

Thriving with Lymphedema (Abstract)

I was diagnosed with primary lymphedema when I was fifteen. It gripped me suddenly one afternoon after cross country practice. My left ankle ballooned painfully, swelling to twice its size. I thought I had just sprained it, but didn't remember falling. What followed this startling onset was six months of medical tests, scans, doctors, and sleepless nights. No one knew what was wrong with me—a healthy, skinny varsity cross country runner with no detectable injuries.

When I was diagnosed with lymphedema, I was initially relieved. The relief of having a diagnosis was quickly overshadowed by dread. No one knew if my lymphedema was going to get worse, if it was going to spread to other parts of my body, if I would be disabled by it. It was terrifying, and I was decidedly alone. Not only did the majority of my peers not understand what lymphedema was, the majority of lymphedema patients were much older than me. I had no one to connect with, no one to tell me it was going to be okay. Just a promise that I would always have a clunky swollen leg and a beige stocking to match, and that was assuming things didn't deteriorate.

Now, as I approach my twenty-third birthday, and I can say with absolute confidence that lymphedema has neither ruined nor dominated my life. In fact, it is merely a small facet of my identity. Due to my relatively quick diagnosis, access to treatment, and diligent management of my condition, my lymphedema has remained in check. Thus, I remain a prime example of why early access to affordable treatment is so critical, something my mother, a physician, and I spent several years advocating for with the Lymphedema Treatment Act. Ultimately, what I want to assure fellow patients, particularly the young ones, of is that it is possible to lead a full and happy life with lymphedema. You have lymphedema—it doesn't have you.