

How People With Dementia Make Sense of the World

The human brain has a way of creating logic, even when it's drifting from reality.

By Dasha Kiper



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Elizabeth often met her husband, Mitch, after work at the same restaurant in Lower Manhattan. Mitch was usually there by the time she arrived, swirling his drink and joking with a waiter. Elizabeth and Mitch had been friends before becoming romantically involved and bantered back and forth without missing a beat. Anyone looking at their table might well have envied them, never suspecting that Elizabeth dreaded these pleasant get-togethers.

Elizabeth, a tall, elegant woman, told me about those evenings in a composed, confiding tone, which only makes her story more uncanny. (Both her name and Mitch's have been changed to protect their privacy.) Once the meal was over, Mitch would invariably give her a wary, skeptical look and say, "Now you'll go to your place and I'll go to mine." Hearing these words, Elizabeth would nod meekly, then duck into the bathroom for a minute before running out. She'd cross the street, wait for Mitch to emerge—making sure that he was headed in the right direction—and then hurry home to wait for him.

It always struck her how normal Mitch appeared. It was herself she barely recognized: the nervous, frazzled woman hiding behind lampposts, following a man who looked so at ease in the world. Then, with a burst of speed, she managed to get back to their apartment a few minutes before he did.

Arriving home, Mitch always gave her the same cheerful greeting: "Hey, honey, how are you?" He had already forgotten their rendezvous.

The nightmare would officially begin after Mitch had made himself comfortable. Without any warning, he'd look up from a magazine or the TV, stare at Elizabeth, and ask her to leave. Calmly at first, he'd order her out of her own home. When she tried to convince him that she was home, he'd scoff. How could it be her home, when he lived there? Although he sensed that they knew each other, he had forgotten they were married. Moreover, he felt threatened by her presence.

When Mitch first began to act this way, Elizabeth had done her best to plead her case. She'd point to things in the apartment and remind him of where they came from. "Look," she'd say. "Our wedding picture, see?"

Unfazed, Mitch would reply. “Yeah? You must have planted it there.”

“But look, I can tell you everything that’s in the closet or anywhere else in the house. We’ve lived here 15 years, me and you, remember?”

“So you’ve been snooping around my apartment. Now stop touching my things and get out before I call the cops.”

Some evenings, when she stalled, he flew into a rage, grabbed her by the neck like a stray cat, and pushed her out the front door, where she sat all night in the hallway.

But Mitch wasn’t predictable—sometimes he seemed perfectly normal in the evenings; at other times, he magnanimously let her remain. But as his episodes grew more frequent and his recalcitrance more extreme, her exile in the hallway became almost a nightly routine. She took to carrying a spare key in her pocket and would let herself in when she thought Mitch had fallen asleep.

Mitch had Alzheimer’s. I met Elizabeth in 2016, when I was a volunteer at an Alzheimer’s organization in New York City. I’ve remained in touch with her since, even after Mitch’s eventual death from the disease, in 2020. Although Mitch had already been diagnosed by the time Elizabeth and I began discussing her case, she was surprised at the turn his condition had taken. Many people with dementia experience occasional delusions and hallucinations, but relatively few become as fixated as Mitch did on the fact that a spouse is an imposter. I once asked Elizabeth

why she thought she continued to argue with Mitch when she knew it wouldn't do any good. She chuckled. "The thing is, he had an answer for everything. No matter what I said or could prove, he had an explanation. I just couldn't let it go."

When patients with dementia have an answer for everything, caregivers get caught in a loop. It's surprisingly hard not to be goaded by a patient's responses. Even if the answers are nonsensical, the patient's ability to provide them suggests that we're still dealing with a functional mind. Indeed, the part of the mind that helps patients produce a steady stream of answers remains intact. It was this part—what the neuroscientist Michael Gazzaniga has termed the "left-brain interpreter"—that Mitch was now leaning on. The "interpreter" is an unconscious process responsible for sweeping inconsistencies and confusion under the rug. When things don't add up, when our expectations are flipped, when our environment suddenly changes, the left-brain interpreter provides explanations that help us make sense of things.

For instance, patients feeling anxious or afraid because of memory loss or confusion will come up with explanations for their disorientation. They'll blame the aide for misplacing a purse or insist that people are conspiring against them. When they feel internal discord, their unconscious mind searches for an external source, and this source gives shape to their paranoia. So when Mitch was confronted by evidence that Elizabeth was his wife, which contradicted his impression that she was someone else, his left-brain interpreter found explanations for that evidence—for instance, that it had been planted in his apartment.

This is partly why so many patients are adept at coming up with quick (albeit wrong) answers and rationalizations for their warped views. The

mind's propensity to create believable narratives is all too human. In a 1962 study that would surely be considered unethical today, the psychologists Stanley Schachter and Jerry Singer administered epinephrine to their subjects. Epinephrine, a synthetic hormone that narrows blood vessels, can produce anxiety, shakiness, and sweating. Some participants were then informed that they had been given a vitamin that had no side effects. The others were told that the pill could produce a racing heart, tremors, and flushing. Those who knew about the possible side effects immediately attributed their discomfort to the drug. Those unaware of possible side effects and who experienced agitation blamed their environment, even thinking that the other participants were responsible.

We evidently have a tendency to find reasons for what disturbs us rather than remain in the dark. This need to ascertain cause and effect is yet another function of the left-brain interpreter, and it plays out in many ways. For example, we'll assign reasons to our feelings despite often not knowing their true cause. We'll twist facts, defend misconceptions, and opt to believe whatever makes sense of what's happening around us. So when patients argue, caregivers may find it difficult to distinguish pathology from the mind's normal tendency to resist what it doesn't know.

At one of our meetings, Elizabeth described a particularly unsettling moment with Mitch. One evening, amid a harrowing confrontation, instead of throwing her out, Mitch suddenly relaxed and turned on the TV. He flipped through the channels, then stopped on the opening

credits to the movie *Doctor Zhivago* and, hearing its music, reached for her hand.

“Imagine,” Elizabeth said softly, looking at me, “we’re holding hands.”

The perpetuation of the sweet Mitch is what kept her off-balance. Because alongside the man who didn’t recognize her was the man who might stroke her hair and ask how she put up with him. Alongside the man who threw her out was the man who made a video for their anniversary in which he confessed how lost he’d be without her. If that Mitch did not exist—if Elizabeth had had only the delusional Mitch to deal with—her left-brain interpreter would have had less to contend with. Instead, her brain was badgered by inconsistency and uncertainty.

When we think of Alzheimer’s, we usually think of it as erasing the self. But what happens in most cases is that the self-splinters into different selves; some we recognize, others we don’t. In fact, the self, or, more accurately, “self-representation” in the brain, is not, as the philosopher Patricia Churchland phrased it, an “all-or-nothing affair.” Instead, our “self” is distributed throughout the brain, which can make Alzheimer’s even more complicated than is generally believed. If the self is, in some sense, already fragmented, its gradual erosion can remain unnoticed behind the ebb and flow of a person’s familiar personality. Cases, of course, vary, and quite commonly Alzheimer’s doesn’t get rid of the self as much as it brings parts of it to the fore.

For Elizabeth, Mitch was still Mitch. A loved one’s identity doesn’t evaporate when change occurs. One reason for this may be our unconscious belief in what the psychologist Paul Bloom refers to as the “essential self.” Early in our development, we attribute to other people a

permanent “deep-down self.” And though our understanding of people becomes more complex as we grow older, our belief in a “true” or “real” self persists.

When experimental philosophers, interested in how we define the self, asked participants to consider what happens when a hypothetical brain transplant affects a subject’s cognitive abilities, personality, and memory, most participants continued to believe that the subject’s “true self” remained intact. Only in those cases where the subject began to behave in morally uncharacteristic ways—kleptomania, criminality, pedophilia, or engaging in other abhorrent behaviors—did participants conclude that the “true self” had been radically altered.

Bloom explains that we’re more likely to associate the “good” qualities in people with their true selves— “good,” of course, as defined by our own values. In this sense, another person’s “true” self is an extension of what we hold dear. So, if the essential self is intuitively equated with the moral self, then the cognitive problems attending dementia can seem peripheral as long as changes in behavior do not run “deep enough” to redefine a husband or a father. The reason Elizabeth kept arguing with Mitch was that she was appealing to the “real” Mitch, the “good” Mitch, the one “still in there,” the one who, in the past, would have come to her aid.

For caregivers, the idea of a “real self” can be a double-edged sword. If, on the one hand, it encourages us to argue with afflicted loved ones in the hope of breaking through to their “real selves,” it can also be a source of great frustration. If, on the other hand, we start to doubt the existence of an essential self, how can we account for the person we’re caring for? Who is it that we are suffering and sacrificing for?

As Mitch's cognitive capacity ebbed, so too did his confusion. He became calmer—and so did Elizabeth. Even so, Elizabeth told me that he could still, on occasion, become upset. One day when Mitch was filling in a coloring book, an activity he previously would have found beneath him, he looked up and said, "I think there's something wrong with me."

"Well, honey," Elizabeth said gently, "you have something called Alzheimer's, and that's okay, I'm here for you."

Mitch furrowed his brow. "No, that's not it. I don't have that. Why would you even say that?"

Telling me this, Elizabeth reprimanded herself: "I felt awful upsetting him." But her response was only natural. When Mitch sensed something was wrong, she thought, for a moment, that she had glimpsed the old Mitch, the true Mitch. So she had confided in him as she had in the past, hoping he'd understand.

This article has been excerpted from Dasha Kiper's new book, Travelers to Unimaginable Lands: Stories of Dementia, the Caregiver, and the Human Brain.