You Are Not an Island: Finding Support for Lupus

by ELENA ANCIRO

The Importance of Lupus Support Systems

When I was diagnosed with lupus, I had just turned 20, hot off the heels of what was intended to be the first of four years going to university in Toronto. I was forced to abandon my studies and limp home, swollen knuckles clenched, every breath pinched by the inflamed lining of my heart.

As I struggled to recover from pericarditis and adjust to the debilitating affects of joint inflammation, I felt like the aspirations I had for my life had been cast out beyond my reach. How could I achieve my dreams when I could hardly lift my arms high enough to undress?

Friends and Family

My friends, too, existed in a world I could not function in; the bustling, youthful existence of working, studying, traveling, and dancing into the early morning hours.

My 22-year-old self had been body snatched, replaced by a swollen, pain-riddled version I did not recognize or want. I watched the life I thought I would be living and the worried expressions of my friends and family drift farther and farther away. They stood like specks on the horizon, a vast ocean of difference between us.

Feeling Isolated

The word “isolated” comes from the latin word, *insulatus*, “made into an island.” And in the years following my diagnosis, that is exactly how I felt.

I became depressed, longing for the sense of belonging I used to have with so-called normal, healthy people. Within the first year, a strange thing happened: I realized that *I wanted to be alone.*

I didn’t want anyone else on this island that lupus had marooned me on. I had no desire to connect with other people “like me,” nor did I want to burden my friends and family with my daily struggles with lupus. I convinced myself that I could still do everything I wanted without changing anything to accommodate my illness.

I lived in complete denial for eight years, and as a result, suffered through three major organ involved flare-ups and a medication-induced case of anaphylactic shock that nearly ended my life.

Everything changed in the summer of 2009. The inflammation running rampant in my joints and tissues moved into my brain, resulting in a complete personality change akin to bipolar hyper mania. I was a helpless observer inside my head, disconnected from the strange and disturbing behavior of a body and voice I did not recognize.

The island I thought I had been on was laughable in comparison. This was what it meant to feel truly alone.

It was this wake-up call that changed my entire perspective on the kind of support I needed in order to could get off "Lupus Island" and fully participate in my life. My long recovery from brain inflammation taught me three valuable lessons.

Sending Your Message in a Bottle: Finding Your Voice

For the longest time, I chose not to speak about my struggles living with lupus. I could hardly acknowledge that I had a disease, much less articulate the emotional support I needed from the people in my life.

When my brain inflammation temporarily changed my behavior, I did many things that were out of character, one of which was starting a blog. When my lucid mind returned, I was horrified to realize that I had been broadcasting my very personal, and at the time, very manic experiences for the entire internet universe to see.

I didn't realize it then, but I would come to understand that my blog was my message in a bottle, that important first step in recognizing I had something to say about my experiences and that it needed to come out, even if I didn't necessarily know if there would be someone out there who would read it.

In order to find the kind of support we need, we must first be able to articulate that we need it in the first place. Whether it's within an online blog or personal journal, expressing and validating your experiences *for yourself* is an important step in cultivating the kind of support system that will allow you to not only survive, but thrive with lupus.

Next page: connecting with fellow lupus warriors for lupus support.

Writing Your S.O.S. in the Sand: Connecting With Lupus Survivors

As it turns out, my message in a bottle was read by lupus warriors and caregivers from around the world and it was their support and encouragement that helped me through the most challenging lupus flare of my life. I started reaching out in other ways online, posting questions on the Facebook group *Hot Chicks with Lupus*. My fears and concerns were met with full acceptance, understanding, and non-judgement.

I joined Twitter and found an even larger network of lupus patients and advocates spreading awareness, positivity, and hope. Connecting with these individuals gave me a sense of community I'd never felt before.

Witnessing their fight for a healthy, quality life with lupus helped me take ownership of my own journey. Having "lupie comrades" and access to our shared experiences online or elsewhere is integral to feeling emotionally equipped to take on our day-to-day challenges with lupus.

Knowing that the pain we're feeling, the medication we're fearing, and the anxiety we've been hiding is being fought through and conquered makes it easier to ask for help and advice. Suddenly, there is a safe place to go, where our S.O.S can not only seen, but truly understood.

The Island Is Not an Island: Perception Is Key

Connecting with caregivers through my blog gave me a new perspective on the role my family and friends play within my support system. In the beginning, I envisioned them as specks on the horizon, incapable of understanding what it felt like to live with a chronic disease.

As soon as I connected with other people with lupus, I realized that asking my family and friends to have that same level of understanding made no sense.

When the caregivers I spoke with expressed the helplessness and inadequacy they felt in trying to support their loved ones emotionally, I realized that the oceans that divide us stretch only as far as we allow them to.

It’s important that when we find our voice and start to articulate our needs, we acknowledge that sometimes the people in our lives can only help us in specific ways.

I learned to seek out my lupus community online when I needed specific advice or an experienced ear and I discovered renewed gratitude for the other ways my friends and family support me: Cooking me a meal when I’m tired, keeping me company when I’m feeling sick, a thoughtful text to check in and see how I’m feeling, etc.

The people who love us feel the blow of our diagnosis as strongly as we do. They feel their own pain as we feel ours. They may seem oceans apart at times, but it’s important to remember that both the caregiver and patient are on common ground and that the caregiver may need support and direction when it comes to meeting their loved one’s needs.

In the end, it isn’t so much about getting off the island, but deciding who you want there with you. I already had access to the support network I needed, I just had to make the choice to connect with it. I learned that tapping into the healing power of shared experience plays just as important role in my overall health as regular exercise and a healthy diet.

The realization that you are not alone is only the first step. Cultivating and sustaining a strong support system requires investment and thoughtfulness from both sides. Ultimately, feeling safe enough to ask for help is what helps us realize that we have the strength to face our disease and rescue ourselves.