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While We Await a Cure for Alzheimer's:

The Mother I Know ©

These days, when friends ask how my mother's doing, I say she's enjoying her Alzheimer's. That may sound shocking, but it seems to be the truth.

And she hasn't always been this way. Her illness has been slow moving and, at times, somewhat of a roller coaster ride. We have faced challenges, sadness, and anguish, interspersed with joy and laughter. But my mother has been peaceful for several years now. And after a life of sleepless nights and ceaseless worry, she's finally enjoying the small stuff in life, like her fingers and the edges of her blanket. In fact, she has become quite the explorer, examining everything with her fingers and her mouth. She seems to get pleasure from discovering things anew each time she explores.

She doesn't speak much anymore, though every once and a while she announces her thoughts in a perfectly coherent sentence or phrase. And she hasn't known my name for a while now, but the intent way she looks at me makes it perfectly clear that she knows I am important to her. She also doesn't seem to notice the card I drew for her with a big red heart on it, although I can't be sure, and I like to think that it brings her comfort when I'm not there.

Unfortunately, I don't get to see her much. She's in Iowa, near my brother, and I am enormously grateful that he's with her almost every day. The last time I was able to visit, I hadn't seen her for a long time and I worried about what I'd find, and how we would spend time together. I still wanted to make a difference in her life.

My brother dropped me off at the nursing home where my mother now lives, and to my surprise (although I wonder now why it was surprising to me) my mother instantly fastened her eyes and her energy upon me, dismissing everyone else in the room, who noticed it before I did.

The staff left us alone together, and we spent the next five hours humming a four-note little ditty that she had made up, and laughing more often than not. Yes, in addition to being an explorer, my mother is now a composer, and she was quite clear that I needed to follow her direction carefully! If I made the tiniest mistake or altered even one of her musical notes, she would correct me with her eyes and a pointed nod of her head. At other times, she would just laugh and start over. But if I stopped humming altogether, she would begin to hum *very loudly* and fix me with a wide, hard gaze. This was the mother I knew. This IS my mother.

When her lunch arrived, she ate the dessert first, eyeballing me steadily and insisting upon my complete attention. And when I tried to get her to eat the protein portion of her meal, she just pointed at the pudding and said giddily and clear as a bell, "But this is so much better!" We laughed at that till we got tears in our eyes, and when she had finished eating exactly what she wanted, which she evidently enjoyed, she resumed her exploration of the world around her.

Alzheimer's disease often horrifies others. Does it horrify you? Why should it? It doesn't horrify her, and it has stopped

horrifying me. Though the challenges and sadness Alzheimer's causes everyone are real, they are usually the only part that people dwell on. But there's more than that to life with dementia, and my mother has given me a great gift in teaching me that; I have learned key lessons from watching her live with Alzheimer's.

I discovered that her spirit and character are largely intact, and that she is perfectly recognizable as herself. Her indomitable will is still evident—changed, but still there. Her determination, joyfulness and laughter, wary watchfulness, sense of humor, sarcasm, love of fun, and need to control are also still there, and in plain sight if I am open to seeing them. She has “attitude,” and still lets you know right quick with a paranoid laugh that you can't put one over on her. What's missing: her anxiety, worry, perfectionism, inability to sleep, and the excessive judgment she apparently internalized from her father and applied mercilessly to herself, she can surely do without. She has, in large part, been released from these withering sources of suffering from her earlier life.

To put it another way — and strangely — my mother has retained her dignity. She still has pride and self-respect. And I have learned that dignity has nothing to do with the fact that she's incontinent or that her mind is changing. No, my mother is not only her mind, or even primarily her mind, and it's clearly not the source of her dignity and humanness.

What I've had the great fortune to learn from her, and from Alzheimer's, is that dignity is a declaration that issues from the spirit. My mother still has tremendous spirit, and she is ahead of many of us in making no judgments and carrying no shame. She has reminded me, once again, of the worth of all human beings.

My old “Mutti” has had an extremely difficult life, and she is first and foremost a survivor. Now, finally, she seems at peace. It would be selfish and small-minded to minimize the apparent

reality of that and focus only on the challenges of this disease. She doesn't, and I have stopped doing that. What I couldn't have imagined was what I would learn.

The fact is, once you can let go of how and what you think a person ought to be, you can see that my mother is really OK. She is simply enjoying her Alzheimer's.

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