REALHEALTH™

The Color of My Skin Shouldn’t Determine the Quality of Treatment I Get

Shantana tells her rheumatoid arthritis story, offers advice and encouragement for others with the disease, and shares her experience and insight as a Patient Governor for ArthritisPower and the Global Healthy Living Foundation.

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My rheumatoid arthritis symptoms started about 16 years ago. In the morning, I would wake up with what I called “old lady hands.” They were achy and stiff and hard to move. It took me a moment before I was able to get out of bed, and even then I’d continue to feel fatigued throughout the day. I’ve always had issues with sleep, so I thought I just wasn’t rested enough.

These were very mild symptoms, but they kept happening. It set off an alarm in my head and made me pay attention. I went to my doctor and showed him where I was hurting and described my other issues. He referred me to a rheumatologist, which could have been the path to my diagnosis, but instead was a terrible experience.

The rheumatologist determined that I had fibromyalgia and started throwing all kinds of medications at my problems, but nothing changed. My symptoms got worse. The pain went from one joint to two, then three, and then they also became tender to the touch. I started losing weight. I started having trouble doing certain things. I’d be holding a cup and all of a sudden my hands would cramp up. I didn’t understand it. But it was because a disease I didn’t know I had was progressing in my body.

Learning to Trust My Own Judgment

When your doctor tells you you’re complaining, overreacting, or that what you’re feeling is all in your head, over time you start to believe those things.

I kept saying, “What you’re giving me isn’t working.” But they were so focused on fibromyalgia that they never did lab work to find anything else. I started mistrusting myself. I believed my doctor knew what he was doing. I didn’t research, I didn’t ask questions. I honestly didn’t know it was okay to question my doctor. After all, they’re the professionals. Who am I to question them?

Finally, I got frustrated enough to find a new rheumatologist. I was very resistant when I first started seeing her because of the hurt I had experienced from my previous doctor. But from the very beginning, my new doctor invited me to be a part of my care plan. I felt heard. She put me through a series of tests and went over results with me. As she was ordering each test, she would tell me what the test was for. She gave me literature and information so I could understand more of what was happening.

She became not just my doctor but my teacher. She showed me what questions to ask and how to be more present in my appointment instead of zoning out. I started to trust her—and myself. I started taking down some of my walls. I realized I'd been operating with the assumption that doctors should be able to figure things out based solely on lab results and symptoms, when in reality, my experiences are a key piece of the puzzle, too.

With this new, healthier medical relationship, I was able to get my RA diagnosis, although it took seven years after I first saw a doctor for my symptoms.

"Because of my advocacy work I can better navigate the health disparities that are ever present in our medical system, but it still impacts me. At the end of the day, I'm always going to be a Black woman."—Shantana Hazel

A Path to Advocacy

Two years prior to learning I had RA, I started having a strong feeling that I must be going through all of these medical challenges for a reason. In addition to my fibromyalgia and undiagnosed RA, I was also dealing endometriosis. I was praying a lot. I had conversations with God to try to understand what my bigger purpose was. I didn't pity myself or feel down, I just wanted to know what I could do with my experiences for the greater good.

And so I birthed the Sister Girl Foundation, an advocacy community for women dealing with endometriosis. I saw it as a way to take control, use my voice, and help other women find theirs. It's no exaggeration to say it saved my life, emotionally, because I had a new sense of direction and purpose. And it also paved the way for dealing with my RA diagnosis. I was able to apply what I'd learned from having chronic disease and what I'd learned through the Sister Girls and implement it as I navigated this new disease.

It wasn't long after my RA diagnosis that my rheumatologist told me she knew of an RA organization doing good work. Because of Sister Girl Foundation, she thought I would be a great addition to their initiative. She introduced me through email to Ben Nowell, the Director of Patient-Centered Research at the nonprofit Global Healthy Living Foundation and CreakyJoints, its patient community for people living with arthritis and rheumatic conditions.

I fell in love with CreakyJoints and everything it stood for. I felt like I had found my people. Before CreakyJoints, I didn't know people who had RA — people who knew what this type of chronic illness meant, who knew what autoimmune meant, or who really understood when I said things like, "my body is not my friend today."

Getting a Seat At the Table

I also got the opportunity to help co-create ArthritisPower, an app that helps people with arthritis and related health issues track their symptoms and participate in research studies.

It was so exciting to be a part of creating technology to help keep track of RA medications, sleep patterns, and symptoms—not only physical symptoms, but emotional ones, too.

With RA, brain fog is real. It's easy to forget the ins and outs of how you've been between doctor appointments. But with ArthritisPower, my doctor could easily see what I'd been experiencing since the last time I saw her. It gave me agency to take better control of my health, and I loved that others would have access to that too.

But more than that, I felt excited that there were people working to build something greater for the RA community. They invited me to be a Patient Governor, which is a patient advisory group that helps ensure patients get to actively participate in shaping research.

During our annual meetings, the investigators would listen to what we had to say as people living with arthritis, and actually use that information to help guide their studies. It made us feel like we were an important part of the RA research community. We were doing something that would impact the world when it comes to rheumatic illness, chronic diseases, and autoimmune diseases.

We were invited to the table.

Why Research Representation Matters

I was fortunate because of the doctor I have and the advocacy work I've done that I got connected to this RA research. But there are so many others like me that can and should be at the table, too. Research isn't accurate if you're not including everyone. If my community—the Black community—isn't involved, how can we be cared for properly? That's not equal health care.

The color of my skin shouldn't determine the quality of treatment I get. Because of my awareness and advocacy experience, I can better navigate the health disparities that are ever present in our medical system, but it still impacts me. Because at the end of the day, I'm always going to be a Black woman.

I have been working for years on having the uncomfortable conversations about the health disparities that my community faces. We can't keep brushing it under the rug. Not enough people are holding themselves accountable when it comes to correcting the issue. Because in truth, minority populations are dying in large numbers from illnesses across the board—look at diabetes, hypertension, even childbirth. It's a health crisis. We're not at those research tables. We're not in those clinical trials. Our pains and grievances are largely dismissed.

These things affect us both physically and emotionally, just like our RA does. I get mad about it. I grieve. But like Jay-Z says, "You can't heal what you never reveal."

So we keep revealing: by using our voices to talk about these issues, by finding a way to the table, and by knowing we are powerful and deserving of abundance.

Adjusting to Life With Rheumatoid Arthritis

There’s no sugarcoating it: having a chronic illness is hard. Rheumatoid arthritis has impacted the ways I’ve been able to interact and be present with my family and friends. I’ve been on several different biologics through the years that have given me more good days than bad. But I had to come off my most recent biologic because my liver enzymes were elevated. I’m currently waiting for my liver numbers to normalize before trying a different therapy.

So these days I’m dealing with more flares that keep me from doing everyday activities such as walking up and down the stairs or getting on the floor to play with my grandchildren. There are times when I need someone to help me get dressed. Sometimes I’m in the bed most of my day because I just don’t have the energy to get up. It can play on you emotionally. Even as a veteran health advocate, I still deal with anxiety, depression, and grief. Because I still have the disease.

The difference now is I have tools for it. I don’t dismiss my pain. I know when it’s coming on and I’ll give myself the rest I need and allow myself to feel my feelings. One of my Sister Girls told me years ago, “Give yourself permission to grieve. You’ve been through a lot and you’re going through a lot. It’s okay to grieve that.”

These are the things that keep me going instead of saying, “this too shall pass.”

And then when I’m ready, I find ways to make it a good day. I find ways to pick myself up and create joy, because I can’t wait for someone else to do that. The power of “I am” is very strong to me. In my home, I’ve surrounded myself with inspiration and affirmations. I have art on my wall that says, “Laugh Lots, Love Much, Dream Big,” and another that says, “Empower You, SG.” SG means Sister Girl.

I speak these things to myself. I say “Sister Girl, you are awesome. You’re amazing.” When you speak positively every day to yourself, no matter what your situation looks like, you can find one thing in the midst of your fog to be grateful for.

My Advice for Others Living With Rheumatoid Arthritis

Empower yourself

Your voice is so important in this process. Be an active part of your care plan, and educate yourself about your disease. Pay attention to your body and emotions and believe what they tell you. And then be honest with your physician about them. Remember: What you don’t reveal, you can’t heal.

Build a support system

Finding your tribe is one of the most important things you can do for yourself, because that provides the support that you need that you can’t get from your family or friends. These are people who understand chronic illness, who are having some of the same experiences as you and get it.

Be open with your doctor

Good care comes from building trust. Tell your doctors if you've had a traumatic experience with a previous physician. Discuss how that's affected you so they can understand any resistance or pushback you might have and navigate an honest doctor/patient relationship.

Keep loved ones in the loop

When you 'arthritis,' people automatically think of something their grandmother has. Educate your family and friends about the different types of arthritis, and don't be afraid to tell people what you need. When I started talking about my RA, I found out others in my family also have it. We weren't talking about it. But the more you know about your medical history, the better care you can get, so it helps everyone.

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

Trust and listen to your body — don't second-guess yourself. It's so important for us to believe what we feel and not allow others to dictate how our bodies are feeling. Be patient with and kind to yourself. Ask lots of questions and do your own research about your diagnosis.

I would also tell myself, "Sister Girl, you got this."

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.

Shantana Hazel is a 45-year-old award-winning health advocate, philanthropist, speaker, and women's health and wellness coach. She lives in Connecticut. She's the founder of Sister Girl Foundation, a nonprofit organization that helps empower women with endometriosis, breast cancer, and ovarian cancer to take charge of their health care. Shantana is the author of 28 Ways On How To Advocate For Your Healthcare and A New Me: Mind, Body, Soul, Health & Wellness Journal.

Shantana is a mother, grandmother, and lover of life. She enjoys spending time with family and friends (even if it has to be virtual right now), and a good round of karaoke.

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