

## A PIECE OF MY MIND

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## Life Is Not Fair

### This isn't about me.

I wasn't the one who was kept alive by total parenteral nutrition (TPN) infusions for more than 20 years. My friend S was.

I didn't have 4 cancers, with radiation treatments that successfully treated the uterine carcinoma but resulted in radiation enteritis. S did.

My family isn't afflicted with Lynch syndrome. Hers is, and she drew the dark, cancer-predisposing mutated gene.

We met about 40 years ago through our sons who attended the same elementary school, were in Cub Scouts together, and played on the same sports teams. The first time I saw her, she was screaming her heart out for her son as he raced with the ball toward the soccer net, and then she laughed with love and resignation when he missed. Instantly, I recognized a unique person. She was tall and fun, confident and beautiful, and lively as a sparkler. She attended all the Parent Teacher Association meetings, sat in the stands at 7 AM Sunday morning peeewee hockey practices, made chocolate-coconut bars for the bake sales.

S was a pediatric nurse and I, a pediatrician at the same children's hospital. We rarely, however, interacted in a professional capacity. Our friendship transcended all that.

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### I wasn't ready for her to leave. Surely, there must be some way to quell the nausea and perk her up.

I was alone in my research laboratory in the early evening when she appeared at the door and told me about her first cancer. We hugged. We cried. She got through it, and so did I.

Following the radiation, though, her intestines didn't slide smoothly over each other. They were sticky. They kinked and refused to let their contents trickle through. She felt miserable and spent many days in the hospital, over and over, until her guts worked again. It was *after* she bought airline tickets for their big trip to Australia that she began to worry about the flight. What if she developed an obstruction while in the air? She didn't want to be responsible for diverting the plane and making other passengers miss their connections. She didn't want to make trouble for anyone. We decided she would take along a nasogastric tube as an insurance policy. Probably someone on that huge plane would know how to snake it through her nose. If not, she could probably do it herself. The flights there and back were uneventful.

Then she developed carcinoma of the colon, cured by resection.

She said she would *never* go on TPN. But she did when her radiation-savaged intestines could no longer adequately nourish her. She said she shouldn't eat anything, but she cheated; she loved crackers and would sneak 1 or 2 or 4 saltines from time to time and then pay the price. She played tennis and golf; she skied and ran miles through our neighborhood, expending those precious calories because she loved being active. She said she would *never* wear an ostomy bag, but she did when she developed an enterocutaneous fistula that refused to heal.

Then she had adenocarcinoma in a colonic polyp, cured by polypectomy.

For decades, she and I had season tickets to concerts at the local auditorium because neither of our husbands liked that much good music. She planned her infusions carefully, so she could be free from the tubes and pump and pouches of white liquid nutrients on concert evenings. On the days when she overbooked, she hauled her equipment in a big canvas bag to the auditorium. We stuffed our coats around the pump, so others in the lower balcony couldn't hear its clicks and hums during the quiet parts of the performances.

S loved to canoe and was particularly fond of the Boundary Waters of northern Minnesota. She was very unhappy when we could no longer enjoy those stunning camps, portages, and trails because of her need for electricity to run the pump. When I spotted an ad for rental house boats—with electrical outlets in the cabins—in Voyageurs National Park just west of the Boundary Waters, she was ecstatic. While our husbands fished and drove the boat

from docking spot to docking spot, S and I lounged on the sun deck on top, taught each other new solitaire games, knitted, paddled our canoe along the shore, and walked the paths through the pines after we moored for the evening. The boat had a slide from the top to the waterline, so S donned her bathing suit and glided down that curvy slide several times to be sure her husband got the best video of that stunt to send to her sisters.

Our last big adventure was a trip along the Bourbon Trail in Kentucky with our husbands. S loved to visit state capitols, so we stopped in Frankfort to check that one out. At supper on the porch of a quaint restaurant overlooking the Kentucky River, S hunted down a table next to a string of twinkling decorative lights and an outlet. She settled into a chair, plugged her pump into the socket, and sipped at a beer while the rest of us ate supper. We toured distilleries—Buffalo Trace, Lux Row, Maker's Mark to name a few. We played euchre in our musty rooms in the 1950s motel where

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we stayed in Bardstown. S told us she preferred her TPN breakfast to the stale Danish and bad coffee provided by the motel. She tired quickly during that trip.

Then she developed adenocarcinoma of the stomach that could not be cured. It was considered unlikely to be responsive to chemotherapy, she wasn't a candidate for more radiation, and no surgeon would touch that abdomen ever again. One medical mess led to another. She felt nauseated all the time, and none of her physicians could figure out how to relieve that. No health system, including the one in which we both had worked and to which we were steadfastly devoted, was able to deliver what we most wanted for her.

She just couldn't shake the fatigue nor the queasiness. She talked more and more about dying.

I wasn't ready for her to leave. Surely, there must be some way to quell the nausea and perk her up. The cancer wasn't curable, but it remained localized to her stomach and could be palliated, at least for a while. She, however, was exhausted in every way—depleted nutritionally, metabolically, physiologically, emotionally. After several days in an inpatient hospice facility without her TPN, she died, taking that vibrant spirit for living with her.

Maybe this is about me, after all, for I miss her so very much. Life is truly unfair.

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