

## Half of older adults now die with a dementia diagnosis

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Nearly half of all older adults now die with a dementia diagnosis, up more than one-third (36%) in just the past two decades, according to a new study published in the Journal of the American Medical Association.

While these findings are disheartening, they also serve to underscore the importance of advance care planning for the care we want – and don't want – should we get dementia.

Thinking through these difficult decisions and having conversations with our loved ones and healthcare providers now, while we are still capable of making our healthcare decisions, will be a gift to our loved ones and to ourselves.

A good time to discuss your end-of-life care wishes with your family is when you are together, like Memorial Day weekend in May. It's important to keep in mind that dementia, as a public health crisis, came as a result of significant advancements in medicine.

As we have discovered cures or treatments for many diseases over the last century that used to be life-threatening, life expectancy has increased, and more people are dying with and from dementia. In short, medicine can prolong how long the body lasts, but not the mind.

However, the default mode within our medical system is to extend the patient's life, regardless of the quality of life, even for people with advanced dementia. We even subject advanced dementia patients to aggressive end-of-life interventions that inflict needless suffering with little thought.

Dementia patients take comfort from their surroundings; transferring them to a hospital causes agitation, upset and in the most extreme situations, trauma. Yet, nearly six out of 10 nursing home residents with advanced dementia (57 percent) go to the emergency room at least once in the last month of life.

Furthermore, emergency room physicians are trained to extend life. This reality means you could be subjecting a patient with advanced dementia to cracked ribs as a result of cardiopulmonary resuscitation (CPR), an uncomfortable urinary catheter, or a breathing tube.

A small percentage of people may want these aggressive interventions. However, more than nine out of 10 Americans (92%) agree that a person should "have the legal right to put in writing in advance that they want their caregiver and medical team to stop medical treatments when they are at a specific stage of dementia," according to a 2018 survey by NORC and the University of Chicago commissioned by my organization.

The way to solve this crisis is to balance our advances in medicine with empathy and respect for the voice and wishes of the individual; to be seen and heard as an individual and not just as a patient.

While every person does have a legal right to forgo treatments, operationalizing this desire is not clear-cut. Dementia is a progressive disease: it's not always obvious to loved ones the point at which their loved one would want to forgo treatments. Is it when they no longer recognize you, even if they seem otherwise happy? Is it only if they get violent? Or perhaps it takes multiple factors (e.g., can no longer eat, speak, dress themselves or carry on a conversation)?

I encourage all of us to give our loved ones the gift of clarity by filling out the free-of-charge Compassion & Choices dementia values and priorities online tool ([values-tool.compassionandchoices.org](https://values-tool.compassionandchoices.org)). This tool helps you create a personalized care plan, based on your selected preferences, that your health care proxy can use to care for you should you get dementia. While unfortunately there is no cure for dementia, we can take proactive steps to die naturally, potentially with less suffering, through advance care planning.

*Kim Callinan is president/CEO of Compassion & Choices, the nation's largest and oldest non-profit organization dedicated to improving and expanding healthcare options to empower everyone to chart their end-of-life journey.*