

THE FOLLOW-UP VISIT

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I had a dream in which I am standing next to my husband's doctor in a crowded elevator. He is so tall, his face looming so far above my head that I cannot see it when I turn to say hello. All I see is a beltful of papers and reams of papers and medical instruments spilling from his white coat. This despite me knowing he is barely taller than I – same height when I wear heels. Feeling somewhat inappropriate to speak to his pockets, I say nothing, and he exits.

I know he has a terminal illness. I have had patients with the same diagnosis. I have held family meetings to explain the symptoms and treatments and poor prognosis; to advise on long term and palliative care. Now I am on the receiving end of such discussions but feel like I know nothing. I know the natural course of the disease, yet each day seems to raise new issues. I am frustrated he is so resistant to complying with standard treatment while he keeps asking about experimental ones. I sometimes do not understand how my husband, a fellow physician, could have so little insight into his own health and abilities. Does the doctor realize that in the whole year since diagnosed, he has not read even a single paper on the illness?

Maybe it is better not to know. He is 39 and will die before his parents. I am 30 and will be a young widow. He most likely will die from aspiration pneumonia. Or maybe one day he will have such a bad fall that something critical will get broken or contused or whatever lands people in the ER for a lengthy, complicated hospitalization that seems to be the last days of so many of our patients now. I know this. He is afraid he will not be able to breathe. We talk of making wills and mandates on our first wedding anniversary.

I have learned about the significance of the follow-up visit. It has been marked on our calendar for months and my workweek – no, month - planned around it. He takes great pains to wear his newest shirt and be meticulously shaved. We arrive 20 minutes early. He totters into the examination room, proud to show he still can walk; oblivious to the fearful cringing faces and darting hands ready to catch him in a blink. We recount a litany of changes since the last visit – all for the worse. Medication suggestions are made. “Anything else to report?” Because there is a meeting, a sick patient on the ward, it is the end of the day. “No, that’s about it.” We leave. We already have overstayed our welcome.

Wait! I want to tell you how my husband is a shell of his former self. He ran marathons and played tennis; he taught me how to ski. He survived graduate studies and medical school and was in a grueling residency program before quitting as strange symptoms we would not see robbed him of speed and dexterity and speech and competitiveness. He is witty and loving though his cognition is slowing. I pick him up after yet another fall and change his diapers; he picks up my spirits and changes my perspective on life. “Anything else to report?” “We are losing hope. Can you help us?”

But I guess these are not relevant to say. I feel inappropriate speaking to his pockets. ■

Biographical note

Wendy Chiu is a geriatrician at the McGill University Health Centre, and was her late husband’s primary caregiver for over a decade until he died in 2013 from complications of multiple system atrophy. She tries to use the experience to better care and advocate for her patients and their families, and hopes they feel understood.