

EDITED BY
NAN BAUER-MAGLIN
AND DANIEL E. HOOD



Loving Arrangements

Stories About

Modern Living and Loving

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MY FATHER'S ALZHEIMER'S ROMANCE

Stephanie Golden

My twice-widowed father had one last love, in an Alzheimer's care facility. Was it true love? I neither know nor care. But I do know that it was, briefly, a blessing.

His first marriage was to my mother, whom he met in a class at James Madison High School in Brooklyn when they were both fourteen. They stayed a couple throughout high school and college, got married in their early twenties, and remained firmly attached until my mother died of cancer twenty-five years later. My father was deeply domestic, so used to being with a woman that he kept trying to turn the two housekeepers he hired after her death into wife-adjacent companions—naively, he thought he could do this without a sexual relationship. The first woman, prim and nervous, was uncomfortable being put in that position and didn't stay long, while the second one tried to climb into his bed, which (he told me) he wasn't looking for. Eventually he began dating, and after five years as a widower, he married my stepmother. That marriage lasted thirty years.

In the 1990s, he developed dementia but was otherwise healthy and strong. At the same time, my stepmother's smoking-related lung condition worsened, though her mind stayed sharp. With her the brains and him the brawn, they managed together well enough for a while. But when she died, he couldn't function on his own. Even in that state, women neighbors in his Florida condo descended on him, bearing casseroles. In the past he

would have gotten a kick out of this, but now they frightened him. So my brother and I moved him to assisted living. He liked the place, and we were relieved that he was happy and safe.

On one of our visits, the facility manager told us, in the most delicate possible terms, that our father now had a girlfriend, who also had dementia. She thought this might upset us, but we were pleased. We met Felicia that same day, since she and my father spent all their time together and slept together too, in his room or hers. She was a handsome, sweet-natured woman about his age. (I'm calling her Felicia, since they were certainly lucky to find each other and clearly happy together.) Whether actual sex was involved I have no idea. They were certainly physically affectionate—in one photo my brother took, they sit side by side holding hands; in another my father leans against the headboard of the bed in one of their rooms while she lies against his chest with his arm around her. On her face is an expression I recognize: the self-satisfied contentment of a woman who has her man—though her eyes are vague. My father doesn't look quite so blissful, though he clutches her shoulder tightly and his gaze has that same vagueness. What comes across undeniably is their familiarity and comfort with each other.

Felicia wore beautiful clothes and tasteful jewelry; I got the impression that her family had money and took good care of her. The four of us had lunch in the dining room, and right away she turned to me and said, with a grand romantic lilt, "Did I tell you how we *danced*?" They were of the generation that grew up on the waltz and foxtrot. "How lovely," I said. Ten minutes later: "Did I tell you how we *danced*?" "Yes," I said, "it sounds so nice." This went on, every ten minutes, during the entire lunch, as though her life were a Rogers and Astaire movie.

After lunch we moved outside to sit on the terrace, and "Did I tell you how we *danced*?" continued. Suddenly, my father's dementia fell away. The old easily irritable Dad popped out and snapped, "Yes!!" As in "I *know*, you've said it fifteen times already!" Fortunately, her short-term memory

was far more deteriorated than his, and if she noticed his tone she forgot it instantly.

I was happy to see him enjoying female companionship again, but shortly after we returned to New York, we got a call from the manager, who explained that Felicia's family was scandalized and insisted that she and my father be separated. Maybe they felt squeamish—or repulsed—at the thought of their mother sleeping with a man at her age, or maybe just a man she wasn't married to. Maybe she was actually still married. Possibly they suspected us of scheming for her money. In any case, the next time we visited, Felicia was nowhere to be seen.

It didn't have to happen. People in dementia care facilities quite commonly fall in love with another resident—sometimes when their spouse is still alive and visiting them—and their relatives may even cheer. In 2005, Justice Sandra Day O'Connor resigned from the Supreme Court to care for her husband, John, who had developed Alzheimer's. When she was no longer able to do this at home, she moved him to a care facility. He was "unhappy" about moving but almost immediately fell for another resident. "Forty-eight hours after moving into that new cottage he was a teenager in love," the O'Connors' son Scott told a Phoenix TV station. "Mom was thrilled that dad was relaxed and happy." She continued to visit, "beaming next to the happy couple as they held hands on a porch swing." I still today wish Felicia's family had been like that.¹

Whether people in care facilities get to enjoy new romances often depends less on their own desires than on discomfort and taboos centered around sex, aging, and gender roles, among both families and caregivers.² Families and facility staff may feel repulsed or fear that the resident is being abused, and caregivers also fear losing their licenses over issues of consent and the legal requirement to prevent abuse.

In one excruciating case in Iowa, the question of whether a person with dementia can consent to sex made it to court. In 2014, Henry Rayhons, a farmer and state legislator, was charged with a felony for supposedly

raping his wife, Donna, who lived in a dementia care facility and was said by her daughters and the staff to be unable to consent. The Rayhons, who married late in life after both being widowed, had been inseparable, a particularly devoted couple. According to Henry, Donna enjoyed sex and during his visits occasionally asked to “play,” as she put it. As he told the prosecutor, “I always assumed that if somebody asks for something, they have the capacity to consent.” A jury eventually agreed and found him not guilty, but Donna’s daughters and the facility management kept him away from her during most of the last weeks of her life. By the time of the verdict, Donna had died; Henry’s legislative career was in ruins, and he was left with his grief.³

The Rayhons were deeply in love, while my father and Felicia seemed more like affectionate companions. My sense was that they were deriving pleasure and satisfaction from performing familiar behaviors from their past marriages. And why not? The need for loving touch and sex doesn’t go away in dementia. Studies have linked sexual expression—ranging from kissing and holding hands to more explicit forms of intimacy—with a decrease in depression and overall improved mental and physical health and quality of life.⁴ The Hebrew Home in Riverdale, New York, has a written policy to guide staff in managing residents’ sexual relationships. “We knew that there was intimacy occurring, and we considered it to be a civil right and a legal right,” said Daniel Reingold, CEO of the nonprofit that runs the home. “We also felt that intimacy was a good thing, that touch is one of the last pleasures we abandon and lose as we age.”⁵

Such a welcoming stance is relatively rare, however. Often residents’ desire for sexual expression runs up against disgust, repugnance, and shame among staff, who feel obliged to discourage their sexual expression. Much research has shown that even in late-stage dementia, people “are capable of meaningful expression of choice and understanding.” Yet in one survey, staff members “assumed that a diagnosis of dementia renders a person incapable of consenting to any intimate or sexual activity”

and “interpreted all sexual expression as nonconsensual,” so they tried to prevent it.⁶

We were lucky that my father's care facility was willing to accept his relationship until Felicia's family objected. It occurs to me now that her family might also have feared abuse. But if they ever saw them together, I don't see how they could possibly imagine he was abusing her. From my perspective, she could well have been the engine driving that relationship.

Donna and Henry Rayhons had been married six years when her daughters put her in her facility, and she continued to love him. She cried when one daughter had her moved into a room with a roommate to deter Henry from sexual behavior and accused her of not liking him.⁷ I doubt that my father and Felicia, who met after their minds had been substantially affected by dementia, had the capacity to form such a deep emotional bond. But I saw clearly how powerfully their companionship supported their well-being. I worried about how my father might react to losing her, but as it turned out—fortunately, given the circumstances—he forgot her pretty soon. I was the one left sad that he'd lost this sweet connection.

Some time after he was separated from Felicia, his behavior became so erratic that he had to be moved from his pleasant hotel-like room to a locked (though still fairly pleasant) ward under more supervision. In the end, he hit his head in a fall and was sent to a nursing home, where he died. I can't help wondering if he might have lasted longer outside the locked ward if he hadn't been deprived of the structure and the physical and emotional stimulation of Felicia's company. Indeed, my brother reminded me of “their need to be always touching, as if that, aside from simple affection, created a point of contact, a grounding.” However one might describe their relationship, it was indeed a relationship—and their brief time together *was* a Rogers and Astaire movie.

NOTES

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2. Alisa Grigorovich et al., "Dementia and Sexuality in Long-Term Care: Incompatible Bedfellows?," *Dementia* 21, no. 4 (December 14, 2021), <https://journals.sagepub.com/doi/10.1177/14713012211056253>.

3. Bryan Gruley, "Can a Wife with Dementia Say Yes to Sex?," *Des Moines Register*, December 13, 2014, <https://www.desmoinesregister.com/story/news/crime-and-courts/2014/12/13/former-legislator-charged-rapingwife-dementia/20305991/>; Pam Belluck, "Iowa Man Found Not Guilty of Sexually Abusing Wife with Alzheimer's," *New York Times*, April 22, 2015, www.nytimes.com/2015/04/23/health/iowa-man-found-not-guilty-of-sexually-abusing-wife-with-alzheimers.html/.

4. Grigorovich et al., "Dementia and Sexuality"; Ed Diener and Micaela Y. Chan, "Happy People Live Longer: Subjective Well-Being Contributes to Health and Longevity," *Applied Psychology: Health and Well-Being* 3, no. 1 (2011): 1-43, https://scholar.google.com/scholar_lookup?journal=Appl%20Psychol%20Health%20Well%20Being&title=Happy%20people%20live%20longer:%20Subjective%20well-being%20contributes%20to%20health%20and%20longevity&author=E.%20Diener&author=M.Y.%20Chan&volume=3&publication_year=2011&pages=1-43&

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6. Grigorovich et al., "Dementia and Sexuality."

7. Gruley, "Can a Wife with Dementia."