REFLECTIONS: NEUROLOGY AND THE HUMANITIES

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Clarity

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Correspondence to Dr. Mendelson: ali.mendelson@uphs.upenn.edu Standing in the doorway of Ms. P.'s dark room, exhausted from a busy night in the intensive care unit (ICU), I could only mutter, "I'll be back tonight," hoping that my face was merely a silhouette so that she could not see the tears welling up in my eyes. Barely looking up from the worn notebook that she always kept within arm's reach, she waved me back in as she scrawled furiously, her words veering off in all directions. Although she'd had a tracheostomy placed months earlier, and I had never heard her speak, I could almost hear the Polish accent in her writing. "I won't be," she wrote. "I'm scared."

She had agreed to have the tracheostomy placed when the doctors first found the lung cancer. They promised it would only be temporary, protecting her airway as they searched for a cure. But days turned into weeks, and weeks into months, with no end in sight, until the morning she called us into the room and announced that it was time for the tracheostomy to come out. She was ready to die. And finally, after a multitude of conversations and psychiatric evaluations, she had convinced us that she was not depressed, not suicidal, just unwilling to live the remainder of her life dependent on a ventilator.

It was nearing the end of my first year of residency when I met Ms. P. As she scribbled away, visibly anxious yet comfortable with the decision she had made for herself, I could not help but recall the previous summer and the anxiety I had felt as I first rotated through the ICU. It was there that I cared for Mr. B., an 87-year-old man who was emergently intubated after his family found him lying unresponsive on his floor. When we first brought him to the ICU, we gathered his family for a meeting. His niece, and only living relative, decided that we should remove his breathing tube, with the understanding that he was unlikely to survive without it. A strong and independent man, who had had a rough life but who always managed to find joy in music, he would have hated relying on a ventilator. As we all crowded in Mr. B.'s small room, I took out my iPhone and turned on Pandora, scrolling down to find the Frank Sinatra station. Soon the voice of Mr. B.'s favorite singer filled the darkness, an unexpected addition to the sounds of the ICU and interrupted only by the loud beeping of the monitors and the soft sobs of Mr. B.'s niece. Her tears hit the crisp, white sheets like raindrops, in harmony with the music. I imagined Mr. B. as a young man, playing his harmonica to this very song, and thought that rhythm must run in the family.

Her tears symbolized years of love and the difficulty of her decision, but with only a quick press of a button, we turned off his ventilator. Sinatra's voice became that of Ben E. King. "Stand by Me" played on as I pulled the breathing tube out. My hands shook, and I prayed no one would see. "When the night has come, and the land is dark, and the moon is the only light we'll see... I won't cry, I won't cry. No I won't shed a tear. Just as long as you stand, stand by me."

As I made my way up First Avenue at the end of that shift, I pulled headphones out of my bag, untangling them from my stethoscope, and just for me, Sinatra sang on. The darkness of the room was replaced by the lights of the city. The beeping of the monitor was replaced by the honking of cars. And my first experience playing an active role in someone's death was forever ingrained in my memory.

Back at Ms. P.'s bedside, I realized that she was lucky. Unlike Mr. B., she had the opportunity to choose her own fate. The morning of her death I brought her breakfast. She had requested an English muffin with egg and cheese, but managed only a few small bites, still full from the frozen yogurt a wonderful nurse had bought her the night before. And she smiled. Scared, but at peace. She had given the doctors a chance, but now she was living on her own terms

I squeezed her hand once more, my own hands now steady. Walking out of her room and straight out of the hospital, the morning light momentarily blinded me. But she saw clearly. And when the sun had set and I returned to the ICU, ready to begin my next shift, she was gone.



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