



## When loved ones are patients

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I learned a lot about dementia in medical school. Through lectures about its pathology and physiology, the vocabulary became mine by diffusion: Apraxia. Disinhibition. Plaques and tangles. On and on. In rotations with geriatricians, I learned to conduct tests of cognitive performance and assess the instrumental and basic activities of daily living. I learned to ask patients about falls and finances and toileting and driving. I learned to always include collateral information from an elderly patient's family, as sometimes the patient's responses to these sorts of questions would intentionally or unintentionally be incorrect.

Later, I would encounter dementia patients on the wards. Typically these were people who had been admitted to an internal medicine service after their previously tenuous balance slipped away: after a fall or a week without eating. Or when caregivers grew too exhausted to go on and dropped the person off at the emergency room. After medical stabilization, these patients remained on the wards, awaiting placement in long-term care facilities, in varying states of awareness and acceptance and anger. On rounds, usually a quick scan of the bedside chart to check the vital signs during the previous 24 hours was all that was deemed necessary for these patients. Sometimes the team would troop into the room, and the staff physician would ask a question that wasn't answered or that was answered nonsensically, and we would understand that there was nothing more to be accomplished there and troop out. Often we wouldn't enter these patients' rooms, as there were unlikely to be interesting physical findings or pertinent teaching points to review after medical stabilization.

Which leads me to my grandmother. She helped me get into medical school, I think, in 2 ways. The first was her constant requests to her higher power that one of her grandchildren become a doctor. The second was that during my medical school interview, I talked about her when I was asked for an example of my experience with how people age, and it led to an intense, fruitful discussion. At the time she was still living independently. Although I spoke then of her increasing dependence and slipping memory, she would spend the next 6 years, while I became a doctor, becoming more dependent still; losing her memories and losing herself.


I'm back home now, medical education completed, considering which job to take and where. In the meantime, I visit my grandmother at the nursing home every day. I bring her doughnuts and tea, which I feed to her, and we sit together. We used to be great talkers. We

used to joke. But now it's hard for her to get the words out. In my time with her, I find that I struggle to understand her as family and a person I love, and as a patient and an individual in an institution. She is both of these things to me now. The one can never be denied because the other exists equally. I am learning a lot about dementia from her.

To her, I am only someone important in her life, in her family, that visits often. After her great desire for it and her pride in my becoming a physician, she's forgotten entirely that this is what I am. There is something comforting for me in this, in being loved as myself alone. It is only someone who has lost the past entirely who can love you solely for what you are in the present moment.

So I was surprised at what she said to me today. It was a normal visit, mostly silent. When she talked, she was confused: she said in fragmented sentences that her aunt lived in the same house as this one, and she said that in the night she had heard an animal in the hall. A bear, she thought. After these few statements, spread over an hour or so, she said nothing. Then out of the blue she tilted up her drooped head to catch my attention, looked in my eyes, and said, so slowly, "How long can I last?"

I found it a profound moment, and a difficult one. After a few seconds I started to say what I have said to every person that has asked me this question: "I don't know exactly ...." What really got to me, though, was that in asking this question, she seemed to be showing—for a few seconds at least—that she was aware of herself, of where she was, and of her stage in life. I was always troubled by our dismissal of dementia patients on rounds. I am not arguing that our behaviour or diagnoses on the internal medicine rotation were wrong; I only find it unfortunate that as physicians we do not have the time, and also perhaps sometimes cannot bear, to seek these moments of connection after diagnosis and active treatment are completed. This is why I could not have spent my life working in the hospital. Too much of the personal is lost there for me to accept.

I said to my grandmother "I don't know exactly .... How long do you want to last?" I answered and asked as a grandson and as a physician. I would have given anything for her to be able to answer. But by the time I responded, whatever alignment had occurred in her brain had ended. She was silent again, eyes blankly scanning the room, fingers fiddling with the buttons of her sweater. 

Dr Sullivan works in London, Ont.

**Competing interests**  
None declared