# Most People with Rheumatoid Arthritis Don’t Look Like Me

Here is Deen’s story, and what he wants other people with RA, especially people of color, to know about getting involved with research and patient advocacy.

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About 10 years ago, I started having ridiculous stomach aches — a continuous combination of cramps, diarrhea, the whole nine yards. On top of that, I was also having pains in my joints, particularly my fingers. My doctors ran some tests and said it seemed like I had inflammatory bowel disease (IBD) like Crohn’s disease or ulcerative colitis.

They put me on a combination of drugs to treat IBD, including the anti-inflammatory mesalamine and an immunosuppressant, 6-mercaptopurine (6-MP), and my symptoms basically went away. In fact, after two years of no recurrences they declared me to be in remission and said I could come off my meds.

Then the symptoms came back with a vengeance.

Even worse, we discovered the original medications I was taking had lost their efficacy. I spent the next couple of years — yep, years — in bouts of excruciating pain. Finally, after I dropped 80 pounds and regularly found myself curled up on the floor writhing in misery I saw my gastroenterologist, who scheduled me for a colonoscopy the following week.

But just a few days later, after spending my work hours doubled over in pain and finding blood in my stool, I decided I needed to go to the emergency room. The doctors there gave me medication to calm things down a little, but they didn’t seem to be interested when I explained I was under the care of a gastroenterologist and going for a colonoscopy soon. At one point, I overheard them in the hallway, and one said, “Yeah, I think he’s a drug seeker. So let’s just treat him and get him out.”

## Solving My Mysterious Symptoms

The colonoscopy a couple of days later turned out to be incredibly revealing. Although I was sedated, I watched the whole thing. Once they reached a certain section of my colon, I was like, “Oh dear God.” There was a six- to eight-inch area of inflamed ulcers on the screen. The doctor said, “This is your problem.”

When I took the results to my primary care physician, he sat down with me and took out a white board and said, “Okay, we’ve got to really figure out what’s going on.”

Using the board, he connected the dots, considering the inflammation in the lining of my chest, the issues with my liver, the bowel symptoms, the joint pain. He said, “I think you might have rheumatoid arthritis.”

I went to a rheumatologist and got tested. Sure enough, the results showed I had seronegative RA. This means I have rheumatoid arthritis but don’t have antibodies such as rheumatoid factor or anti-cyclic citrullinated protein (anti-CCP). Many people with RA have these antibodies and are considered seropositive, but there are plenty of seronegative folks out there too.

I was lucky my primary care doctor was thorough and looked at everything that was going on with me — not just my GI symptoms. My first set of doctors felt that they had figured out what was wrong and that was it. I did more research and began to see the connection. It turns out that GI pain and discomfort is common in people with RA, probably because of the inflammation, changes in the immune system, and imbalances in gut bacteria.

“When more Black men with RA can connect, advocate, and participate in clinical trials, we don’t just create community, we move the needle on the development of drugs that will help people of color have better control over their disease.”—Aberdeen “Deen” Allen.

Adjusting to Life With Rheumatoid Arthritis

But because I thought I had IBD for so many years, getting that rheumatoid arthritis diagnosis was the biggest shocker of my life. I had no idea what RA was. It didn’t run in my family, I didn’t really know anyone with it, and everything I read told me it primarily impacted women.

I didn’t see anything about Black men at all. I thought, “No, they got it wrong. This can’t be it.”

But once they started to dig deeper and really monitor my symptoms, it turned out that was absolutely the case. So here I am, a Black male with rheumatoid arthritis.

To this day, I’m still in shock about it.

But I’m also a research chemist, so I love to research. Once I was diagnosed, I immediately jumped on the internet and tried to learn everything there is to learn about this disease. I was also hungry for patient stories like this one. And what I discovered pretty quickly was that the number of men that were out there talking about RA was really, really, really small. There were a few sharing their stories, but for the most part, it was primarily women.

I set up a Google search alert for the term “rheumatoid arthritis.” It sends me a compilation of anything that pops up on the internet about RA every day so I can read about it. I also set an alert for “rheumatoid arthritis and African-American men.” You know how many alerts I get for that combination of search terms? Virtually none. There’s just nothing out there.

It’s taken a while to find a medication regimen that works well for me. I started off on the disease-modifying antirheumatic (DMARD) methotrexate and the biologic Humira, but the Humira stopped working after about a year. I moved to Enbrel, which also ultimately failed for me. Then I started Remicade, which I’ve been on for a long time now. [Note: All three of these medications are types of biologics known as tumor necrosis factor (TNF) inhibitors, which block an immune system protein that causes inflammation.]

But it makes me wonder — how many other people have to go through this trial and error to find the best treatment? If we had bigger, more diverse populations in clinical trials, we might better understand which drugs work best for which patients and help others avoid years of misdiagnosis and inadequate treatment.

Even though my current treatment plan working, I’m still dealing with damage that the disease has already caused. I’ve had two hip replacements and cervical spine surgery to repair some RA damage. My ability to get out and do the stuff that I used to do isn’t the same. My level of physical activity has dropped significantly.

I still try to stay active through yoga, spinning, and walking. But it’s been a big psychological adjustment, because I’ve always loved mountain biking, running, hiking, and doing other stuff. I’ve always been a type A, always-on-the-go guy. Having to really dial that down is still a major adjustment for me.

Instead, the way I live now is “do what you can, when you can, and how you can.” I’m more in tune with my body and my surroundings than I was before. I just take every day as it comes in.

Using ArthritisPower to Advocate and Connect

After living with RA for a while, I decided I wanted to speak out about my own experience. After several conversations with my rheumatologist about my desire to share my story with others, she connected me with the ArthritisPower team.

I was already familiar with the app—I knew it as a fantastic source of information about RA, and I also used it to track my symptoms. I use it to follow my daily mood and record any issues and concerns I have regarding my health. I like that I can chart my progress and see how I’m doing overall. As I approach any doctor appointment I go back and print out info to discuss with my doctors. Having the ability to create and send reports to my rheumatologist instead of trying to remember everything that’s going on takes a huge burden off of my shoulders.

Last year I started working more closely with the ArthritisPower team as a volunteer patient advocate. One of our goals is figuring out how to get more men and people of color involved.

I know that there are more men out there who have RA and probably don’t even know it or don’t want to talk about it. Instead of hiding in my home afraid of the stigma that is attached to chronic illnesses, I want to be candid about my situation. I want the world to know that not only does this disease impact men; it impacts Black men.

Another reason I'm such an advocate for telling my story is because of the problems I experienced during my journey to getting diagnosed, which I think is because I am a Black male. [Note: It's well-documented that people of color experience disparities that span the health care system, leading to lower-quality care, worse outcomes, and even shorter life expectancy.]

It was nearly three years of pure hell before I finally got a proper diagnosis. My inflammation was just being written off as something else and nobody was really taking the time to listen to me. That was the most frustrating part.

## Making Research More Diverse and Inclusive

One of the things that I've become interested in is how many people of color are included in research, because even though they say immune systems in all bodies are pretty similar, there may be nuances that can impact treatment. I hope that by putting myselg out there, other people will be willing to say, "Hey, yeah, I want to share my story, too."

We need to get a wider variety of people to participate in clinical trials so that we can see the efficacy of RA drugs in more types of bodies.

While racial and ethnic minority groups make up around 40 percent of the US population, they only represent 16 percent of the population in rheumatoid arthritis clinical trials, a 2019 study showed. And the percentage of men who enroll in clinical trials nationally is much lower than the percentage of men who have RA.

## Helping Men With RA Get Support

And in addition to that, I hope to encourage other men who are in my situation to seek help. This disease attacks you mentally as well as physically. There's a cultural expectation that men aren't supposed to be sad or struggle in that way.

And you can add another layer on top of that for Black men: Therapy is largely taboo in our communities. But it's so important that anybody with chronic illness has someone to check in with to say, "Hey, I don't know how to process this. How can I change my mindset so I'm no longer distant from my family and distant from my friends, or most importantly, distant from myself?"

For me, there was a time period where I just didn't even know who I was. I was just so encompassed by the diagnosis and the pain that I was really finding myself getting sucked into an awful and dangerous whirlpool. And it was at that point that I realized I needed to talk to somebody. My counselor—who's a gem—really helped pull me out of that cycle so my feet felt like they were on firmer ground.

I've also met a really great group of people through Creakyjoints and ArthritisPower. They've connected me with people I otherwise would never have met, and it's been life changing.

## My Advice for Others Living With Rheumatoid Arthritis

Sometimes I meet other Black folks who have been newly diagnosed with RA or other similar conditions. And I give them all some pieces of advice I've learned along the way:

You're not alone

This is a hard disease to control, and it can be difficult to manage the emotional, mental and physical toll. But there are others who are going through exactly what you are. Reach out and join a good support group. And know that these groups aren't one-size-fits-all. If it doesn't feel right, keep looking—your people are out there.

Find a fantastic team of doctors

For me, this is the gold standard. A lot of people who are newly diagnosed just think that they can rely on their rheumatologist to be the end all, be all. But your rheumatologist is a specialist, so they're not going to be able to fully understand the skin issues that you might develop, the eye issues that you might develop, the heart issues, etc. Take the time to find the best primary care doctor and rheumatologist for you. Then they can act as train conductors and send you where you need to go when other issues arise.

Seek counseling

I encourage others to find a professional to help you process your emotions so that as you move on in your years of having this condition, you're in a good mental state to be able to handle everything that comes along.

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

RA has helped me realize that I'm much stronger than I thought. I've always been a pretty tough guy — I served in the military, trained for triathlons, was an avid hiker — but that was more of a physical toughness. What I realize now is how I've grown mentally and emotionally.

And if I could go back to the early days of my RA diagnosis, that's what I'd tell myself, and it's what I'm telling you now: You're a hell of a lot stronger than you even know.

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.

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*Aberdeen "Deen" Allen is a 54-year-old research chemist who lives in New Jersey with his wife of 25 years, Rosalyn, and their two kids. In addition to his work developing new antibacterial liquid*

*hand soaps and other products, Deen enjoys teaching middle school students STEM topics, practicing yoga, and going for walks with his dogs. Deen lives with rheumatoid arthritis (RA) and is a patient advocate with ArthitisPower, an app and patient-centered research registry from CreakyJoints that helps people with rheumatic conditions track their symptoms and participate in research studies.*

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