

Cancer's unknown country

Joe Feuerherd | Oct. 18, 2010



ESSAY

It was my first night in the nursing home. 4:00 a.m. and quiet -- until the screeching, the increasingly loud yelps resulting, one supposes, from inattention that early morning staffing schedules beget, continued.

She pleaded with exclamation points. "Help me! Help meeee...!" came the screams from down the corridor. "Someone change my diaper! I'm all wet! Help meeee...!" Begging, particularly when screamed by an elderly woman (or what I thought was an elderly woman), can be especially disconcerting.

An hour or so later it was over, only to repeat itself at different times, including the dead of night, over the next week or so. Then it stopped. Hardened by the routine, I sunk to black humor. "What do you think they did with the screamer?" I whispered to my wife.

I was in the suburban Maryland "home" as a rehabilitation patient. The surgery to remove the large cancerous tumor from my right buttocks the week prior had gone well -- with one exception. The procedure's legacy was a large wound that needed time to heal, which meant that I could not rest at a 90-degree angle -- the sitting position -- for fear of ripping the tender area open.



Now the inability to sit even for a brief moment may not sound like too

big a deal, but try it for a while. It means you can't get out of bed without assistance from at least two hearty people, trained to lift as they would open an ironing board -- prone to standing without a stop in between. Which meant, with the assistance of two physical therapy assistants, two brief walks down the hall and a short trip to the physical therapy room daily. Otherwise, bed. The most frustrating and, at times, despairing period in an

otherwise blessed 46-year-long life.

Cancer

My cancer first hinted its existence a year ago when my wife and I bought a pair of bikes in an effort to get in shape. A short spin on a beautiful fall day brought with it, quite literally, an aching pain in my butt and a noticeable bruise. Of enough concern that I scheduled a doctor's appointment. I figured a minor case of arthritis.

The young doctor performed a thorough examination everywhere but the one area I highlighted for his review, which he glanced at. If it gets worse, he said, come in for an MRI. This little oversight may have cost me dearly, for it was time lost, and when you're talking about cancer, time matters. (One plus: For a short time, thanks to the prescription for fungi-fighting Lamisil, I did have the best looking toenails in town.)

Two months later, I was back in his office fresh from a 1,200-mile car trip, the last 200 miles of which was carried out under severe pain. The bruise now dominated my right side. Damn butt!

Back to the young physician's office. This time he looked closely and looked deeply concerned. He suspected the worst, ordered the MRI and CAT scan, and by the end of the day, I was off to the specialist.

Diagnosis: soft tissue sarcoma, a relatively rare and frequently fatal tumor with a strong tendency to spread. The Catholic writer Flannery O'Connor, who suffered from lupus, once said that having a serious illness is like traveling to a foreign country. She was right. My family and I were headed to an unknown land -- full of surprises, some hilarity at the natives' expense, and levels of anxiety previously unexperienced.

Treatment

The treatment for soft tissue sarcoma is, according to the Google searches, pretty straightforward. I wish.

First, remove the tumor, this one large and getting dangerously close to the spinal column. Worst outcome, the surgeon can't get the tumor without impinging on the spinal column and the patient is crippled.

Luckily, we secured the services of the leading surgeon in the field and the worst was avoided. The five-hour operation was declared a success.

Next, radiation treatment to rid the body of any pesky cancer cells so small as to go undetected by the PET scans, the CAT scans, the MRIs, the Doppler tests and the rest. Thirty-seven zappings later and all looked good. Meanwhile, that persistent wound broke down as a result of the radiation and needed more tending too -- in bed, but this time at home. To this day, my wife changes the dressing twice daily -- I can't quite reach the area -- a skill for which too many doctors and nurses to mention have complimented her.

Six weeks pass. And then more bad news. The various scans conducted in the months following radiation show that the cancer has metastasized, spread to just outside the ribcage and, given the difficulty in detecting all the little buggers, God knows where else.

More radiation, but this time a relatively new type called "cyber-knife radiation." This high-tech method was, we were informed, particularly well-suited to eliminating the tumors in my chest.

"It almost always works," another young doctor, this one a radiologist at one of the nation's top hospitals, told us. By which he meant that the 10 treatments of two- to three-hour duration would greatly reduce or virtually eliminate the tumors, at least in the short-term.

He was wrong. It didn't work.

Next up: chemotherapy. We told the oncologist our preference for the most aggressive, though prudent, treatment possible. The unfortunate result was a "severe adverse reaction" to the combination of drugs ingested. Normally, being the political junkie I am, I can tell you who was undersecretary of transportation in the Ford administration. For 24 hours, I had no idea who the current president of the United States (a man I had interviewed) is.

Now, I'm on a more moderate course of chemotherapy. I write this from the infusion room where I'm undergoing weekly treatments over the course of two months. It's going well -- the pain in my side is gone, an indication, perhaps, that the chemo is doing its job and the tumors are shrinking.

It's unlikely that I'll ever be "cancer-free." Sarcomas don't lend themselves to full remissions or cures. The good news is that millions of Americans are now living with chronic cancer -- get the worst behind you and deal with the day-to-day inconveniences necessary to manage a serious illness.

Lessons

There are, I know, some lessons I am supposed to have learned from this ordeal. I offer some these modest thoughts:

- Have good insurance. I haven't added it all up, but the cost of my care -- the hospital stays, the drugs, the high-tech radiation, etc. -- has perhaps a \$500,000 tab. And there's more to come. Our expenses, by contrast, have been manageable, comparable to a car payment.
- Get a sympathetic employer. I've missed a lot of work and had to request numerous accommodations (I now work largely from home) necessary to make me a productive employee. When you've got a job that you love (like I do) work is important. Thank you, *NCR*.
- Appreciate the medical professionals. I'm constantly amazed at the level of caring and knowledge demonstrated by most everyone (the first young doctor above excepted) with whom I come in contact. They do things no one could pay me to do. And, with rare exceptions, they do it with the love that only genuine commitment brings.
- Have a sense of humor. If you can't laugh at the absurdity when the ambulance driver from the nursing home, whose skill is to get you to your doctor's visit safely, starts giving medical advice to the surgeon in the procedure room, then you've lost a sense of balance.
- Rely on family and friends. Our friends, veterans of soccer games and swim meets and the occasional cocktail over the years, have been there for us in some remarkable ways. Our children -- ages 20, 22 and 24 -- have spent nights in hospital rooms, sterilized and cleaned the home front, and been there whenever we've needed them. Not sure where all that came from, but we're delighted it's there. Likewise, despite the inconvenience of distance, my siblings and in-laws have stepped in at key moments when life simply got overwhelming.

Finally, and most importantly, have a partner or spouse who will do anything, anything, for you. Serious illness is not something anyone can do alone. Friends and family (see above) can help, but they have their own lives and crises. Someone completely devoted to your well-being, the "caregiver," is essential to recovery.

In my case, this is my wife, Becky, who has, at least temporarily, given up a good career, and forsaken more than I can describe to fight with bill collectors, oversee medication management, negotiate with doctors, and tend to my wants and needs. All out of unconditional love. Thank you, Becky.

And if all else fails, there's always the direct method of the elderly woman in the nursing home. "Help me! Somebody help me!?"

I think it worked for her.

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