

If You'd Only Listen: A Medical Memoir of Gaslighting, Grit & Grace

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INTRODUCTION

It's 1:30 a.m. on Wednesday, March 17, 2015. I'm all alone in the cold cavernous hospital waiting room where I've shoved together three sizeable ottomans of hard burgundy vinyl, a makeshift place for me to lie down. Because they refuse to accommodate my 5'9" frame, I'm curled up in the manner of a cat, holding tight to my body heat, trying to halt my limbs' inexorable slide over the edge, like spaghetti slipping over the rim of a colander.

My carry on suitcase stands upright like a sentry. I had packed in a hurry—a crazy person tossing in a baggie filled with almond butter slathered on crackers, organic walnuts, a thermos of my favorite green tea, my cervical bed pillow, my phone charger, Steve's wallet, his medical ID necklace, who knows what else.

Steve, my soul mate of 16 years, is now lying on a steel table in the frigid operating room being prepped to receive a new liver. I'm calling upon

every ounce of self control I possess to breathe smoothly—in and out, in and out—nothing to worry about, just in and out.

It's been four exhausting years since his diagnosis of non-alcoholic, cryptogenic, end-stage liver disease—a very long slog for him and for us as he slowly deteriorated and had to relinquish a teaching job he loved.

If you ever have a question about linguistics and the English language, Steve is your man.

Today is the day we've been waiting for, though not believing it would really come to this—the day his sick liver is being replaced by a newer, healthier model. Even though I know he's in the operating suite, nothing about it seems real. I'm playing possum with my feelings—fear and panic are not my friends. Steve and I grew up in the Midwest (Illinois, Indiana) where stoicism reigned and where sucking it up quietly was *de rigueur*.

After Steve's gastroenterologist informed him four years ago that he was suffering from end-stage liver disease and would eventually need a transplant, Steve said to me, "I felt a cold white wave of fear flashing up from my toes to my head, thinking I was going to die."

As the years of waiting dragged on and his physical deterioration continued, he retreated into a dispassionate turtle shell, leaving me to manage

the logistics of our impending move to this out-of-state hospital, along with our unacknowledged roiling anxiety.

Now that the day has finally arrived, I confess to him how scared I am to let him out of my sight. He simply shakes his head, his brown eyes flashing, and says, "Let's just get'er done!"

Nothing more can I do but trail behind the two strong young men who wheel him into the surgical suite. My breath catches when the doors hiss shut, leaving me on the outside. Alone. Feeling icy and hollow, I weep as I traipse into the empty waiting room and find a seat, struggling to find my breath.

I've read that liver transplant surgery is considered an "ultra major" operation.

Are we strong enough to prevail? Or will I be bringing him home in a box? What if everything goes to hell? What then? I'm 2,000 miles from home. I've never felt more alone.

The only advantage of having had an abusive father is that in order to survive, I had to toughen up. I lived in a neighborhood full of boys, including my older brother, where I learned how to throw a punch with one hand and a spiral football with the other. And outrun them all.

But will I be able to rise above the vicissitudes of Steve's transplant? This has to work; it just has to.

There is no backup plan.

Steve barely escaped death during his evaluation week here at this same hospital two months ago. Due to the negligence of the evaluating gastroenterologist, who ignored my concerns about Steve's deteriorating condition, we ended up in the emergency room on our second day where the surgical resident on call nearly killed him by ordering a medication that could have ended Steve's life, just like that. Had I not been there and known that the med was dangerous for Steve and blocked the nurse from injecting him, he wouldn't even have lived long enough for a new liver. At least now he's getting a chance, but will it work?

And what if it doesn't?

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Death, as an abstract concept, is easy to dismiss. *Nah, not me, not today.* But when Death shimmers around you, eager to claim someone you love, you can't breathe it away. You can't hum it away. You can only hold fast and hope Death moves on to someone else, not your sweetheart. Please, not your sweetheart; please, not your friend.

I don't know if I could have lived through the death three years ago of Carolyn, my funny best friend of 29 years, if not for two beloved kitties,

Turtleman and Sonny Gray, who paved the way and whose deaths acquainted me with the architecture of grief.

This is how it begins: a squeezing, sickening tug in the gut that, if allowed to continue, will sink you to your knees. The only way to stop its progression is by taking deep, labored breaths. Your spine goes rigid, you're afraid to move. It can't be true. Maybe if you don't move it won't be true. Maybe if you stick to this spot right here it won't be true.

But then, somehow, the dreaded words sink in: "Turtleman's cancer has returned. Surgery won't help."

"Sonny Gray is old, his kidneys are failing."

"Carolyn died this morning."

The sharp intake of breath, the dizzy near-swoon, the tears, unattended by relief.

More tears, fought back at first. If you cry, it's real; if you don't, it's not. And later, the panic of nothingness that swoops in at 3:00 in the morning. You light a candle next to their photos. You say aloud how sorry you are, so very sorry, over and over and over again. You hope they hear you. You listen for a sign.

The fiercest element of grief is the void. No more cuddles with Turtleman during his treasured bedtime ritual.

Your home is now an empty pit of sorrow.

No more sweet greetings from Sonny Gray during my rounds at the homeless cat colony I care for. No more giving into his demands that I pet and talk with him before he will eat.

Losing them initiated me into the tribe of mourners, smacked me down in the ways of grief.

When Carolyn died, I was already familiar with the contours of heartache. I took solace from my furry boys whose passing taught me well.

As she lay dying, I sat at Carolyn's hospital bedside, holding her hand, telling my comatose friend how much I loved her. Her adult children and I consoled each other in the exchange of sweet and amusing stories about our dear Carolyn.

Later, at home, I lit a candle by her photo and took to my bed to read the Lee Child thriller I had just gotten for her. She'd think that was funny.

But just because you've been through Death more than once does not mean you're inoculated from its future ravages.

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After I complained to our health plan coordinator in California about this near-fatal error and told him I was freaking out at the idea of bringing Steve back here for his transplant, he reminded me that the surgeons were

excellent and that the patients they referred here had received good outcomes. He also informed me that our health plan had contracts with hospitals in two other states, and we were welcome to go visit them.

Neither of us could have survived that sort of schlep.

This has to work.

It's cold enough in here to preserve meat. I'm shivering under my black sweats and the pink fleece jacket I bought before we left California for this out of state hospital, thinking it would cheer me up. *Why do hospitals have to be so cold? To keep the germs drowsy*, is what I've heard, but who knows. More likely to save money. Hospitals have massive overhead to consider—must perform a lot of transplants to keep abreast of expenses. The combinations are staggering: liver & kidney; liver, kidney & pancreas; heart & lungs—miraculous pulsing bundles harvested from one generous gifter, to be flown here and installed into the welcoming viscera of a grateful recipient. We know nothing about Steve's donor—man, woman, where she lived, how he died, how many grieving family members did she leave behind, what had he planned to do with the years he thought he had left? We might never know.

A nurse, gowned in pale gray scrubs and hat, her mask dangling against her chest, had floated in on crepe-soled shoes to see me at 11:35 p.m. last

night, to let me know that as Steve was being administered the happy drugs, he started spouting limericks. Perfect for St. Patrick's Day.

"Oh," I said, sitting up and reaching for my glasses. "I hope he didn't launch into his favorites."

"Yes, I'm afraid he did, but I know a few dirty ones, too, so we had a high old time." She laughed. I laughed. Just two gals in a bar, sharing a funny story.

That's my honey, I thought. Still talking. We've often joked about him being an out-loud linguist, one who loves nothing more than an overfull class of university students needing and sometimes wanting his wisdom about linguistics.

I often tease him, "You'll still be talking even after you're dead, won't you, Sweetheart?"

She also let me know that Steve's surgery had been delayed thanks to the opaque killer fog shrouding the airport. The private jet conveying his life-saving liver has been circling round and round for the past thirty minutes.

"What if there's an accident?" I said, my voice quavering. "How much longer before it can land and be taxied to us?"

"This happens all the time around here," she said. "We're in a fog belt. No need to worry."

Easy for her to say.

At 1:45 a.m., the nurse returns. No jokes this time. The liver has landed. Steve is doing well. I tell her that even though Steve is ill, he still possesses the natural constitution of an ox. All those years of childhood, working on the family farm in Indiana.

At 2:12 a.m., another nurse bustles out to tell me the surgeon has made “the cut.” This is transplant speak for *we are slashing your husband from one side of his abdomen to the other*. My stomach clenches. The rubber is now meeting the road. It will be another seven long hours or more before we know if this has a happy ending. I think about the donor’s family. There is no happy ending for them. How do you grok that someone has to die so someone else can live? If I were religious, I’d feel a chill.

“Are you okay?” the nurse asks.

“I’m really cold. Do you have any blankets?”

“Sure.” She pivots and scurries down the hall as if she’s off to save another life. She returns with four heavy covers.

Three TV’s, one in each corner of the waiting room, are tuned to the “Wendy Williams” show. Blah blah blah blah, *Spanx*, blah blah, blah blah, *Botox*, blah blah blah. I search for the “off” button, but can find only the volume control. I reset it to low, but it’s still too loud. My earplugs fail to keep the broadcast from laying claim to my mind, thwarting a craving to curl in

upon myself, to shut out the babble. To dive down for one worry at a time, hauling it up to polish the rough edges like a gemstone until it's less likely to nick me and make me bleed.

Repeating the process seriatim, I struggle to make sense of the nonsensical.