

# Dementia and End-of-Life Care

## Dementia Impacts Millions

Dementia is a devastating, incurable condition affecting an estimated 5.8 million older adults in the United States.<sup>1</sup> That number is expected to grow as the number of people entering older age surges. By 2050, the number of people age 65 and older with dementia is expected to soar to 14 million.<sup>2</sup>



Today, one in three older adults dies with some form of dementia. Alzheimer's disease, the most common cause of dementia, is the sixth-leading cause of death among all adults and the fifth-leading cause of death for people age 65 and older.<sup>3</sup>

As death due to other chronic diseases (such as heart disease) declines, more people live to an age where the risk for dementia is highest.<sup>4</sup> For example, deaths from heart disease have decreased by 9% while deaths from Alzheimer's disease have increased by 145% over the last 20 years.<sup>5</sup> The steadily rising toll of dementia is creating a public health crisis.

## Dementia Progression

Dementia is a progressive condition with no cure. People may live 8 to 10 years after diagnosis, with some living as long as 20

years.<sup>6,7</sup> For Alzheimer's disease specifically, 40% of this time is spent in the advanced stages of the condition.<sup>8</sup> During these advanced stages, most people endure irreversible loss of mental and bodily function in which they:

- Cannot recognize loved ones
- Cannot recognize surroundings
- Cannot speak or make oneself understood
- Experience personality changes
- Cannot respond to the environment, speak or control movement

Many people (45%) regard being confused all the time as a fate worse than death.<sup>9</sup>

The majority of people with dementia spend their last days in a care home. Up to 60% of deaths from dementia occur in nursing, hospice or long-term care homes, as compared with 28% of people dying from all other conditions.<sup>10</sup>

## Advanced Dementia

Advanced dementia is not treatable — there is no hope of recovery of mental function. Quality of life may be so poor at this stage that treatment for underlying conditions is unlikely to make a difference and may cause unnecessary suffering.<sup>11</sup> Instead of treating dementia like the terminal illness that it is, medical technology may draw out the dying process — often without consideration of quality of life.

People with dementia may endure implanted defibrillators, mechanical ventilation, feeding tubes and other invasive interventions — all given with the intention to improve health, but often at a cost of diminished quality of life. Even seemingly simple treatments like chest x-rays, urine samples (which often require bladder catheterizations), blood draws and hospital transfers may become uncomfortable and invasive for those who are bedbound, incontinent and profoundly cognitively impaired.<sup>12</sup>

One study found that, in the last month of life, 57% of nursing home residents with advanced dementia had at least one emergency department visit. Of those, close to half were admitted to the hospital.<sup>13</sup> In another study, in their last 3 months of life, 41% of people with dementia underwent at least one burdensome intervention, such as hospitalization, emergency room visit or tube feeding.<sup>14</sup> A third study revealed that 42% of dementia patients in nursing homes were on antibiotic therapy during the last two weeks of their lives.<sup>15</sup>

Such tests and treatments may place people with advanced dementia in situations that go against the best evidenced-based practices in dementia care, such as keeping a person in a familiar environment, establishing routines and ensuring circadian rhythms are maintained.<sup>16</sup>

## Preference for Comfort Care

Every adult with the mental capacity has the right to document their desire to forgo medical treatments. The vast majority of Americans (92%) believe 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 asked how they would like to be treated if they had advanced

dementia, most preferred to be kept comfortable and avoid suffering, as opposed to seeking best available treatments to prolong life.<sup>17</sup>

People with advanced dementia who have a valid advance directive most often document a preference for supportive care at the end of life.<sup>18</sup> Studies also show that people who have an advance directive are less likely to have burdensome treatments at the end of life, including feeding tubes, hospitalizations and intensive care unit stays in their last months of life.<sup>19,20</sup>

Among those with advanced dementia, the tests and treatments given to improve health and vigor oftentimes lead to more suffering.<sup>21</sup>

Similarly, healthcare agents, or proxies, who choose hospice or palliative care for a loved one with dementia at the end of life are usually more satisfied with the quality of their loved one's medical care. Moreover, studies show that health proxies who believe their loved one is close to the end of life are more likely to opt for comfort-focused care, and the patient is more likely to receive fewer grueling tests and treatments, such as tube feeding and hospitalization.<sup>22,23</sup>

## Planning for End-of-Life Care With Dementia

The needs of people with dementia at the end of life are unique and require special consideration. Decisions about care can be challenging — and because people with advanced dementia no longer communicate clearly, they cannot share their concerns. That's

why planning for end-of-life care with dementia should happen now, before a dementia diagnosis, or at the early stages of a diagnosis before thinking and speaking abilities fail.

An advance directive is one of the primary ways to ensure one's end-of-life care wishes are fulfilled. Yet, few people have one. Studies show only a fraction of Americans (36.7%) have any type of advance directive in place.<sup>24</sup> In fact, of nursing home residents living with dementia, only 55% have a do-not-resuscitate (DNR) order, and just 1.4% have a do-not-hospitalize (DNH) order.<sup>25</sup> Even for people with dementia who do have an advance directive in place, it does not clearly indicate the various treatments they would or would not want.<sup>26</sup>

Studies show those who do have them are less likely to receive treatments at end of life that can prolong suffering, such as feeding tubes, hospitalizations and intensive care unit stays during their last months.<sup>27, 28</sup> Conversely, patients who lack a DNH or are not enrolled in hospice are more likely to receive possibly unnecessary tests and treatments.<sup>29</sup>

## Tools to Finish Strong

The time to start planning for end-of-life care is now. Advance planning involves making thoughtful choices, putting them into a written advance directive and discussing those choices with others. The actions you take now can preserve autonomy and dignity later.

## Determine Your Values and Priorities.

Compassion & Choices' [Dementia Values & Priorities Tool](#) will help you identify your personal values and wishes so that you get the care you want in the event of a dementia diagnosis. The tool gives you a set of clear instructions for your loved ones, outlining your intentions through a personalized care plan called a Dementia Healthcare Directive. This takes the burden off loved ones to make difficult decisions when you can no longer make those decisions yourself.

## Talk With Your or Your Loved One's Doctor.

Whether you have a dementia diagnosis, are newly diagnosed or are supporting a loved one who has dementia, the [Dementia Decoder](#) will help you create a list of questions so you can get the information you need from your doctor

## Endnotes

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