

Letter

What It Means to Me to Have Juvenile Arthritis: One Patient's Definition

To the Editor:

I was diagnosed with juvenile arthritis at the age of two. Until recently, if you had asked me to describe my experience of arthritis, I might have told you about a cluster of symptoms: Having arthritis means I experience pain and swelling in my joints, have a particular set of elevated blood markers, and sometimes experience stiffness if I am in one position for a long time. I may have shared with you my understanding of the mechanism for arthritis: My immune system does not recognize my joints as part of my body and instead sees them as something to “attack.” Or I may have told you about a set of treatments: Having arthritis means I take medication, get blood tests, do physical therapy, and see my doctor regularly.

All of these are narrations that were offered to my little-girl self, to try to help her understand why she was hurting and being asked to do things that were uncomfortable or risky. As little me listened to conversations about symptoms and treatments and mechanisms, and about what I should and should not do with my body, I also heard this message: Your body is broken. It does not do what it is supposed to; there is something off in its wiring; it is dangerous. Arthritis is something we hope goes away, something to manage, something to watch very carefully. It is something to be sad about or even ashamed of, to seek others' opinions about, to organize your activity around. Reducing the symptoms of arthritis is worth risking your eyesight or your bone density or your stomach lining.

Of course, these are never things that are said overtly, especially not to a little person. What is said masquerades as “objective,” using language about symptoms, treatment, probabilities, et cetera. But kids know better than to just listen to the words adults say. What I learned by *watching* the adults in the room with me is that I was not safe in my body. Being able to tell you the symptoms, mechanism, and treatment for arthritis did not make me feel any safer; in fact, it cultivated a sense of separation from my body that meant I never felt fully at ease.

What has brought more ease is a process of reemodiment and nervous system deescalation with the help of a skilled team of practitioners. Here is how I would now describe what it means to me to have an autoimmune disease: It means having a high level of sensitivity and responsiveness to

stimuli, including material, relational, and pathological stimuli. My body feels these stimuli acutely, sometimes more than others do. This means that I am awake and alive to how things are in any given place and time, with a wisdom and a keen vision for what is wrong. This “awakeness” often has big costs for me, including pain, exhaustion, and nervous system overdrive. Because most environments are not designed for people with systems as sensitive as mine, it means I find myself in burnout-recovery cycles, and my life regularly feels unpredictable.

Importantly, this emerging narration does not transcend the pain and difficulty of having an autoimmune disease; it acknowledges the costs of living in a body like mine. Just as importantly, it does not frame my body as broken. My body is different, in a way that asks for extra support, and it brings a unique gift of sensitivity and insight.

I think my story issues a number of invitations for providers who work with patients with arthritis. One invitation is for providers to adopt more complex definitions of arthritis—specifically, definitions that take into consideration what it feels like to live in a body with arthritis. Another invitation, then, is for researchers and practitioners to create spaces for conversations with patients about their own experiences with arthritis. These conversations cannot be framed solely in terms of the medical model of the body or use only language constructed by Western medicine. These models/language often treat arthritis as pathological—as a “problem” that lives in the bodies of patients—rather than acknowledging that arthritis is a label, a tool constructed by Western medicine for diagnosis and treatment. Having Western medicine be the exclusive voice in defining arthritis has added significantly to the pain I have experienced. Reclaiming my agency to define arthritis for myself has been a part of my healing journey.

Specifically, thinking of arthritis as a heightened sensitivity and responsiveness has helped me to see that arthritis is not just something to be suppressed but also something to be supported. It no longer feels like enough to put my system to sleep—not just because I do not want to walk through the world asleep, but also because it is not possible for a sensitive system to stay asleep in a very loud world. What I want is to find rest while I am awake and alive. Certainly, supporting arthritis would look different for different patients; for me, it currently looks like nervous system support, in conjunction with immunosuppressants.

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