kidney failure or heart failure, dementia causes people to lose the ability to direct their own care fairly far in advance of their death, Gaster says. "It's the most common reason that people lose decision-making capacity for often a year or two or three years before they die," he says.

How can a dementia directive help caregivers? Bob Knickerbocker of Seattle filled out a dementia directive after being diagnosed with Alzheimer's. His wife, Linda, age 88, says filling out a dementia directive was an opportunity for her family to discuss Bob's wishes and agree on his care. He made clear in those discussions and in the directive that he didn't want extra medicine or treatments at the later stages of his disease, which gave Linda reassurance when she directed doctors to discontinue blood thinners meant to treat blood clots that had developed in his lungs.

Bob was adamant about not being remanded to a nursing home. "He wanted to be at home, not in a strange bed somewhere. He didn't want the whole atmosphere of the nursing home," Linda says. Honoring his wishes, Linda arranged for in-home hospice, and her husband of 65 years died in January 2025 at age 89.

Who should consider a dementia directive? Anyone can fill one out, but it's especially advisable for people with a family history of dementia or who have been diagnosed. But there's also no harm in filling one out well before your senior years.

Some people may feel it's enough to give verbal instructions. However, Jonathan White, trusts and estates partner with Jordan & White in Danvers, Mass., says it's better to get your wishes in writing, even if it's just for the caregiver's peace of mind. "It's nice to have a paper backup, because if you're in a position that you have to make a decision, it's nice to have reassurance that you're doing what the person wanted you to do," he says. Cheryl Winokur Munk is a writer in New Jersey. She can be reached at reports@wsj.com.