From the Other Side—The Family Disease

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It's a cold Tuesday morning in December, and the cool infusion running into the bruised vein on the back of my hand makes me colder sitting here in the infusion center, watching the medication drip, drip, drip as the infusion pump ticks off each drop. Nurses are busy with other patients also receiving infusions of different sorts—some for chemotherapy, some for antibiotics, and a growing number of us for monoclonal antibody therapy. I've been a primary care doctor for (it takes me a moment to calculate) 31 years, but now I'm sitting on the "other side" of the table.

The last few months have been a whirlwind. As I was providing primary care in a clinic, my supervising physician asked to speak with me, invited me into our conference room where our human resources personnel sat, and told me patients were complaining because I was repeating myself. She had been monitoring me and was concerned about my performance. I had no idea I had a problem.

OK. That's not exactly true. When COVID-19 hit, and I had a mild case, my grown children began asking my wife why dad couldn't learn to play the new board game during our holiday together. We figured it was all because of COVID fog, and my wife tried to monitor and help me out. So, I knew I was having "issues." But when my boss at work a year later brought the patient complaints to my attention, I had to face my problem. In baseball parlance, I got "benched."

I called one of my long-time buddies, a neurologist who invited me to "drop by" his office. That began my own personal patient-odyssey into the world of medicine from the "other side." MRIs, lumbar puncture, blood work (multiple tubes—do we really need that many?). My p-Tau/Abeta42 level was twice the normal limit. I have the disease. My father's disease. His father's disease. We have Alzheimer's in our family.

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The family gathered last week to honor the memory of my father. He recently died at 82, a truly great and loving man who made his mark on his mid-sized, Mid-western city. Hundreds of people packed into the family's place of worship to honor him. Few but his closest friends and our relatives saw him "failing" over the last few years. As he worsened, it became imperative to sell his car, which grew into a logistical battle when he threatened to disown us for suggesting it. He began wandering at night, falling outside his home. The family made adjustments to help "preserve his dignity" while ensuring we kept him safe.

The last 6 months of his life were difficult. I never knew patients with Alzheimer's developed such weakness in their legs and torso, but I've been reading about it and have observed it up close. I stayed at my parents' home as things progressed since I was newly "retired," and had the time to help care for him. Hospice was eventually called upon and his last week was spent in a medical home-care bed. My mother and I administered his "comfort" medications every four hours, taking turns at night. Our family gathered around him when he passed, and I was thankful we were with him when he breathed his last. The stillness was jarring. My mother's weeping broke the silence.

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How many patients have I treated for dementia over the last 30 years? Well over a thousand. Charting their slow, inexorable demise over time with a mini-mental status exam, and using medications that promised to stimulate the brain. It always felt…hopeless? The inevitable would be just around the corner at the next visit, and soon we'd be asking for a hospice consult.

Their caretakers' worried faces looked like my own spouse's does now. She's battling insurances, navigating COBRA, dealing with mounds of online "paperwork," conversing with "health navigators," and weeping softly at night in bed when she thinks I'm sleeping. She's juggling a full-time job while making sure I get to doctor appointments. I've become the "house-husband": cooking, cleaning, and working on home projects. I love writing and practicing my musical instruments. Fortunately, I'm a homebody at heart—an introvert who would be exhausted at the end of a clinic day after seeing patients every 20 minutes.

But, to leave it all behind? And not by choice? That's not me—I can't sit around, stop learning, and quit "working," though I may not be employable as a clinician. Last week, I reached out to the Alzheimer's Association to see if there are ways I can help. They envision enlisting me to help with patient education.

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Brent W. Beasley, MD, MBA is retired.

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Fortunately, there's another difference with our generation—a real game changer. The research and development of monoclonal antibody therapy promises to make a difference for me, and for any of my children and grandchildren who inherit my genetics. This isn't experimental anymore. We know the mechanism of what causes Alzheimer's dementia and we are actively treating Alzheimer's disease to remove the abnormal protein from our bodies.

And recent trials are hopeful—amyloid markers are reduced (biochemical evidence) and they've documented a decrease in mental decline (clinical evidence).[1]

My oldest son is a writer—much more talented and better than I. I'm hopeful he won't have to experience a tap on his shoulder some day, suggesting to him it's time to "hang it up." My middle child, a daughter, is a physician, an internist like me. She's pregnant with my first grandchild. IF she has my Alzheimer's gene, and IF my grandchild has my Alzheimer's gene, there's hope for them to avoid having to take an unanticipated "early retirement." For my youngest, another daughter, I'm hopeful she'll keep trailblazing, hiking miles over hill and dale as she loves to do with no concern for Alzheimer's disease.

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