

### 3—Confusion Sets In

The light turned on and woke me up. The ritual of finding veins and filling tubes had become my morning routine. The hospital was not a place of rest. All night, people came in and out of my room without care or concern I might want to sleep. In the hallways, IV machines beeped, carts of different sizes were being pushed and pulled, and occasionally, it was imperative that the floors be buffed and waxed at 3 a.m.

Hours later, the nurse came and gave me my medicines. She informed me the doctors would no longer be attempting to control my fever with aspirin, ibuprofen, and acetaminophen. It appeared the duration and doses of these drugs had caused kidney damage and acute liver failure. Instead, they needed to start me on high dose steroids. I wanted to protest, for all I heard was trading in one poison for another.

“How will the steroids help?” I asked, pleading for a rational response.

“To help with the inflammation,” came the reply.

“What inflammation? This didn’t begin with inflammation. It was just a fever that wouldn’t subside. Fevers mean infection, don’t they? And so, if there’s an infection, then my immune system should stay online and functional?”

“The doctors think your lupus is out of control,” the nurse explained. “It’s creating too much inflammation and destroying your kidneys and compromising your liver. We need to act quickly to save your kidneys.”

“My kidneys were perfectly fine before I started on the Dapsone. And that was barely ten days ago. Are you telling me that suddenly the lupus started acting up? It doesn’t make sense.”

“Hon, the lupus can be quite unpredictable. The drug wouldn’t have done this.”

“No, what about all the aspirin, ibuprofen, and acetaminophen I’ve been taking? Aren’t they to blame, and not necessarily the lupus? Didn’t you just say that?”

“You would need to talk to your doctor.”

After a few more questions and unsatisfactory answers, I had the distinct feeling I was killing a messenger. I would have to wait until the doctors came.

The nurse finished her routines and hung the IV bag with 125 mg Solu-Medrol (methylprednisolone, a common corticosteroid). I watched the first beads of fluid dripped into the tiny tube prior to entering the line connected to my arm. I made a silent resolution to simply watch this fluid and count my breath.

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My mind returned to its last memory of steroids, given a month earlier to control the allergic reaction to Plaquenil. The doctor had said Plaquenil was a safe medicine, one of the safest and most widely used medications to control lupus symptoms. I didn't think the lupus needed to be controlled, for I'd learned how to live with all of its symptoms. I'd accepted the few small bald spots, adjusted my schedules to match my energy level, made accommodations for the random attacks of mouth ulcers and joint pain, and made peace with the pencil tip-sized red dots that decorated my face. The worst symptom was the pain at some of my fingertips; every time I touched something, the pain pierced through my body like jolts of fire. Zippers hurt; typing hurt worse; opening cans impossible.

"Would the Plaquenil help this pain?" I asked the doctor. It was the only symptom that caused me significant distress.

"I'm not sure about the pain in your fingertips. It's unique to you," the doctor explained. "I'm confident that Plaquenil can alleviate the rash on your face."

"What? These flea bites?" I attempted to minimize the situation. I had always had clear skin, so I did not mind being slightly defective. "I didn't tell you the story of these dots? Once upon a time there was a tribe of circus fleas, and they decided to trek across the wide, open horizons of *The Face*. They started out in the right ear, camped a little, then continued on, up and over the mountain of the cheek bones, camped again, then moved over the ridge of the nose, camped some more, and down they went, to the other mountain cheek, camped yet again, and finished home to the left ear, and, yes, they camped again. So, there you have it, clear evidence that circus fleas exist."

It was difficult to finish my joke because the doctor kept a straight face.

"May I remind you that lupus is an inflammatory disease and that it still can kill?" he said as he leaned back and crossed his arms.

"But my sedimentation rate was normal," I countered.

"Yes, that may be so, and this is all the reason to keep it normal. You don't wait until the fire burns through the whole forest. You quench it when it's a small brush fire."

"So, these meds will prevent the lupus from flaring up?" I asked.

"Yes," his eyes lit up like he had won the argument.

I paused before continuing. I wanted to stitch together a strong defense for myself, so chose my words carefully. "I don't see it the way you do, doctor. I've had these symptoms and learned to live with them for two years. The symptoms are stable. I know what they

are. I'm hesitant to trade in my set of known-symptoms for a medication that has a long list of potential side effects. I'm even more hesitant because you want me to have two medications with long lists of side effects."

His victory disappeared into a sneer. He uncrossed his arms and leaned forward. "If you don't want to take the medicines, then don't come to me. I am telling you what you have. I am telling you lupus can have dire consequences, even death if you are not treated properly. And I am recommending you these medicines. Take it, or..."

He actually left me hanging as if I was free to insert my own ultimatum or insult. If I said anything contrary to his expectations, would he discharge me as a non-compliant patient? I still needed to understand his form of preventative medicine. I still had so many questions about the list of side effects.

I looked one last time into the doctor's eyes, deciphering the mood of his spirit. I wish I could say all that was in my heart. *Doctor, why would you use an anti-malarial to treat an autoimmune disease? Or why for some patients, an anti-leprosy medication is more effective than anti-malarial? Doesn't that suggest a monkey wrench in your system of thought, a hole in your theory for the cause of disease? Why can't a low-grade fever mean an infection? Perhaps we just couldn't see the causative factor yet. It took awhile to walk away from the now-laughable theories of spirit possessions to arrive at viruses and bacteria as causative factors for disease. This happened only when the microscope came along. What if we don't have the tools to look at the cause of lupus, rheumatoid arthritis, or multiple sclerosis? Cause unknown does not mean there is no cause. Please, do not point your accusatory finger at my body because you have nowhere else to point it.*

Frightened by all that I had read, knowing what I read was only a fragment of what is known about this disease, and seeing no kindness in his eyes, I finally submitted. The list from the prednisone was longer than the list from the Plaquenil. The most common side effects were certain weight gain versus possible blindness. I was not vain, but I chose blindness. At least it could be monitored and possibly stopped before real and permanent damage began.

Everyday, I took my medication as instructed. I observed the lupus symptoms to document changes: hands still hurt, rashes remained. Two weeks went by, I did not lose hope, but two weeks was how long it took for the first signs and symptoms of an allergy to show, only I didn't know what the signs and symptoms meant.

First, the skin of my nostril peeled, followed by the corners of my lips and eyebrows. Over the next few days, the itch intensified. I would soon claw my nails deep into my skin to tear away the offending flesh. The pain soon accompanied the itch, and the two became twin demons in the night. The pain flashed through my body like an electric wire mesh, and the itch crawled through my skin like an invasion of beetles, bugs, and worms.

At first, I thought I had an allergy to food, but after seven days, I could no longer pretend the itch and electric shocks were related to a food allergy. I called my doctor, and in his office, I explained to him what had been happening. He listened without saying a word, his face stern. He remained silent even after I finished my story. I sat across from him, unable to resist the urge to scratch myself, offering myself as evidence to the story I had just told.

“You’re allergic,” he concluded. “You be taking Plaquenil. I’m taking you off of it right now.”

I appreciated his candor, his sure voice, but I wished he had said, “You can’t take the Plaquenil.” The syntax was minor but important.

Instead of Plaquenil, he prescribed prednisone. “Only a dose pack,” he reassured me. “No long term side effects. Take it now to control the allergy symptoms.”

When I got the medication, I read the insert and considered every word, scanning for anything that might trigger caution. What was written did not translate completely in real life. While on prednisone, my energy revved up a thousand times. I spoke with the energy of an angry Spaniard and gestured wildly like an Italian in love. I could not sit still, nor could I sleep. I was glad for the itch relief, but the pain subsided more slowly.

As the steroids tapered off, I began to feel like my usual self. I could not help but start a tally in my head. Zero for two, or two for zero. Meds won twice. I lost twice.

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Laying there, watching the drip of the IV steroids, I wondered what effects it would have on my body. I’d heard so many things about steroids: I knew I did not like the manic overdrive, but I didn't have many options.

I’d gone through so many test procedures, poked and prodded at every place, but there was no definitive cause for the fever so the only logical conclusions my doctors came to was, “It’s your lupus.”

In the few months since my diagnosis, I had read many books on lupus. It is the only autoimmune disease that has no boundaries, capable of attacking any tissues, from heart to kidneys, lungs to liver, bone to brain. The most commonly involved organs are the kidneys. All other autoimmune diseases are more limiting: Lou Gehrig’s disease limited to motor neurons, multiple sclerosis to muscles, diabetes to pancreas, Grave’s disease to the thyroid.

There are approximately eighty diseases in this family of autoimmune diseases. I wondered what connection lies between them, for they say, if you have one autoimmune disease, you are more prone to have another. A mild grade fever is common, generally not attributed to infections, but to a state of inflammation.

I did not consider 103°F to 104°F as mild fevers, yet, in my case, the doctors called it a lupus flare up. The only presenting symptom was a fever, and the heroic efforts to manage that fever resulted in inflammatory damage to the kidneys and acute liver failure. What would have happened if I left the fever to run its course? Was there such a thing when it came to lupus fevers? Perhaps there was a reason why they called lupus the disease of a thousand faces. No one really knows, even doctors, they are probably just doing their best to guess.

I did not like the uncertainty. There was no peace in anxiety, no confidence in fear. For several days, I received the IV steroids, and I watched each bag dripped slowly into my veins. It was so fascinating how one drop after another eventually emptied the whole bag. I thought if I were just as consistent in any of my endeavor, little by little, drop by drop, I could accomplish anything I wanted.

The formula seemed too simple. Time plus consistency plus persistency equals result. Have I simplified it too much? Or have I only seen a facet of truth? In all of us, there is a hare: when desperate, runs rather fast; but we tire quickly, liking the rest, needing something else to scare us into the run again. There are few tortoises among us, and fewer who admire and aspire to become tortoises.

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The days and nights merged into monotony and I was grateful for the cheerful interruptions of friends. They brought me reminders from the outside world: happy thoughts inscribed on balloons, flowers to inject life into the white wearisome walls, and delicious foods to replace the tasteless meals cycling between inedible chicken, limp fries and soggy green beans.

Faculty also came, among the first was the director of the PT program. I thought I'd burned a bridge during an honest evaluation of her class where I signed my truth in the space that said, Name (optional). She was the only person who came twice to sit by my bedside, and the significance was not lost on me.

The last conversation we had was in her office, doors closed. My evaluation sat plainly in sight on her desk. As she invited me to sit, her gesturing hand swept through the air like a magician prepping a trick, revealing on the table a gun that only I was meant to see. I didn't say much. I couldn't say much. She had meant the conversation as a show of power, to remind me who she was, and who I was.

I sat tall, not wanting to be small, even as I was being threatened. I rummaged through my inventory of skillful means to get me out of this unexpected prison, to open that door. Explosive diarrhea could be quite convenient.

Truth can hurt, but truth can also heal. I had made my choice hoping for the latter, but sitting there being sacrificed, I thought I had made a mistake. Somewhere from the time of my absence to her presence by my bedside, the healing had begun. Our last conversation did not leave room for me to make peace, but I was glad to accept the olive branch when it was offered. During her second visit, we watched the lightning storm that passed through Austin that night and communed in silence. Each flash illuminated a different scene of the same story that lay before us, and the rain washed away the secret story behind closed doors.

Somewhere in the merging of the days, my little sister came and brought her happy spirit. We had become like best friends over the years with our secret understandings and the jokes that needed no elaborate storytelling.

My mother also came, bringing me soft silken tofu, something bland but nutritious, and tofu made as a dessert. She came with my dear friend, a past love, a petite woman with a spunky spirit. We did not have any fallout. Time and circumstances simply separated us. She was kind to have brought my mother who could not have driven the distance.

My mother looked distressed. I watched her as she watched me, not quite sure who seemed the sicker. My sickness resided in my body; hers seemed to linger on in the soul. She looked at me as if she had already lost something.

“I am all right, mama-friend,” I said reassuringly.

She offered me her knowing smiles. In her eyes, I could see the quiet negotiation, whether to God or to herself. Her eyes spoke of a calm acceptance. We talked for a little while longer. They did not stay for long, and soon, came my discharge to go home.