SJ Edelheit **Kidney Not**

"We're lucky to have an OR ready. You have fifteen minutes to decide," said Dr. S. He was tall, muscular, dark-haired, wearing black-framed glasses, a Clark Kent look-a-like. As he shifted impatiently back and forth on the balls of his feet, I tried to make sense of what to do and how I wound up here.

Two days earlier, I'd woken up with sharp pains in my left lower back. Maybe just muscle spasms, I thought. But this felt like no spasm. I could only walk by leaning over from the waist like a bent ninety-year old. So I made my horizontal leaning way to the hospital for a last minute appointment with a nurse practitioner, the triage person on call. By then, the pain had become excruciating and it took her all of five minutes to tell me it sounded like, probably was, a kidney stone. "You need to go to the ER now!" she said. "Sit, sit!" she barked. "We have to get you an ambulance."

"An ambulance! For a 30-second ride across Longwood Avenue?"

"Yes, that's the protocol," she said in an abrupt, clipped voice that left no room for argument. So back to the waiting room I went. And waited. And waited. When I complained I was in pain, bad pain, the receptionist, a cheery but no-nonsense black woman, said she would find out what was going on. She dialed a number, held on for a few minutes, then hung up and said, "The ambulance service must be busy today. They'll be here soon, honey. Just a little longer." A half hour later, two burley guys with South Boston accents arrived with a stretcher.

The ambulance guys are jokesters, tossing off puns and ribbing each other, but are quite nice to me, commiserating over the absurdity of the long wait for the short ride. Once in the ER, however, the joke was on me. I'm wheeled in my stretcher to the back of the reception area and left there, forgotten, for another 40 minutes of pain. The ER staff seems trained to make no eye contact and hurry past as quickly as possible. You may be suffering but you're not their problem. Meanwhile, a parade of other sufferers crowds in: the old, the hard of hearing, a scrawny, disheveled guy without a shirt who complains loudly that he just wants to go home. And a young, lovely dark-eyed woman with some kind of bug bite who smiles and waves at me as she passes by.

Finally, when I moan and complain more loudly, the next wandering staff person looks annoyed, mumbles something in my direction, and disappears through the double doors to the treatment area. Eventually, another sullen aide arrives to wheel me in to the ER itself where I'm parked into a cubicle and a curtain pulled to wall me off with my pain. Then, as inevitably happens in ERs, a series of interns appear to ask the same questions several times over.

After more waiting and a two-minute visit from the attending doc, a mustachioed 30-something, they send me upstairs for a CT scan. Several inconclusive hours later they insist on admitting me. I protest. "I'm ok, the pain's not so bad now and...and I have a dog."

The young, attractive Asian resident is tough and no-nonsense. Call someone to take care of your dog," she says. "Your creatinine is way too

high. Until it comes down, you can't leave." She makes a note on my chart and hustles away without looking at me.

I make several desperate calls and find a friend to come to the hospital for my keys so she can go get Mollie, my rambunctious rescue pup. After the key exchange and a soothing "don't worry, it will be ok" from my friend, I'm wheeled to an elevator and installed in a room high above the city. My roommate in the next bed drawls a "hi". As I get settled, we chat some introductions. He's pleasant, round-faced, very sweet, and very Christian. Originally from Texas, he's now living in Portland, Maine, which explains his winding up in a Boston hospital. Over the next few days, I get to know him and his slight blonde wife and their two unbearably cute young kids who come regularly to pray with and for him. They are all so nice and so polite and so mysteriously cheerful. Mysterious to me because Mattie, my roommate, has already lost one kidney and is here for surgery for renal cancer on the other. With, for good measure, he tells me after his family leaves, suspected metastasis to the lungs.

I try to contain my moaning and fretting but Mattie and company take note and ask me to join them in prayer. And when I politely decline, they include me anyway. "The Lord is with you," Mattie says, staring to the ceiling. "He'll come, He will, and take away all your pain. Trust in the Lord!" Yeah, ok, I think, as long as He doesn't come and take me away. I'm not ready, no way. And what about dog care in the Christian hereafter, I'm tempted to ask. If we're going to do this, let's get down to the nitty-gritty and make it real. But I manage to stifle my cascading anxieties and mumble a "thanks" as I turn over and pull the blanket up against the wall of prayer on the other side of the curtain.

The next 24 hours is a nervous blank. No food, no water, says my Haitian nurse. And when I ask, no info either. "They want you ready for some tests in the morning," is all she'll say. And when I press her for more about these "tests," she just shakes her head and smiles. "Don't worry, honey," she says, and I notice her prefect, white, white teeth, and realize how thankful I am for that "honey".

Early the next morning, my superman surgeon is standing at the foot of my bed telling me how lucky we are to have an OR ready. I'm groggy but an OR, really? I press him for details but he glides over these like a wily politician. Something about needing to get a close-up look, "under the hood," as puts it, check those renal pathways and...and half-way through he stops to check his watch. "Hey, no big deal," he tells me, "has to be done, better sooner than later." Tired, hungry, scared, and just worn down, I give in with a quick nod. He thrusts some papers for me to sign, and when I do, he says, "Great! We'll get you down right away," and turns and strides from the room, no "honeys" floating on the air as he leaves.

I'm in a state of bewildered shock that I've agreed to a procedure I know next to nothing about with a doctor I neither trust nor like. I look over to my suite-mate for some non-supernatural comfort. He just stares back and says nothing.

Ten-minutes later, the transport team arrives. They're two young Jamaican guys, one with his brown-blonde hair in short, half dreadlocks. As with most of the aides and lower-level staff I've met so far, they're nice,

kind, human, in a way most of the docs, so intent on expressing their status and very busy importance, are not. They very gently help me up and onto a gurney and begin wheeling me down the long hallway. We take an elevator ride two floors up, then another long hallway push to a second elevator. This time down two floors and out onto what looks like a bridge between two buildings.

At this point, my anxiety crashing over me, I say, "Hey guys, this is the longest trip I've had since I went to China. Am I going to need a passport when we get there?"

The Jamaicans stop the gurney and burst out laughing, one leaning against the wall for support. "Passport!" he says. "Mon, you funny dude!"

"Yeah," says the other. "Passport, that's good. We almost there, brother."

A few minutes later, we reach the OR entrance. My dread-locked friend pushes a button and nods at the doors. "Another country there," he says, then stretches a hand to squeeze my shoulder. "You be fine." He smiles. "You got your passport." They both wish me the best as the doors open and a masked nurse relieves them of the gurney and pushes me inside the doors. All I remember next is the too-bright lights, the nurse leaning down to insert the IV, and then her slowly counting down as the haze descends.

When I'm finally fully awake in the recovery room, Clark Kent is there in all his bouncy cheerfulness. "Well, the good news," he says, "is you don't have cancer." Wow, he had never even mentioned that as a possibility! "The not so good news," he continued, "is we still don't know what's causing the kidney problem. Just stay hydrated," he tells me, "and tomorrow the catheter can come out." Catheter! He never mentioned I'd have one of those either. Then he just bustles off and that's that. My intuitive dislike for this guy has now become a rational loathing. He's an arrogant jerk and he has no idea how to talk with, rather than at, patients.

Back in my room upstairs, I glance over at my evangelical suite-mate. He looks pale and sweaty and the cheeriness is gone. His wife sits at his bedside and holds his hand in both of hers. They say nothing to each other, don't look at me or acknowledge my presence. So it doesn't look good for Mattie, prayers or no prayers.

I spend a worried day myself, try to eat some dinner but feel like I'm choking, aspirating the food, and so push the tray away. And the catheter, my body plugged like this, seems unbearable. Why am I so resistant to that?

My GP comes by for a visit. I appreciate his calming presence and he's a truly nice and decent guy. But he has no clue what to do next and I begin to think he's pretty ineffectual. When I press him on what he recommends, he just shrugs and looks uncomfortable. Then he says maybe I should see a "stone guy." I ask, jokingly, "a mason?" He doesn't laugh, just says no, a nephrologist, a kidney stone specialist. He says he'll set something up if I want, and I tell him sure go ahead. When I complain about the catheter, he tells me if my blood work, mainly my creatinine levels, come back ok, they'll unhook me and send me home.

The next morning, my roommate is gone. I ask an aide what happened

to him and he just shrugs. "Don't know, man. They come, they go. Big hospital, you know." After he leaves, a middle-aged, black nurse shows up and asks how I'm doing.

"Ok," I say, "except for this." I flip the blanket up to show her the hated catheter.

She smiles. "Well, I'm here to take that out. Your tests came back normal and no more need for that."

She sits in the chair next to me and pulls on her latex gloves. But before she gets very far, a tall, white and white-coated doctor I've never seen before comes into the room. He sees what she's about to do and frowns. "Ah, I think you better wait for the nurse to do that," he says.

I see a flash of deep hurt and anger in the black woman's eyes. She looks up at him and says hoarsely, "I am a nurse!"

The doc takes a step back as if pushed hard and mumbles, "Well, ok then." He looks over to me. "Your numbers are better and so you can be discharged." He hands me a sheaf of papers for me to sign, and when I do, he grabs them, nods, and hurries out.

I want to say something to the black nurse but she just shakes her head and says, "Take a deep breath, hon."

Freed from the catheter, clueless doctors behind me, I escape the dreadful machine of the hospital. You know the one, where you are caught up in the giant gears of care, become a failing body part, numbers on a chart. I have a free week at home and find myself thinking about Mattie, my good Christian roommate. His mortality and my own.

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The following week, I'm off to see the wizard, the "stone guy" my GP recommended who turns out to be a stone gal. Dr. H is very sweet and gentle with me. But before I can get in to see her I have to suffer through a prolonged history taking with her "fellow". He's a short, badly shaven, young guy with an unpronounceable Eastern European name. He batters me with questions, doesn't listen to what I say, interrupts me again and again, talks at me, and in general treats me like an idiot. When he again shuts down my attempt to ask for an explanation, I just go silent. He rambles on for a few minutes taking no notice, then stops and stares me down. I stare back. Then I get to my feet and say, "This isn't working. You may be a fine doctor, but you're a really crappy listener and you shouldn't be doing this." I go back out to the waiting room and take a seat.

Twenty minutes later, Dr. H appears. She's tall, thin, with a nervous smile. She says nothing about my crash and burn interview with her fellow. Instead, she goes over various test results and says "Hmm..." when we get to the urine analysis. After several tries and the downing of what seemed to me a Niagara of water, I was still unable to produce much of anything.

"I think this is key," says Dr. H with a satisfied nod. "The issue may not be stones per se, but dehydration!"

She fills me in on the liters per day I should be consuming, and I have

to confess I'm coming up short. "There you have it!" she says happily. "Just to be sure, we'll do a 24-hour urine capture test. But drink, drink, drink!" she advises me as she stands, grips my shoulder, and tells me she'll be in touch when the urine capture results come in.

I am so relieved I practically float back out to the waiting room. And when I see Dr. H's fellow there with another patient, I have a thought of floating up to him and apologizing. But I don't. Instead, I stumble towards the elevator in a blissful fog. A simple, straightforward, painless answer. Drink and you shall be healed! I bounce my way home and immediately quaff a liter of water. I feel better already.

The next 24 hours is an orgy of drinking and then peeing into a vast orange container that looks like those you have to use when you run out of gas in the middle of nowhere. When the capture results finally come back several weeks later, Dr. H pronounces them within normal range except for a slight potassium deficiency. So a life of more water, more bananas. I can do this.

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Fast forward another two years. I've mostly been fine, drinking my liters, exercising my aging body, trying to eat right, gluten-free, plenty of beans now to keep me in protein and potassium. I'd even found a new love. She was a Gloucester artist who had cured herself, she said, of terrible, disabling nerve pain through deep body meditation taught to her by some long-distance guru she called Hawaii Dan. Then one morning, in her lovely little house on the water, I turned over in bed and felt a dull, persistent ache in my left side. It wasn't the terrible pain of years past, so I mostly managed to ignore it as the weeks went by. But it didn't go away and this morning ache became a constant companion.

My partner consulted a friend whose brother had been urology chief at a big Boston hospital. He recommended someone and, after some dithering, I made an appointment. Dr. M was a rather sour-looking Midwesterner, but he was competent and thorough. And when the usual tests came back indicating kidney swelling and impaired function, he got on the phone and set up a nuclear medicine test later that week.

I wasn't happy at the thought of being "nuked," but the procedure, to measure flow in the kidney, was mostly painless. And after being pumped full of fluid and irradiated, the results came back quickly. "A significant blockage," said Dr. M, looking even more sour than usual. Surgery, he indicated, and soon. "You don't want to wait on this," he said. So he referred me to someone he pronounced "the best of the best," a specialist in reconstructive urological surgery.

So I'm to be "reconstructed". I'm not thrilled with the thought of that and I'm nervous, almost phobic, about the prospect of abdominal surgery. With my partner's encouragement, I go to meet Dr. E at Brigham and Women's, a large, prestigious, Boston teaching hospital. Much to my surprise, after all my ornery run-ins with stiff, arrogant jerks in white coats, I like him immediately. He's calm, thoughtful, kind, and responsive. In his mid-thirties, tall, dark, good-looking, Dr. E, judging by his name, may be Middle-Eastern or Eastern European.

"The kidney is worth saving," Dr. E says with a slight nod to the report he holds and has just finished reading.

I take a deep breath. This is the first I've heard it was ever in danger! Then Dr. E explains in some detail what will be done. Four to five hours of robotic surgery to snip out the blockage and construct a new pathway. A few days in hospital, with another catheter, maybe a month or two for recovery. And then?

"And then I'll follow you forever," he says with a grin. He tells me the surgery won't be scheduled for several months, probably not until late October. When I ask why the long wait, Dr. E shrugs and says with a laugh, "The robot is very busy." He jots something down on a card and hands it to me. "I'll be in Europe next few weeks. But here's my cell. Call me any time, any reason."

In late September, my relationship comes undone. There were many, complex reasons, of course, but the rolling anxiety and dread of the coming surgery didn't help. Now, more vulnerable, more alone than ever, I'm feeling I'm about to step off a ledge with no arms to catch or comfort. Then Dr. E calls. He's in Lisbon, was thinking of me, and just wants to see how I'm doing. I say not great and tell him about my recent breakup. He's calm, compassionate, truly feeling. "I'm so sorry," he says. "Look, we can postpone the surgery." But I tell him no, I don't want to disappoint the robot, so let's just do it. I put myself, my body, soul, kidney in his hands. I trust him.

The October surgery date finally comes and I march off to the hospital feeling like the condemned. The pre-op waiting is long, lonely, tedious. The post-op is worse. My stomach, pumped full of CO2 (to allow the robot room to operate), is distended and painful. My poor, shaved body looks like a battered and plucked chicken. The recovery will be longer and more fitful than I had hoped, but experience has taught me it will come. In small, painful steps. In the hard work of rebuilding the body and the equally hard journey of refashioning the spirit. Believing in myself, in my physical presence and capacity, in my ability to again reach for joy and peace and self-acceptance, that struggle will be ongoing. But, strangely enough, I'm now more ready for it, more resilient. Sometimes in this life, maybe most times, you will put up a good fight and lose. But I know I'll put up the fight.