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Not too late

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As a movement disorders fellow, it may not be wise to admit that Parkinson disease is my least favorite disease. After all, it is the most common condition we see. It also happens to be the first movement disorder I was introduced to as a medical student, eventually drawing me to the field of neurology. However, having watched my grandfather's journey with Parkinson disease, I still feel a dull ache when I see the expressionless faces of my patients, something I had seen so often in my grandfather. When my patients ask what the future holds for them, I say what every neurologist would say: every person is different and it is impossible to predict. Just as I was unable to foresee the future for my grandfather.

I often imagine the neurologic examination that I never performed, as I was only a teenager when my grandfather's symptoms began. I remember a bilateral, asymmetric hand tremor when he was using utensils to eat. Was it bilateral from the very beginning? Not sure. I also do not remember whether the tremor was present at rest. What I do remember is how family members would comment on the tremor improving with alcohol. His voice was also tremulous. Later on, as a medical student, I made further observations, but only to notice the bradykinesia and rigidity around the time I began my neurology residency.

Eventually I realized that it did not really matter whether it was essential tremor that turned into Parkinson disease or Parkinson disease from the very beginning. What did matter was that my grandfather seemed to be getting slower and slower, something that became very obvious to me each time I visited him. After much persuasion, he was taken to a neurologist, who gave the diagnosis of Parkinson disease. My grandfather was started on levodopa, which resulted in little symptomatic benefit but caused prominent dyskinesias. On my next to last visit, I found

him bedbound, demented, and minimally responsive to his surroundings. My grandmother, his primary caregiver, would ask in distress why he complained every now and then of abdominal pain. I told her what I knew, which was that it was common for patients with Parkinson disease to feel pain in various parts of the body. I dreaded visiting my grandparents' home, feeling helpless as I sat face to face with my grandfather in the end stage of Parkinson disease.

Frequent visits to the intensive care unit inevitably ensued. Between moments of taking sneak peeks at the daily laboratory values, I would read aloud to my grandfather poems that he had written many decades ago during his career as a literature teacher. When asked about the meaning of these poems, he did not seem to remember. He did, however, enjoy listening to old songs that we would play for him on a tape recorder. He would then sing the songs through the night, annoying the neighboring patients and their family members. Ironically, this situation would bring joy to our family, as those were the good days even if it did not hold much medical significance to the physicians.

My grandfather died 2 months after I had already said my silent good-byes. He endured feeding tubes, joint contractures, decubitus ulcers, pneumonia, and renal failure. It was the end of all his physical, and very likely emotional, suffering. It has now been almost 2 years since his death, yet I am reminded of him when I see my patients. In a way, he has not left me, for I see the familiar hand tremor, feel the rigid extremities, observe the slow gait and difficulty with balance. I am now a little older, perhaps wiser, and more experienced in movement disorders. It is too late for my grandfather, but not too late for me to embark on other journeys with my patients. After all, Parkinson disease is my least favorite movement disorder, but the one closest to my heart.

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