
A PIECE OF MY MIND

Can We Agree to Disagree?

I SPOKE TO MY 90-YEAR-OLD GRANDMOTHER, ANNE, TODAY about her goals for medical care as she reclined in her hospital bed. Our conversation resulted in a considerable amount of déjà vu. It was five years ago this month that I had had a similar conversation with her and my grandfather Phil—a conversation that changed the way that I, a geriatrician and hospice and palliative care physician, talk with patients and their families about advance planning for end-of-life care.

My grandfather had a history of diabetes, congestive heart failure, chronic renal insufficiency, and a host of other smaller medical problems that added up to a laundry list of medications and disability. Six months before his death, he was hospitalized due to a fall and a hip fracture. Hip surgery and a long hospital stay led to generalized deconditioning and extensive heel decubitus ulcers. What ensued was a horrible six-month ordeal of multiple transfers back and forth between the nursing home and the hospital for surgical wound care, infections, exacerbations of congestive heart failure, arrhythmias, gastrointestinal bleeding, and deep venous thromboses. Although his physical function continued to decline, my grandfather retained his mental faculties and was able to visit with my grandmother and other family. Despite my pleading, his physicians had not initiated a discussion about my grandfather's goals for medical care. His specialists and hospitalists continued aggressive treatments, including dialysis and surgical wound debridement, with little discussion about what he wanted.

I decided it was time to talk with my grandfather about his life goals. I met privately with him and my grandmother, and we had a very frank discussion. My grandfather spoke about how he had had a good life, how much he loved his wife of 65 years, and how he was tired and not afraid of dying. He felt that if his heart were to stop or if he were to stop breathing that it was a sign from his Maker that it was his "time to go." He did not want to be mechanically ventilated ("No breathing tubes!") or resuscitated ("No shocks and no pushing on my chest. Just let me go.") He was willing to receive the treatments that he was already getting such as dialysis and wound debridement, but only if the treatments "make me feel better. If they are giving it to me just to give it to me, then forget about it."

At this point, I turned to my grandmother, the often forgotten surrogate decision maker. I asked her if she understood what my grandfather was saying and how the discussion made her feel. "Sad," she replied. At this point in the conversation with my own patients, I used to turn my attention to comforting the patient and surrogate decision maker

and answering their questions. However, because I wasn't sure if my grandmother understood, I asked her what she would tell the doctors to do if my grandfather's health deteriorated—if his heart were to stop or if he were to stop breathing. "Well, darling," she said, "of course I would tell the doctors to do everything possible to keep my husband alive."

What? I was stunned. Hadn't I just had this lovely, frank, direct, and specific discussion with my grandfather? Hadn't my grandmother heard him? I asked her to tell me what she had heard my grandfather say, and she was able to repeat his wishes. I then asked her why she would ask the doctors to use invasive life-sustaining treatments despite what my grandfather wanted. She told me that she loved my grandfather too much to let him go. "If he is with me just one more day, it would be worth it to me." Given my grandfather's comorbidities and poor functional status, we discussed the poor likelihood of successful resuscitation. We further discussed that even if such efforts were successful, my grandfather would likely require ongoing life support and would most likely not leave the hospital. When asked again, she said it would be worth it to her for my grandfather to receive life-sustaining treatments even if he were "hooked up to machines and not able to talk to me."

I then turned to my grandfather.

Me: "Did you just hear what Grandma said?"

Grandfather: "Yes, I did, sweetheart."

Me: "Uh, well . . . how do you feel about the fact that Grandma may tell the doctors to do something you don't want? You just told me that you wouldn't want a breathing tube or shocks, but it sounds like Grandma would tell the doctors to do those things. Is that right, Grandma?"

Grandmother: "Yes, darling."

Me: "Grandpa, is this OK with you?"

Grandfather: "Yes, it is. I am ready to go, but if it helps your grandmother to feel that she did everything possible for me, even if it is because she doesn't want me to go, that is OK. She is the one who has to go on living with her decision. If this is what she wants, then this is what I want because I love her."

This interaction struck me like a ton of bricks. I had been taught to try to facilitate communication between patients and their surrogate decision makers to ensure that the surrogate understands the patient's preferences and will honor the patient's wishes. After similar goals of care conversations with my own patients, I have often felt satisfied that I helped patients express their wishes and therefore confi-

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dent that their surrogates would honor those wishes. My grandparents turned this notion on its head. Maybe the congruence between patients' stated treatment preferences and surrogates' decisions is not the best gold standard for advance care planning after all. My grandmother's wishes differed from what my grandfather stated, but I would not say that my grandfather's wishes were not honored. Although it was hard for me to fathom, my grandfather's wishes were to have my grandmother make the decision that she could live with. At the end of the day, relieving her emotional burden was what was most important to him.

Addressing surrogates' needs in decision making is an important aspect of advance care planning that is often overlooked. I almost overlooked my own grandmother's. Now, when I talk with my own patients and their surrogates, I keep the conversation with my grandparents in mind. I ask surrogates if they agree with their loved one's wishes, what

is important to them, and how this will affect their decision making. Before I finish the conversation, I try to make sure that everyone is on the same page.

One month after this conversation with my grandparents, my grandfather was found unresponsive in his nursing home bed. Per my grandmother's wishes, resuscitation was attempted but was unsuccessful. My grandmother said that she felt better knowing that she had given him a chance.

Today, when I was speaking with my grandmother, she told me that she was comfortable, not afraid to die, and looking forward to seeing her husband soon. "I don't want any of those tubes for breathing. But, if my son needs to make a different decision, honey, I will understand."

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Death often weighs heavier on us by its weight on others, and pains us by their pain almost as much as by our own, and sometimes even more.

—Montaigne (1533-1592)
