

No EXCUSES

a journey into
overcoming physical
challenges to create a new me

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Each day is a gift and an equal opportunity for me to live life to the fullest, and it doesn't matter what challenges there are to my health. That was what I had to remind myself when I was diagnosed with Lupus. The reality is no one, healthy or sick, knows whether or not another day will be granted.

People have told me that there should only be a plan A. In my world there is a plan A, B and C. Having an illness with no cure changed a lot in my life, but it was no excuse for not pursuing opportunities. I didn't want a life that consisted of trying to maintain employment to afford to pay that 2% of an ever-increasing pile of medical bills from the cycle of doctor appointments, lab work, and treatments. I realized early on, that if I want a life where I explore my possibilities, then I have to fight for it. No existing as if the disease had already taken me out. My focus has to be on creating new memories, achieving goals, and continuously working towards improving my life. The journey of adjusting wasn't simple. Wanting it and actively doing it are two totally different things.

Months before I was officially diagnosed, my mom asked if I was okay. I said, "Yes." I was trying to be positive and not worry her despite feeling weak enough that I had to use the wall to assist me in walking. She insisted I go to the urgent care. I'm glad she did because I was far from okay. Blood was pooling on the inside of one of my thighs, which could have led to my death. My concept of "being positive" had to be redesigned to mean being honest, but hopeful about the future. Lying to myself and others in an attempt to be positive did me no good. If I wasn't careful, it would land me six feet under sooner than later. I had to accept that being honest didn't necessarily equate to not being positive.

The loss of my independence, the death of my confidence and negative triggers were a few of the issues I had to work through to be able to function in my new norm. Friends and family had to understand that while I appreciated their help, they couldn't "baby me". They had to allow my attempts

to do tasks as I figured out my new limits. I didn't want to create habits that would have me leaning into the role of being sick even when I was feeling better. The process was frustrating.

Having my independence snatched away may have been the hardest for me. Early in life, I'd learned that if I waited on people to do activities with me, I risked missing out on experiencing life. I went where I wanted regardless of if I had someone to go with me. Lupus forced me into the opposite position of being dependent on people. The mix of medicines and my physical condition determined whether or not I could drive. If I couldn't, I required someone to attend certain events with me. During those moments when I couldn't get up and go, I'd get caught in a comparison matrix of my old life versus the new one. I had to stay away from social media; because seeing people, living life in a way that I couldn't was difficult.

The first few months after being diagnosed, I was in a physical and mental struggle. My mind required a project to focus on, one that didn't center around my health or recovery. Publishing a second book became that something I could focus on instead of being sick. The effort led to me planning a book and panel titled *The Good, Bad, and Ugly of Love*, which created a special kind of energy that was good for my soul.

Somewhere between the first and fourth visit to the hospital, Lupus became a confidence killer. I literally didn't trust my legs to hold me up. My hair texture was constantly changing and falling out in sections. I would swell from head to toe. Lips looked dry like the Sahara Desert. My skin appeared as if it had been dipped in white powder after I put on lotion. My mom used to say, "If you don't feel good at least look good." Unfortunately, some of the time, describing me as "hot mess" would have been an understatement.

The one thing I couldn't do is hide my sickness. The little energy I had was used to get my body out of bed and to work. It didn't matter that I looked like something the cat had dragged in with every intention of dragging it back out. Many times, I was pushing the envelope to show up and be present in my life. Walking into a room with confidence when I was praying that I wouldn't fade away was difficult. At one point, one of my doctors put me on a restriction that kept me from walking anywhere except

the bathroom. I had to remind myself I was alive and tell myself to stop creating stories behind the looks I received from others. And also realized that some people who are in perfect health also struggle with confidence. My attention had to be on keeping one foot moving in front of the other. Those physical issues could bother me, but they couldn't stop me from honoring my commitments.

Even today, I have to avoid triggers that put me in a negative state of mind when my condition is getting the best of me. Normally, I avoid looking at photos taken of me. Not that I don't have physical issues to remind me, but something about seeing it in a photo throws me off my game. I also steer clear of people who repeatedly tell me to stay positive and want me to have this "happy go lucky" persona.

Interestingly enough, conversations with certain doctors had to be kept to a minimum. One of my doctors was determined to diagnose me as clinically depressed. I could not allow anyone to feed depression into my spirit. I had enough issues without adding that to the list. To say that visiting up to five doctors at any given time, getting needles stuck in my arm on a regular basis, and dealing with some type of physical ailment that sprang up every single day, didn't on occasion get a little sad and depressing, would be a lie. But I truly believe it had, and has not, gotten to the point where it matched the doctor's definition. I didn't need anyone treating me for something I don't have, especially when some of the drugs used to treat depression makes people suicidal.

The process of not allowing my illness to be an excuse has been a rocky road. Pushing myself too hard can be detrimental to my productivity. Strategy became key. I needed to be strategic in how I tackled my projects in order to not to cause problems with my health. Doing too much could have me in bed sick for days, or worse could send me to the hospital. One thing I did was assign days to do minimum work and to rest in order to have maximum productivity on other days. No waiting to the last minute to meet a deadline, starting earlier is always better. My issues are unpredictable. If my body shuts me down and I don't get it done, I still have time to get it completed before the due date

When I was shooting my first short film, I scheduled some rest time in, but lupus still reared its ugly head. After filming, my schedule was filled with more lab work and doctors' appointments. By the time I hit the editing stage of the project, the doctors were talking biopsy and chemo. Once I knew there was a chance that I may not be in a condition to personally follow through on the film post-production, I contacted my plan B and put them on notice that their services may be required.

Flexibility and creativity play a big part in my being able to tackle big tasks. I work like I will be there and plan as if I won't. I normally host a panel discussion for my book releases not only because I'm not a big talker, but also because it allows for someone to step in, if needed, and keep the event going. It takes some of the stress off if I'm in a push-through mode. I feel confident knowing that if I'm unable to host an event, it will go on without me.

Since stress can set off my Lupus, it's important to keep it to a minimum. There is no committing to anything that I don't feel I can complete. In a circumstance that doesn't allow for someone to replace me, the best I can do is inform the event planner. The first Cavalcade of Authors I participated in, I had to skip eating breakfast and show up only to read an excerpt. It took me awhile to shake off that feeling as though I was encased in a concrete suit and get moving. When I arrived, the food looked absolutely deliciously, but if I had indulged, it would have put me out of commission for hours. While I dread speaking, it is also the area where I'm stretching myself. Which means I had to alter the other elements within my control

to be able to execute the task. In this scenario, I had to skip breakfast and grab food later to make sure I could get through that three-minute read.

Live beyond your self-imposed limits was the instruction I received from someone I admired long before I was diagnosed with Lupus. If I wasn't supposed to allow my fears to be an excuse for not executing tasks and stretching myself further, then I cannot allow my condition to be one. When the voice inside quiets and no longer screams "fight", I'm grateful to be blessed with people who encourage me to keep going another day. I know I will stumble, falter, and fall on this journey. Yet, I have to get up and dust myself off. I think of the instances when I've slipped on ice, fell and hurt myself. I didn't stay stretched out where I fell wallowing in the pain. I got up, wiped the snow off and limped to my destination. It's the same thing I do now with Lupus. Stand up and dust myself off. I'm hurt and barely shuffling my feet some days, but I'm still moving forward. I acknowledge the reality of my situation without being bound and gagged by it.

One of my doctors once told me while I was lying in a hospital bed, "You should have died. This should have killed you." It didn't, and I continue to fight for my life like it didn't. To explore the opportunities life presents. To try and fail miserably, then try again. To cross more items off my "anything is possible" list and empty out my treasure chest. Lupus may have flung me into darkness, and it may have taken a while for my eyes to adjust, but they now see the stars clearly. My possibilities are as endless as they were when I felt like I was standing under the rays of the sun.

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