Finding the Upside

Category: Stories
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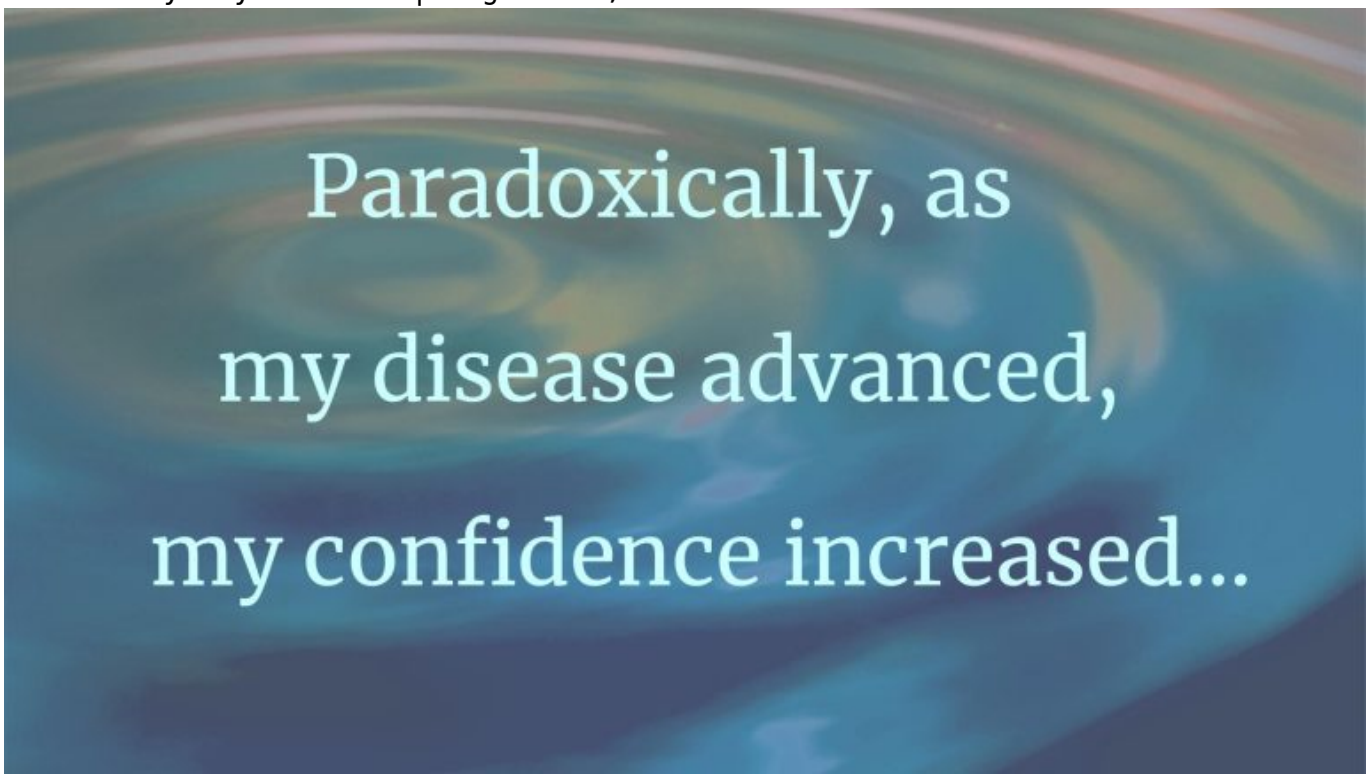

Editor's Note: This piece was a finalist in the Pulse *writing contest, "On Being Different."*

Being different is often viewed as bad. At a young age, I learned that it meant you didn't belong. I vividly remember watching the *Sesame Street* puppets dance and sing about an object that "didn't belong" because it was "not like the others."

Throughout my school years, I tried hard to fit in. Being overweight, and as uncoordinated as they come, I constantly felt out of place in my body and among my peers. I remember trying so hard to make people laugh, to win them over.

Sometimes that strategy worked, as it did with my lifelong best friend. I found out later that she loved me for *me,* not because I was funny; but mostly my classmates thought I was trying too hard, which left me feeling isolated and self-conscious.

The harder I tried, the clearer it became that I was *not* a typical teenager. I made it my mission to find out what other kids liked to do for fun, like painting or roller skating, and then invited them over to do those things, which in reality I had no idea how to do. My overzealous attempts strengthened my classmates' view that I was weird.

Then, two months after my nineteenth birthday, I received solid proof of my

difference: I was diagnosed with scleroderma.

I'd started to feel stiff and tired all the time—fatigue that no twenty-minute power nap could cure. I also had bad joint pain, especially in my hands and wrists; I couldn't even make a fist. Finally I sought medical attention, which led to my diagnosis.

Scleroderma, an autoimmune disease, affects the skin and other organs. Its main symptoms are thickening, tightening, inflammation and scarring of the tissues in the lungs, kidneys, heart, digestive system and elsewhere. It has no known cause—and no known cure.

When I first received the diagnosis, I felt numb. I had no idea what it might mean. The doctor described scleroderma as a mysterious, incurable disease that mostly affects older women.

"Scleroderma is a progressive disease," he added, advising me to "get your affairs in order" and to work as long as I could.

Hearing this felt devastating. I had my whole life ahead of me; I'd made plans for the future. Now life felt so uncertain. Still, I didn't look or feel terribly sick, so I brushed off the diagnosis, telling myself, *I'll beat the odds.*

Over the next five years I floundered around, searching for ways to deny my diagnosis—and I struggled to communicate my thoughts and feelings about it, even to my family members. Scleroderma had made my worst nightmare a reality: I *was* different. But talking about the diagnosis would make it feel even more real, so I suffered in silence, keeping my fears to myself and isolating myself from the people I loved most.

Meanwhile, my physical appearance—my facial features, my height, even my shoe size—began to change. I was slowly becoming unrecognizable, even to my family. I began to despise the sight of myself in the mirror. The inner pain and loneliness felt unbearable: At times, I thought of taking my life.

One bright spot amid the torment was my wonderful rheumatologist. Together, we worked with my other specialists to counteract my symptoms with medication and lifestyle changes. Nonetheless, I still felt a disconnect between my physical reality and my emotional states.

My disease's erratic progression added to the confusion. Sometimes I felt great—pain-free, happy, excited for the days ahead. I enjoyed painting as a means of expressing the emotions I didn't want to voice openly. Other times, my life felt like the movie *Groundhog Day*—weeks of stiffness, ulcerated sores, breathing problems and more.

Seemingly in the blink of an eye, nine years passed—and I'd been through dramatic changes. Too sick to attend college, I'd taken a medical leave; eventually I quit my full-time job and went on Social Security disability. But these losses led me to seek out new opportunities.

For instance, I still hadn't met anyone else who was living with scleroderma.

I needed to find a tribe. So I shared my story on social media, thinking, *If I could connect with scleroderma patients, my fears of being different might dissipate.*

I joined a local support group and made some amazing new friends—but they'd all been diagnosed later in life, so I couldn't shake my sense of not fitting in. Still, they encouraged me to open up to others about my struggles. Gradually, I began to speak honestly and vulnerably with my friends and family.

Paradoxically, as my disease advanced over the next seven years, my courage and confidence increased, and I grew more comfortable in my skin.

I also discovered that I possessed a sharp tool: my voice. I used it to cut through my feelings of distress by educating others about scleroderma. The more I opened up and shared my story, the more empowered and less lonely I felt.

In 2016, I agreed to be a keynote speaker for the Steffens Scleroderma Foundation. Based in Albany, NY, the Foundation was planning a patient-centric interprofessional education event with the nearby medical colleges.

This was the first time I'd ever spoken to a crowd of students, medical professionals and my peers, and I felt extremely nervous. But when I took to the stage, I felt I'd come home. This was the role for which I'd unknowingly been preparing, ever since my diagnosis.

The words I spoke that day have become my mantra and lifeline: "You are enough, you are strong, and you belong!"

Since then, my life has improved dramatically. Not only has the Steffens Foundation allowed me to take a leadership role as a patient and as secretary to the board, they've also enabled me to use my knowledge and skills to create a training program for other patient educators.

As terrible as living with scleroderma may sound, I've realized that my diagnosis was not a negative thing. It has guided me to become a confident speaker, a dedicated advocate and a leader and sounding board for patients, medical professionals and caregivers. I now sit on three nonprofit boards and speak all over the country. Despite the progressive symptoms of my systemic scleroderma, I've continued to work, helping to educate more than 1,200 rising healthcare professionals so far.

I may not look like a typical forty-two-year-old: I'm not married; I don't have kids. I am disabled and will probably die sooner than most. But it is the unique idiosyncrasies of my life that have shaped my role as a patient educator and advocate for the past twenty-two years.

I still have days when I feel angry or sad about the life I've been given. But I've learned that being different, which I used to abhor, is actually the best thing about me. Differences make the world go round, and embracing my differences has freed and empowered me to find my purpose.

In Popeye’s famous words: “I am what I am, and that’s all that I am”—even with scleroderma trying to hold me back.