

Unmarked Territory: A Diagnosis & Its Consequences

by
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Dying is an adult activity. This has been one of its bigger surprises for me, so far. I find I'm needing to leave behind the child side of my self in order to go where I now need to go, in order to do what I now need to do. This child-self has been a constant companion of my adult years. It's helped me slog through the gobbledygook of career, mock the pomposity of achievement and, sometimes, levitate against the downward-sucking gravities of title and résumé. Death and I are walking toward each other, no doubt about that. We've made eye contact, and I get the feeling it's walking at a slightly quicker pace than I. Where I'm traveling to is not the kind of place a child should go. And my famous destination, about which so much has been written, is not marked clearly on the map, strangely. Instead, where 'x' ought to mark the spot, there's merely a note telling one to go over to the other side. Any child, spotting this trap, would turn tail and run. That would be the right thing to do, the reasonable thing to do, for a child.

The first sign I had that something might be wrong appeared in London, where my wife and I had flown to mark my 60th birthday. My feet and ankles, hands and wrists, began to swell during the seven-hour, trans-Atlantic, flight from Kennedy. This swelling got worse, day after day, for a week, spreading up my arms and legs. When we returned home, my internist ordered lab tests and changed my blood pressure medicine. The swelling went down but did not go away. Three weeks on, lunching at a chowder house across from Lincoln Center, my cell phone chimed. It was the internist. "There's protein in your urine. I've called Saint Barnabas, and they're expecting you."

That first hospital stay extended through five days. Kidneys, I learned, filter about 200 quarts of blood daily, the equivalent of a person's whole supply passing through a couple dozen times. Healthy kidneys recycle protein into the blood and dispose of something called creatinine; unhealthy kidneys do the opposite.

Discovering the cause of a kidney disease begins with non-invasive tests and, if these don't finger a culprit, a biopsy follows. This procedure turns out to be not so bad as one might fear. You lie flat on your stomach inside a CAT Scan machine, extending your arms forward, as if diving from the starting block in a swim meet. A blood pressure cuff cuffs your left arm, inflating and deflating from time to time, while a soft clamp on your index finger monitors blood oxygen. A nurse stands in front of you and keeps asking if everything's OK. Somebody to your rear—invisible and anonymous—shoots anesthesia into a small spot in your lower back, predicting, "You'll only feel a pinch." (It's true.) For the biopsy itself, a long needle is inserted through your back into one kidney. This sounds perfectly horrid, but it doesn't hurt, just so long as you don't use your imagination. A surgeon guides the needle into the kidney and then snips some renal tissue. You can actually hear these snips—three, in my case—which startled the heck out of me.

My disease is called Primary Focal Segmental Glomerulosclerosis, FSGS for short. Three adjectives cling to the name, none susceptible to ambiguity: *progressive*, *irreversible*, and *incurable*. At first, I had trouble repeating these. But not anymore. Now, sometimes, I perform a minor riff, switching in *fatal* for *incurable*. Not long ago, the diagnosis of a fatal disease would be accompanied by a confident textbook prognosis, as in, “You have between *this* and *that* amount of time to live.” Today, predicting a person’s dying can sound more like predicting the futures market. Survival keeps getting extended by the most wondrous, death-defying, inventions—alchemical pharmaceuticals, futuristic diagnostic machines, and surgical robots. Physicians resist putting a number on dying because there are always “a few more things we could try.” Telling one’s family and friends that one is dying can leave the question of *when* suspended high in the oxygen tent for an improbably long time.

My longest hospital stay to date has been eleven days. Experiencing acute kidney failure, I was admitted to the burn unit, because of its sterile environment. For the first several days, my wrists and hands, feet and ankles, face and abdomen, remained swollen beyond recognition. My legs became as rigid as an overstuffed doll’s. Whenever I tried to get out of bed, I looked like the Michelin Man attempting the pommel horse.

My roommate and I—he was there for an amputation—watched demonstrations from the Middle East on our separate TVs. We watched the Super Bowl together. I cheered for the offense. He booed the defense. For four mornings in a row, a nice chaplain stopped by to bestow blessings. My roommate always said “no thanks.” I always said “yes please.” On the fifth day, I fessed up that I didn’t share the chaplain’s religion and had been receiving her blessings under false pretenses. She tried to mask her disapproval, soldiering on bravely. “Bless you anyway,” she said, and blessed me anyway. After that, she didn’t return.

Failing kidneys can be uncomfortable, but they’re not painful. At least, mine aren’t. Not yet. The sole exception was a particular potassium treatment, my third one. For this procedure, you lie on a hospital bed with a plastic bag containing clear liquid attached by IV to your right arm. Pressure cuff and oxygen clamp attach to left arm and index finger. Before starting the IV drip, a nurse warns that “you’ll feel a burning sensation,” and that “it’s going to hurt.” For my first two sessions, this was true: it did hurt but not too bad. My third time, however, was a different story. Pain zoomed right past my threshold. “Stop this!” I screamed. My heart monitor went berserk. The nurse rushed around the side of the bed and stopped the IV.

She said it might help if she slowed the drip, and left the room to consult with her supervisor. A few minutes later, she returned to report, apologetically, “I’m not allowed to do that. The drip rate is regulation.” I said I’d give it another go.

She waited while I took a few deep breaths, and then she turned on the valve. I watched the drip begin again into the plastic tubing. One. Two. Three. Four.

“*Stop!*”

My heart monitor went crazy, again.

The nurse turned off the IV drip, put a cool hand on my forehead, adjusted the rate to half, and started it again. For this act of insubordination, she risked getting written up. I felt the familiar burning sensation from previous treatments. Not bad, really, all things considered.

Two symptoms of kidney failure are fatigue and weakness, the first more annoying to me than the second. I’ve tried different approaches to ameliorating increasing fatigue. I’ve tried apportioning energy evenly throughout a day. I’ve tried banking it for two days and then spending it on the third. Neither works. The best approach, I’ve found, is to expend all my energy in one fell swoop. This surge usually lasts for about four hours, during which time I imagine that I’m

giving a performance of *King Lear*. I pretend to be Derek Jacobi or Christopher Plummer—the first is 76 years old, the second 85, and I’m 64—and give it everything I’ve got, starting with “Attend the lords of France and Burgundy” and keeping up the intensity clear through to “Look on her! Look her lips, look there, look there!” In the future, as my stamina diminishes, I plan to switch from Shakespeare to Ibsen, probably *Ghosts* or *The Master Builder*. When energy declines still further, I’m debating between Samuel Beckett and Neil Simon. Simon would be more fun, but Beckett would be more challenging. There’s time yet to decide. Meanwhile, it’s *King Lear* all the way. Who could ask for anything more?

Some nights, I have trouble sleeping. That’s when I tip toe into the living room, lie down on the sofa, and listen to music. I’ve become a groupie of Hector Berlioz, wild for his *Requiem*. I’ve probably listened to the entire thing twenty times. It calls for an enormous chorus and orchestra, plus antiphonal brass choirs that play halfway back in Carnegie Hall, which means that Robert Spano, the conductor, must have eyes in the back of his head. Who’d believe that a mass for the dead could be so majestic, so uplifting? Benjamin Britten is another composer I’ve come to admire. His *War Requiem*, however, does not inspire middle-of-the-night reveries. I’ve listened to the first two minutes of that composition exactly once. It’s the scariest music I’ve ever heard, unless you count Elvira Gulch’s maniacal bike ride with Toto trapped inside her handlebar basket. Both compositions are enough to make a boy want to run into the kitchen and hide under the table.

Our living room sofa is made of leather and wonderfully cool to the touch. I’m almost always hot. Lying on it, on my back, I peer through the picture window at the silhouettes of trees. On occasion, in the moonlight, I catch a glimpse of our neighborhood hawk, perched on the highest branch of the center tree. Every night I spot at least one shooting star, sometimes four or five. Seeing them, I always wish for the same things. A left-handed starter for the Yankees. Calorie-free Girl Scout cookies. A lap pool. I should have known that my shooting stars weren’t really shooting stars, but jetliners descending steeply into Newark Liberty, twelve miles away. If you wish upon a Boeing 737, you do not get a swimming pool. I keep wishing for one anyway, just in case some 3:00 AM United flight turns out to be a shooting star after all. Do not let cynicism screw up your chances for a calorie-free Thin Mint. That’s what I believe.

Around sunrise, I like to play the piano. In the spring, for the past two years, a mama bird has nested her babies in a tall bush just outside our window. The babies, when they’re not sleeping or eating, like to sing along with my piano. I’ll play a slow arpeggio and then stop. They’ll chirp a response. I’ll play another arpeggio and stop again. They’ll chirp another response. We can keep this up for minutes, like monks chanting in a darkened sanctuary, all except our chants are jolly. The birds’ favorite tunes are *Autumn in New York* and *Moonlight Becomes You*.

St. John of the Cross was a 16th Century Carmelite mystic, very spooky. The only thing I know about him is that he wrote a poem titled ‘Dark Night of the Soul.’ Today, that phrase refers to the deep end of depression, where, it happens, I once swam many years ago and nearly drowned. That was then. Nowadays, happy to report, despite having this fatal disease, I float on my back through starry nights of contentment.