

## 1—Down the Rabbit Hole

*Oh, no! It's happening again.* The thought ricocheted through my mind as I struggled to stay in my lane. I tightened my grip on the steering wheel and thought back to the last time something strange had happened. It was only three weeks ago. The skin around my nose and eyebrows had peeled, followed by discharges of electrical shocks in my skin. The doctor had subsequently identified these symptoms as allergies to Plaquenil (hydroxychloroquine), a common medication to treat lupus.

*What now?* I scanned my body, latching onto sensations as they arose. The physical world around me pulsed: sometimes the steering wheel felt closer, other times the road receded back. I felt like I was surfing on the fabric of space and time; now and then, someone played dice and caused the space-time continuum to warp.

*I don't drink. I don't smoke. I don't do drugs; except for the one they prescribed me three days ago. But that was three days ago! What are the odds of a second medication allergy? I've only had two prescription meds.*

I paused to consider alternatives. *Maybe it's something I ate? Or strained fascial tensions from an injury I hadn't resolved? Maybe it's another defective car from Ent-----!*

I stopped thinking and fumbled with the radio dials. I wanted the music to drown out my thoughts, but all I found was noise. The words melted; the rhythms jarred; the road continued to swerve. In the distance, I saw Austin's skyline shimmering against the black velvet of night. *I'm almost home. Let's focus on the breath.*

I focused on the gentle waves of the inhalation and exhalation, allowing the rhythm of the breath to measure the miles. Thoughts arose; fears lingered; I kept returning to my breath.

At last, I pulled into the driveway. I stepped out of the car and discovered I had no strength to bring in the food my mother had packed so lovingly just a few hours ago. Undaunted, I struggled with the cooler, leaning my whole body weight onto it, over and over, until I freed it from the trunk packed full of other essentials.

I made my way into the house and onto my bed. Lying still, I listened to the pounding of my heart against my eardrums until the beats gave way to silence. I raised my hand toward my forehead, but my hand refused to move. I repeated the command, but there was no response. Changing tactics, I raised my body up, contracting abs, hips and neck muscles. Only in this upright posture did my arms work again.

*Fatigue is understandable, but fever is not.* I reached for the thermometer, pushed the button, and waited for the digits to calibrate. I placed it under my tongue and pulled it out when I heard the beeps. 101.5° Fahrenheit. *No problem! Two ibuprofen coming right up!* I popped the pills, called my mother, and crawled back into bed.

A weird wetness woke me. I glanced over at the clock. It was only 3 a.m., yet I felt like I'd slept for days. I reached up to my hair and discovered it was soaking wet. I checked my shirt and shorts and found they were also soaking wet. I scooted to a dry spot on the bed and noticed my body had stiffened. I shook my head in disbelief as I went through the same ritual with the thermometer. *Ibuprofen had never failed me. Why now?*

The beeps brought me back to reality, and I looked down at the numbers. 102.3° Fahrenheit. I ran a perfunctory systems-and-engine-check of my body parts and wondered whether I should trust the thermometer. *Do I feel well? I didn't feel bad; I just had a temperature. And a sweat-soaked bed.* Uncertain of what to do, I convinced myself a good sweat breaks the fever so I'd feel better in the morning.

Morning came, and I felt no better. I called in sick and waited until 8 a.m. before I called my doctor. I did not have the energy to engage in the circus of unkind and uncaring answering services. *Is this a medical emergency?* they'd ask with a sourness to their voice. *No*, I'd say and relay my message, but I was never sure if the doctor received the page. Paging and waiting had been added recently as new players in the game of my life.

Caught between sleepiness and wakefulness, I lay there listening to my heart. If I were still, there was only the soft rhythmic pulsation measuring the passage of time, but if I moved, even just a little, I felt my entire rib cage strained as if to contain the escaping beats. I imagined a PVC on the EKG machine—often described as bizarre and capricious—followed by regular heart beats with their P and QRS waves following each other one by one. I wanted to reach for my stethoscope and put it over my heart. Instead, I closed my eyes and imagined what my heart must be feeling, its wild electrical impulses lost in this erratic environment. How would the vectors add up? Could they find their way through the bundle of His and spread evenly through the Purkinje fibers to give a coordinated, rhythmic contraction? Or was there an obstacle blocking their way? Were there irritated foci—drawn as unhappy faces in my flip-and-see cardiac rhythm made-easy book—or was there an all-out-angry uproar?

When the doctor returned my call, I found her answers were no better than the guesses I'd made: viruses, bacteria, or bad food. I asked about Dapsone (diaminodiphenyl sulfone, an anti-leprosy drug commonly given to treat skin manifestations of lupus) that she had prescribed three days earlier. *No, it couldn't be that*, she informed me, *but to be sure, to be safe, why don't we stop the medication, and call me if anything changes.*

*What kind of changes?* I asked the doctor, but she had already hung up. *Rashes, headaches, skin peeling, joint pain, fatigue, the usual lupus stuff? Do I even know what the usual lupus stuff is?* Though I'd had fatigue and mouth sores for almost two years, it was only three months ago that the doctor made the diagnosis. I was new at this, and right now, in the midst of alternating chills and fever mixed with severe heart palpitations, wasn't a convenient time to sit myself at the computer to do more research and educate myself about this disease.

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The fever and the sweating lingered. I was too tired to change the sheets, so I created dry sleeping areas by putting down new bedding. I couldn't keep up. Even the comforter got wet, and I only had one.

Trapped between the sweat-soaked sheets, I had a strange realization: my own body disgusted me. Yet, it was the truth. Even my little kitty cat was moving away from the evolving wet spots.

Hunger woke me on day three, but I couldn't get up from the bed. My body was heavy with fatigue despite the marathon hours of sleep. I struggled against gravity and logrolled myself out of bed. My movements lacked control; my muscles fired without coordination. I overshot my target, as did my heart and blood pressure control system. I felt woozy and fell back to bed.

*No problem!* I said to myself and logrolled again, this time, extending my arms and legs to create a wide base of support. The woozy feeling came and passed, and I remained upright though my arms trembled with my weight as I sat at the edge of my bed. *Stupid fever, you cannot defeat me!* I chuckled maniacally and pretended to glare my opponent into submission.

Just as soon as I finished congratulating myself, I discovered I could not stand. Even the treasured technique of leaning forward, nose-over-knees, did not work. I tried once again, this time leaning as far forward as possible without falling and bringing my center of gravity squarely over my base of support.

*Ready, set, go!*

Except there was no go. My buttocks remained glued to the bed.

I refused to give in. I pushed hard with one hand and pulled hard with the other. *Tada!* I shouted my victory to the walls and the windows, but only my cat responded by running away. I stood still in victory as the dizziness passed.

I marched to the kitchen and went to the fridge. *Damn, the lights are bright.* I mumbled as I squinted my eyes until they were mere slits. The lights were still too bright. I couldn't see anything, much less be able to decipher what food my mother had packed a few days ago.

As I groped through the fridge for its contents, a strange sensation of heaviness overcame me. *Oh God, am I falling? No, just leaning. Left or right? Definitely left. But why? Why left? Too much sleeping on the one side? Have the otoliths shifted in my ears? Oh, no, heavy, heavy, leaning, still heavy, falling, hang on to the fridge, hang on to the handles, yes, that will hold, yes, the handles will hold. Damn, you're heavy. Damn, I'm weak. Still leaning. Close the damn door, it's more stable that way. Okay, I'm stable. What just happened?*

Something happened. *Did I black out? Did I let go and not know it? Let's just make it back to the room. Don't fall here. The cat will pee on you just out of spite, even if she can't help it.*

Before I went back to my room, I remembered I had gone to the fridge for something to drink. I couldn't find where the juice was, but the milk sat where it should. I grabbed it and went back to bed.

I sat and rested, and sweat began to pour from my pores again. *I'm awake, dammit! And that was only twenty feet!* I shook my fists and threw curses into the air for whatever entities present in the room. I could hear them laugh at me; I could see them write down "sweating profusely" in their notes. Water was leaking out of me, passing through me as if I didn't exist.

I drank the milk and went back to bed. This time, it was my hands that woke me. No, not hands, but claws. All my fingers had contracted, the thumb stuck between the third and fourth fingers, my double-jointed fingers strained and swan-necked. The tendons of my hands cramped and tightened despite my attempts to relax them. *Raynaud's?* It couldn't be since the same spectacle was occurring at my feet. *Maybe ischemia? Or I'm just really hungry?* I went through the differential diagnosis list and checked for the red, white and blue colors of the fingers and toes. *No red, white and blue—just white—so not Raynaud's. Let's try drinking more milk.*

My hands were useless. They looked like claws and functioned like paws. I steadied the milk, careful not to spill and add stickiness to the sweat. I palmed the lid and got it unscrewed. Palming the bottle, I lifted it to my lips. As I drank, I remembered that lactose was a slow-releasing sugar, and I was unsure of my lactose-tolerance status. Diarrhea at this hour would be the worst joke the universe could play on me.

Scanning the room, I found the stash of soybean milk behind the guitar. I hobbled over to them and hobbled back to the bed. I jiggled a can free from its pack and held it between my legs. Using one paw to steady the top of the can, I clawed at the tab with quick thrusts and jabs. Every movement was painful, but I was desperate. I focused my mind on what I wanted, and somehow my body managed the task.

I chugged the soybean milk, happy at the success of my efforts. When I had emptied the whole can, I turned my attention to soften the contractures in my hands, massaging the fingers of one hand with the knuckles of the other. Whether I had exerted too much effort massaging my hands or the coolness of the soybean milk sitting in my stomach, I noticed my hands shaking. The convulsions crept up my arms, and, soon, my whole body shook. I felt cold, yet I was still sweating. I felt stiff even though my whole body shook. Would my doctors have an explanation for what was happening? Were these symptoms the usual lupus stuff?

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The next day continued like the night had, except now a new opponent had entered the game: mouth ulcers. I slathered on canker sore medicine, gobs of it everywhere, and repeated the same ritual of sleeping and waking up soaking wet, popping pills and getting up to urinate, getting up to drink more juice, to eat something, or to sit up just long enough to dry my back. My body temperature bounced around 101 and 103.5°F despite a consistent self-medicating regimen of ibuprofen. I checked the expiration date before calling the ER nurse. I listed my

symptoms and asked if I should admit myself. *104°F is borderline dangerous, 105°F is definitely dangerous*, she said and rattled off a list of potential consequences.

A 105°F temperature is dangerous for people with normal 98.6°F body temperature. I hadn't been part of that 98.6°F club for years, so should I have gone to the ER a long time ago? *No*, I decided. I felt fine. *What else should I do to control my temperature?* She paused before answering. *Why don't you try alternating between ibuprofen and acetaminophen? Take them every two hours instead of the four to six hours as the instructions say on the bottle. And drink lots of water.*

I repeated back the instructions, thanked her, and hung up. *Yes, I can do that. Yes, I will try that. Yes, I will try anything!*

In the middle of the night when I woke, the thermometer read 99.6°F. *Yes!* I cried. *Welcome back to normalcy!* Relieved, I searched my bed for that one elusive dry spot and went back to sleep.

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In the morning, I drove to school with eyes that did not belong to me. The world seemed larger and farther away than it should have been. *Had my arms lengthened? Or had my body shrunk?* Even the car did not feel like it belonged to me. I was somehow smaller this morning than a few days ago, and the mirrors needed much adjusting.

I turned on the radio, switching from station to station. Today, it was just noise, so I turned it off. Slowly, I pulled out of the unpaved driveway and headed to school. The sun appeared brighter, but it was a welcoming sight. Cars passed by me and changed lanes at various speeds, and I was part of the life-sized video game. The game-maker must have switched on the challenge-of-the-day by changing the densities of the air around me so the normal Newtonian laws of motion no longer applied: I felt the drag of the air with each passing car, on my vehicle and inside my body, pulling me toward them. To keep from drifting from my lane, I kept my eyes locked forward, both hands on the wheel, precisely at ten o'clock and two o'clock.

When I got to the Austin State School where I was interning as a physical therapy (PT) student, I felt embarrassed that I was ninety-minutes late, but no one seemed to notice. We simply carried on as if nothing had happened.

The day dragged on. I put on a happy face but not a smiling one. I wasn't quite ready for that. Throughout the day, I monitored my temperature with the back of my hand, fearing a thermometer in the mouth would be too obvious. People would question: *Should you be here? Shouldn't you be home in bed resting, sleeping, and recovering your good health?*

*I feel fine*, I heard myself telling them in my head. *I don't need more sleep, and I don't want more rest. I just want to be vertical and appreciate gravity at my feet. Upright is all right. I could walk and talk. That qualified as high functioning, right?*

The day ended, but I still had a PT appointment at Brackenridge Hospital for my neck and back pain. Two or three weeks ago, someone had rear-ended my car while I was at a complete stop; I was looking left prior to making a right turn. I had developed mild headaches after the accident, so I looked forward to my appointment with highly skilled physical therapists who called themselves “the McKenzie Boys.”

As soon as I walked in the hospital, the chills came over me and sent my body into violent convulsions. I walked to the reception counter like a short-circuited robot, shocked by the scribble that spelled out my name. When I said my name and the purpose for my appointment, the words came out as broken English. The receptionist acknowledged me and pointed to the rows of chairs facing the automatic doors. I scanned the lobby and resigned to sit down in one of the chairs, bracing myself each time the door opened.

After a few minutes, the McKenzie boys came out and greeted me. They were not boys, but men, men who took themselves too seriously. We exchanged a few words, and as we felt familiarity between ourselves, their polite faces faded into concern. Their eyes followed the random movements of my body. *It's cold*, I offered. *You shouldn't be shaking so much*, they countered.

My PT evaluation had begun. One of them was a visiting therapist from Sweden, here for a visit and to taste-test the culture. He conducted the interview while the resident McKenzie guru sat to the side, hands folded politely on a still perfectly pressed pair of pants at almost 5 p.m.

They interspersed questions with requests for movements, and I tried to comply, knowing how much these McKenzie boys valued what the movements do, how much movements created or robbed me of my range of motion, and which movement did just what to the pain I was feeling.

After a few rounds of movements, their smiles hardened into grimaces as the McKenzie boys became frustrated with my body and its strange saccadic movements. They demanded to know why I was shaking; demanded to know why I was feverish; demanded to know why I hadn't all the answers; whether or not these strange movements were lupus-related, medications-related, flu season-related, or some other unidentified infectious scenario.

I apologized for my ignorance. As I was still learning about lupus, I didn't know what it could or couldn't do, though apparently, it can do a lot. Lupus, “the Great Pretender” as it is also known for its ability to mimic so many other diseases, is “a disease with a thousand faces” because every patient with lupus presents differently. I had met only one face—my own—and an “n” of one (indicating how many patients is in an experiment) is always a poor experiment.

The McKenzie boys sympathized and offered to have me back when I was feeling better. *No charge for this visit*, they consoled me as I left.

I walked out of the hospital into the warm November afternoon. Immediately, as though I had passed through a magic curtain, my nerves rebooted themselves: I walked

upright with smooth, symmetrical, coordinated movements. Briefly, I toyed with the idea of entering the hospital to short-circuit myself again, and then exiting back into the warmth of normalcy. It would be a cartoon-world, a world of instant animation and whimsical changes, a world of flip-on switches and push off buttons. But I was too tired, too dizzy from the many movements, from the uncontrollable impulses, from willing too hard, from trying too long.

Inside the car, I felt the familiar smallness-of-being enveloping me. *Have these mirrors moved within the last hour?* I decided the game was still on, so I adjusted the mirror and flowed back into traffic.

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When I awoke from my nap, the thermometer read 104.8°F. It was time to go to the ER, for I knew I did not belong to the 98.6° F club.

I called my two friends who live close by and put in my request: *Could you come and take me to the hospital? High fever, 1000 mg acetaminophen, with shakes.* I popped in another 600 mg of ibuprofen while I waited and had enough sense left to gather a few personal items before I left.

My friends drove me back to the same hospital I had just left. The long wait line snaked through the lobby, and when it was my turn at the window, I gave the woman my information for triage. The woman helping me was a stranger, but I offered her my intimate details. *I have a theory*, I pleaded. I wanted to share my theory so the doctors would have a lead, so to give them a head start to find the cause, so they wouldn't have to go poking around too much, digging around too deep, because all that would take time and money, money I didn't have because I only had student health insurance which didn't cover anything non-essential.

The woman listened but didn't write down anything I said. She only took information that would help her categorize me and prioritize my case. She then asked me to sign my name. *This is just for your consent*, she explained and waved me to take a seat.

The hours passed by, giving me plenty of time to ponder what constituted consent. I knew it was for legal reasons, but I wanted to tell her, to tell anybody who would listen, that I didn't consent to this. I didn't consent to any of this! I just want out. I just want to feel better. *I don't consent. I am giving myself over because I am desperate, not because I consent!*

Finally, a technician wheeled me into one of the ER rooms, and only one of my two friends could accompany me. *Someone will be with you in a minute*, a stranger without a smile informed us.

Thirty minutes later, someone came in wheeling a computer to take my insurance information, make copies of my cards, give me gowns, and before she walked away, she told us that the doctor would be by to see me in a few minutes. This time, my friend spoke up and asked for clarification. The woman with the computer cart dutifully explained. *It usually takes thirty to forty minutes before the doctor comes*, she said. Numbers were good; they were

quantifiable, accountable, and maybe even reliable. We thanked her and counted down the minutes.

Thirst and hunger prolonged the agony of the wait, but I was not allowed to eat or drink until the doctor came. A nurse came, drew blood and left the plastic needle in my arm in case they needed to give me IV medicine or saline. Another nurse came with instructions for urinalysis.

By now, I had become a professional with this procedure. I wiped myself in the appropriate places with the appropriate number of wipes and settled myself over the cup so I would be ready for a mid-stream clean catch. The urine didn't come, save for a few drops.

I handed the cup to the nurse and explained that I was thirsty. She paused before giving me permission to drink, only because drinking may produce more usable urine. I gulped down the water and imagined it rushing through my veins, washing my body clean of whatever was ailing it, catching the culprit on its way out and depositing it onto a petri dish behind closed doors.

The nurses were nice; the doctors were nice; but the waiting was long and tedious. I got up to turn off the light and tried to pass the time with sleep.

Sleep was difficult in this cold and unforgiving environment with people passing by, entering and exiting, wondering where to go next. Here and there, nurses would come in and hang an IV bag or check my oxygen saturation level. Then one of them would give me supplemental oxygen through a nasal cannula. I resisted breathing in this foreign substance—foreign only because air should not have a smell—and this oxygen smelled metallic. *Keep this on*, I heard the firm voice instructing me, *you really need it*.

So I lay there, gowned and hooked up to IV and oxygen, exactly the picture of a patient in an ER. I wanted answers, I wanted food, I wanted a doctor to show up, I wanted test results to show themselves, but everything proceeded on their own time without any haste. Like at the end of every other decision for the past several days, I decided to doze off.

I woke up when the attending ER doctor came in. She looked too white to be real, but maybe it was just the lack of color in this place. Her hair was tied up neatly in a bun, but my eyes kept surveying the frizzy frayed ends of her hair.

She held my hands and looked straight into my eyes. *We'll have to admit you for tonight, just for observation*, she told me. *We found some bacteria in your urine and are now culturing them. That might be the cause of the fevers, but we want to be absolutely sure. We'll need to run some tests because we're concerned about your shortness of breath. There could be a pulmonary embolus lurking. We'll be wheeling you to CT scan shortly, but you'll be staying here for tonight, just as precaution.*

A pulmonary embolus, a clot lodged in the airways, could be deadly but not likely, as my symptoms had been mild and evolving slowly over days. I was sure I did not need the CT



scan, or “computerized tomography,” a more advanced and more costly version of X-ray imaging. The doctor left before I could ask more questions.

A few minutes later, another nurse came in and he whisked me away from the ER and we entered the hospital proper. *The CT tech will be with you in a minute*, he said as he helped me lie down on the CT platform.

Ten minutes later, a face showed itself in my field of vision. It was an unfriendly face: old, serious, unsmiling, unexpectedly belonging to a woman, though I could not pinpoint why it should belong to a man.

The woman adjusted dials and pushed knobs, causing the CT platform to slide in and out of the CT scan tube. I couldn’t help but stare at the hole with a sign that read, “Laser Opening! Do not look directly into the beam.” The machine spoke, instructing me to breathe in and hold my breath. Again, the CT platform moved in and out of the CT machine.

After a few minutes of calibration, the woman told me in a deadpan manner that I was to lie still while she checked on another machine. *Don’t touch anything*, I heard her caution me as she exited somewhere above my head, outside my visual field.

An unknown amount of time passed, and the woman came back with new warnings: the next few scans might feel hot, but I was not to move but to follow the instructions from the machine. Again, the platform moved in and out, but this time, the CT disk rotated around my body while the air around me seemed to penetrate inside my body. The image of turkey slices spinning inside a microwave oven popped into my mind. I felt the heat churning inside my body, the turbulence rising and falling, swirling and twirling masses of hot and cold colliding with each other and being pulled apart. I couldn’t tell if my head was being cooked, too, or just my thoughts. Two more passes like this, and it was all over.

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I checked into the room, and the nurse checked me out. She pointed out the amenities of the room and emphasized its privacy. She finished her inventory of questions and turned off the light so I could sleep.

I woke with a start and saw at the side of my bed a woman with black hair plastered to her forehead. She peered over my veins, tracing them with half-gloved fingers. She had placed her toolbox stuffed full of tubes and needles directly on my bed. She looked grim as she tightened the tourniquet and repeated the procedure to find my veins.

The phlebotomist scowled, but I begged her to give them a chance. I offered her a little story, of me as a 15-day-old babe and a Catholic nurse trying to find a place to rest an IV in my vein that would deliver life-saving saline to a shriveled-up mass resembling more like monkey than any baby a mother could love.

The woman smiled at me but trusted her own faith. She traced down my arm to my fingers and up my arm again. She moved to the other side of the bed and repeated the procedure. She glanced back as if wondering if she had wasted time switching sides.

She shook her head and gloved fully. After uncapping the needle, she jabbed it at my vein. She stretched my skin with the fingers of one hand while the other hand turned the needle left and right, changing angles and depth of insertion with each pass. Occasionally, she pulled on the syringe, but there was no blood in the tube. Her brows knitted together, and I knew the vein had rolled or collapsed. I urged silently. *Give it up lady. You've missed it. The plane of intersection was not where you'd expected, and it did no good to crochet my veins.*

The woman tried again and, thank goodness, the third time proved to be a charm. She apologized for the trouble but offered that it was because my veins were so small. I nodded in agreement. I had always known that. I thanked her for her efforts but secretly wished she'd never come back.

I turned to look at the clock. It was only 5 a.m.

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The next few days passed like a whirlwind. Nurses came in wheeling this or that machine, strapping this or that device onto my arms, wrapping cords around my head, sticking tubes up my nose, asking me to sit up so they can listen to my heart and lungs, asking me to lie down so they can get a better listen at my abdomen or look into my mouth, nose, and throat.

As long as they were looking, I told them about the ulcers. *Where?* they asked. *In my mouth, down my throat, along my gum lines, on my tongue, up at the roof of my mouth, peeling away from the insides of my cheeks,* I told them.

The sores made it painful to eat. I asked if I could have pureed food, but the nurses shook their heads, for only a doctor could order changes to the diet and she'd gone for the day. *But I'm so hungry,* I told them, *even water hurt.* They apologized and promised they'd figure something out.

Breakfast, lunch, and dinner resembled each other in their monotony. The nurses urged me to eat, but I could not bear the burning sensations in my mouth. Even milk and juice were cold and biting as they slithered down my throat. I knew I needed to eat to counter the nausea from the steroids, antibiotics, and all the pills that I had swallowed. All I could stomach was juice and milk.

As always, after any encounter with the doctors or the nurses, I fell back asleep.

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It cycled like this for another day or two. My temperature was still up, so I swallowed more pills; six hours between this one, and eight hours between that one. *Keep that tube up your nose*, the nurses kept telling me. *I know you can't breathe with it inside your nose, I know it's raw inside, I know it smells metallic, but keep it up there because oxygen will make you feel more rested. You poor purple thing, keep your oxygen on.*

It's not just the tube that prevented me from breathing, but a gang of lupus lesions inside my nose. They hang on to the nasal septum like barnacles, thick and crusted, seemingly dead but pulsating with sensitivity, refusing to let me pick at them. Yet, I dug, prying at the barnacles with my little pinky finger, the tip with its own painful lesions, tugging at what I could. *Please, don't anyone come in at this moment.* I felt thankful for the privacy as I engaged in a necessary struggle for life.

Every time I poked, a twinge of nervous energy shocked smartly through my system. My entire body shook in crisp whispers of pain. I imagined what would happen if I succeeded in pulling off the barnacles from the walls of my nasal septum. Would there be a hole? Would there be a gush of blood?

I gave up on the tugging and looked for other options. I needed something softer, more soothing, like a lotion, a wax, or if I'm lucky, some petroleum jelly.

I reached for my lip balm and smeared my finger thick and gooey with the waxy substance and stuck it up my nose. The wonderful minty taste that I enjoyed on my lips now stung like rabid fire up through my brain, right at its most primitive parts. I fired back with curses but hoped that the self-inflicted torture would bring relief.

Minutes passed by but everything remained the same. I tried wetting a towel with the hottest water the faucet would give up. I breathed through the towel, hoping to lend some moisture to soften up the desolate walls where the thick barnacles clung. Again, my little pinky finger searched about and tugged. Each sweep of the finger would result in hysteria of pain. A little pressure was all I needed to knock this barnacle off, yet any amount of pressure was too painful for the lesions at the tip of my pinky finger.

I gave up. I couldn't breathe. But I couldn't give up for long because I needed to breathe. The battle with the barnacles continued into the night, and by some sheer effort or luck, they eventually let go, I finally banished them from my nose. Blood and curses, I could breathe again.

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The nurse woke me up for another round of vital signs and changed the sheets that had soaked with sweat. *Drink some water*, she encouraged. I drank but suddenly I vomited it all up. I didn't have time to grab the pale pink plastic bucket beside my bed, so I threw up in the towel that I was holding. That wet, I threw up into the jacket that I was wearing. That wet, I threw up on the sheets and blanket I was wrapped in. The nurse came back, and I apologized.

*It's okay, she said, things like this happen in hospitals.* I was grateful for her kindness; there was no trace of reprimand in her manner or speech.

They gave me medicine for nausea, but it sent me into a Dumbo-like world of fantasy. I couldn't remember who came and went, but I remembered being there in a fantasy land where consciousness lay next to me like a melted marshmallow and I was stuck in the middle of the whole sticky mess.

When I came to, it was Friday. My friends had called, my friends had come, and they had left flowers, balloons and well wishes scribbled in cards and on the walls. I couldn't remember any of it. I resigned to trusting the presents left in the room that they had been by, and what I was told of their presence was true and accurate. I wondered what my friends had seen when they sat beside me. It was too late to defend myself, and the chance to reassure my friends of my health had passed.

I imagined my friends sitting in the hospital room with only the bed rails separating us. I wondered if each of us would be perched on our own edge of sanity, facing the unknown. I could hear us speaking words we didn't really believe, but they would be words from the fantastic kingdoms of hope and faith. Before something is real, sometimes we have to make-believe.

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Saturday mornings had always been a blessing because my mind existed in a cartoon-world. I turned on the television and let it bring me back home. As I enjoyed the silliness of the cartoons, a strange man stepped into the room, introduced himself as the rheumatologist in charge of my care while my usual doctor was out of town.

The doctor spoke briefly of lab tests. He acknowledged my complaint of an odd odor coming from my urine the last few days and suggested a 24-hour urine collection to determine if there is proteinuria (proteins found in urine). The foulness spoke a truth: my kidneys were suffering, and it appeared my liver was suffering, too.

I didn't know about the liver; this was the first mention. I asked him to explain further. *Was it from the meds I took to control the fever?* I did a quick count of how many days, how many doses, I took of the aspirin, acetaminophen, and ibuprofen. I wondered what the safe dose was.

Instead of intelligent answers, I received subtle insults. He smacked his lips before he spoke. *Well, there are things your liver does, and these we call "functions."* *Right now those functions aren't working just right.* I pressed for more specific answers, asking for etiology and prognosis, but he repeated his words, avoiding any connections between the medications and the liver failure I was experiencing.

*Oh, right, just like there are people called "doctors," and right now those doctors aren't saying anything useful,* I thought to myself.

After a few more rambling repetitions, he remained quiet and expected me to do the same. He straightened the collars of his starch-white lab coat, as if to remind me he was the doctor in the room. He remained silent as he finished writing his chart note by my bedside.

I looked at him incredulously. I wasn't impressed by his white coat, which merely draped over his broad shoulders that dwarfed his small head. He dismissed any possibility that I might know as much about anatomy and physiology as he did, but unlike him, I lived inside a body that suffers from a disease he could only study in the pages of medical books but could never truly experience the agony and the unpredictability of a living disease. This disease had become my teacher, even if the lessons had just begun. He failed to acknowledge me, much less my teacher.

The rheumatologist finally broke the silence and continued on with his monotone, looking at labs while talking but not saying much. If he had any compassion, he did not show it. If he knew how to heal my body, he did not communicate it. He left me furious, but I resigned to keeping the peace.

Peace did not come, and anxiety kept watch over me. I felt inadequate and regretted that I did not go to medical school. Would the doctors have treated me differently had I been one of their peers?

All through the hospital stay, I'd pleaded in vain to anyone who would listen: *Give it to me straight and square, doctor, I understand more than English. What's happening to me? What's happening to my kidneys? What's happening to my liver? What's happening to the lupus?* I wanted to know, I needed to know. It had only been a few months since the diagnosis, but already, I was forced to accept a bitter truth. A great majority of doctors would always be aloof and insulated, thinking they know it all. What they don't know is that they should also say it all and say it with heart and compassion. Communications is more than the words we say. Words make up only 7% of what we hear. How we say it—our tone of voice, our body language—makes up the other 93% of the message. *Please, doctor, I am a patient with a diagnosis, and not a diagnosis that is your patient!*

A phone call interrupted my fury, and a friendly voice spoke. The soup wasn't ready yet, but last minute requests for extra pasta were taken. I hung up the phone, but the friendly voice stayed inside my head. The laughter in her voice swept through my body like bubbles of joy surfacing, and I thought about the distance she would have to travel just to get the soup with lots of little pasta bits into my belly, filling me up for the first time since being here in this hospital.

The door opened and my best friend came. She brought me news from the outside and roses from her mother's garden. A few had bloomed, but one was still asleep. The card that accompanied them suggested "*Sometimes it helps to throw a handful of change into a well and make a wish. Other times it helps to throw whoever's bugging you into a well and run!*" We laughed at this and other past good-riddance plans we'd had. We sat and shared stories for a long time until a woman walked by and waved wildly outside my door. Actually, it was her wild curly hair that waved.

She entered the room as I reached for my eyeglasses, and realizing it was my lady, I let out a little soul-gasp. Thoughts of her beauty always swirled inside my head but never escaped these parted lips.

She pulled up a chair and greeted my friend. We three were something of a trio in school and in spirits. My friend retorted that my lady had picked a good day for a visit at the hospital, for yesterday I had just been laying there limp and semi-conscious, which was disconcerting but it was no fun at all. My wonderful friend with her wonderful wit and perfect timing jabbing me alive just in the right places. Time didn't allow her to prolong the torture, and she got up to leave, leaving me alone with my lady.

I ate soup as my lady surveyed the room. A flash of memory surfaced upon her forehead. She slapped it dead on its track then reached into her bag and pulled out a black piece of paper. It contained two drawings her little niece had sent to be delivered as a promise for a date this coming Sunday with the witches and wizards of Harry Potter's magical world. She asked me which picture I preferred, and my choices were between a lost looking fish and a stingray with mischief in his eyes. I pointed to the latter, but she raced to the wall and put up the former. She stepped back and ruminated, playing with her lips as she paced the room. *Yeah, I like the other one better too.* She was always fighting for the underdogs, and I adored her for that.

She turned and faced me, smiling definitively. *Yes, that's a date, this coming Sunday, one-thirty sharp, or well, maybe somewhere there about. Yes, it's a date,* I agreed, *with you, your family and the kids.* Why hadn't I ever told her so? That I love her, her family, and the little ones. She tarried a while longer but time caught up with her so she excused herself back on the road.

My lady was the first of many friendly faces who traveled far to sit by my bedside and share the stories in their hearts to fill the emptiness in mine. My professor and chair of the PT department was the first of faculty, followed by others who taught me all I know about this world of movement, of bodies moving against forces, and forces moving against each other, interacting in predictable manners if I could look deeply enough to find the intersection of vectors and angles, the imprints forces create as they encounter flesh and bones.

I stared up at the ceiling and wondered about forces, how essential they are to the practice of physical therapy. They are steeped in physics, outlined by equations with mysterious symbols that seem all two-dimensional. Yet, we live in a four-dimensional world where symbols are actual moving body parts moving through time, encountering resistances, physical or emotional, expected or unexpected, getting hurt all the same.

While most forces are invisible, their effects are not. They can shatter mountains or cause someone to implode quietly. I wondered what adjustments I needed to make in my eyes in order to see these invisible forces when they are occurring and long after they have left. Even if I had eyes that could see what cannot be seen, what updates would I need to the software in my mind to comprehend what I was seeing?

My mind drifted off to sleep. The evening news droned on in the background. Just two months ago, the World Trade Towers had crumbled, and in the long shadow of its remembrance chaos and confusion had percolated into the world. Pray when it's convenient, or polls positively, but go to war if it would win more points with the public.

Things change. Shit happens. Impermanence exists. These are forces we contend with on a daily basis. As my mind surrendered to sleep, these forces softened as they settled inside of me. The forces I was fighting now were nothing grand. I was only concerned with the simple stuff: eating and drinking, sleeping and waking, letting go and hanging on, maintaining temperature, counting the hours, sitting up, going to the bathroom, getting back to bed, and just breathing.

*How did my life get reduced to such simple forces?*

For a moment, I feared I had just missed the exit sign out of my cartoon-world.