

## A Difficult Conversation

By Kelly Elterman

In my years as a physician, I have had many difficult conversations. Conversations about expectations, outcomes, goals of care, do-not-resuscitate orders, and perioperative complications, both expected and otherwise. In the beginning, these conversations were awkward, burdened by long pauses and uncomfortable uncertainties. With time and practice, the rhythm of the conversations became easier, more fluid on my end. Yet despite an improved outward apparent ease, internally these conversations have never felt any easier. It seems that there is always a heaviness to them, no matter how smoothly or gently the conversation flows. This is because the information conveyed in the conversation itself is always heavy, pregnant with misfortune, sadness, anger, helplessness and despair.

The most difficult of these conversations occurred in my tenth year of practice, in the living room of my grandfather's apartment, on an ordinary Saturday afternoon in October. Unlike any previous such conversation, however, it was one for which I felt entirely unprepared.

Five days earlier, before I could have even imagined such a conversation, my mother called to say that my grandfather's kidneys had failed.

"The nephrologist said it's end-stage now, that he needs dialysis," she said.

I gripped the phone tighter, inhaled sharply and exhaled slowly. Staying momentarily silent, I gathered my thoughts. My grandfather was 93 years old. A conversation about his kidneys was one my mother and I had had many times.

"What did the nephrologist recommend?" I asked, cautiously.

"He said it probably would be more of a bother to him than a benefit," she admitted, defeatedly.

I breathed a sigh of relief.

"And Grandpa?" I asked. "What does he want?" Even at 93, my grandfather was very sharp. His kidneys may have abandoned him, but his mind had not.

"He said he does not want dialysis."

"Well, then there's that," I said. "Simple. No dialysis. Just let him live out the remainder of his life."

“But... isn’t there something... what should we do?”

“What we should do,” I told her sternly, temporarily reversing our roles of parent and child, “is spend time with him. There is no way to know how long he will live or how many lucid days he has left. He will become more and more confused as his kidney function declines.”

As the only physician in my family, I am the only one who has ever seen symptomatic kidney failure. In the eyes of my family members, this suddenly elevated me from youngest grandchild to family expert.

My mother was quiet on the other end of the line. And then, “What should we tell him?”

My family immigrated to the United States decades ago from a country with a heavily paternalistic culture where in medicine doctors make decisions for patients and in families respect for elders includes not disclosing potentially distressing news. Neither my parents nor my grandparents would think it wrong to hide a fatal diagnosis from an afflicted loved one. My grandfather did not speak or understand English well and so certainly could not have understood what the nephrologist had said in his office. In that moment, an odd mix of frustration, anger, and compassion rose in my chest as I realized that my mother had not yet told him anything.

“We tell him the truth,” I said firmly.

That same day, I made arrangements and booked airline tickets to visit him the following weekend. I called my brother and told him to do the same.

“We should see him while he still feels well,” I said. “While he can still appreciate our visit.”

A week later, my husband and I were on a plane. My grandfather’s impending kidney failure had been insidious, and so this trip initially did not feel any different than any other. It was not until I met my mother and brother for lunch before seeing my grandfather that I learned how different it would be.

“We’ve all talked about it,” my mother announced after we finished eating. “And we think you should be the one to tell him.”

“What?” I asked, furrowing my brow. “Me?”

It was completely unexpected. We were talking about my grandfather, my *mother’s* father - not mine. A man who had two daughters and four grandchildren, three of which were many years my senior. By all rules of respect and familial hierarchy in our culture, as the youngest grandchild, I should be the last person to have such a conversation with him.

“Yes,” said my mother. “You should be the one to tell your grandfather what is going on. You are a doctor. You would do the best job,” she insisted.

Whether this request was born from confidence in my experience as a physician or from my mother's own discomfort at the thought of such a difficult conversation, I will never know. Regardless, it was a strange request, and one that made me feel simultaneously honored at the thought of being able to make this moment easier for my grandfather and frustrated by being asked to take on such an unconventional role. Ultimately, the desire to ease his anxiety persevered and I agreed.

That is how I found myself in his living room on that Saturday afternoon, facing the most difficult end-of-life conversation I have ever had.

The moments between my mother asking me to have this difficult conversation and the instant I met my grandfather's eyes as I walked into his apartment are blurred in my memory. I do not remember walking to my car or pushing the buttons in the elevator. I vaguely remember opening the door and seeing my mother, brother, and grandfather, making meaningless small talk. What I do remember clearly, however, is the look on my grandfather's face and his zealous smile, the joy he had in his eyes at seeing us all together.

After we finished our usual greetings, the air suddenly felt thick. Everyone stood in the middle of the room, quietly, as if suddenly unsure of what to do. I sat down next to my grandfather on the sofa and took his hand in mine, as the rest of my family gathered around us, watching. I took a deep breath and exhaled slowly. In my mind, I pretended for a minute that this wasn't his living room, that I wasn't his granddaughter. I pictured myself sitting at the edge of a hospital bed in my white coat instead of on a couch in a yellow sweater and jeans, and him in a hospital gown attached to beeping monitors, instead of his favorite T-shirt, surrounded by an expectant silence. I spoke softly and carefully, as I explained to him what was happening to his kidneys and what foregoing dialysis would mean. I laid out, in the simplest of terms, a potential clinical course, and of course told him repeatedly that there was no way to know how he would feel or when anything would happen. I could hear my brother translating quietly to his wife and children as I spoke.

My grandfather listened attentively. He looked into my eyes as though I had been his lifelong physician. He furrowed his brows and nodded occasionally.

Anxiously, he asked, "Will there be pain?" I assured him that kidney failure was often painless, that he may even pass very peacefully, perhaps from an arrhythmia in his sleep.

We were both quiet after that. He squeezed my hand. I could hear my sister-in-law sniffing quietly. After another pensive moment, he looked up at me and then across the room. "Oh..." he said. "Now I understand. You have all come here to say goodbye."

It took every fiber of my being not to cry in that moment. Even thinking of that moment now, over a year later, still brings me to tears.

Then, suddenly he smiled, a big mostly edentulous smile and patted my hand.

"Thank you," he said. "Thank you all for coming to see me."

A short time later, we did say goodbye. My mother, my brother, his wife and his children all took turns hugging my grandfather. My husband hugged him too, and then shut the door behind them to give me and my grandfather a few moments alone.

I could no longer pretend that I was in my white coat or he in a hospital bed. There, in that moment, I was no longer a physician, only his youngest grandchild. In my yellow sweater and jeans, a grandchild he had swaddled as an infant, walked to school as a child, and chauffeured as a teenager. A grandchild saying goodbye. I hugged him tight, swallowed hard, and tried to keep my voice steady, hoping he would not see me start to cry.

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