

“Dad, What Do You Want My Role Here to Be?”

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HOW TO CITE: Mahon KM. “Dad, What Do
You Want My Role Here to Be?”. *Fam Med.*
2025;57(4):305–306.
doi: [10.22454/FamMed.2025.854157](https://doi.org/10.22454/FamMed.2025.854157)

PUBLISHED: 3 April 2025

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It was a regular fast-paced morning of office hours, shortly after the holidays in 2020, when I received a group text from my mother to me and my two brothers:

“Your father can’t swallow any food or his medications.”

Coughing and choking with meals was one of my father’s first presenting symptoms of Parkinson’s disease, but this inability to swallow was completely new.

I paused...

Stared at the small screen . . .

I knew this was the beginning of the end of his life.

My father was diagnosed with Parkinson’s at age 67, although it was probably affecting him for years prior to this. He loved big presidential biographies, listening to sports radio, and never missed an opportunity to tell his kids how much he loved them. He did well for several years after his diagnosis, but the last 6 months of his life were difficult; he lost a substantial amount of weight and could not complete most of his ADLs without my mother’s help. Eight years prior, he had been the long-standing General Counsel of Philadelphia’s branch of the Federal Reserve Bank.

Shortly after sending this text, my mom took my dad to our local hospital. This hospital is actually in the network of hospitals where I work and a stone’s throw from my office. I decided to leave work, and I went to my dad’s lawyer’s office to obtain a copy of his living will; my mom couldn’t locate it during this hectic moment. His living will clearly stated that he did not wish to receive heroic measures, including artificial nutrition, at the end of his life.

With his will in hand, I met my family in the local ER’s uncrowded, small waiting room. My father looked far more gaunt than he had appeared when I had last seen him just a half week beforehand. But, as usual, he asked intently how I was doing.

A daytime talk show was playing on the TV in the waiting room. My dad rolled his eyes, and we shared a laugh, realizing together the absurdity of this tawdry background to such an important moment in our lives.

He had a chest X-ray that showed mild aspiration pneumonia. Still, we knew it was his advanced Parkinson’s causing his inability to swallow more than anything that would be reversible. As a family, we decided that it was best for him to be admitted to the hospital, and then the hospitalist came down to the small exam room to do the admission.

The hospitalist had probably heard I was a network doctor; when she entered the room, she only looked at and talked to me. My dad, although affected cognitively by his Parkinson’s, was completely conversant and able to understand the situation. My mom, also present, had never worked in health care but was very health literate and knowledgeable of my dad’s condition. Without notes, she was always able to spout off his list of medications, specialists, last appointments, and procedures. Neither one of them was pleased about being excluded from this conversation.

I tried to direct some of the hospitalist’s questions to my mother and father, but both my nonverbal and verbal cues did not seem to be reaching her. The hospitalist next whispered to me a question about whether my dad should go on hospice. At this point, my father said:

“What are you guys talking about?”

I stopped talking to the hospitalist, went to the head of the bed, and essentially had an end-of-life discussion with him, explaining that his Parkinson’s had progressed and the only option would be a feeding tube.

He reiterated what his living will said: He didn’t want the feeding tube and agreed to go on hospice. After one night in the hospital, he was transferred to inpatient hospice and passed away with us by his side 4 days later.

What was I supposed to be in that small ER room 5 years ago?

- ▶ advocate?
- ▶ decision-maker?
- ▶ navigator through a complex health system?
- ▶ daughter to a dying father?

This is the complexity and the conundrum of being a family doctor when your loved one is sick—in my father’s case, terminally so. There is no formal code of conduct for this scenario, and we are often left to delicately manage the competing expectations of our family members, the health care team, and ourselves.

- ▶ Will the treating physicians welcome you as someone they can efficiently exchange information with, or will they see you as obtrusive?
- ▶ Will your family member welcome your guidance or feel like their autonomy is being undermined?
- ▶ Will you be able to sit with the heavy responsibility of bringing your medical knowledge to bear during such an enormous personal moment in your life?

Years later, I still look back on this moment. How could I not? It was one of the last cogent moments spent with my father. In the first few months after his death, I found myself often reliving the time in that small, curtained ER room and wondering whether I had done the right thing. Did I overstep by running the end-of-life conversation? Or maybe I should have personally had a conversation with him ahead of time about artificial nutrition, eliminating some of the drama of that day. With time, I was able to see that experiencing doubts and questions about that moment was in fact the way I was grieving, and it was uniquely affected by being a doctor myself. Sometimes I do imagine what would have happened if I started our interaction that day by saying, “Dad, what would you like my role here to be?” But then again, my dad, being who he was, would have let me know what was most important—that I be a daughter saying goodbye to her father.