

My Family History of Dementia

Category: Dementia

written by Nancy L. Glass | March 15, 2025

Many people are afraid of developing dementia, which is increasingly common as we live ever longer. I have a compelling reason to harbor that fear.

My paternal grandmother developed dementia in her early sixties. The diagnosis was made without any of today's imaging and biomarker techniques, but the course of her decline, it's clear in retrospect, was typical for Alzheimer's. Luckily, she never lost her sweetness or her Southern-ness: she remained hospitable and cheerful to the end, politely hiding her pills under her linen napkin. One afternoon during a drive through the rural South, she kept promising us that the White Cliffs of Dover were just over the next hill!

Her oldest son, my Uncle F, a brilliant man, developed Alzheimer's and suffered a 15-year decline, with many hospitalizations and surgeries. In the middle phase of his disease, he made suggestive remarks and exhibited behaviors that were completely out of character for him and profoundly sad for me to observe.

His brother, my father, also developed Alzheimer's, although it took a while to diagnose. Dad became quieter and less engaged and began to lose track of documents and bills. The psychiatrist who finally diagnosed him told me it was common for engineers to present that way. In Dad's newly quiet state, he was trying to analyze what was happening around him or being discussed. His course with Alzheimer's was short, as it was accompanied by heart failure. It was a blessing he didn't linger.

Prior to an orthopedic procedure a year after his death, I had genetic testing performed to see if I have a mutation affecting the metabolism of the anticoagulant Coumadin. My husband, a geneticist, reviewed the raw test data. I forbade him to examine any genes associated with dementia, because I didn't want to know. I also didn't want him to know and to withhold the information from me.

After my recovery from surgery, he told me I do not carry the dementia genes. I was relieved, of course, and I hope he told me the truth. I have made it clear to my family that I do not want a feeding tube if I can no longer swallow. And my husband knows I will haunt him if he ignores my wishes!

I worry sometimes when names or details escape me, but usually I recall them within hours, so I think my cognition is normal for my age. Even so, fear of dementia is my constant companion.

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