

How precious is waking up? Dreams softly fade into reality. For a fleeting moment - as you open your eyes - you can almost convince yourself that your dream *is* reality. I often think back to the moment before I knew I was sick.

Before pain engulfed my senses.

Before my future was tethered to uncertainty.

Before I lost my identity and voice.

If I had known what I was waking up to, I would have held on to that moment a little longer. I imagine stretching that last naive moment of sleep out as long as I can but the eventuality is that the rubber band always snaps - jolting me into consciousness.

That first morning, I awoke to pain that I couldn't comprehend. It felt like my muscles were on fire. Never had I been so aware of each tiny tissue, capillary, and cell in my body all sending competing pain signals to my brain. I stumbled out to the living room couch trying to process it all.

"You look like hell." My fiancé states suspiciously.

"What did I drink last night?" I ask, trying at humor to lighten the mood. My hands find my temples and begin rubbing. "Maybe I should see a doctor," I say defeated.

"You'd have to go to urgent care. And what about your job? He questions. "Is it smart to call in sick?"

I'm unsure but respond, "Something feels really wrong." I pause trying to think clearly. "I'm so tired," I say. "I'll just stay home today and hope I feel better tomorrow."

With that concession, I take two Tylenol to dampen the pain. The medicine does nothing. Despite knowing deep down that something was very wrong, I doubted myself. This seemingly benign interaction was the first domino in a long line of downplaying my experience, my pain - my truth. This was the first, but it wouldn't be the last.

After waiting a month to be seen, my fiancé and I arrived at the doctor's office. My symptoms had become increasingly distressing. In addition to the pain and exhaustion, I had started to show signs of physical weakness. I struggled to stand from a chair or hold a glass of water. My coworkers had begun to notice something wasn't right. My boss joked that he needed to put pillows around my desk chair in case I fell off. And yet, I still carried on - assuring everyone that I had this under control. I was terrified to be a burden but desperately needed help.

When the primary care physician called us into her office, she noted that I'd lost weight and asked me to describe my symptoms. I recalled how I felt tired and could barely lift my arms above my head. She asked me to demonstrate. I lifted

my arms with difficulty, to which she replied, "See! You can do it." The doctor ordered bloodwork but assured me that I just needed to sleep more and take vitamins. "I see in your chart that you sought out therapy in the past," she said. "I think you're just depressed."

Once again the rubber band snapped. I'd been holding out hope for support and help from this physician - or at least an answer. I had lacked confidence and been afraid to advocate for my own truth. My voice was lost in her lab coat and those two letters... "M.D."

The bloodwork came back flagged for an autoimmune disorder and I was referred to a rheumatologist. I waited another long month to be seen. A month in which my hair began to clog our drains. During which my fiancé learned how to help me get dressed and blow dry my hair. I had also begun to fall. I could no longer reliably keep the front of my foot tipped up when walking. Every so often, my foot would drop and I'd inevitably trip. Most times I caught myself but sometimes I didn't.

I prepared for this doctor's visit. I practiced the words I wanted to say and the symptoms I needed to convey. I spoke my truth. Within ten minutes of meeting this doctor, she had determined a likely diagnosis: Dermatomyositis. With that, the kaleidoscope turned and the colors of my world changed. They painted themselves into a new view. The deep blues of my pain mixed with brighter yellows. I had a diagnosis and hope for the future.

Having a chronic illness has given me many opportunities to practice speaking authentically. Advocating for my truth has made my biggest dream possible - becoming a mother.

Today, the morning sunlight creeps through the blinds in my son's nursery. Rocking together, I can tell he's transfixed by the alternating lightness and darkness. I hold his head against my heart and breath in. In goes hope, love, and courage. I exhale fear and doubt. My dear son, may you always see the light and dark in the world. In the dark, you'll find purpose and strength. But relish in the light. Appreciate it, devour it and find your truth. Life's waiting for you, my dear.

xoxo mom