Peabody's Corner

"... for the secret of the care of the patient is in caring for the patient."
— FWP

Marilyn Todd

A Blueprint for Life and Love

My husband Ed recently died of amyotrophic lateral sclerosis (ALS), better known as Lou Gehrig's disease. His death march lasted 2 years, and I was with him every step of the way.

Ed and I met on a blind date in 1961. We married 4 years later and remained so for the next 50 years. After we completed college, I began a teaching career. Ed subsequently earned his MD and PhD and ultimately became chief of cardiothoracic surgery at a Midwestern medical school.

In 2000, Ed retired from surgery, which allowed him time to enjoy traveling and spending time with the family, especially on our farm. Ten years later, Ed and 4 of his retired colleagues founded a nonprofit organization named ABLE (Assisting Better Living Everywhere). Ed was the first president. The purpose of ABLE was to help the underserved, especially needy children, the disabled, and the elderly. Besides operating local and national projects, such as helping financially stressed seniors and disabled individuals needing home repairs, ABLE led mission trips around the world. Volunteers went to Belize, Bolivia, Burma, Kenya, Haiti, Ghana, and Mexico, primarily to build schools and orphanages and to conduct medical clinics. These efforts were quite successful.

Normally a very strong person, Ed began losing his strength early in 2014. Swimming wasn't as easy as it used to be, nor was lifting bags of grain for the cattle on our farm. After a while, Ed realized and admitted that something was wrong with his body. Desperate for answers, we sought help at a well-known clinic. There, he underwent a series of evaluations during the day, but he was unable to sleep at night because of difficulty breathing while lying horizontally. His oximetry reading had plummeted from 96 to 66! After 4 days of testing, the verdict was in: Dr. Ed Todd received a death sentence. He had ALS.

When we got home, we immediately ordered a bilevel positive airway pressure (BiPAP) machine. After Ed put it on, he fell asleep immediately for the first time in a week. He could now breathe and sleep simultaneously. He would have died without the BiPAP machine.

We knew that as ALS took its course, walking and normal daily activities would become more difficult. Ed could expect weakness in his hands, legs, ankles, and feet. There would be muscle cramps in his arms and shoulders. He would develop slurred speech, trouble swallowing, and difficulty holding his head up. Eventually, his breathing would be extremely compromised.

A plethora of machines began to fill our home. A suction device and a nebulizer kept Ed's airway open, and an oxygen saturation device monitored his oxygen intake. We also used a high-tech food blender to puree Ed's food to prevent him from choking.

Helping Ed with mobility was imperative. He used walkers and manual and electric wheelchairs. We had a wheelchair ramp installed, and got a van to accommodate Ed in his wheelchair. An adjustable bed was necessary to transfer him from bed to wheelchair.

Because I had no training as a nurse, I needed to be taught everything about Ed's care. I was blessed that Ed, as a physician and a teacher, could express his needs to me, and I was a quick study. We made a good team and loved one another unconditionally, "until death do us part." Our faith in God, along with the help of our wonderful children, extended family, and generous friends, made Ed's disease manageable.

Ed's illness forced him to relinquish his independence, not only to me, but eventually to other aides and caregivers. We were blessed to come into contact with a former medical technician in the intensive care unit where Ed had worked in the 1970s and

Reprints will not be available from the author.

1980s. She gave me medical and emotional support as I navigated these unfamiliar territories and watched the love of my life decline. This disease was forcing me to grasp the inevitability of our mortality and to accept it as a reality, as it consistently and viciously robbed Ed of his health. We were threatened by our separation after his death, but the promise of eternal happiness through faith was a reward to be anticipated.

One month after Ed's diagnosis, we were advised to go to the ALS clinic at the medical school. There are only a few of these clinics in the nation, because the disease is relatively rare. We were fortunate to have a clinic so close to our home, where we saw respiratory, occupational, speech, and physical therapists bimonthly. Despite the assistance of these well-meaning therapists, Ed's abilities diminished, and his breathing became more difficult.

He finally agreed to home hospice care. Even though I helped him shower, he could barely go through the maneuvers, because of extreme exhaustion and difficulty breathing. He slurred his words so much that I could not always understand him. Transferring him to the electric wheelchair had become much more difficult. I remained Ed's primary caregiver, but the assistance from the hospice staff was a blessing, especially as Ed's disability increased.

Before bed, Ed and I had a ritual: medicines, teeth-brushing, and a back massage to sooth his aching muscles. Then our litany of prayers for our family, friends, and country would begin. One evening, Ed completed our request for healing by saying, "But Thy will be done." He looked at the crucifix and said, "If Christ could suffer this excruciating death for our sins, I can surely handle ALS."

The time came when we could no longer go to public places because of Ed's compromised immune system. For Father's Day, our children gave Ed a large-screen television that provided him with a source of entertainment. They also ensured our safety by having a security system installed in our home.

As caregiving for Ed became more intense, our friends began bringing meals on a regular basis. Our dear priest friends came to our home to celebrate Mass for our large family, because Ed could no longer go to church. While he napped each afternoon, my thoughts would stray to the inevitable permanent separation to come. I could not imagine what I would do after his death. Tears came easily, but we tried to be brave and to remain "Todd Strong," a motto our children adopted. It helped us focus appropriately.

Meanwhile, Ed faced ALS head-on without feeling self-pity. From the time of his diagnosis, his attitude was not "Why me?" but "Why not me?" It seemed extraordinary to hear such a profound sentiment coming from a heart surgeon whose life's work was healing people, and now he had a disease with no known cause or cure.

Our family spent more time with us as Ed's condition worsened. Near the end, about 20 family members and our dear friend Father Gino gathered at our home. I fed Ed's dinner to him in the family room. Father Gino said Mass for our 8 grandchildren in the basement. Ed was too uncomfortable to attend the Mass.

It took 4 of us to help Ed into his bed that night. He cautioned us not to give him too much morphine or Xanax, because he wished to remain alert. He slept soundly that night, but at 6 AM, he reached for me and said in a hoarse voice, "Help me." I immediately summoned 3 family members who had helped the evening before. We lifted Ed into his electric wheelchair as he wished. He then directed us to give him his medicines and to start the breathing-assistance machines. As we surrounded his wheelchair, he began gently removing his face mask. Knowing that it was his lifeline, I cautiously tried to replace it. He then removed it, assuring me that he no longer required it.

As I held him in my arms and his head rested on my chest, he breathed 9 smooth and even breaths on his own, without a struggle. His breaths slowed and finally stopped.

We all wept as I embraced him, barely able to comprehend what had just transpired. Ed's journey on Earth was complete. Our caregiving responsibilities were over. God was in charge. Our emptiness was tempered by the knowledge that Ed's new life, filled with peace and unimaginable joy, had just begun.

It is beautiful to witness how God allowed us to endure, cope, grow, and blossom during this passage from denial to acceptance. The result was a spiritual transformation that miraculously enabled us to escape the predictable and unpleasant human condition of ALS and to experience something divine during the progression of Ed's illness.

In this journey with Ed, I witnessed the metamorphosis of a man, stronger than most, who changed into a person incapable of walking, talking, holding up his head, swallowing, and ultimately breathing. It was a dreadful 22-month-long experience. Nevertheless, by his faith, dignity, and grace, Ed gave us a blueprint of how to live and love, and finally, how to die. He was teaching until the end.

Submissions for Peabody's Corner should 1) focus on the interpersonal aspects of a specific patient–doctor experience; 2) be written in storybook fashion; 3) contain no references; and 4) not exceed 5 double-spaced typescript pages.