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Opinion: Let's help Alzheimer's patients manage their own lives with dignity

Families deserve dignity, compassion, and control

California's Medical Aid in Dying (MAID) law currently excludes those who may need it the most — individuals in the early to mid-stages of Alzheimer's disease who still possess cognitive capacity.

As we mark Alzheimer's Awareness Month during September, we honor the millions of Americans and their families navigating the profound challenges of this devastating disease. Yet, amidst our awareness, we must confront a harsh reality: California's Medical Aid in Dying (MAID) law currently excludes those who may need it the most — individuals in the early to mid-stages of Alzheimer's disease who still possess cognitive capacity.

In 2020, roughly 720,000 Californians, or 12 percent of those over 65, were living with Alzheimer's. This number will rise as the size of this age group continues to increase. Despite this growing crisis, our laws fail to provide a compassionate option for those facing the terrifying loss of cognitive function. Many people in the early to mid-stages of Alzheimer's retain the mental ability to make informed decisions about their end-of-life care but live in fear of a future where that ability is lost. They are aware of what lies ahead — a slow decline into confusion and dependency. Allowing these individuals access to California's Medical Aid in Dying would enable them to make a proactive, dignified choice about their end-of-life care, preserving their autonomy.

California's End of Life Option Act, passed in 2016, was a significant step forward in providing terminally ill adults with the choice to end their lives peacefully and on their own terms. However, the law's requirement for mental competence at the time of request, and the ability to self-administer the medication, effectively excludes Alzheimer's patients, whose cognitive decline is a hallmark of their illness. While Alzheimer's is undeniably a terminal illness, its progression is unpredictable, making it nearly impossible for patients to time a request for California's Medical Aid in Dying before losing their decision-making capacity.

This is more than a legal issue — it is a moral one. By excluding those with Alzheimer's from accessing California's Medical Aid in Dying, we are denying them the right to die with dignity, forcing them to endure a prolonged and often agonizing decline. My mother was among those denied this choice. Diagnosed with Alzheimer's, she made the brave decision to travel to Switzerland, where she could end her life on her terms, with dignity, and surrounded by her daughters. The fact that she had to leave her home and country to achieve this is a travesty. No one should have to cross international borders to die with dignity.

California has long been a leader in end-of-life care, but it is time to extend this compassion and dignity to individuals with Alzheimer's disease. We must revise the End of Life Option Act to allow those in the early to mid-stages of Alzheimer's, who still have cognitive capacity, to qualify for California's Medical Aid in Dying. Many people with dementia would prefer a peaceful, dignified death over years of decline in a care facility, even if it means giving up good days to avoid bad years. They deserve the right to make this choice.

My mother's journey to Switzerland was not just an act of self-determination; it was an indictment of a system that forced her to leave her home to die peacefully. It's time to change the law so that people like my mother can choose to die with dignity in their own homes, surrounded by loved ones, without the need for international travel. We owe it to those facing the devastating reality of Alzheimer's to provide them with the same end-of-life choices available to others with terminal illnesses.

This is Alzheimer's Awareness Month, let's take action. It's time to ensure that those with Alzheimer's can live their final days with dignity, compassion and control.

Christie Golemb is a founding member of A Better Exit, a nonprofit dedicated to expanding California's End of Life Option Act. She lives in Kensington.