

Dying at Home

By Jen Baker-Porazinski

I hadn't seen Jean for over two years when her hospice papers arrived on my desk for my signature. She'd always been in good health so I hadn't worried about her absence from my schedule. Besides, I saw her occasionally in town and whenever I did, she looked radiant— like someone who took care of herself physically and mentally. And she did.

Jean attended yoga and tai chi classes regularly. She excelled in rug hooking and fabric arts. She was involved in her community, giving back where she could—knitting hats for premature babies, donating blood. Sometimes I ran into Jean on the sidelines of the soccer field cheering for her neighbors' children. I saw her at the local theater and fundraisers. She was a mother and grandmother and a happily married wife. She was a paragon of wellness—healthy in mind, body and spirit. She should have lived to play with her great-grandchildren.

So, I was shocked to learn she had been diagnosed with inoperable cancer and decided to forgo further treatment. I called her husband Ed and arranged to make a home visit, something I was grateful my job allowed me to do for patients too sick to come into the office.

I didn't know what to expect as I drove up the quiet back road through the woods. I worried about what help I could offer Jean. I worried about Ed. I turned onto a dirt driveway and drove up a steep path. I parked the car and stepped out to a beautiful summer day. Birds sang in the trees and butterflies fluttered in the fields. I took a moment to look around, admiring Jean's flower gardens, before facing the truth. It was unimaginable I had arrived at the home of a vibrant, but dying woman.

I was greeted by Ed who, despite his years as a helicopter rescue pilot, looked like a man facing the most difficult battle of his life. He managed a smile and thanked me for coming. We spoke in low whispers outside the back door as he caught me up on Jean's condition. After a few minutes, we were interrupted by another family member. "Jean wants you to come inside and stop talking about her out here," the woman said. I was happy Jean was feeling well enough to admonish us about her exclusion.

We entered through a tidy kitchen and turned down a short hallway into her bedroom. Jean was propped up in a hospital bed nestled between the foot of her real bed and her dresser. She faced an open window with a view of the rolling green Taconic Mountains. A curtain waved in the warm breeze blowing in across her bed. A large dog rested at her feet, snoring loudly. Ed told me that this dog usually followed him around exclusively, ignoring Jean. Since she became sick, though, the dog wouldn't leave her side.

Despite the warm weather, Jean had several quilts tucked around her small frame. She'd lost weight and looked small in her bed. Like Ed, she was pale and tired. With considerable effort, she straightened up in her bed when I entered the room. She smiled warmly and thanked me for coming. "How's Digby doing at school?" she asked of my middle son. I answered her as I pulled out my stethoscope and blood pressure cuff. Jean looked relieved at the sight of these familiar tools of doctoring. Although I knew my measurements wouldn't be of much help, they showed her I hadn't given up, even though we both understood the awful truth of what was coming.

I asked her if she was in pain. She shook her head "no" as a tear slid down her cheek. I sat down on the bed next to her and reached for a tissue to wipe it away, wishing I could do more. "I'm so sorry, Jean," I said. I squeezed her frail hands in mine.

"I just want it to be over," she confided.

But Ed and I weren't ready to let her go.

I visited her weekly, as much to check on Ed as to see Jean. I worried about him. He rarely left her side. Despite suffering a massive heart attack years earlier, Ed shouldered Jean's weight as she became weaker, carrying her to and from the bathroom and occasionally taking her outside. The mechanical lift meant to hoist her sat unused on the side of her hospital bed. Every time Ed picked Jean up it was an act of love—an intimate dance. At the slightest indication from her, Ed jumped up and darted to Jean's side. He made her popcorn, the one food she still ate (but just a few kernels, he told me). Every few minutes he brought a straw to her lips and urged her to drink.

Jean had a lot of support—children and grandchildren, siblings and friends who poured into the small bedroom to be with her. Before she became too sick to leave her bed, her tai chi group held a special class out by her pond so she could join in from a wheelchair. When she could still speak, she told me how she treasured listening to a recording of her grandkids singing, their voices bringing beauty and life into her bedroom.

Jean's condition deteriorated quickly. Over the next few weeks, she became more anxious. She awoke from a nap and called out to be with her deceased mother. I convinced Ed, who was hesitant to over-medicate her, to give her the anxiety pills hospice had recommended when she seemed upset. I continued the comforting routine of listening to her heart and lungs at each visit. Although she always made an effort to rouse herself when I was there, she interacted with me less each time.

Jean died a few weeks after my first home visit. The very last time I saw her, Ed told me she was no longer waking up. I held her hands anyway and announced that I was there to check on her. Her eyes fluttered open and a brief look of recognition came across her face. She looked serene. I'm sure she woke up just to let me know the struggle was over and she was at peace.

Unlike nurses, doctors are accustomed to seeing patients after they've already been cleaned up of vomit and urine. I was usually sheltered from the less sanitized aspects of sickness so I wasn't sure what to expect during my visits. My weekly arrival was planned and, while she was

still able to, even Jean presented her best self. The messier aspects of caregiving, like toileting and bathing, were not something I had to witness or participate in. These were the domain of her loving family, hospice nurse, and especially Ed. He slept little in those last weeks. His back ached from carrying and repositioning and standing watch over his beloved. He held her hand and listened to her as she begged him to let her go. He stood vigil over her gasps and groans. Not to acknowledge this part of her illness would be to minimize Ed's love and dedication. There was pain.

The beautiful truth about Jean's final days, though, was that she spent them at home with minimal discomfort, under the dotting care of a loving spouse, surrounded by her family. I wish all of my patients could be so lucky.

A few months after Jean's passing, I saw Ed on the sidelines of my youngest son Orion's soccer game. He was with a neighbor, cheering on her children. After the game, he came over to where I was waiting for my son. "I just wanted to thank you for all that you did. I never had a chance to let you know how much your visits meant to us," he said.

I reached for his hands and reminded him he had already thanked me many times. "I should be thanking you," I told him. "It was my honor and privilege to help you take care of Jean." And, I meant it. Despite the deep sadness, I was grateful to help ease Jean's suffering— to do what I became a doctor to do.

Jen Baker-Porazinski practiced primary care medicine for over two decades in her rural community before taking a position in Canyon Ranch's Health and Performance Division in January 2022. In this role, she performs diagnostic medical services and consults with patients on preventative medicine. She also lectures and contributes regularly to their blog. In addition to Family Practice, she is Board Certified in Integrative and Lifestyle Medicine. She is writing a book about her experience as a doctor in the American healthcare system, including her story and the stories of her patients. She lives in upstate New York where she and her husband of nearly 30 years have raised three sons. Read more of her work on her blog, [Pound of Prevention](#).