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IDEAS

BY [JE BANACH](#)

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Banach, an original faculty member of the Yale Writers' Conference, is the author of more than 100 guides to works of world literature for Penguin Random House, Simon & Schuster, Houghton Mifflin Harcourt, and HarperCollins. Her short stories and essays have been published by Story Magazine, The Atlantic, Granta, The Paris Review, Vogue, and Oprah Daily

In 2018, I woke up on my birthday around 2 or 3 a.m. with a funny feeling in my left hand. It started as a slight itch on my thumb that quickly morphed into a different sensation—the feeling of the thumb beginning to swell, followed by the same feeling in my fingers and sections of my palm, until my hand was almost double its normal size. Later that morning, I visited an orthopedist I’d seen once or twice before for other reasons. He gave me a shot to prevent further swelling, and I went on my way. It was an unremarkable visit. Soon after, another strange thing happened: My hands began to feel like they were on fire—a painful and odd occurrence that I would soon come to know as the hallmark of [Erythromelalgia](#)—or “Man on Fire Syndrome.”

James Baldwin famously [said](#), “You think your pain and your heartbreak are unprecedented in the history of the world, but then you read.” Sometimes, though, your pain might really be unprecedented—so rare that no stories about it yet exist. In that case, *you* must be the teller of a story that renders your experience real.

Only [1 in 100,000 people](#) in the U.S. have reportedly been diagnosed with Erythromelalgia (or what many of those of us living with it prefer to call “EM”). A neurovascular illness, EM causes the blood vessels—meant to keep blood flowing and supply the body and its organs with nutrients and oxygen—to malfunction, leaving them unable to successfully undertake the process of normal narrowing (vasoconstriction) and widening (vasodilation) necessary for their most basic, crucial function—a breakdown that leads to the sensation of a self-immolating body. If I step outside for too long on a sunny day, if I get a little bit warm walking around, if I exercise or even mildly exert myself, if I wash my hands or my dishes, and sometimes, for no

discernible reason at all, it happens: My hands turn a fuming shade of red, become tight with swelling, and begin burning. My face, my ears, and my feet all joined in at some point or another, too.

When I use the word “burning,” I imagine that most readers interpret this to mean “hot,” as if the parts of my body are just very, very warm. But it is crucial here that you understand that I actually mean *burning*. Hand flares feel as if I am placing my hand on the burner of a stove and bring back memories of the sensation of sticking my hands in snow as a child and foolishly running them under hot water to warm them up. A flare in my ears feels as if someone is holding a lighter to my skin. Face flares feel as if I’ve gotten a terrible sunburn without any of the fun of having first been at the beach. When I feel the sensation in my feet, it is like walking across hot coals. And there are “hangovers” on days after flares—a sensation that I liken to rubbing one’s hands and feet in pink insulation or a tray of crushed glass.

It is believed that there is a primary version of the illness caused by genetic factors and a secondary version related to underlying disorders like polycythemia vera and neuropathy, or autoimmune illnesses such as lupus and rheumatoid arthritis. Episodes can increase in frequency with time or remain unchanged over years or decades. For some, the condition can increase in severity rapidly and become disabling within months. Efforts to temper the burning of one’s body parts with water or ice can lead to severe infections and gangrene and further damage to blood vessels. There are stories of people who want to amputate their own limbs because of the unbearable severity of their pain or even worse—to end their own life. And there is currently no cure.

To make matters worse, almost no one has heard of EM. The fact that it is so unknown can make the condition harder for those living with it to bear, leaving us strangers stranded alone in a very strange land. To date I have met only *one* doctor who was familiar with EM. In fact, it was not the orthopedist who first saw my body reacting to this condition but a specialist in misunderstood illnesses like Myalgic Encephalitis and Fibromyalgia, who serendipitously recognized my symptoms during a visit for other long-term chronic issues.

I know only two people living with EM like me. One, Kevin, a 55-year-old father and former educator who lives almost 2,000 miles away, met me on Twitter, where we both tweeted about life with EM. He quickly became a close friend. We text almost daily about our lives with EM, not only about how it has changed our lives, but also how it has changed *us*. We talk about the pain, flares, and the lack of treatments. We talk about how difficult it is to do just about everything. I talk about what it is like living with EM as a single woman with multiple chronic illnesses. He tells me what it felt like when he had to stop working and about his first time using a wheelchair in public. I always feel better after talking with him. He tells me the same. And we talk about this too—about the value of friendship, mutual understanding, and empathy in the face of suffering, about the pricelessness of being able to share our stories.

The subject that we talk about most often, though, is the shocking level of misunderstanding that we face on a regular basis. We are like aliens on a faraway planet. It is impossible for our family members, our friends, our therapists, and even our healthcare providers to understand what a life with EM is. And for those who are not close to us, it is completely unimaginable.

Losing the ability to do things that one was previously able to do is a common human experience. Feeling as if one is burning alive is not. No one wants to believe that such a fate is possible. So, for many, it is easier to tell themselves that Kevin and I are simply lazy, weak, malingerers, liars, and weirdos. Some tell us directly. I would be lying if I said that I didn't mind or ever find fault with this, but I still try not to blame others for misunderstanding. How can someone understand a thing that they didn't even know exists?

Erythromelalgia is only *unimaginable* until I tell you my story. And it is only unbearable if there is no one to listen.

Chronically ill people need to be able to tell their stories—and to be believed. Along with many others living with such curious conditions, I have witnessed a perpetual, fundamental, cultural misunderstanding about why people like myself tell stories about our lives with these conditions. It isn't to garner sympathy or to complain. It isn't to offer one's self up as a figure of inspiration. *It is to be seen.*

If we are not seen, there can be no dialogue, and without dialogue there can be no progress—not in the way that we see and treat those who are suffering nor in the actual elimination of these devastating, life-shattering diseases.

So this is the story of a person who goes barefoot as much as possible, even in winter. Long walks are now impossible for her. Playing tennis for hours in the summer sun as she had before is just a dream. She leans against doorways when stopping to have a conversation in order to avoid standing flat on her feet. She sometimes finds it difficult to hold up a pan filled with water, sometimes even something as small as a mug filled with coffee or

tea. Cooking causes her hands to burn. So does vacuuming. Showers or a bit of sun turn her face into the bright red mask of a devil. She can still recall the day when it occurred to her that holding a baby would now, most likely, be out of the question.

This is the story of a burning body with a yearning spirit and a churning mind, and, with any hope, it will be a story that starts conversations for cures.

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