

We were at 35,000 feet coming home from Park City with our grandchildren when my husband told me he had blood in his urine. He had some problems after his prostate cancer in 2011 but I wasn't particularly worried. He's like the Energizer Bunny – he never slows down.

Bob called the urologist and waited for a return phone call. We called again and finally got the return call. "We're scheduling you for surgery," the nurse told him. Didn't he need a preop exam? At least a phone call would have been helpful.

I sat at my husband's bedside while he was awaiting surgery. The urologist came in and explained what he was going to do. We signed the operative permits, and I moved to the waiting room.

Several hours later, the doctor came in and sat down beside me. "Bladder cancer."

"My grandfather died from bladder cancer," I told him.

"Yeah, but back then they probably did cystoscopies with a candle," he laughed. It wasn't funny. I remembered how hard the diagnosis was on my grandparents.

"There are two kinds, high-grade and low-grade, and we won't know until the pathology comes back which kind it is. In the meantime, do not get on the internet and scare yourself. We'll call you with the results and reschedule a follow-up cystoscopy to see what's going on."

I couldn't shake the vision of my grandfather standing in front of the sink in the powder room of my home, struggling to manage his ileostomy. My grandparents stopped traveling soon after.

The pathology report was terrifying. High-grade urothelial cell carcinoma. "The treatment of choice is BCG infusions into the bladder each week for six weeks, but we can't get BCG, so we'll see you in a year."

A year? When there was a treatment for bladder cancer? Were we supposed to accept this? Images of my grandfather kept coming back. Doing nothing was unacceptable.

We called Dr. James Bennett, his previous urologist in Atlanta. Dr. Bennett had treated Bob for prostate cancer and he saw us right away. “I can get the BCG, but there is a worldwide shortage. It may take a couple of weeks.”

Four months later, the cancer was back. Another round of BCG. This would be our routine for the next eighteen months. Dr. Bennett and his office were wonderfully supportive.

We’re six years out and now he’s cancer-free. Scar tissue from the cystoscopies caused multiple urinary strictures, but Optilume has helped. Two weeks ago he got an artificial urinary sphincter to help with the incontinence.

This journey has been a team effort. I’ve been his caregiver and advocate throughout the process, and I now have a YouTube channel to help other caregivers and advocates, @CaregiversUnited-y9u, and a book is in process. Our healthcare system is complex and it helps to have someone to help you navigate the process.

Know the warning signs. If you see blood in your urine, get checked.