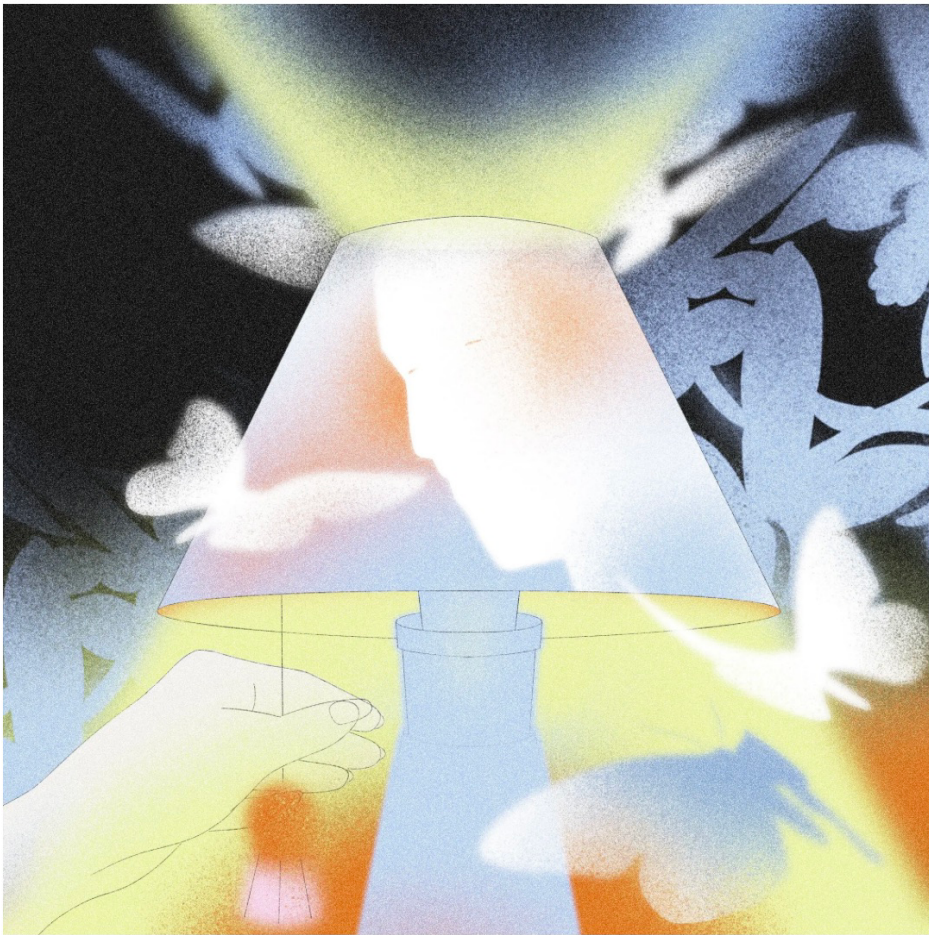


We May Soon Be Telling a Very Different Kind of Story About Dementia

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By Lynn Casteel Harper

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If you've heard about Molly Jong-Fast's new memoir, "How to Lose Your Mother," it won't surprise you that a great many readers are coming for the juicy matricidal takedown of the feminist icon Erica Jong. I came for the dementia.

Ms. Jong-Fast bracingly challenges the sentimental conventions of so many family stories, refusing to sacrifice her story to preserve appearances. The telling of her mother's cognitive decline, however, follows a pattern that shapes how we write and even talk about dementia, a condition that affects 57 million people worldwide. It's been described as the tragedy narrative. Perhaps you've noticed it, too.

In its various iterations across books and films, the dementia tragedy narrative tells a story of inexorable decline and universal diminishment, in which the afflicted person steadily vacates her body until she becomes essentially absent. While this process may include moments of lucidity or levity, nothing substantially positive, life-giving or new can emerge for the person or her family and friends — because the person *as person* is disappearing. "My mother is just a body now," Ms. Jong-Fast writes. "She has dementia. She has breath and hair and pretty blue eyes but Erica Jong the person has left the planet." She is "dissolving," "slipping away," "a faint fragment," "an echo," "a zombie."

The trouble with this well established approach is not that the tragedy narrative is completely false. There are indeed losses and suffering associated with dementia, experiences that confound and aggrieve, and these descriptions resonate with many people's own experiences. The problem is that narrating them in this manner, turning a multidimensional phenomenon into a story of unidirectional decline and disappearance, reinforces stigma around cognitive disability. And the notion that people are gone before they are dead directly harms the care they receive, exactly when they need it most.

People with dementia are extremely vulnerable to being abused and neglected, financially drained (even just to get necessary care), improperly medicated and restrained, infantilized, ignored and socially abandoned. The tragedy narrative obscures the reality that a significant measure of their suffering emerges not from the condition alone, but from the social response to it — the part of the situation we are most able to fix.

These assumptions are easy to find. They're sprinkled liberally throughout everyday language and metaphors, appearing anytime dementia is imagined as

ceaseless suffering that turns people into shells, husks, the living dead or at least less “real” versions of themselves.

You can find it in “Still Alice,” the popular novel and movie about a professor’s early onset Alzheimer’s. We see her stumble embarrassingly while giving a lecture, get lost on a run, forget buildings on her own campus and, in the end, fail to register her daughter as her daughter. The unraveling of an accomplished, 50-year-old professional heightens the tragic dimensions of her decline. “I remember I used to be very smart,” she tells her husband in the novel. Later she adds, “I never planned to get like this.” While the story contains elements that transcend the tragic (in the epilogue, Alice and her daughter share a special moment of connection and love), the narrative hinges on imagining dementia’s horror.

Amy Bloom’s “In Love: A Memoir of Love and Loss,” about her husband’s diagnosis and its aftermath, follows the tragedy narrative to its natural end. “It took Brian less than a week to decide that the ‘long goodbye’ of Alzheimer’s was not for him,” she writes. “I’d rather die on my feet than live on my knees,” he tells her. The “long goodbye”— the idea that Alzheimer’s entails an unending march of grief — is the tragedy narrative’s hallmark image. And it is an unquestioned truth in the book, as Ms. Bloom sets about carrying out her husband’s wishes by helping him secure access to physician-assisted suicide. Snapshots of his forgetfulness pepper the book, hinting at the future decline that the couple will mercifully avoid. The only way to head off dementia’s horror, says the tragedy narrative, is to find a cure or to take matters into your own hands.

My interest in the subject is not just literary. My mom’s dad and my dad’s sister, cousins, aunts and uncles all died from Alzheimer’s, the most common dementia-producing disease. Both of my parents carry a copy of a gene variant linked to later-onset dementia. My 72-year-old father (asymptomatic so far) is in a drug study for people at high risk of developing Alzheimer’s. I have served as the chaplain on the dementia unit of a nursing facility and as the minister of older adults at a large church. I am involved with a dementia advocacy organization, largely spearheaded by people living with dementia.

I have seen up close that dementia is not just a decline unto death. It can also involve ascendant humor, compassion and connections beyond the strictly rational. It’s important for us to talk about it, to tell stories about it, to write books and make movies about it. But we need new ways to do so.

The good news is that other approaches are emerging, stories that offer multifaceted depictions of dementia, situating the condition and those it affects back on the spectrum of human experience. Rebecca Barry, in the beautiful [essay](#) “Alzheimer’s Can Be a World of Endless Second Chances,” frames her evolving relationship with her father, who has the disease, as filled with the freedom of new experiences, the surprise of having more of her father, not less, and the graces of developing “the heart connection.” Suzanne Finnamore, the author of “My Disappearing Mother: A Memoir of Magic and Loss in the Country of Dementia,” writes of her mother’s deep dementia as the land where her mother lives, rather than the totality of who she is. After grappling with the initial shock of the diagnosis, Ms. Finnamore discovers the “unexpected gifts” of traveling with her mother to “the land of Dementia.” Meeting her wherever she resides in that moment makes room for a range of feelings and memories to emerge. “There is dignity in Dementia if we say there is,” Ms. Finnamore [writes](#). “There is wisdom and humor and radiance if only we can see it.”

In “Dad, You’ve Got Dementia,” the poet Kristen Phillips turned her conversations with her father into poems, a particularly suitable form for a condition that resists the linearity of traditional storytelling. Rather than noting only what was lost, Ms. Phillips says she heard “magic and beauty in what Dad was saying as his brain searched for words.” A new film, “[Familiar Touch](#),” tells the story of a woman with dementia who is transitioning to life in assisted living, told from her perspective. The director, Sarah Friedland, in a director’s note, says she resisted framing the story “within the trope of the decline narrative.”

People living with dementia are also telling their own stories beyond the tragedy convention. Samuel Simon’s [play](#) “Dementia Man” tells of his at times frustrating journey to diagnosis, his insistence that he is not vanishing and his emerging sense of justice for those living with the condition. Sy Safransky, the founding editor of The Sun magazine, [writes about his dementia](#) with a sort of wry nonattachment, declaring, “Dementia is what it is, not bad, not good. And anything can happen in anyone’s life, anywhere, anytime.” He continues, “Things fall apart. Move on.”

Book-length memoirs written by people living with dementia, such as Dr. Jennifer Bute’s “Dementia From the Inside” and Christine Bryden’s “Dancing With Dementia,” offer nuanced and unexpected approaches. Dr. Bute, a retired physician, calls dementia a “glorious opportunity” to increase her empathy for

what others, including former patients, have experienced. Ms. Bryden speaks of her increased ability to “connect at the deeper level of spirituality,” as certain cognitive abilities fall away. None of these stories denies suffering. Suffering is simply not the centerpiece.

Toward the end of Ms. Jong-Fast’s memoir, she describes a point during her stepfather’s funeral when her mother wants to speak. Ms. Jong-Fast accompanies her to the podium, trepidatious about what she will say. Ms. Jong offers a few heartfelt sentences about her husband of 30 years. The section ends with Ms. Jong-Fast taking her mother’s hand and reassuring her that she did a good job. This tender moment gestures toward the possibilities — even amid fraught relationships and difficult diseases — of story lines beyond the tragic.

<https://www.nytimes.com/2025/06/14/opinion/dementia-alzheimers-family-memoir.html>

How we selectively seize upon differing aspects and presentations—even outliers—to craft narratives trying to dominate definition a variegated subject! Dementia is many things with a variety of presentations, but I do not know how it could be “wished” on anyone or rationalized so cheerily.

As a son who dealt directly with escalating engagement my mother’s idiosyncratic dementia for years, first at home and then supporting her in Long Term Care—she was in care for 13 months and 2 days, and I was present for every one, running interference with staff, working with them engaged with an at-times “difficult” character, and striving to prevent her quick descent into becoming just one more senile old lady moaning in a bed—I learned something of what “good” can be salvaged from such processes, and what cannot. What I am sure of is that it is hard work. Staying fully involved with my parents through their last debilitating years was the hardest thing I have ever done—and the best. It cost me a career and financial freedom, but I would do it all over again, only better and with my whole heart from the beginning.

There are some videos (if they still play) posted on this site that back this up.

But a friend of mine has a beloved father dying held in the iron grip of vascular dementia. Nothing can assuage the pain of this for those watching—and for whatever intermittently and faded is left of a larger-than-life great man watching it all from the inside. No one deserves this, and any compensations and consolations are very, very meagre at best. One can only pray for comfort and peace, relief and release for him and everyone who loves him. TJB