Amy Gietzen

Scleroderma

I was diagnosed with systemic scleroderma 22 years ago at the age of 19. Over the last two decades, I have developed several more issues because of scleroderma: interstitial lung disease, heart failure, and – as of 2018 – pulmonary hypertension. I have spent 85 percent of each day in bed for the past five months due to the side effects of medications I am taking to try to stop progression and relieve the symptoms I am experiencing which, up until last year, had been effective.

I haven't decided if my current state is worth staying on these meds. Right now, these symptoms of dizziness and lightheadedness make my life unenjoyable, and when dealing with a chronic illness that has no cure, enjoying what life you have left is paramount. When you're chronically ill, you sit in this tough emotional space where you're trying to be positive, but whenever there is a health issue, it sets you back to square one.

You can't help but wonder sometimes, in your darkest moments, what you did to deserve something like this. I've had those conversations with myself plenty of times. I was just a teenager when I was first diagnosed, entering my twenties really, so I wrestled a lot with acceptance. I didn't feel very sick at the time – with scleroderma, I just had issues with my hands and skin, but I could still pretty much live my life like a "normal" human being. So, initially I was just in denial that I was sick.

When you deal with a disease that just progressively gets worse, that doesn't really go away, it's almost like you're living through the stages of grief – as if someone you love died. Because that "someone" is you – who you used to be, a healthy person. The goals and dreams that you used to have and your aspirations. All of that is no longer there, and so you must go through that grief.

I had a lot of anger toward letting go of the life that I had thought I was going to have. I felt kind of isolated, like I didn't really know anybody that was young like me living with all these comorbidities and I just felt like I couldn't connect. On a deeper level, I was dealing with all these emotions and not knowing where to put them.

It is scary as a young adult to have such a debilitating disease. I should be reaching all these milestones and achieving my ambitions such as graduating college, embarking on a career, getting married and having kids. I didn't get to do any of that or really live my life the way that I had envisioned it growing up. On top of my physical issues, I was dealing with so much on an emotional level and this also took a toll on my mental health.

However, I still have a life to live and so I had to wrestle with the denial, the anger and then moved forward through to acceptance. A big part of that process was dealing with the question of, “What do I want to do now?” Given that I have this illness, what is it that I can do with this new reality? Where can I find my purpose? That led me to social media. I started using it to find information like most other people do. However, it morphed into a tool that helped me to connect with others by sharing my story and that has given me purpose. To be able to use my voice and communications skills to speak out and advocate for patients is a path I willingly accepted.

In order to walk this path, however, I had to become more vulnerable and more honest with the feelings I was going through as well as much of my life and struggles I was willing to share. Connecting with other people who live with the same illness helps me climb my way out of that helpless space of asking, “what did I do to deserve this?” to, “what can I do to help others who feel as alone as I do?”

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I feel like living with these diseases has offered me an opportunity to give back. I get to educate clinicians, students, and other patients about my perspective and hopefully enable other patients to feel empowered enough to share their own experiences. All our voices count.

I am now a columnist for a scleroderma-related publication, as well as a patient advocate, public speaker, co-founder of a national podcast, as well as being involved in several other business ventures. Being able to share my story, as I look back on my body work, has been quite cathartic for me. When I go back and read through my columns, it is like a narrative of the emotional journey that I have been on while living with illness. ●

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Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as an autoimmune disease. The word “scleroderma” comes from the Greek word “sclero”, meaning hard, and the Latin word “derma,” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease varies from individual to individual. Scleroderma is not contagious, infectious, cancerous, or malignant.

The exact cause or causes of scleroderma are still unknown, but scientists and medical researchers are working hard to make those determinations. It is known that scleroderma involves an overproduction of collagen

Currently, there is no cure for scleroderma, but there are many treatments available to help particular symptoms. Some treatments are directed at decreasing the activity of the immune system. Some people with mild disease may not need medication at all and occasionally people can go off treatment when their scleroderma is no longer active. Because there is so much variation from one person to another, there is great variation in the treatments prescribed.

Learn more

scleroderma.org