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Chronic

by Lisa C. Krueger

The body doesn't care how wealthy you are, or famous, or intelligent. The body has more power. Illness reminds us that we are beholden. No matter our level of fitness or personal determination, our depth of spiritual connection or self-affirmation, the body wins. Illness, that unwelcome guest, strips away the black belt. There are only so many moves to make when facing a fever. A failing heart. A lung that won't expand. A cell that won't stop mutating.

Twenty-five years ago, when I was a young psychologist and my daughter was four, she became ill with an array of debilitating symptoms that no one understood: lethargy, swollen glands, an enlarged spleen; wrists, ankles, knees that hurt. Stomach pain. Doctor's visits circled around everyone's private fear of cancer. Repeated blood tests, physical exams, appointments with specialists offered no clarity. No one talked about Dysautonomia, POTS, Ehler's Danlos, Mast Cell Activation Syndrome, or Chronic Undifferentiated Tissue Disease – diagnoses that would be confirmed a decade later. Instead, doctors and educators talked to us about tolerance. The importance of resting, then getting back out in the world.

"How bad is the sore throat, really?" one teacher inquired. The administrator of her school told me my daughter was probably just depressed. Our pediatrician informed me he suspected an ulcer, and that he was sure my husband and I were putting too much pressure on her. A friend took me to lunch to tell me, "You should consider boarding school in the future. It would be good for her, and for you."

Illness is something every parent searches for and hopes never to find. Yet we always do, at some juncture of the journey – the flushed face, the fever in the night, the listless body. Is our baby alright? Our child? Our teen? It can't be too serious, right? It has to pass, right?

Carry on. Health, for many – if they are lucky – feels like a right. An entitled wealth, even. Illness, then, can seem an aberration. A mistake. I have noticed that people often feel sorry for the sick child – the first grader who misses a week of school for the flu, the high schooler with mono who can't go to prom. But the ill child elicits different feelings. The ill child alludes to life's mysteries, the larger powers of nature or god or circumstance – depending on personal belief – that we can't comprehend or control. The ill child reminds us of what doesn't blend in with the lights and glitter of yearning and hope. The ill child reminds us of darkness.

Throughout my years of work as a therapist, I have been deeply affected by the isolation of illness. How often people who endure some of the most painful experiences in life – depression, panic, phobia, paranoia – feel completely alone in their suffering. Connection and community are necessary to healing. Yet we abandon one other.

The pandemic has opened my heart even wider to the ways in which we suffer. People have sought therapy for problems they never expected to encounter - issues related to family, friends, and community, questions about personal identity or sense of self that had never arisen before COVID. The current global health crisis has required many to rethink beliefs and life choices. Most significantly in my therapy practice, the pandemic has eroded a fundamental resilience that many took for granted, leaving them feeling less capable, often less hopeful, about their future.

Today, many of my daughter's health challenges from Dysautonomia resemble those of COVID long-haulers: exhaustion. Tachycardia. Joint pain. Sleep issues. Digestion issues. Brain fog.

Her brain fog is my nemesis. I can hardly bear it, some days, how suddenly she can't think straight or speak clearly – or at all. Brain scans show a sixty-two percent reduction in cerebral blood flow for her when she has just a mild episode of syncope – meaning there is barely enough oxygen going to the brain. We might be cooking together, or driving on an errand, or just sitting, and one of many triggers will elicit a change. Her autonomic nervous system is exquisitely sensitive. Sometimes I think of it like a finely tuned, specialized race car. One minute my daughter is here, in this life: thinking, feeling, articulating her amazing self. Then she is gone. As though she left, all of a sudden, on an unexpected trip. Persephone.

One of the things I admire most about my daughter is what I think of as her philosophy of endurance. Sometimes she is so ill that she is barely conscious. Then her body finds its way back; she picks up where she left off and goes on. I think of her as a tree in the wind. She bends but does not break. Keeps growing.

My daughter spends much of her life alone: resting, recovering, gathering strength to be in the world, as health allows. She is an incredible artist and writer. She helped create a support network for people with POTS and has a wonderful online community of friends. "Together, alone," she says to me about her life.

There is so much to come that we can't predict. The pandemic world is filled with change and uncertainty. My daughter has learned to navigate the pitfalls and pain of life with an attitude of grit and expectation: she gets through difficult episodes to anticipate better times.

I wish for everyone that health challenges and life challenges might open doors to new ways of seeing and being. I wish that COVID might connect all of us to a larger purpose – and to each other.