

ALZHEIMER'S FANTASY IN THE KEY OF G, A MEMOIR

By Kirsten Levy

Alzheimer's Disease: Caregiving or Storytelling?

My mother's Alzheimer's decline lasted eight years. The experience was nearly 20 years of time—the caregiving while she was alive and the reflection and writing when she passed. I've thought long and hard on what mattered and wrote a memoir about it.

Alzheimer's Caregiving

I reached out for advice, resources, made the arrangements. When she confided to me that she felt "something different," insisting on neuropsychological testing, I set it up thinking she was very brave to face up to this illness that she feared the most. I attended seminars. I stayed with her. I consulted lots of dementia guides and how-to. I lobbied my siblings for assisted care. I felt powerless.

Then came her hospitalization and there I was, in her hospital room, waiting for the staff to finish up so that we could have a full patient conference with her entire team—nursing coordinator, activities coordinator, facility representative, rehab specialist, and hospice coordinator, a lot of people! And the doctor would be joining us soon.



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In their eyes I'm just a rookie, I thought to myself.

It was before lunch. At least it wasn't after, for you know, after lunch is the most desolate time in an institution, the residents dozing only to be awakened in a flurry of activity when visitors come, as everyone tries to interest them in what's going on.

Before lunch wasn't so great either. I dreaded the talking about food. They had already told me that my mother had no appetite, it was common. I had asked them to spin the menu by calling it 'French' to trick her into eating, kind of like saying if you don't like the gift you might still like the package it came in. I felt justified. I still thought I was responsible for her appetite. "Just create an appealing menu that I can brag to her about that she will eat and that will be that."

But it was way more complicated than that. Alzheimer's care is beyond complicated, to use food as an example. Things deteriorate. In the time since her hospital admission and the regular conference call evaluations with her team a thousand miles away I began to realize that no improvements were likely. I noticed an evolution in attitude, too, a change in tone. The updates began to say that she was more docile, would continue to lose weight. Physical systems would shut down. In their reports on weight and appetite I sensed a process to condition me, to groom me without my knowing it, toward a new paradigm, toward that stage of understanding that food was no longer important to the patient now, toward the end-of-life.

The hospital staff had already moved past food. My mother, too, was there. All the time spent on communication was really only marking the time it would take for me to get there. Was I there, could I get there? Not at first. These were seismic shifts in thinking and I was reeling from the shock and the need to understand it.

Writing the Story

So there I was in her room. She had moments of clarity and moments of seeming transported to another place. While sitting there I imagined where she was going, who she was



seeing; could she take me there in this fantasy? Ruminations, imaginations and rudiments of truth became the foundation for a story taking shape in my head despite my starting out greatly at a disadvantage, as I did not really know the people she came from. I did know her character and her witty expressions came from somewhere; she had funny, sharp and colorful sayings, cozy and familial, that spoke of generations of Irish culture. It appealed to me, to do it for her, this grandchild of Irish immigrants, born, educated and grown up in a place she loved, and left, but always wanted to return to.

Thoughts like these made my caregiving suddenly seem so totally in a void that I had to rectify it.

But my approach, when I sat down to write, had to be from another angle than the guidebook. Sharing the experience, yes, but more the family story than the day-to-day, which as you know is not pretty. My choice had to be something different, a way to use fantasy to get into her brain. I went into her head because by then she was non-verbal. Kind of a paradox to use her dementia to tell the story, right? To examine memory in a place where there is none.

What Really Is the Story?

Those caregiving years were fraught. It's the same for everyone. There's discord about what kind of care, huge efforts to accomplish nothing. Readers, you will recognize your own trajectory. But while Alzheimer's caregiving opens and closes my memoir, it is not the tale I want to tell.

Rather, it's the moments in between the beginning and the end, when my mother and I had times of togetherness in thought and action, we were synchronous. I loved those moments for it was as if I hitched myself to her shooting star in imagining her story, many stories, to carry them forward, and backward, realizing that what I thought was hers was my own. She was my guide. And it mattered. And it will matter to you. ■