

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

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Hi, I'm Amy Robertson, and I'm the author of the Letter to the Editor entitled, "What It Means to Me to Have Juvenile Arthritis: One Patient's Definition."

In this letter, I share pieces of my experience as a person who's lived with autoimmune disease since I was diagnosed with arthritis at the age of two. Part of my story is that I internalized the language and ways of thinking about arthritis that were communicated to me as a child. Alongside better understanding of the symptoms, the treatments, and the mechanism for arthritis, and thus why I was being asked to do particular things with my body.

I also internalized the idea that my body was broken, that arthritis was something we hope goes away, and that arthritis is something I was expected to orient to and organize my life around. Having Western medicine and these stories that came along with the language and the ideas of Western medicine be a primary voice in defining what it means to have arthritis has added significantly to the suffering that I've experienced over the course of my lifetime.

Another part of my story is that I have recently reclaimed the agency to define what having an autoimmune disease means to me. And this is supposed to be a teaser, so I won't give it all away, but I'll just close by re-issuing a call to researchers and healthcare providers to initiate conversations with patients about patients' own experiences of autoimmune disease. And it's really important, I think, for these conversations not to ask patients to use the oftentimes pathologizing language of Western medicine to describe their experiences, and instead to really start and then stay with the language and the ideas that patients are bringing forward in these conversations.

It was through the process of asking myself this question, of what it means to me to have an autoimmune disease, that I was able to articulate both the cost and the gifting of arthritis, and of living in a body like mine, and then to seek care that has supported me in thriving in body that also hurts. Read my letter to hear more about the texture of my experience, and what I'm pressing the medical community to do in response.