



On Being Present

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WHEN MY FATHER died of idiopathic pulmonary fibrosis or IPF in April 2004, I did not anticipate what a profound effect it would have on me as a clinician and as a daughter. IPF is a progressive, untreatable, uniformly fatal disease that is frequently described as having a worse prognosis than many forms of cancer. IPF often presents with increasing shortness of breath and a dry hacking cough that does not go away. That nagging cough led my father to undergo a barrage of tests, culminating in an open lung biopsy in February 2001 that provided the final diagnosis. When I first heard the diagnosis, the word “idiopathic” seared into my brain. “My father was never a smoker. He never worked in asbestos. How could this be?” I thought. I do not know how he initially received the diagnosis but hearing it left me in utter disbelief. As his days, weeks, and months passed, Dad clearly recognized the gravity of his situation and wanted every potentially effective treatment. He completed a pulmonary rehabilitation program and became active in an IPF support group. After completing a course of high-dose steroids that provided no noticeable benefit, he participated in a Phase 3 trial of Interferon gamma-1b—a medication that required nearly daily injections and has many disconcerting side-effects. Despite the Interferon leaving him irritable and tired, I was thankful he persisted with this trial.

Over the next year, I did not notice that he declined much physically, but it was evident to me that his spirits often plummeted, sapping his determination. Early one summer after his diagnosis, he declared he would not plant a garden that year, an activity he had long cherished. My mother persuaded him to plant a few tomato plants and his dahlias. His interest in dahlias stemmed from his grandfather, who, many years earlier, had raised such prize-winning flowers. Planting dahlias linked him to his own past and the anticipation of new blooms gave him resolve for the future. Every spring, Dad presented me with dahlia tubers to plant in my own garden—it would not be until later that I realized I would be carrying on a generational tradition. I treasured this offering, but at the same time I recognized it was an unspoken signal that he

was slowly surrendering. His health gradually but inevitably deteriorated over the 3 years after his diagnosis. In February 2004, I could see that his health was failing more rapidly. Dad could no longer sing in the church choir, an activity he had enjoyed for over 60 years. In March, Dad became weaker and required continuous oxygen but was still at home. He developed flu-like symptoms and stopped the Interferon injections. When I visited him for a weekend in March, I was distressed and tormented by his prolonged, paroxysmal coughing spasms; I can not imagine that he slept much at all. Before returning to my home several hundred miles away, I made an agreement with his pulmonologist to page me when his condition worsened so that I could head home to be with Dad. That call came on April 1, 2004.

It was a stormy, blustery day and, as I drove, I encountered an unexpected snow squall. The ground was warm but the air was cold; as I came over the crest of each hill and started to descend on the other side, I was met by a dense fog. On that April Fools' Day, like the fog outside, haziness invaded my thoughts and I wondered what path lay before me. Was I foolish to hope for a positive outcome or was the storm only a temporary but cruel obstacle between me and my father's demise? Dad was admitted to the hospital that night and I was able to be present at his bedside in the hospital during much of his final weeks.

My father had been an engineer. He was accustomed to precise measurements and detailed planning. He was used to being independent and in charge. In the hospital, his mind remained sharp, but his current situation of being nearly totally dependent upon others was completely foreign to him. As the days passed, he became increasingly restless and anxious. One day, shortly after his admission, my sisters and I left him for a few hours as we went out for lunch. We returned to find the hospital chaplain at his bedside. “What happened?” I asked. He replied, “I needed someone here.” He could not tolerate being left alone for so long. Guilt haunted me for not recognizing his need to have someone present with him.

Later that week, he confided to me that the process was taking longer than he had anticipated. He was tired of

dying, but more importantly, he feared the process of dying more than death itself. From my medical training, I knew that one of the greatest fears of dying patients is to be physically and emotionally isolated; I had not anticipated the intensity of Dad's fears. I suggested that my sisters and brother and I take shifts, planning who would stay overnight to be with Dad. One day, I entered his room where family members and our pastor were at his bedside. Nonetheless, he appeared very worried. Sensing the tension in the room, I decided to share with him a story that I had not related to my family before—my experience with one of my patients when I was a resident in pediatrics many years earlier.

As a third year pediatric resident I took an elective in Pediatric Hematology-Oncology. Every day on rounds, we stopped to see Zachary (not his real name), a young boy who had been diagnosed with acute lymphoblastic leukemia shortly after his first birthday. I had seen Zachary prior to his diagnosis as a patient in our primary care clinic, where I had known him as a bright-eyed, playful and inquisitive infant. I had been on the inpatient service at the time of Zachary's initial diagnosis and would pop in to see him and his mother during that admission. His initial treatment resulted in a remission. When he came back for his outpatient visits, I would spot Zachary and his mother in the hallway or clinic.

As the months passed, I could see Zachary was meeting all of his milestones; he was curious, as happy as any child his age. Zachary's presence was striking—his sparkling dark eyes, his gleeful laughter, his magnificent smile. Later that year, however, Zachary's leukemia returned. A second course of treatment failed to achieve another remission. Only a little more than 1 year after his initial diagnosis, after therapeutic options had been exhausted, he was admitted to the hospital for comfort care—what I recognized as end of life care. Zachary was thin and tired. His eyes were dull and it was clear he needed the help he could receive only in the hospital. His mother also was in need of help. She was just 20 years old, single and very much alone. Zachary was her only child. She had no family to depend upon and Zachary's father was not involved in his care. She was bewildered by what had happened to her child—his cancer diagnosis, all of the tests and treatments, her hopes that had bubbled up with his remission, but now she was frightened, terrified by the return of Zachary's leukemia. She already had needed much support to face each crisis of Zachary's illness. As Zachary's strength declined, the team met with her to discuss his care. She agreed to a change in direction and that Zachary's care would focus on relief of his pain, palliation rather than cure.

I often returned to Zachary's bedside, coming back after the rest of the team had moved on to other responsibilities. Sometimes his mother turned to me with questions that she had not been able to voice when the entire team was present. Frequently, I felt that I did not have sufficient answers for her, but she accepted my imperfect

responses. I could not explain what caused his leukemia; it had no identifiable cause. He was dying and there was no going back. There would be no last minute improvement. Zachary hardly resembled the bright-eyed, playful boy who crawled across my exam table less than 1 year earlier—that boy was gone. His care focused on making him comfortable and eliminating interventions that caused him pain. Zachary's IV fluids were discontinued—and soon he could only take a little juice from a bottle. He became increasingly quiet, sleeping more and more.

On what would be the final day of his life, I stepped into his room in the afternoon. I felt the air press heavily upon me as I sat down next to his mother. I watched Zachary sleeping while his breathing became increasingly erratic. His mother caressed and cradled her dying son and as the hours passed, his breathing became more and more irregular. His mother became increasingly anxious and could no longer bear the stress. She turned to me, crying and pleaded, "Please hold him for me!"—And I did. I held him and rocked him while his mother sobbed and as his breathing and heartbeat finally ceased. I was able to be present for Zachary and for his mother. I kept my connection with Zachary and his mother through this transition.

I recounted this experience to my Dad—and told him that I would be there for him, too. I would hold his hand and be present for him and with him. Three nights later, Dad became increasingly restless and required more frequent doses of morphine. His breathing became more irregular, and in a final act of resignation, he forcefully pulled the oxygen mask from his face. I tried to push the mask back to his face, but he was right—he no longer needed it. I stayed at his bedside and held his hand so I was present for him and connected with him in a deeply primitive and profound way.

I do not spend much time on the inpatient floors or the intensive care unit now. In my work in the pediatric outpatient setting, I do not deal with terminal illness very often. However, I now recognize my role as a go-between for my patient and that which lies ahead, is unknown or often unspoken. I focus on being present with and connected to my patients through the sometimes prolonged silence that precedes a difficult question, allaying their fears about an upcoming evaluation, or acknowledging the uncertainty about the outcome of a child with a disability or chronic condition. I recognize that whether it is in the outpatient clinic or the intensive care unit, we may not always be able to treat or cure disease, but we can practice compassion and value being present with our patients.

And every spring, as a tribute to that presence, I plant the dahlias.

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