I Didn’t Realize the Value in Connecting with Other Rheumatoid Arthritis Patients

Here is Deige’s story about how her approach to her rheumatoid arthritis diagnosis has changed over the years and how she is using her experience to effect change as a member of the Patient Engagement Advisor Panel for ArthritisPower and the Global Healthy Living Foundation.

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When I was 16, my family and I traveled to Disney World. As we waited for our room to be ready, I should have been thinking about the rides I’d go on and the famous park food that I’d eat. But all I could think about was the pain in my arm.

Between traveling and waiting, I had been carrying my luggage for a long time. Now, this would make anyone’s arms weak. But the pain in my limbs went beyond a normal soreness. Even after I put down my bags and some time had passed, my hands were like claws; unable to be opened or closed.

Later that night, I found myself in the emergency room. My elbow to my fingertips, as well as my ankles, were completely frozen and stiff. I didn’t know what was wrong with me and, as it turns out, neither did the ER team. They chalked it up to the soreness and sent me on my way. A day or two later, my hands were back to normal, and the episode was forgotten.

Until it happened again.

My Grandmother’s Intuition

In the weeks that followed, this paralyzing pain would appear out of nowhere. First, in my left hand. Then in my right ankle, followed by my left ankle. Around and around the pain would go.

Then one day I tried to get out of bed and I fell on the ground. My mom thought these were growing pains—not because she didn’t believe my pain, but because she didn’t see the larger picture. I went to the pediatrician, who tested me for a few ailments and said I might have Lyme disease, but never officially diagnosed me.

It was my grandma who got everyone—myself included—to understand how serious the situation was.

“We need to figure out what’s wrong here,” she said. As one of 11 children, almost all of whom had total knee or hip replacements, she just knew something wasn’t right.

We traveled 30 minutes out of town to meet with a juvenile rheumatoid arthritis (JRA) specialist, who was finally able to solve my medical mystery: I had rheumatoid arthritis.

Finding the Right Treatment

I don’t think I fully understood what it meant to have RA at that time, especially as a teenager. And I don’t think I cared to find out. After all, I was 16. I was more concerned about whether I could get a pair of the trendiest sneakers rather than whether I could wear them with RA.

As it turns out, I couldn’t because RA can often shift the position of your bones in your feet, causing “flatfoot deformity.” You feel pain in the tendons in the arch of your foot, and on the inside and outside of your ankle. Or you may get fallen arches. Not only did this limit my fashion choices, but it caused immense pain.

My doctor agreed to put me on prednisone to help with that issue. I didn’t think to ask about the side effects or other options. I just wanted the pain to go away. It turned out to be a terrible decision I still regret. It made me gain 30 pounds in two months. As a senior in high school, the sudden weight gain did a number on my self-esteem.

I tried several medications, including methotrexate and a biologic and then a second biologic, which was the first treatment that really worked for me. I took it until I turned 19, which is when I got pregnant with my first son and had to take a medication break. But after I had him, I got back on it and I’m still on it today. It’s been the most consistent medication for me.

“Until now, only the people close to me would have known I have this disease. But participating in ArthritisPower has allowed me to step out of my comfort zone and speak up about the things that affect me and others.”—Deige Williams

The Road to Remission

After the birth of my son in 2004, my doctors told me I was in remission. I was having little to no flares, due largely to my medications, and that’s continued for the most part since then. These days, I rarely have to think about my RA during my daily life.

I did have one pretty bad flare-up about two years ago, but my history with RA has helped me learn how to alter my lifestyle and movements in ways that make dealing with sudden flare-ups easier. This means changing my shoes to a pair that provides more relief (like flats) or stop bending to the ground to pick things up, which becomes too painful. Knowing what joints to think about and protect can be an adjustment, but it makes a big difference. Otherwise, your brain automatically moves your joints the way you’re used to moving them.

I’ve also gone through several procedures that help relieve pain and make my joints more mobile. For a long time, my left hand wasn’t able to rotate. I struggled with simple tasks, like collecting my

change from the cashier in a drive-thru—I would always drop the change on the ground. Eventually, I had synovectomy surgery on my left elbow. This procedure removes the synovial tissue around a joint in order to provide relief from inflammation.

But overall, my joints are holding up pretty well for someone who with RA for more than 20 years—the majority of my life. In my early 20s, I set a goal to get to 30 without having any joint replacement. I saw many family members undergo many joint replacement procedures over the years and wanted to avoid a similar fate. And here I am—38 years old and joint replacement-free.

Learning to Make Connections

Because I was so young when I was diagnosed with RA, I didn't realize the value in connecting with other RA patients. In fact, it was only a few years ago that I actively became a part of the chronic illness community. At the time, my friend Shantana had been diagnosed with RA and asked about my experience with it. I answered her questions, connected her with my doctor, and told her about CreakyJoints, a website whose Facebook page I followed but didn't regularly interact with.

A health advocate at heart, Shantana asked me to join her in raising awareness about RA. But that had never really been my thing; I preferred doing small, behind-the-scenes work. She kept asking and eventually convinced me to step out of my box and raise my voice.

Now, I am not only interacting with CreakyJoints regularly, but I'm a member of the Patient Engagement Advisory Panel for ArthritisPower. ArthritisPower is an app and research registry that lets people with different kinds of arthritis and rheumatic diseases track symptoms and disease activity and share results with your doctor. You can also participate in voluntary studies about managing arthritis.

As a patient advisor, I share feedback about everything, from treatment, to health care, to app design, with a goal of making research more patient-centered. I provide firsthand experience, such as RA symptoms, medication side effects, and app use, to help inform research so that decisions aren't made solely on what doctors think RA patients need.

I am able to advocate not only for myself, but for other RA patients—and it's empowering.

Until now, only the people close to me would have known I have this disease. But participating in ArthritisPower has allowed me to step out of my comfort zone and speak up about the things that affect me and others.

My Advice for Others Living With Rheumatoid Arthritis

Trust your gut

It's easy to think the doctor knows best. You may also worry that questioning them is rude. But you know your body best, and it's up to you to tell them when something isn't right. When my most recent flare-up lasted for a longer-than-normal period, I felt like it was worth trying something new. But my doctor wasn't going to listen to me, and I had to find one who would. In

doing so, I eventually started new medicine and a regimen that worked.

Find a doctor you love

Health care is not a one-size-fits-all and having a doctor who looks at how the illness impacts you personally is important. It's also crucial that your doctor makes you feel comfortable and not stupid. My doctor speaks clearly and makes sure I understand everything she says before I leave her office.

Do your own research

I'm a firm believer in Googling. I know many doctors get frustrated by it, but I think doing a little research beforehand helps you to advocate for yourself and to know what questions to ask.

If I Could Say One Thing to My Newly Diagnosed Self…

I would tell myself to learn more about the medications used to treat RA. Educate yourself on their side effects and how they may affect your lifestyle. And find some support. There are people out there dealing with what you're dealing with — step outside your comfort zone and they'll be there.

Be a More Proactive Patient With ArthritisPower

ArthritisPower is a patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions. You can participate in voluntary research studies about your health conditions and use the app to track your symptoms, disease activity, and medications — and share with your doctor. Learn more and sign up here.

If you're interested in being a patient advocate with ArthritisPower and helping our efforts to engage more diverse patient groups in research, check out our Patient Engagement Advisor Program.

Deidra "Deige" Williams is a 37-year-old creator, graphic designer, and brand builder who lives in Connecticut.

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