Never Thought I Would

I hate getting older. I should be proud of every grey hair, but I’m not. So I avoid those cameras (all of them now, it seems) that showcase the lines on my face and my sagging neck. I no longer time my daily runs. And I keep in touch with old friends, who make me feel as if we’re all still 20.

Cindy was my college roommate. I have a photo of her taken after her first kidney transplant. She’s wearing a snap-at-the-shoulder hospital gown, with a bandage on her neck from a recently removed IV. She’s speaking into an ancient black rotary phone, and her smile extends the width of her young, prednisone-puffy face.

I always imagine that it is I she is speaking to on that phone. Since graduation, Cindy and I have never lived in the same city; we’ve often lived on different coasts. So, while we visit in person occasionally, mostly we are telephone friends.

Because of Cindy, I knew more about lupus than almost any disease when I started medical school. Over the years I’ve learned more from her about dialysis, transplants, losing kidneys, second and third transplants, and the hazards of immunosuppression, than I ever expected to know.

My first memory of her illness is of cleaning vomit from our dorm room floor when she was too weak to get to the bathroom. A few months later she was on dialysis. Then the wait for a kidney, months of the ups and downs of having toxins removed only three times a week. From living with Cindy through those days, I know that those of us with 24/7 toxin removal can’t begin to understand how that feels. She endured months of shuttling to and from multiple hours-long dialysis sessions. Months of feeling constantly crappy.

Cindy’s life history is filled with touchpoints that chart the perils and progress in transplant medicine over the last 30 years. She lost her first transplanted kidney to a cytomegalovirus (CMV) infection, before antiviral prophylaxis became routine. She was living in San Francisco during the height of the AIDS epidemic when she received her second transplant. A close friend had AIDS, and she remembers her anguish about whether or not to visit him when he was losing his eyesight to CMV. That kidney lasted her for 21 years, and was lost to clots from anti-phospholipid syndrome, rather than infection. Today she lives in New York City and feels not anguish, but guilt for asking the non-profit prison diversion program, where she teaches art to adolescents, to pay her cab fare because now, with transplant number 3 on board, she’s no longer willing to risk infection on crowded subways.

I was reminiscing with Cindy the other night—on the great-grandchild of the black rotary clunker, my salmon-colored iPhone—about all the changes since her first transplant. “They let me get much sicker before I started dialysis the first time—I guess I was younger and stronger. This time they said, ‘You need the transplant now!’ ‘Surely I can wait, I’m not that sick yet,’” she laughs, “‘No, now!’ they insisted.” She got this kidney from her husband, so there was no wait.

In the years that have passed, transplantation has become routine, for better or worse. Cindy continues, “For the first 2 kidneys, I was really special; everyone in the hospital knew me. I’d walk into the ER, and the nurses would shout, ‘Cindy!’ This last transplant was like an assembly line.”

“And the prednisone, so much prednisone in those early years,” she says. “Now, hardly any.” Decades of prednisone took their toll last year, though, when a minor fall landed her in bed with a broken hip. And unfortunately, whatever form it takes, immunosuppression is immunosuppression—Cindy visits the dermatologist regularly for squamous cell cancer removal.

We reminisce some more. Then, as conversations now often do, our talk turns to growing older. I gripe about the slow runner I’ve become. Cindy’s concession to age was staying overnight in Washington, DC when she went to the women’s march—years ago it would have been a day trip. We both complain about memory lapses and reading glasses.

Then, out of the blue, Cindy says, “But I like getting old.”

“What?” I reply.

“I really like getting old,” she repeats, then pauses. “Because I never thought I would.”

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