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A Multiple Myeloma Diary: Kellie Smith

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

November 11, 2021 As told to Bob Barnett

August 2018

Before cancer, I was a stay-at-home mom, very active, always running from A to B, taking my child, E., to school and to dance and classical guitar lessons. I also was an avid gardener. That was one of my great joys.

But at the end of the summer, I started having severe back pain.

The pain was unusual because it would dissipate in one area, then pop up again elsewhere: upper back, lower back, left side, right side. My chiropractor sent me to our family doc, who thought it was muscular, ran tests and prescribed pain meds, steroids and muscle relaxers.

But it was rough. Because of the pain, my life screeched to a halt. I went from being a person who made everything happen to having to ask people for help. I couldn’t drive, I had to hold on to others to walk or walk close to a wall for support. I was so exhausted.

November 2018

At the beginning of the month, I experienced severe abdominal pain and constipation for nine days. I assumed it was due to the pain medications. The pain intensified on the ninth night, so 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 the lungs.

My GI docs scheduled surgery, resection of the colon, for mid-November. They didn’t send me to an oncologist. My husband, Yaphet, recommended that we talk to my integrative medicine doctor, a trusted adviser. We did a telemedicine appointment that day, and she didn’t understand why there was such a focus 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 slept in an electric recliner we got on Craigslist. I lived in that thing. It was horrible, being confined to a chair all day.

Yaphet and I followed up with an in-person appointment with my integrative MD. Upon seeing the state I was in and asking me a few questions, she immediately made a call to an oncologist, who saw us within an hour. The oncologist pulled my medical records from the hospital, then scheduled a bone marrow biopsy and a needle biopsy for the pleural mass. That's when I got scared. We started requesting additional medical records, and I reached out to my family for medical history details to look for any clues that seemed related to my symptoms.

December 2018

On December 3, the oncologist came back with the results. I had multiple myeloma (MM). Apparently, my form of myeloma was difficult to diagnose because I didn't have readily detectable levels of monoclonal proteins. I had never heard of multiple myeloma, so it was a lot to process all at once. It's speculation, but I think the multiple myeloma was not only causing the back pain but also inflammation that led to the sigmoid volvulus.

We told E. that I had MM that night at dinner. I saw the look of fear and alarm. "Are you going to be OK?" E. asked. I said, "We're going to do everything we can to fight this disease and get good medical care. And I don't want you to change your life, to skip doing something you want to do. Live your life and we'll work around this."

My husband bought a book called the The Patient's Playbook and became my advocate, learning about research and treatments, reaching out to MD Anderson Cancer Center in Houston to schedule an appointment for me there, looking for MM experts and patients. He found Gary Petersen, an MM survivor and patient advocate, who encouraged Yaphet to participate in the Stand Up To Cancer PROMISE study.

The study tests certain healthy individuals who may nonetheless be at higher risk of developing multiple myeloma. Multiple myeloma risk factors include being 40 to 75, and there is a higher incidence of the disease among African Americans and people who have a close family relative with MM or another blood cancer. We were mostly concerned about our child, who is already at higher risk since I have MM. If Yaphet had precursor conditions, the risk for E. would have been even higher. Yaphet committed to joining the study.

As the days passed, my back pain worsened, and I began using a cane and then a walker. Fortunately, friends and family began bringing meals and helping with laundry and dishes.

Near the end of the month, I started my first appointments at MD Anderson. There was lab work, bone X-rays, pulmonary and heart tests, an MRI and a PET scan. We met my myeloma specialist and the rest of my medical team.

As a result of the imaging, I learned that I had two fractured vertebrae caused by the myeloma. Those fractures were causing my back pain. I received pain medication and scheduled a procedure known as kyphoplasty to repair the fractures with cement. It couldn’t come soon enough. Every bump in the road on the three-hour drive to and from Houston was excruciating. And we made four trips that month!

January 2019

While at MD Anderson, we asked about clinical trials, but I wasn’t a candidate for any. So I started treatment in preparation for an autologous stem cell transplant in six months. The goal was to get the MM numbers, specifically my lambda light chains, close to zero. (I was relieved that, unlike an allogeneic stem cell transplant, the autologous transplant would use my own stem cells, so I wouldn’t have to find a donor.)

Though I was working with a specialist at MD Anderson, I received treatment in Austin under the guidance of the oncologist who originally diagnosed my MM. I was truly fortunate that she not only encouraged and embraced my decision to seek out a specialist but coordinated closely with my specialist on every aspect of my treatment.

Every week, I went in for lab work in Austin on Wednesday and got a combo of non-chemo treatments, including an immunomodulating drug, via an IV, on Thursday and Friday. This happened three weeks in a row and then one week off. It took a lot of coordination to arrange folks to drive me to appointments and sit with me during infusions. I usually saw my doctor at MD Anderson on my off week.

I experienced some taste changes and nausea during this time but nothing too severe. The steroids affected my sleep patterns. I’d go two or three days with very little sleep and then crash once the steroids wore off. I also started getting hot flashes.

On January 24, I got my kyphoplasty! The only pain I felt was soreness from the procedure, which lessened daily over the next week or so. I was able to stand, sleep in bed and walk short distances unassisted. Waves of joy washed over me at being able to return to these simple activities because I had begun to fear that pain, canes and walkers might be a permanent part of my life.

February 2019

I started weekly physical therapy sessions. I needed to increase the length of time I was able to walk, and I wanted my body to be as strong as possible in preparation for the toll the stem cell transplant would take.

Our family also started talk therapy as a preventive measure to ensure we managed the emotions and stresses we might face in the future. I’m grateful we did this, since it helped us maintain an even keel and focus on treatment.

May 2019

I had my last treatment. I had my ponytail cut and donated it to Locks of Love, [which gives ponytails to children with hair loss]. My new short hairstyle allowed me to try on wigs so I could choose one before losing my hair. I researched what to expect during the transplant and what to bring for a long hospital stay.

June 2019

We moved from Austin to Houston for the summer to prepare for the stem cell transplant. We packed up as soon as E. finished the high school year. There was a lot of prep work—a bone marrow biopsy, catheter insertion, heart and lung tests and imaging, and then I started getting injections for stem cell growth so they could harvest my stem cells.

I decided to shave 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, and I was there for three weeks. In the hospital, I had two forms of chemotherapy over the course of seven days.

The first two days I had the first chemotherapy treatment. It was titrated based on my metabolism; a nurse came in every hour to do a blood draw over the course of eight hours. After a three-day break, I received another form of chemotherapy for two days. I had one more day off, and then on July 9, the team reinfused my stem cells into my body.

It was a pretty smooth process, and the nurses were great. They were like coaches who want you to win. My body was wiped out. It was hard to muster up energy to walk a lap around the transplant floor, but I did it, and E. or Yaphet walked with me.

During this time, Yaphet enrolled in Stand Up To Cancer’s PROMISE study by submitting a blood sample for testing. Yaphet, fortunately, found out that he didn’t have precursors for multiple myeloma.

I was finally released on July 22. I rested a lot. Yaphet and I took short evening walks inside our apartment complex while my immune system recovered.

My white blood cell counts and other numbers were close to normal in early August, so my transplant doctor cleared me to move home to Austin.

Kellie Smith and her family Courtesy of Kellie Smith

October 2019

It took me a few months to get out of that fatigue zone. I had physical strength to some extent, but I got worn down, took lots of naps. I was not a napper before. 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 very demoralizing. It felt like we had to start over.

November 2019

I got a port installed 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 due to the medications. In order to receive the next course of treatment, I got injections to boost my blood cell counts.

March 2020

With COVID in full swing, we stayed very close to home. Fortunately, Yaphet works from home, so this was not much of a change in routine. In addition, we had become accustomed to wearing masks to prevent infections during the stem cell transplant, so we did not hesitate to don masks again as the pandemic spread.

September 2020

E. left for college—Harvard! Because of the COVID-19 pandemic, it was possible for E. to get an extension to stay on campus the whole year because I'm immunocompromised. I didn't want E. to worry about bringing the coronavirus home, so it was easier to stay in one place and have more freedom. We missed having E. home for the holidays, but we Zoomed, including on Thanksgiving, birthdays and Christmas morning.

March 2021

I got the first dose of the COVID-19 vaccine in February and the second dose in March. I didn't have much of a physical response. The pandemic adds an extra level of worry to my life, which is already a little complicated anyway. Because my immune system is compromised, we continue to limit visitors and outings. I just don't know how my body would react if I contracted the virus.

The worries of the pandemic receded later in the month when I learned that I am officially in remission! Another bone marrow biopsy confirmed it. I'll be staying on the treatment I started last November for at least two years, then we can consider other options, such as reducing the dose of one of the medications. We'll see what my body says.

September 2021

I got my third dose of the Moderna vaccine, the booster. I was very tired the next day, so I attribute that to my body mounting a response. Fingers crossed!

November 2021

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’m doing physical therapy to regain muscle, core strength and balance that I lost over the past two years. I get help to do it safely.

I feel good about life. I feel as close to normal as I’m going to feel. I know my life has a rhythm, with monthly maintenance treatments, energy levels and sleep patterns. Physically, I’m doing OK, but like any cancer patient the thought of What if it comes back? is always at the back of my mind. There’s murkiness about what happens next. How long will treatment last? How long do I have in remission? You can’t take your body for granted, and you just hope it’ll be OK. 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—my friends and family, my medical teams at MD Anderson and here in Austin.

For anyone facing cancer, if you are able, see a specialist because they understand how your particular cancer works and will be up on the latest treatments.

Second, I know it’s hard because of COVID-19 safety protocols, but if you can, take someone with you for appointments or have them on the phone as another set of ears to ask questions and clarify information. It’s important to take notes.

Third, there’s a lot of power in support. If you can find a support group, it helps so much. People want to share their experiences and help you with your journey. It can be really tough, but you don’t have to do it alone, and they may have resources they can share.

For example, I was connected with a multiple myeloma survivor of 14 years. She gave us the ins and outs of MD Anderson and things you wouldn’t think to ask about, like parking, elevators, and lodging as well as side effects and dosages. It’s good to just have someone who encourages you, to say, “Hey, this is really crummy, but it’s going to be OK. “

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