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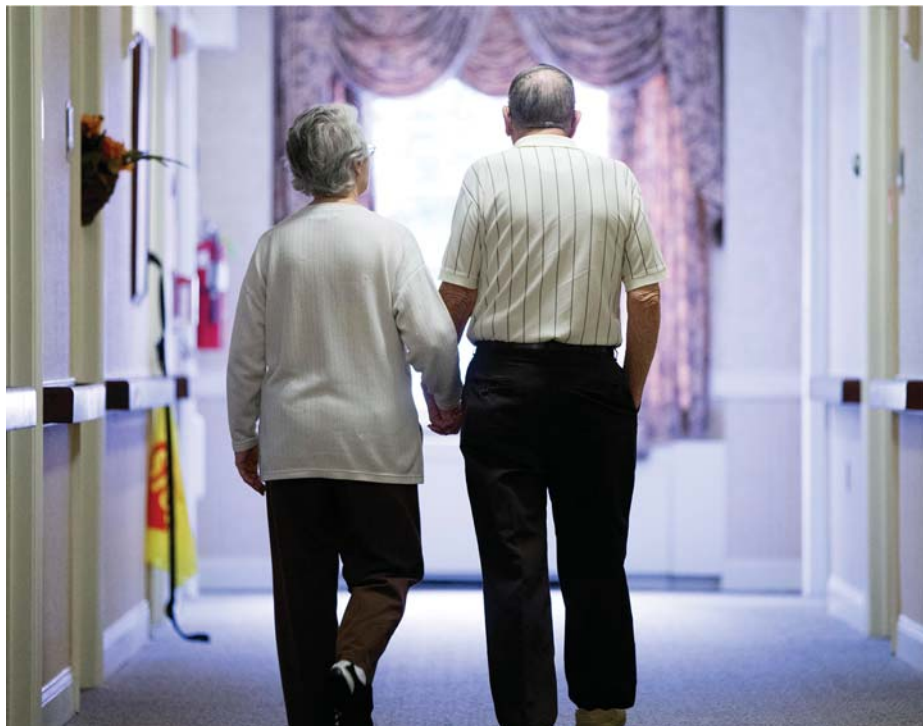
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ENTRY POINT



Patients' preferences: Decima Assise, who has Alzheimer disease, and Harry Lomping walk the halls at the Easton Home, in Easton, Pennsylvania. One key challenge in supporting people with the disease is ensuring that care preferences are honored.

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Advance Care Planning With Alzheimer's: A Tortuous Path

In striving to honor the wishes of patients with cognitive impairment, caregivers face great uncertainty.

BY REBECCA GALE

Dr. Esther Oh waits until the second or third visit to bring up death.

"It's not something I discuss when I first meet a patient; I need some time to establish rapport," says Oh, associate director of the Johns Hopkins University Memory

and Alzheimer Treatment Center. All of Oh's patients have cognitive impairment, and some have already discussed their advance directives with primary care physicians.

Oh keeps the conversation neutral. She is very deliberate about the language she uses and explains that she raises the

topic with all of her patients. "If you say, 'I want to discuss end-of-life care,' they ask, 'Am I dying?'" Oh says. Instead, she asks if they have an advance directive, and the conversation proceeds.

Oh has long recognized the importance of asking about an advance directive early in her relationship with patients. For those with Alzheimer disease, a terminal illness for which little mitigating treatment is available, patients' ability to guide their own course of care—including how and where they ultimately die—often depends on how early an advance directive is created.

Both clinicians and informal caregivers face myriad challenges unique to caring for Alzheimer patients at the end of life. Chief among them is determining care preferences—a task made much more difficult by the patient's compromised mental state and, sometimes, his or her family's inability or unwillingness to envision the complicated care and comorbidities that lie ahead.

Advance Directives

Fewer than 30 percent of Americans have advance directives, according to a 2014 study published in the *American Journal of Preventive Medicine*.¹ Many Americans prefer to avoid such emotionally fraught conversations entirely.²

That tendency can be especially problematic for patients and families facing a serious but uncertain prognosis. Indeed, the term *end of life* does not accurately describe most patients with Alzheimer disease or other cognitive decline, who could live another decade with their disease, says Dr. Diane E. Meier, director of the Center to Advance Palliative Care at the Mount Sinai School of Medicine. In communicating with patients and families investigating treatment options, Meier prefers using the term *serious illness* as opposed to *advanced illness*³ and recommends focusing the discussion on the quality of life, rather than on the end of life.

Unfortunately, not all physicians are attuned to the importance of such distinctions. In a national survey of physicians who regularly treat patients over

age sixty-five that was conducted in 2016 by PerryUndem Research/Communication for the John A. Hartford Foundation, Cambia Health Foundation, and California HealthCare Foundation, nearly all of the respondents said that having the end-of-life conversation was important, but 46 percent admitted that they didn't know what to say.⁴ Fewer than a third of the respondents said that their practice or health care system had a formal system for assessing patients' end-of-life wishes and goals for care, and a similar percentage reported having had formal training on talking with patients and their families about end-of-life care. As a consequence, a 2015 report by the Alzheimer's Association found that fewer than half of dementia patients are told their diagnosis, and patients were more likely to receive a diagnosis by their doctor after the disease had become more advanced.⁵

"Alzheimer's is slow onset; there is no specific organ failure that causes it," says Dr. Julie Bynum, a geriatrician and associate professor of medicine at the Dartmouth Institute for Health Policy and Clinical Practice. "With cardiac disease, you have heart attack or heart failure. But when your brain is gradually failing and your organs are fine, it's harder to see [the decline]."

Absent obvious evidence of a decline, patients and their families might not feel the same urgency to have serious conversations or to complete an advance directive that someone with a terminal cancer diagnosis experiences.

That is especially problematic because patients with cognitive decline in particular benefit from thinking about and making clear to their families and caregivers what kind of treatment and interventions they do and don't want. Just as important is taking those steps well before the patient's ability to communicate his or her wishes diminishes.

"When people are severely impaired, the advance directives have an impact and reduce aggressive treatments, including ventilator, dialysis, and feeding tubes," says Bynum. In a 2014 *Health Affairs* article, Bynum and colleagues found that for patients in cognitive decline, having an advance directive was associated with significantly less aggressive end-of-life care, including lower likelihood of having an in-hospital death

and using the intensive care unit.⁶

Once in the hospital, patients with dementia fare poorly,⁷ as the change in setting and complications from pain mean that they are more likely to have delirium,⁸ become confused and agitated, and act out.

Underlying these trends is simple human nature. Dr. Amber Barnato, a preventive medicine and public health physician and the Susan and Richard Levy Distinguished Professor of Health Care Delivery at the Dartmouth Institute for Health Care Policy and Clinical Practice, points to people's tendency to make "affective forecasting errors." People are typically unable to predict how they will feel in the future. As a result, she says, "the preferences we articulate when we are well do not always apply to the future selves who are sick. I might say now, 'If I were quadriplegic, I'd rather be dead.'" But evidence suggests that patients who have actually suffered such a tragic fate typically adapt, realizing that they still find joy in life.⁹ Barnato continues, "I might find that I am still happy to be alive as long as I can still talk to my kids, watch Netflix, and read novels."

Patients with full cognitive abilities can articulate their own changing perspectives over the course of an illness. For people with dementia, that is a lot more difficult and sometimes even impossible.

"An Alzheimer's patient may be able to tell you what they want for breakfast, or what flavor milkshake they prefer," says Dr. Eric DeJonge, executive director of the Medical House Call Program at Med-Star Health in Washington, D.C., a practice centered on making house calls for elderly patients. "But they cannot tell you [whether they understand] the risks of a feeding tube, or risks and benefits of end-of-life decisions."

Caregivers' Burden

Alzheimer disease places a particularly heavy burden on caregivers, many of whom are not prepared financially or trained medically to take on such a difficult role—especially one that grows harder as a loved one's cognitive abilities decline. The burden can be even greater on caregivers who are unsure whether the decisions they are making truly align with the patient's wishes.

"These caregiving needs become more

complex. Older adults living in the community can require insulin injections and needle sticks to test their blood sugar. While older independent people might have done their own diabetic blood tests, in dementia, families with little to no training do the tasks," says Amy Berman, a registered nurse and senior program officer at the John A. Hartford Foundation.

Berman, who has lived for six years with stage 4 inflammatory breast cancer, has thought and written a lot about how people, herself included, navigate the complex decisions and challenges of managing a serious illness.¹⁰ She believes that families of dementia patients should be given tools—such as formal training, state or federal funding, increased coordination, or professional support¹¹—to help them understand their caregiving role. For example, more than half of the people who care for family members say that they manage the patient's complex diet or administer insulin.¹² Previously, such resources were developed only for physicians and nurses, not family members—though there has been a recent shift to focus more on the skilled tasks¹¹ performed by family members.

"It's a very fragile system. Such caregiving also affects the health of the caregiver. They have more depression, absenteeism from work, presenteeism at work," says Berman. "If we don't support the family, everything falls apart."

One key activity for which family caregivers often feel ill equipped to perform, says Meier, is in responding to loved ones' unexpected behavior changes, such as "wandering, pushing away food, refusing to bathe, withdrawal, or agitation."

"In dementia patients, behavior is communication," Meier explains. "The vast majority of the time, changes in behavior such as restlessness, agitation, or violence are an expression of pain or discomfort." This can feed a vicious cycle: Among patients receiving a surgical hip fracture repair, for example, those with dementia got a fraction of the pain medication doses that cognitively intact patients received.¹³ That is due in part to the fact that dementia patients often cannot answer questions about their own pain or ask for additional relief. Uncontrolled pain, in turn, can make

cognitive impairment even worse.¹⁴

“People in their eighties and nineties have lot of physical distress,” says Meier, citing arthritis, constipation, and urinary tract infections as examples of ailments people are more likely to have as they age. “You and I can say that we’re in pain or uncomfortable, but the dementia patient cannot, and instead [they express] distress in the only way available to them: through changes in behavior.” Meier cites forward-thinking nursing home models that treat behavior as communication.¹⁵ When a resident’s behavior changes, staff members check for causes of pain, such as inflamed joints, bruising, or bedsores.

Not A Cure In Sight

To understand the challenges of providing Alzheimer patients with the most appropriate care, one must begin with the basic fact that, despite great uncertainty about how much time patients have left, the prognosis is always terminal. That reality runs counter to the common narrative about our vast medical system and national research enter-

prises: that their fundamental mission is to identify and dispense cures. “It’s ‘the American way,’” says Dr. Joanne Lynn, a geriatrician and director of the Center for Elder Care and Advanced Illness at the Altarum Institute. “We want a cure or procedure, but dementia has none.”

Joshua Wiener, a senior researcher at RTI International and author of several studies of end-of-life care options for patients with cognitive decline, agrees that such optimism is prevalent, even without the scientific breakthroughs to support it. “The medical community has always said a significant medical breakthrough is only five years away. I have heard that every year since 1975, and we are still nowhere,” he says.

Much of the national funding for Alzheimer disease is directed toward researching a cure¹⁶—which of course is important. But other underfunded areas could have a substantial impact on how patients and families experience the disease. This includes nonpharmacological approaches, such as engaging social workers to support caregivers and devel-

oping tools to teach caregivers how better to provide care.¹⁷

In 2016 Medicare began paying doctors for the time they spend discussing advance care planning with patients. Yet as the PerryUndem survey found, physicians and health care providers still lack formal training in having these conversations with patients at the onset of disease.⁴ Putting resources toward such training could equip physicians to raise end-of-life care issues more frequently and effectively.

Advocates argue that investing in these areas achieves multiple goals. It helps ensure that people with Alzheimer disease get the end-of-life care that matches their values and wishes. It can also provide patients and their families—who often feel hopeless in the face of the terminal prognosis—with a sense of control over the days to come and how they intend to live them. ■

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NOTES

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