TuSalud

When They Don’t Recognize You Anymore

People with advancing dementia regularly fail to recognize beloved spouses, partners, children and siblings.

May 16, 2025 By Paula Span and KFF Health News

It happened more than a decade ago, but the moment remains with her.

Sara Stewart was talking at the dining room table with her mother, Barbara Cole, 86 at the time, in Bar Harbor, Maine. Stewart, then 59, a lawyer, was making one of her extended visits from out of state.

Two or three years earlier, Cole had begun showing troubling signs of dementia, probably from a series of small strokes. “I didn’t want to yank her out of her home,” Stewart said.

So with a squadron of helpers — a housekeeper, regular family visitors, a watchful neighbor, and a meal delivery service — Cole remained in the house she and her late husband had built 30-odd years earlier.

She was managing, and she usually seemed cheerful and chatty. But this conversation in 2014 took a different turn.

“She said to me: ‘Now, where is it we know each other from? Was it from school?’” her daughter and firstborn recalled. “I felt like I’d been kicked.”

Stewart remembers thinking, “In the natural course of things, you were supposed to die before me. But you were never supposed to forget who I am.” Later, alone, she wept.

People with advancing dementia do regularly fail to recognize beloved spouses, partners, children, and siblings. By the time Stewart and her youngest brother moved Cole into a memory-care facility a year later, she had almost completely lost the ability to remember their names or their relationship to her.

“It’s pretty universal at the later stages” of the disease, said Alison Lynn, director of social work at the Penn Memory Center, who has led support groups for dementia caregivers for a decade.

She has heard many variations of this account, a moment described with grief, anger, frustration,

relief, or some combination thereof.

These caregivers “see a lot of losses, reverse milestones, and this is one of those benchmarks, a fundamental shift” in a close relationship, she said. “It can throw people into an existential crisis.”

It’s hard to determine what people with dementia — a category that includes Alzheimer’s disease and many other cognitive disorders — know or feel. “We don’t have a way of asking the person or looking at an MRI,” Lynn noted. “It’s all deductive.”

But researchers are starting to investigate how family members respond when a loved one no longer appears to know them. A qualitative study recently published in the journal Dementia analyzed in-depth interviews with adult children caring for mothers with dementia who, at least once, did not recognize them.

“It’s very destabilizing,” said Kristie Wood, a clinical research psychologist at the University of Colorado Anschutz Medical Campus and co-author of the study. “Recognition affirms identity, and when it’s gone, people feel like they’ve lost part of themselves.”

Although they understood that nonrecognition was not rejection but a symptom of their mothers’ disease, she added, some adult children nevertheless blamed themselves.

“They questioned their role. ‘Was I not important enough to remember?’” Wood said. They might withdraw or visit less often.

Pauline Boss, the family therapist who developed the theory of “ambiguous loss” decades ago, points out that it can involve physical absence — as when a soldier is missing in action — or psychological absence, including nonrecognition because of dementia.

Society has no way to acknowledge the transition when “a person is physically present but psychologically absent,” Boss said. There is “no death certificate, no ritual where friends and neighbors come sit with you and comfort you.”

“People feel guilty if they grieve for someone who’s still alive,” she continued. “But while it’s not the same as a verified death, it is a real loss and it just keeps coming.”

Nonrecognition takes different forms. Some relatives report that while a loved one with dementia can no longer retrieve a name or an exact relationship, they still seem happy to see them.

“She stopped knowing who I was in the narrative sense, that I was her daughter Janet,” Janet Keller, 69, an actress in Port Townsend, Washington, said in an email about her late mother, diagnosed with Alzheimer’s. “But she always knew that I was someone she liked and wanted to laugh with and hold hands with.”

It comforts caregivers to still feel a sense of connection. But one of the respondents in the Dementia study reported that her mother felt like a stranger and that the relationship no longer provided any emotional reward.

“I might as well be visiting the mailman,” she told the interviewer.

Larry Levine, 67, a retired health care administrator in Rockville, Maryland, watched his husband’s ability to recognize him shift unpredictably.

He and Arthur Windreich, a couple for 43 years, had married when Washington, D.C., legalized same-sex marriage in 2010. The following year, Windreich received a diagnosis of early-onset Alzheimer’s.

Levine became his caregiver until his death at 70, in late 2023.

“His condition sort of zigzagged,” Levine said. Windreich had moved into a memory-care unit. “One day, he’d call me ‘the nice man who comes to visit’,” Levine said. “The next day he’d call me by name.”

Even in his final years when, like many dementia patients, Windreich became largely nonverbal, “there was some acknowledgment,” his husband said. “Sometimes you could see it in his eyes, this sparkle instead of the blank expression he usually wore.”

At other times, however, “there was no affect at all.” Levine often left the facility in tears.

He sought help from his therapist and his sisters, and recently joined a support group for LGBTQ+ dementia caregivers even though his husband has died. Support groups, in person or online, “are medicine for the caregiver,” Boss said. “It’s important not to stay isolated.”

Lynn encourages participants in her groups to also find personal rituals to mark the loss of recognition and other reverse milestones. “Maybe they light a candle. Maybe they say a prayer,” she said.

Someone who would sit shiva, part of the Jewish mourning ritual, might gather a small group of friends or family to reminisce and share stories, even though the loved one with dementia hasn’t died.

“To have someone else participate can be very validating,” Lynn said. “It says, ‘I see the pain you’re going through.’”

Once in a while, the fog of dementia seems to lift briefly.

Researchers at Penn and elsewhere have pointed to a startling phenomenon called “paradoxical lucidity.” Someone with severe dementia, after being noncommunicative for months or years, suddenly regains alertness and may come up with a name, say a few appropriate words, crack a joke, make eye contact, or sing along with a radio.

Though common, these episodes generally last only seconds and don’t mark a real change in the person’s decline. Efforts to recreate the experiences tend to fail.

“It’s a blip,” Lynn said. But caregivers often respond with shock and joy; some interpret the episode as evidence that despite deepening dementia, they are not truly forgotten.

Stewart encountered such a blip a few months before her mother died. She was in her mother’s apartment when a nurse asked her to come down the hall.

“As I left the room, my mother called out my name,” she said. Though Cole usually seemed pleased to see her, “she hadn’t used my name for as long as I could remember.”

It didn’t happen again, but that didn’t matter. “It was wonderful,” Stewart said.

The New Old Age is produced through a partnership with The New York Times.

This story was published by KFF Health News on April 28, 2025. It is republished with permission.
