

# I Was My Mom's Caregiver When She Was Terminal. I Was Shocked By What I Didn't Know About Dying.

249

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*The author and her mother.*

The afternoon we found out she had six months to live, Mom and I watched "Hello Dolly." My freshman year of high school, the same year Dad left and my older brother Bob joined the Navy, Mom and I had Streisand's "Broadway Album" in the tape deck as we ran errands or drove to the Burger King by the mall for our chicken sandwich meal deal. Her hands at 10 and two on our Mazda's blue steering wheel, she'd wink at me and say, "Just you and me, kid," like she wouldn't have it any other way.

The film's message, Dolly Levi deciding to once again embrace life after mourning the death of her husband, now felt grotesque. By the time we got Mom's diagnosis at the end of May, her oncologist, Dr. Li, told us surgery wasn't an option. The cancer was everywhere.

When I became Mom's full-time caretaker, I anticipated days of reading together and having emotionally agonizing but closure-providing conversations. I imagined myself being the perfect daughter, returning all of

the care and patience Mom had showered upon me, upon all of us. I would take my new role in stride and be admired for it.

However, moving Mom into my daughter's downstairs bedroom with horses on the wall, there were things I didn't expect:

### **Like that I would be cruel.**

Mom's first radiation appointment left us with just enough time to get home and log Henry, my 6-year-old son, on to a Zoom with his new therapist. I knew Dr. Namdari would've been forgiving of a phone call to say we were running late, but leaving the parking structure, I was hell-bent on *making it*.

The ticket machine wouldn't work. Or my card wouldn't work. Or I needed singles. I let out a growl, letting Mom know that her appointments, her stage-four cancer, her cumbersome walker, her *needs* had impeded on my role as a mother. I wanted her appreciation, no her *submission*, to the fact that a lot of people needed a lot of things from me. In that cruel exhale, I was letting her know that my kids came first, she and her cancer came second.

But cancer doesn't accept second place. The constant roulette of symptoms that require never-ending adjustments to medications, the appointments, and the falls, demand first, leaving patient and caregiver chained to a gruesome game of Whack-A-Mole. While I was caring for Mom, the kids would come second, though none of us wanted it that way. Least of all, Mom.

Our roles being almost completely reversed made us both resentful. I'd been barely keeping my head above water with three kids, and now I had another. Bob would tell me later, Mom had confided in him with the exasperation of someone being harassed, "She's trying to bathe me like one of her kids!"

### ***Mom would be in denial.***

After a second harrowing hospital stay in which we weren't allowed to visit due to COVID, Mom decided the cancer was simply gone.

"The topic is not open for discussion," she said when we attempted to argue. It was a phrase she'd used often when raising us, to end our case-making for why we needed to keep the litter of kittens born on the floorboard of our rusted-out Chevy Nova, or get a hotel room for prom.

The effort it took to accommodate her denial was exhausting, but with the way she'd batted away early attempts to acknowledge the cancer, it was clear we'd be rolling with Mom's version. When we met with Dr. Li, I'd make up a reason to speak with him alone before bringing Mom into the room, reminding him: "Nothing about dying." I met her nurses at my front door and asked them to remove their white coats that read "Salus Hospice" on the lapel. Before family Zooms, I'd call aunts and cousins who thought they were saying goodbye, to awkwardly prep them.

I called Bob, huddled in my van in the driveway, so the kids wouldn't hear.

"We have to make her face it!" I said. "We've got to get on the phone *together* and say, 'Mom, you're dying. The cancer in your kidney is still there; it didn't go away.' *We have to!*"

I heard myself shrieking.

Calmly, from 850 miles away, Bob said, "Yeah, I hear what you're saying. I get it, I do. But she's only got a few months, maybe, left? What if we just let her think that, if that's what's getting her through? It's not hurting anyone. I mean I know it's driving *you* crazy, but," he paused. I could feel the love in his recalibration: "You're the one who's there, doing this. If you wanna tell her, I'll get on a call with you tomorrow. It's up to you."

We didn't confront mom.

It wasn't even her denial I was railing against. It was that her rejection of her terminal diagnosis put a galaxy of space between us. We were living in two different worlds when we'd always been a unit.

The unprecedented loneliness I felt in her presence filled me with a sorrow that would've undone me if I hadn't turned it into anger. Her brain chose to reject the truth. We were both doing what we needed to do to survive. Or, in her case, to die.

### **Sadness wasn't my overriding emotion.**

In the fall of 2020, the kids had in-person, socially-distanced school for two hours each morning. I was thrilled when Henry came home with a scribbled note asking me to, "Text Owen's mom."

We met Owen and his mom, Kim, at the park, and the boys took off on their bikes. Thanksgiving was coming up, and Kim asked what we had planned for the holiday.

“It’ll just be our family,” I said. “I’m taking care of my mom — she has cancer, so we’re being really careful.”

“I’m sorry,” she said, meaning it. “I hope she gets better soon.”

“Thank you,” I said. “But she won’t. It’s terminal, so we’re just trying to keep her comfortable, give her lots of time with the kids...”

My eyes were focused on the far side of the field, watching for the boys to crest the hill. When I looked back at Kim, tears trembled in pools before spilling onto her cheeks. She searched my face, unsuccessfully, for the emotion she felt.

*Why hadn’t I just said we were having a family dinner and left it at that? I’d pushed Kim into The Cancer Pit and wasn’t even willing to jump in with her. She was imagining her mom back in New Hampshire who probably got down on the floor and raced Matchbox cars with Owen. I was imagining Mom nodding off on the toilet due to exhaustion and level-three opioids.*

I sat there nodding at Kim with a sympathetic smile. There was not a second playdate.



The author and her mom on her wedding day.

## **The physical changes that happen at end of life.**

As a younger woman, I’d pictured the end of Mom’s life: She was in a bed in a book-lined alcove in my home. A glass pitcher held a large bunch of daisies, sunlight streamed through clean window panes. Mom read and slept, and her closest friends came by to tell long-perfected stories.

In reality, during the last two weeks of Mom’s life, she was non-verbal, non-ambulatory, and had lost the ability to swallow. Her skin was starting to separate, or as the nurses said, “losing its integrity.”

Alex Trebek and Mom were dying of cancer at the same time. The unwelcome news of his death was beamed into her bedroom as I fumbled

with the remote. The announcer said Alex had spent the last day of his life on his backyard swing, chatting with his wife, Jean. The screen filled with a photo of the two of them, Alex in full TV makeup, including brow pencil, coiffed hair, and what looked like a blue cashmere sweater. Jean was turned toward him, the adoring, younger wife to her fatherly and famous husband.

I guaran-fucking-tee Alex Trebek was not on his backyard swing the day he died. He was most likely on liquid morphine, his mouth hanging open, and at least one of his eyes refusing to close, because as the hospice nurse gently explained, “It takes more energy for them to close their mouth and eyes than it does to keep them open.”

Each death is unique, but cancer deaths have a similar trajectory and non-verbal, non-ambulatory are par for the hellish course. There is no Instagrammable filter on death.

### **What the actual moment of death would look like.**

The Monday before Thanksgiving, our hospice nurse Sandy told me Mom was transitioning and had maybe three days left. I spent the afternoon taking pictures of our hands clasped together against the creamy backdrop of her blanket. In the evening, when her nurses, Liliana and Princess, arrived to change her, I moved off to the side and scrolled on my phone so they wouldn't feel I was judging their work.

Princess began reclining Mom, the electric *nnnnnn* of the hospital bed and the wet catch of her labored breathing filling the room. And then, silence.

I looked at Mom, then to Liliana and Princess, to see if what I thought was happening was really happening.

“Her color,” Princess whispered, nodding at Mom.

She'd turned white instantly, like a magician had waved his hand and drawn the last warm hues from her cheeks. The moment didn't feel at all how I'd imagined it would. Mom was loved so profoundly, so fiercely. How could her leaving be this small? This quiet?

I was holding Mom's hand when Liliana, or Princess, or maybe both, yelled, “*Her rings!*”

Mom had been dead less than a minute and they were yelling about her rings? *Did rigor mortis set in that quickly?*

On her left hand, Mom wore the flat, marquise-shaped Black Hills Gold ring Bob and I gave her to cover the indent her wedding ring had left, which sounds like a bummer but was the opposite, a gift given and received with joy. On her right, she wore her mother's engagement ring, a modest but perfect 1930s diamond on a slender 24-carat band.

Mom had tried to give me Grandma's ring years before, as we strolled through Legoland with my kids — Jack running ahead of us, Kate in the stroller.

"This'll be yours someday. Why don't you just take it now?" she said.

"I don't want it," I said, feigning indignation. "It's *yours*."

"Not 'til you have to pry it off my cold, dead hand, huh?" she'd said and we'd laughed in the California sunshine, smug in our abundance.

I slid the rings from Mom's fingers and dropped them into a zipper pocket in my purse without looking at them.

### **I'd want a do-over.**

If I could do it again, instead of being Mom's nurse with an Excel spreadsheet, I'd be her daughter. I'd ask her about Doty, her tiny hometown made up of women and children because all the men were at war. I'd ask her to tell me again about her toughest assignments as a revenue auditor for the State of Washington.

Whenever it starts to haunt me how often I related to her as an Efficient Nurse and not her daughter, the only way out of that particular grief sinkhole is to bump the whole dying/caretaker scenario up a generation and imagine my daughter, Kate, driving around 30 years from now, feeling guilty about the ways she believes she failed me. I'd do anything to take that weight from her.

And isn't it funny that when I hear my own from-beyond attempt to relieve Kate of her guilt, I hear it in my mom's voice?

"You did the best you could, honey," she says. "You did everything just right."