Cambridge Quarterly of Healthcare Ethics (2026), 35: 1, 32–39
doi:10.1017/S096318012500012X

CAMBRIDGE UNIVERSITY PRESS

RESEARCH ARTICLE

How do Persons With Dementia Suffer?

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Abstract

This essay argues that suffering in persons with dementia is more than a matter of personal experience. It is knowable by others and does not need to rely on the reports of the patient to affirm it. It is even possible for a person to claim not to be suffering—"I'm doing fine"—but for others to conclude to the contrary—"You are suffering." A key property of this objective account is the caregiver observes the suffering. This observation is a product of the work of caregiving and this work relies on perceiving and supporting the mind of the person living with dementia. When that work of mind support is successful, it creates a feeling of being at home. When it is not, suffering ensues.

Keywords: dementia; caregiving; mind; suffering

The subject of this essay is the problem of identifying suffering in persons living with dementia. It is also about the moral significance of that suffering.

That persons with dementia suffer seems obvious. Dementia is dreaded. Period. In the category of "states worse than death," dementia is the marque state.[1,2] Consider the stories of Janet Adkins and Brian Ameche. Janet Adkins, diagnosed with Alzheimer's disease, was Jack Kevorkian's first "client."[3] Kevorkian offered her his services for self-administered death using his "thanatron." She died in the afternoon following a morning tennis game with her husband. Kevorkian explained she did not want to suffer with her incurable disease.

Amy Bloom's memoir *In Love* recounts her husband Brian's decision to end his life.[4] Brian had early-onset Alzheimer's disease. Despite moments of clarity and some good days, Brian's feelings of slow decline reaffirmed his plan to take a self-administered lethal dose of sodium pentobarbital. He died in a suburban Zurich apartment courtesy of the services of Dignitas, a Swiss-based organization that administers aid-in-dying.

Now consider the story of Dan Gibbs. Gibbs is a neurologist forced into early retirement on account of Alzheimer's disease. His autobiography *A Tattoo on My Brain* recounts in vivid detail his experiences living with the disease.[5] He knows his diagnosis, is aware of his reality—he cannot manage finances, for example—and that his problems will worsen. He spoke to my class on Alzheimer's disease about his diagnostic journey and life after his diagnosis. There was a moment that stands out. He suddenly stopped talking.

"What was I going to say? I'm embarrassed. No, no I'm not," he insisted. "I'm not embarrassed. I used to be embarrassed, but not anymore. This is just who I am."

Adkins, Ameche, and Gibbs were aware of their diagnoses, the impact of the disease on their daily lives, and what to expect in the future. That awareness is the fertile ground from which grows the sufferings of dementia. Notably, awareness of diagnosis and prognosis is among the core criteria for persons to be allowed to choose to pursue physician-aid-in-dying. We can respect Ameche and Adkins' decisions. So too we can accept Gibbs' assertion he is not suffering. This is just who I am.

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https://doi.org/10.1017/S096318012500012X Published online by Cambridge University Press

But a common, though not universal, sign of dementia is anosognosia—some degree of a lack of awareness. Patients may, for example, state they are "doing fine" and report no problems with day-to-day life. When this happens, can a person with dementia suffer? The disease introduces other tricks that destabilize our reliance on the subjective as the account of suffering. There will come a time when as a result of aphasia Dan cannot write, cannot talk, cannot tell us he is not suffering, that he is not embarrassed by his problems. Brian or Janet might have developed notable amnesia. Meaning, they may have experienced the problems that caused them to suffer and seek aid in dying, but several minutes later, forget the problem and so forget their suffering. Simply put, if you do not fully know what is wrong with you—diagnosis and prognosis—if you lack these symptoms, how is it possible to suffer?

Anosognosia, aphasia, and amnesia—these three common signs and symptoms of dementia alone and together conspire to suggest that persons with dementia can only suffer if their symptoms are sufficiently mild to be able to remember and coherently recount their signs and symptoms. This suggests we generally cannot know if a person with dementia is suffering, especially persons at stages of dementia when some degree of anosognosia, aphasia, and amnesia are common. This uncertainty is a dark irony because these stages are precisely when persons with dementia may experience notable and often intractable disabilities and behaviors such as aggression, behaviors rightly categorized as disturbing. The question "Do persons with dementia suffer" is a hard, confusing problem.

If suffering in persons living with dementia is entirely subjective, if it is like tasting coffee, the experience, the meanings from the feelings of having dementia, or of coffee's warm bitterness (some delight in the warm bitterness; others must add spoonfuls of sugar), are intensely personal. The very nomenclature of how we speak of Brian, Janet, and Dan suggests this subjectivity. Each is "a person living with dementia." Each person decides if he or she is suffering and, if so, its features. It seems the dementia label adds no useful information to an assessment of suffering. Dementia is a state of personhood. To say persons living with dementia suffer is to say life is suffering. That does not get us very far.

This essay pushes back on the idea that subjectivity alone is the basis to determine whether a person with dementia is suffering. It argues the question "Do persons with dementia suffer" can be answered from a third-person perspective. Suffering from dementia is more than a matter of personal taste. It is knowable by others and does not need to rely on the reports of the patient to affirm it. I will even assert that it is possible for a person to claim not to be suffering—"*I'm doing fine*"—but for others to conclude to the contrary—"*You are suffering.*"

I offer two cases to illustrate the objective features of suffering in persons with dementia. The first is the woman whose apartment nearly killed her and the second is the miracle kitchen. What is common to these cases is that a caregiver observed the suffering. I will argue this observation is a product of the work of caregiving and that this work relies on perceiving and supporting the mind of the person living with dementia. When that work is successful it creates a feeling of being at home. When it is not, suffering ensues.

The woman whose apartment nearly killed her

An 85-year-old woman was brought to my care by her son who reported she had experienced a sudden and dramatic decline. She had experienced mildly disabling "memory issues" for some time, but in the past few weeks, she had transformed. He witnessed an escalating, frightening decline in her memory, attention, problem-solving skills, and in her mood. This rapid decline started after she moved from her house to an apartment in a continuing care retirement community.

There, she would forget what she was looking for, repeat the same question that, just minutes before, he had answered. She would put something down, and within minutes ask for its whereabouts and when told where—"Mom, the letter's on the desk"—she would struggle to find it because she could not remember where was her desk.

This marked amnesia made her forget tasks she had just completed. Every time her dog moved towards the door, having forgotten she had just taken the dog out for a walk, she perceived this as a signal

https://doi.org/10.1017/S096318012500012X Published online by Cambridge University Press

the dog needed to go outdoors. Yet again—7, 10 times a day—she leashed him up and set out. Multiple entreaties from her son to cease the multiple walks were to no avail. Likely, she forgot those entreaties.

Once outside, she would become lost, requiring neighbors or the staff to escort her back to her apartment. One rainy day, the staff found her and the dog, standing still, soaked, and entirely lost. Her ability to perform daily tasks such as preparing a simple meal became so impaired that, within a week, her son hired a person to assist her. She would forget who the person was and why they were there. Agitation ensued.

Her son summed up the problem "She's experiencing a deep dive." She was descending into dark and dangerous waters. She developed a crippling anxiety. Repeatedly, like Janet Adkins and Brian Ameche, she told her son "I want to die."

When I saw her at the Penn Memory Center, her son filled in details of how she had been doing for the past few years. Memory problems were causing mild but notable disabilities. She had given up driving because she had gotten lost. There were some changes to her judgment and decision-making. Always a generous and giving person, that behavior had become increasingly disinhibited. She had been the victim of several scams disguised as charities and so now her finances were under his close supervision.

The decision to move her to the apartment was a proactive, planful move. The space was simpler than her home of some 40 years, closer to her son and, given the emerging memory issues, promised easy access to his care. He also explained how something had gone terribly wrong with his mother. His choice of verb tense—"had gone"—that was notable.

After about 2 weeks in the apartment, her son moved her back to her home. The minute she returned to her house of some 40 years, the darkness lifted. Her memory loss, confusion, agitation, anxiety—this frightening assembly of problems, they all receded into the past perfect. Almost in an instant, she transformed from miserable to happy. Her subjective suffering ceased.

In the days to follow, she resumed life. She took her dog for just a few walks, talked to her neighbors, read the paper, and sent her son emails about items in the news she thought would interest him. She was once again living in the here and now, with fulfilled expectations, a sense of her past, and a look into her future.

The Miracle Kitchen

After 7 years of work to improve the care of persons living with advanced-stage dementia, Steve McAlilly beheld his results and the results were spectacular. (personal communication) The residents of the memory unit at Alder Gates Retirement Community were experiencing notable improvements. A man so disabled in his ability to eat that he required a feeding tube was now feeding himself dinner. Another man who had been confined to a wheelchair was walking. The nurses reported prescribing fewer doses of psychoactive sedating medications. What was this medication that awakened these patients, that transformed persons who had been reduced to labels such as "feeders," "bedbound," or "wanderer" into people who were eating, walking about, and enjoying their days?

It was not a medicine. Steve is not a physician or scientist. He is a lawyer. He was the chief executive officer for the Methodist Senior Services in Tupelo, Mississippi. What he had done was implement a new way of caring for some of the frailest and most vulnerable persons living with dementia. Notably, these are persons with deficits in multiple domains of cognition and require substantial assistance with performing daily activities.

The Methodist Senior Services ran Alder Gates Retirement Community, a large residential long-term care facility dedicated to the care of older adults. Soon after Steve started his leadership position, he began to discern something disturbing in the care the residents were receiving. He called it "the peeled paint syndrome." He explained it as an insight made possible by being an outsider who was recently brought inside. "I notice the peeling paint in your house, not mine."

The Alder Gates staff had the best mission-driven intentions for the residents, and yet, bad things kept happening to these residents. "I was stunned. The complaints from residents and families, month after month, they just kept coming."

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The problem was not the people, it was the place, the physical space. And he had arrived at an auspicious time to do something about the peeling paint before he too ceased to notice it. Alder Gates was about to embark on the construction of a brand-new state-of-the-art 120-bed addition to their residential facility. Steve became convinced the plan to build yet another structure modeled on the design of a vast dormitory cum hospital was a mistake.

"I told the board of directors, 'Don't do this.'"

Steve set out to convince his Methodist senior services colleagues to work with architects to adopt the Green House Project model of design. This model, originally developed by geriatrician Bill Thomas, with funding from the Robert Wood Johnson Foundation,[6] models residential care after a family's home.[7] Living areas house 10 people. An open kitchen flows into a common dining area. There, a communal dining table is set near a fireplace, all within a short walk to ten private rooms, each with its own bath and a view into the common living space. A large ground-floor doorway leads out to a garden space enclosed by a handsome wrought iron fence.

What do these stories tell us about an objective account of suffering in persons with dementia?

The answer begins with understanding what is dementia. Dementia describes disabling cognitive, perceptual, and emotional impairments. Disabling means a person has problems performing day-to-day tasks, such as shopping or paying bills or taking the dog for a walk. The disability is not physical but it is not only cognitive. Persons with dementia have impairments in emotional processing and expression, with what is called social cognition. They also have problems with perception, such as the loss of smell or distortions in the spatial arrangement of objects. The former can cause problems with relationships such as confusing the identity of a once familiar person, and the latter can cause a person to struggle with utensils and dressing. Altogether, the problem of dementia is mental. Dementia is a disease of the mind.

My patient was the subject of her son's awful, albeit unintentional, natural experiment on her mind. His intervention was the move from her home to the apartment. The outcomes were his perceptions of her mind—of what it was like to be his mother. The results show how a change in her environment profoundly, but fortunately reversibly, damaged her mind. What happened to her? What caused her to move from desiring to live, but then wishing to die to once again desiring to live?

My assessment showed a dense amnesia. She did not need to or want to see me because, she explained, she had only minor memory problems. She had for example largely forgotten the horrifying days at the apartment. She was however respectful that her son was concerned about her memory and grateful for his help. Her performance on measures of language—such as the ability to name objects or generate a list of animals—measures of attention, spatial function, and multitasking were largely intact. She told me she enjoyed her days at home in the company of her dog and her neighbors.

She has a disease called LATE.[8] The term is an acronym for Limbic Associated Age-Related TDP Encephalopathy. This is not Alzheimer's. The pathology is entirely different. The early and dominant lesions are in the hippocampi and adjacent structures of the medial temporal lobes, such as the limbic system and frontal networks. The result is problems with memory, social cognition, and executive function (remember, she had been the victim of several scams). Compared to Alzheimer's disease, LATE is relatively unknown, but like Alzheimer's, it is a common cause of dementia.

Putting all this together, the hippocampi are the regions of the brain that allow us to learn new spatial and temporal information. They create the mental map of a place such that we learn where we are so that when we return, we know the place. Her hippocampi were unfortunately profoundly damaged. The move to the new space essentially subjected her to an incessant memory test. She would take it, fail it, and then take it again. And then yet again fail it. And then again.

Recall her son's account of how when he told her to find a letter on her desk, she could not find the letter because she could not remember where was her desk. She knew she had a desk and when she saw the familiar piece of furniture, she recognized it, but in the new environment, she could not remember where was her desk. The letter, like her, was essentially lost in space.

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So too her entire home, the new apartment. She could not find it when she left to walk her dog. These repeated failures of memory were distressing and as her distress amplified, it unleashed a mind-destructive cycle. Once back to her home of some 40 years, the place she knew, that she did not need to learn, the endless memory test mercifully ceased. She was restored and resurrected. She resumed being herself.

Her home is a kind of splint for her damaged mind. With it, in it, and through it, she is able to experience the world and act on her intentions. She awakens and decides, "I want to read the newspaper. It will be at the front door, delivered there every morning." She reads something about the university where her son works and sends him an email or text to inquire or comment about the event. Later, she looks out the window. It is sunny. She wants to enjoy that warmth and so she takes the dog out for a walk and visits the neighbors. And if it starts to rain, she knows the well-traveled road back to the house that is her home.

The move to the apartment took away these splints. The treatment was a return to that house that gave her a feeling of being at home.

The second case further illustrates how manipulating the environment can cause or relieve suffering in a person with dementia. How can a space make the lame walk or the mute talk?

In what Steve called "the old world," the staff cared for some 120 people. Three meals a day, 7 days a week. "They need to get everyone into the dining area. It is easier to put people in wheelchairs to get them there, and it is quicker." Over time, the frail transported by wheelchairs simply lose the ability to walk. In the new world, with only 10 residents in an intimate space, the walk to a dining table is much shorter. Moreover, they are being called to a table not by someone's command ("it is feeding time"), but by their own feelings, by their perceptions of the smells, sounds, and sight of a meal being served. When the man with the feeding tube was set before the table, he brightened and began to eat. "There is," Steve concluded, "Something about home and food that does something to a soul."

I will swap in "mind" for "soul."

Over time, in this new world, table talk ensued. People began to connect. Steve recalled one woman began to read the obituaries and crime reports to her table mates. Some families visited less often. These were those members designated with the label of "responsible family member," meaning the persons who had been sending Steve the many complaints that stunned him. They visited less because there were fewer and fewer problems to complain about.

Instead, other, previously unseen family members began to visit. An 8-year-old boy who had never visited his grandmother when she resided in the "locked unit," now visited so often that he came to learn the names of all of the residents. "It was always the good son. Now, it is all of them visiting," Steve concluded.

What do these cases tell us?

Mind is the product of an emergence from an interaction between the brain and the environment.[9,10] There is a bidirectional feedback/feedforward loop. Diagrams, whiteboards, and models represent ideas. We keep lists and notebooks to organize and consult in decision-making. We create words and acronyms to represent our ideas and use pens and computers to write them out and then give them to other people to help us make sense of the world. Or perhaps just offload them on those people, such as an administrative assistant. If we cannot think of the words, we google or if we really want to know, ask ChatGPT.

Dementia is a disorder of the mind—it causes impairments in perception, sensation, thought, or feeling that impair a person's capacity to experience the world or to be an agent. The woman whose apartment nearly killed her, and the residents of the "old world" at Alder Gates all experienced this. Both cases show the role of the environment in creating the mind and how modifications in the environment can either precipitate or alleviate suffering. A person with a disease of the brain that causes dementia, a disease such as Alzheimer's, LATE, or Lewy Body disease, is living with a disease that disrupts the emergence of the mind.

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Both cases also show the role of other people's minds in supporting the mind of a person with dementia. Steve decided to persuade the board not to build the usual dorm-style residence. He worked with architects to design the home-like space. The woman whose apartment nearly killed her did not decide to return to her home. Her son did (instead of taking her to the emergency room to evaluate her for acute agitation). A human and an environment—together they create a coupled system for a brain damaged by disease to fill in what is missing and so splint a damaged mind. The result? The person has the agency to act on intentions and so has meaningful experiences. The person is objectively not suffering.

Perhaps this objective account of suffering in dementia asks whether a person had "nostalgia" with an emphasis on the term's original meaning, a state of psychic pain caused by forced separation from environment and family (think home and caregiver). The 17th-century Swiss physician Johannes Hofer coined the term. It combines the Greek *nostos* and *algia. Nostos* means homecoming and *algos* means pain. He used it to explain his observations of soldiers or servants who experienced distress over the experience of living far from home, and in those times, connected only by a slow and uncertain system of written correspondence.[11]

To create this absence of nostalgia, a person with dementia needs mind support. This means living in a world with people and objects that are reliable, trustworthy, and available.[12] A caregiver is a key part of this mind support. A caregiver uses the environment—the space, objects, other people—to identify and relieve sources of suffering, to prevent nostalgia.

The concept of home here is not necessarily the home the person has dwelt in and the people they have known for decades. Marvin is a patient of mine who has dementia caused by Lewy Body disease. This causes him to distort his perception of home and the people within it. When he is in his home of many years, he insists, this is not my home, but another home that has been replicated to look like my home. So too his daughters and sons, who devote their days to caring for him and efforts to convince him that he is at home. He says they are not his children but people replacing them.

Bizarre, surreal efforts unfold to relieve his nostalgia. His children take him out of the house and drive him around as they tell him they are going to that home. In time, they return to the house they just left. Sometimes this theater of the surreal works. Sometimes it does not and Marvin becomes aggressive and angered. Antipsychotics have been prescribed.

These distorted perceptions are common in persons with Lewy Body disease, and some patients become so "homeloose" that in addition to antipsychotics, I prescribe a new home, one of those residential units that persons like Steve build and direct. In time, in this entirely new place and among new people, he adjusted. Perhaps he forgot about his home.

The absence of nostalgia is not simply the absence of agitation. A person who seems content may be suffering. Consider the case of a person with dementia who does very little all day but sit in a common TV room, struggles to speak more than 6 words, and has profound anosognosia. We should assess the mind support they are receiving. Is this person living in and capable of interacting with people and objects that are reliable, trustworthy, and available? Are these people and objects correcting their disabilities? Does this person, like the residents in Alder Gates' new world, have meaningful experiences? If the answers are negative statements, then the person is suffering. No matter what they say. Or cannot say. Or forget to say.

Some minds that are receiving available, trustworthy, and reliable mind support are subjectively suffering. Amy Bloom recalls the good days and bad days with Brian. A good day was watching a Scottish murder mystery on TV together in bed. She would fall asleep, awaken and he would explain why the chicken coop was covered in blood. They would eat cookies. The bad days were when a heavy gloom descended on Brian—she writes, "It makes for a dark house."[13]

This account of suffering as nostalgia has a morally significant feature. Another person has a substantial role in providing mind support; meaning, another person identifies and relieves suffering. We commonly call these people caregivers. Caregiving seems to be the quite ordinary work of an unpaid housekeeper, and yet, the decisions made by the caregivers recounted in this essay show how behind the ordinary are some quite extraordinary consequences. Steve could have gone along with the status quo and built a dormitory cum hospital-style addition. My patient's son could have taken his mother to the

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emergency room for an evaluation of acute agitation. Undoubtedly, she would have been hospitalized and a cascade of mind and body destructive events unfolded. These persons intimately wrapped up in observing and relieving the sufferings of another person have a morally significant role.

Amy Bloom recounts how a moment of brightness comes to Brian. It is an email from a friend. Would Brian, an accomplished fishing guide, like to arrange a fishing expedition on the Housatonic River for this friend and her husband? He likes the idea. Amy does not.

She reflects on how this expedition will affect both of them. The labor of this caregiving, of this mind support, so he can have this meaningful experience, means she will have to set up the expedition and backstop Brain all the way.

"He mulls it over and I keep my mouth shut. At a couple of points, I actually lay my hand over my mouth. He can't do it. He can still fish and he could show someone how to cast, but he can't arrange an expedition and I don't want to do it. I don't want to help them have a once-in-a-lifetime day of fishing on the Housatonic River."[14]

He muses aloud on the idea. And then he makes a decision. No. No, he will not do it. He steps away from the email. She is relieved but then she is not. "I want to run after him and say we can do it if you really want to."[15] But she remains still.

A few months later, they are seated side by side on a couch in a suburban Zurich apartment. There, Brian takes his lethal dose of phenobarbital. He was there because he wanted to be and also because of her meticulous administrative support. She recounts for example how during a call with the Dignitas staff, she writes "Alzheimer's" in all caps on a page of a notebook so that Brian can correctly state his diagnosis and not one of the word substitutions he had started to commit: "Anheuser" or "Arthritis."[16]

As he gets comfortable on the couch, Amy takes his hand, but in time she has to release it because he is gesturing as he tells a story. It is about his college years as a football player. Amy writes, "The stories are all about football at Yale and his coach…I cannot manage to look interested in these stories, because I am not."[17] She then writes an extended parenthetical. "Brian says nothing about his life, about our life, about our love, about the children and grandchildren, not about the beautiful public housing he designed and cared so deeply about or the work he did for the conservation and open spaces or even, and you know I must be reaching here, about fishing."

This is her account of her thoughts. What about her feelings? She writes. "I try not to look like I'm in agony, which I am."[18] In her entire life, she has never felt so bad about "being me." The relief of Brian's sufferings—subjective and objective—caused her to suffer.

Persons with dementia can suffer because they tell us so. Or, as in the case of Dan Gibbs, they tell us they are not suffering. We too can assess whether they are suffering because they lack reliable, trustworthy, and available mind support. What is notable is how the person in that role also suffers. It is a caregiver's efforts to balance amongst these sufferings, to decide how much of whose suffering is enough, that is the tragedy of living and dying with dementia.

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Cite this article: Karlawish J (2026). How do Persons With Dementia Suffer? *Cambridge Quarterly of Healthcare Ethics* 35: 32–39, doi:10.1017/S096318012500012X

https://doi.org/10.1017/S096318012500012X Published online by Cambridge University Press