A Multiple Myeloma Diary

Kellie Smith, 52, lives in Austin with her husband and child. She has multiple myeloma.

March 14, 2022 As told to Bob Barnett

August 2018
I was a stay-at-home mom, very active, taking my child, E., to school and to dance and classical guitar lessons. Gardening was one of my great joys. But I started having severe back pain, which would dissipate, then pop up elsewhere. My family doctor prescribed pain medications, steroids and muscle relaxers. Because of the pain, my life screeched to a halt. I couldn't drive. I had to hold onto others to walk. I was so exhausted.

November 2018
I experienced severe abdominal pain and constipation for nine days. My doctor sent me to the ER. CT scans revealed that I had a sigmoid volvulus—my colon was twisted shut—plus swollen lymph nodes, which could mean lymphoma, and a small mass in the pleural cavity next to my lungs.

The GI doctors straightened out the volvulus and scheduled colon surgery to prevent recurrence but didn't send me to an oncologist. My husband, Yaphet, and I made a telemedicine appointment with my integrative medicine doctor, who didn't understand why the focus was on surgery when there was a suspicion of lymphoma. "If it was me," she said, "I would get that looked at first."

I canceled the surgery. That was the beginning of my cancer journey. My back pain was now so bad that I couldn't sleep in a bed. I was confined day and night to a recliner; it was horrible. When my MD saw the state I was in, she called an oncologist, who saw me within an hour, pulled my records and scheduled biopsies. That's when I got scared.

December 2018
The oncologist came back with the results—I had multiple myeloma (MM). I had never heard of it. We told E. that night at dinner. I saw the look of fear. "Are you going to be OK?" E. asked. I said, "We're going to do everything we can to get good medical care. We want you to continue your activities, and we'll work around this."

Yaphet became my advocate, researching and reaching out to MD Anderson Cancer Center in Houston. He found patient advocate Gary Petersen, who encouraged him to participate in Stand Up To Cancer's PROMISE study for healthy individuals at higher risk of developing MM. Yaphet promised to do so. Since both African Americans and family members of MM patients have a higher incidence of the disease, if Yaphet had an MM precursor condition, then the risk for E. would

have been even higher.

We met my myeloma specialist at MD Anderson, who did lab work, bone X-rays, pulmonary and heart tests, an MRI and a PET scan. I was using a walker. I learned that I had two fractured vertebrae caused by the myeloma. I received pain medication and scheduled a kyphoplasty to repair the fractures with cement. It couldn’t come soon enough. Every bump in the road on those three-hour drives to and from Houston was excruciating.

January 2019
I started treatment in preparation for an autologous [self-donated] stem cell transplant in six months. My Austin oncologist continued to treat me, coordinating with my MD Anderson specialist. For three out of four weeks, I got a combo of non-chemo treatments, including an IV immunomodulating drug. I experienced some taste changes and nausea but nothing too severe, although steroids really affected my sleep. On January 24, I got my kyphoplasty! Within five days, I was able to stand, sleep in bed and walk short distances unassisted. Waves of joy washed over me.

Kellie Smith in the hospital, with her family Courtesy of Kellie Smith

February 2019
I started physical therapy sessions so my body would be as strong as possible. Our family started talk therapy to ensure we managed our emotions.

June 2019
We moved to Houston for the summer. There was a lot of prep work—a bone marrow biopsy, catheter insertion, heart and lung tests and imaging and, finally, injections for stem cell growth. I shaved my head proactively. I didn't want to wake up one day and have a lot of hair on my pillow.

July 2019
I was admitted to the hospital on July 2. I had two forms of chemotherapy over seven days. On July 9, the team reinfused my stored stem cells back into my body. The nurses were great, like coaches who want you to win. I was wiped out. Yaphet enrolled in the PROMISE study by submitting a blood sample for testing. We were overjoyed to learn that he didn't have precursors of MM. I was released on July 22. I rested a lot. Yaphet and I took short evening walks inside our Houston apartment complex. In early August, I was cleared to move home.

October 2019
It took me months to get out of that fatigue zone. I got worn down, took lots of naps. Although I had a very good partial response to the stem cell transplant, a bone marrow biopsy showed that my myeloma was active again.
It was so demoralizing. We had to start over.

November 2019
I got a port and began a new 24-cycle regimen: a targeted antibody, an immunomodulating drug plus a steroid. Near the end of each cycle, my white blood cell count would fall; I got injections to boost my blood cell counts.

March 2020
With COVID-19 in full swing, we stayed very close to home. Fortunately, Yaphet works from home.

September 2020
E. left for college—Harvard! Because of COVID-19 and my immunocompromised status, E. stayed on campus the whole year. We missed having E. home for the holidays, but we stayed in touch via Zoom.

March 2021
I am officially in remission! I'll be staying on my treatment plan for at least two years, then we can consider other options.

September 2021
I received my first and second COVID-19 vaccine dose in February and March and got my booster dose this month. I was very tired the next day, so I attribute that to my body mounting a response. Fingers crossed!

January 2022

I’m in a good place. That first year as a patient, my life revolved around appointments. Now, there are weeks when I don’t have to go to a doctor. I feel good about life. Like any cancer patient, though, the thought of “What if it comes back?” is always at the back of my mind. I take it day by day. Like water, I go with the flow.

I have so much more gratitude in my life now. There are things I will never again take for granted, like walking up a flight of stairs or sleeping in a bed. I’m grateful for the physical things I can do and for all the hands and hearts that have touched my life.

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