The Hardest Words
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In medical school it’s easy to convince yourself that you won’t fall into the seeming laziness of neglecting end-of-life issues. With a student’s naïveté, I once assured myself that I would always address end of life in my outpatient pulmonary clinic, never considering the constant pressure to keep on schedule, the endless paperwork, and phone calls awaiting me following office hours. It never occurred to me that my pager would harass me with admissions from the hospital. In practice, I began to notice the words “end of life issues next visit” appearing on my notes. When the next visit would come, the discussion would inevitably get postponed. There was never an ideal, or enough, time.

My first lesson presented itself when I first met Gene in clinic. I liked him immediately with his friendly eyes and round face. We shook hands as I introduced myself to Gene and his son, Steven. A glance at the chart revealed that Gene had pulmonary fibrosis diagnosed 2 years previously, at age 58. I explained that I was a first-year pulmonologist, a fact I found unnerving. Despite my personal fear of opening the proverbial “can of worms,” I opened the conversation cautiously as I introduced the topic and the words “end of life planning.” “You think I’m going to die?” he erupted, once the words escaped my lips. I held my gaze steady and tried to set aside my insecurities. I glanced at Steven who looked equally concerned. Although Gene and Steven had insight into this disease, they didn’t equate this to the inevitability that Gene was, in fact, dying. Confronting this was the only way forward. The words came out clumsily as I went through Gene’s options. I focused on the way we might manage his disease as it progressed, describing Gene’s options from mechanical ventilation to the benefits and resources of palliative care, including hospice. I tried to reassure Gene that despite the fact that he was dying, there was still much that we could offer in terms of symptom control, medical care, and emotional support.

We talked for over an hour, and our meeting adjourned with no decisions but a promise from Gene to think about his wishes after he had time to digest the information. We set a follow-up appointment and hugs abounded as we said goodbye.

In the weeks after, Gene’s frequent pages ceased. I feared the worse and called to check in. Gene didn’t return.
my calls, which was highly uncharacteristic. Perhaps he was upset with me for bringing up end-of-life issues. Perhaps he was scared. Perhaps he had died.

Finally, one afternoon Gene’s name appeared on my schedule. I was eager to see him, but the appointment came and went, and he didn’t show. In fact, Gene never came back to see me. I couldn’t ascertain whether Gene was admitted to another hospital or perhaps chose another doctor, but the impact of losing Gene to my practice was one beyond the typical “no-show.”

I’m thankful for Gene’s vital lesson and regretful that I wasn’t able to continue in Gene’s medical care. With reimbursements low and patient care prioritized, it’s easy to understand why discussions about end of life care are pushed aside. Perhaps the fear of upsetting or even losing a patient serves as an excuse for avoidance. Yet, we must broach the subject anyway, despite the risk of upsetting or even losing the patients we care so deeply about, knowing that when done correctly, guiding a patient through the ongoing process of advanced care planning can be overwhelmingly rewarding. After all, physicians have a responsibility to initiate difficult conversations and owe it to themselves and their patients to learn how to say the hardest words.

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