

I'm a Triathlete with Lupus. Nothing Is Going to Hold Me Back.

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Medically reviewed by [Daniel Bubnis, MS, NASM-CPT, NASE Level II-CSS](#) on April 20, 2018 — Written by Barbara Brody

When Emily Ali, 28, learned she had a chronic illness with no cure, she was devastated. Nearly a year later, she completed her first Ironman — and she vows that it won't be her last.



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Health and wellness touch each of us differently. This is one person's story.

Last summer, after finishing a double shift cycling people around on a pedicab, I jumped in the shower and watched as clumps of hair fell out in my hands and circled the drain.

I was exhausted, physically and emotionally, and I just couldn't keep it together anymore.

Itoweled off, called my mom, and started sobbing. I couldn't stop. I couldn't breathe.

My mother, who knew I had a history of [depression](#) and [anxiety](#), panicked.

She lived about an hour away, so she called the local police and asked them to check on me.

The next thing I knew, I was being dragged to the ER and treated like I was dangerous to others and myself. Needless to say, the ordeal didn't make me feel any better.

But there was no denying that I was spiraling downward.

I had recently learned that I had [lupus](#), a chronic [autoimmune disease](#) that I'd never even heard of until that point.

It was the second major blow of 2017. Earlier, in January, I'd received a diagnosis of [cervical cancer](#).

Mental health issues aside, it would've been a lot for anyone to handle.

My cancer was caught in stage 1, so after surgery I was given the all-clear from my doctor.

Lupus, however, is something I'll have to deal with forever.

At first, my diagnosis felt like a death sentence. But I've finally come to understand that my life isn't ending — it just needs to be readjusted.

Signs something was off

Until last year, I never had any serious physical health ailments.

The cervical cancer diagnosis — detected thanks to a routine [Pap test](#) — took me by surprise. I was upset and scared initially, but I didn't expect it to sideline me for very long.

Being active was like breathing to me.

I completed my first triathlon with my dad when I was 11, and since then, I've done about 10 more.

In high school, I was a swimmer, ran cross-country, and was on the rowing team. I went to the University of Rhode Island on a full scholarship for rowing. After graduation, I took a full-time job in Newport as an account executive for an IT consulting firm, but I never stopped moving.

When I wasn't riding a pedicab, I was swimming or running or heading to the starting line of another race.

But shortly after recovering from cervical cancer, I realized something was off.

My hair started falling out, and I broke out in rashes all over my body. The rashes were so painful, it felt like I was being pricked with needles.

My doctor dismissed it as stress. I'd just been through a traumatic experience, and I had an underlying anxiety disorder. It made sense at the time. Sort of.

I'd also been feeling more sluggish and was getting dehydrated more easily than before. That was especially true anytime I had alcohol, though I was hardly a heavy drinker. I'd have a glass or two and feel really out of it for several days. That had been happening for years, but I thought I was just someone who didn't react well to alcohol.

Then, the beginning of last summer, I got an awful rash on my hands. I thought it was windburn and sunburn, since I was doing so much cycling outdoors.

But when my hands became so red and swollen that I couldn't hold a pen and could barely sleep, I finally called a dermatologist and said it was an emergency. She took one look at me and immediately knew what was wrong.

My hands were what got my attention, but the dermatologist also spotted the so-called butterfly rash on my face, a telltale sign of lupus. (I thought it was the sunburn and windburn.)

She took a biopsy of the rash, and the results confirmed her suspicions.

I had lupus.

Photo by Emily Ali.

Coming to terms with lupus: 'It might not get better.'

I knew nothing about lupus. And although it sounds superficial, when I received my diagnosis, I was most concerned about what I [looked like](#).



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I hope my determination and grit will inspire others to achieve their goals, whatever they might be.

- Emily Ali

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I remember asking the dermatologist if my hair would grow back and whether my skin would clear up.

She had to give me a reality check. I had bigger concerns now.

The dermatologist explained that lupus was a chronic autoimmune disease.

There's no current cure, but medication can suppress the symptoms so flare-ups aren't as frequent.

In addition to the skin and hair issues, lupus often goes hand in hand with fatigue, shortness of breath, and joint pain.

The disease progresses differently in different people, and it's hard to say what will happen to me.

I've since also consulted with rheumatologists who've explained that my condition might get better — or not. Someday, my organs might shut down.

I've had doctors tell me that I might not be able to keep up with the level of activity that I'm currently used to. But so far, no one has told me that I have to stop. So I won't.

In fact, I've resolved to continue doing as much as I can with my life for as long as possible.

I decided not to let lupus get in the way of my dream: competing in an Ironman

Shortly after my lupus diagnosis, I accepted a job offer that required me to move from Newport to Dallas, Texas.

Before I left Rhode Island, I decided to do one more race in the state. It was really challenging, but I didn't notice any difference in my body compared to how I've felt during previous races. I was really happy about that.

This fall, I completed an Olympic triathlon (0.9-mile swim, 24.8-mile bike ride, 6.2-mile run), and in April, I completed my first Ironman in Galveston, Texas. It was a half-Ironman — a 1.2-mile swim, 56-mile bike ride, and 13.1-mile run — and hands down the most intense athletic event I've ever participated in.

The Ironman mostly went well, despite a few obstacles. I was nervous at the start, but as soon as I jumped into the water, I felt more calm and centered.

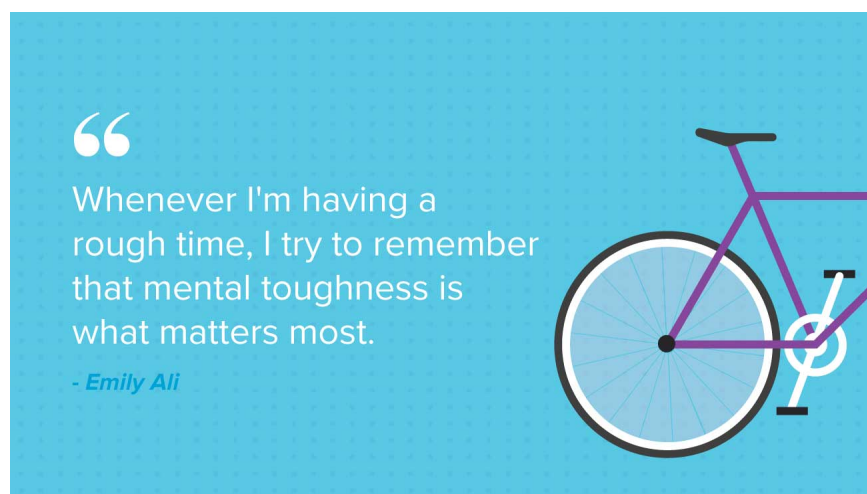
It was my first time in the ocean — my happy place — since moving to Texas, and I almost cried when I ran onto the beach and hit the water.

Thanks to the cold temps and strong winds, my joints got really stiff, and a volunteer had to help me put my socks on and lace me up as I transitioned from the bike ride to the run.

But I met my goal of finishing in under 6:30 (I finished at 6:13:25), and I learned a lot. I'll be better prepared and stronger next time.

Meanwhile, I'm adjusting to my new home. I love my new job as an account executive in the swim market at Active Network. I also just got a Yorkie-rat terrier puppy who wakes me up with kisses.

I'm in a good place.



I don't mean to make any of this sound easy, because it isn't.

I have bad days, when I just don't feel like I have any energy.

My potassium level often gets low: I feel weak, dizzy, and like I'm not getting enough oxygen. I start getting cramps from dehydration — and it's not even necessarily when I'm training or racing. I could just be sitting at my desk at work and feel it hit me.

I also have to get blood tests every few months, and I hate it. I feel faint every single time. I also have to take medication: I'm on [hydroxychloroquine](#) (Plaquenil) daily, and I have topical medication for when I feel my skin about to flare up.

Some days my body just hurts and I don't want to do anything. But I still push myself to go to the pool.

Swimming doesn't put a lot of pressure on your body, and it's like therapy for me. In the water it's quiet, I'm alone with my thoughts, and I can re-center myself. I can remind myself that I'll be OK.

Whenever I'm having a rough time, I try to remember that mental toughness is what matters most.

I can't let worries about the "what ifs" hold me back from hitting my dreams.

I'm really hoping that my condition doesn't ever get to the point where it restricts me from doing the things I love, and I hope my determination and grit will inspire others to achieve their goals, whatever they might be.

Racing and training is what makes me happy, so I'm going to push myself until the end.

This is Emily Ali's story, as told to Barbara Brody.

Barbara Brody is a freelance writer and editor specializing in health and wellness. A former glossy women's magazine editor (Shape, Woman's Day, etc.), she now contributes to a variety of digital and print outlets, including WebMD, Prevention.com, and Family Circle. She's also an avid traveler (Iceland, Ireland, and Portugal are among her favorites) and mom to a feisty preschooler. A native (suburban) New Yorker, she talks fast and types faster. Head to her [website](#) or follow her on [Twitter](#) to learn more.



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