Episode 1: Eileen's Story

Narrator 00:00
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Eileen Davidson 00:14
Those different whirlwinds of emotions where it's like excitement of starting a new treatment and then getting the frustration out of it because you don't feel like it's working yet you so badly want to have your medication work so you can, you know, be in less pain, have energy, and dysfunction normally again.

Daniel Hernandez 00:33
Welcome to Let's Get Personal, a podcast that shares the rheumatoid arthritis treatment journey. Hi, I'm Dr. Daniel Hernandez from the nonprofit Global Healthy Living Foundation. Through my work, I have the opportunity to speak to many inspiring people living with rheumatoid arthritis. And we wanted to share some of their stories with you. So, welcome to our podcast, where we'll chat with people within our community about their experiences and hopefully through their stories inspire you in one way or another. Let's begin. In this episode, we'll hear from Eileen Davidson, a patient leader and advocate who has rheumatoid arthritis. Eileen is an expert in speaking up for yourself in the doctor's office, with insurance companies and in daily life. But even though she's an expert, she still goes through the same anxieties and frustrations that anyone with a chronic condition like rheumatoid arthritis goes through. Eileen has a very candid conversation with us and offers some great sensible advice. Let's start. Can you just talk to us about the emotional and mental challenges that you faced trying and failing a treatment?

Eileen Davidson 01:45
I think it starts off at the beginning of my diagnosis. I didn't really know what rheumatoid arthritis was. I had no idea that arthritis could even be an autoimmune condition, let alone I could get arthritis before I had gray hairs or wrinkles. I wasn't even 30 when I was diagnosed. So it was my first time I've ever been told that I had to take medication for the rest of my life. Every time I was sick before I would take something and it worked. I never had to try multiple of something. When I met my rheumatologist, and she laid out all the different medications that I had to try, and you know, they make the side effects and the risks, they're right there aware for you. And so I was really scared. But at the same time, I was excited to start a treatment plan because by the time I did get my diagnosis of rheumatoid arthritis, I had to be placed on disability. I had never been that sick in my life. I was at the point where I could barely handle a six minute walk to the bus stop. And that was on a flat surface. I couldn't even handle grocery shopping. So I was really kind of torn between, you know, the fear of these medications. And what was going to happen to me, but also, like so hopeful to find relief of my condition. And I was really scared because during the week of my diagnosis, my aunt who had lived with rheumatoid arthritis for 40 years prior to me, actually passed away the same week of my diagnosis. And I saw her really suffer. I saw her curled fingers. I never saw her walk more than a few steps. She was always in a wheelchair. And she was morbidly obese, had many comorbidities, and I thought that was going to be my case. But you know, there's more and more medications coming out. And she unfortunately was diagnosed long before biologics.
Daniel Hernandez 03:43
That is what many people think whenever they get diagnosed with rheumatoid arthritis, that it's a path towards this deformity of your limbs. And it's not the case anymore, like you just mentioned, because of the medications that are out there, these DMARDs, the disease modifying antirheumatic drugs. But as you also mentioned, it causes this sense of being scared and also excited at the same time. Is that still present to this day? Or does that go away once you get more used to these DMARDs?

Eileen Davidson 04:22
I would say it lessens. It never goes away. I, at the beginning of my treatment journey, I had to try a whole bunch and so we had to start the treatment journey. So that was difficult having to go through that first year. And I think at that point, I felt like giving up but you know, there's a level of anxiety starting any new medication or treatment, you know, you don't know how you're going to react to it. You don't know if you're going to be that small percentage to have a severe side effect. Or you don't know if you're going to be one of those people that find relief through a treatment. But then there's also the fear when you do find a treatment, is it going to stop working.

Daniel Hernandez 05:09
There's three different buckets. There's these conventional DMARDs, which are the oldest types of DMARDs out there. There's also the biologics and biosimilar DMARDs, which is another bucket, and then those third buckets, which is the synthetic drug DMARDs, which is the JAK inhibitors. Eileen, how do you go about advocating for yourself and trying to work with a rheumatologist? Is there a specific way that you found that was a little bit more effective in communicating with your rheumatologist, but especially during this time?

Eileen Davidson 05:46
Yeah, I think it took communication. I had to be really open and honest to my rheumatologist. She called me a paradoxical patient, because I would take a medication and I would have adverse reactions to it from, you know, rashes to some of them would even like make my mental health worse. It would make me very forgetful. I felt like I was in a fog all the time. So I would tell her these. And it was she said to me, "No matter how big or small or embarrassing, the side effect, let me know." And there is the understanding of side effects, after you take your medication may last for a little bit. I call these like medication hangover. But is it persistent and lasting forever, then it's definitely time for a change.

Daniel Hernandez 06:32
How do you know if you're being too pushy or not pushing enough, especially with these types of medications?

Eileen Davidson 06:39
For me, it took a lot to understand how long they take to start working. So you have to try a medication. And if you're not having many side effects from it, you have to wait anywhere from three, four to six months for them to start showing a difference in working. And so that can be really frustrating there you know, those different whirlwind of emotions where it's like excitement of starting a new treatment, and then getting the frustration out of it because you don't feel like it's working yet, you so badly want to have your medication work so you can, you know, be less pain have energy and just function normally again. And you don't know how long or how many of these you are gonna have to take but till you find you know, the right one or how insurance works can be really, really frustrating to go through. But I don't
think you can be too pushing. Or I think you can definitely be not vocal enough. But I don't think you can be too pushy if you have a rheumatologist that isn't quite understanding what you're saying. So if you feel like your rheumatologist isn't really listening to you, maybe don't walk into their office unannounced but asked if you can get a second opinion or have somebody else review your labs. Because sometimes, I've heard this from others, it seems like doctors can get really set in a certain way. And fresh eyes can offer another opinion. I've actually done that with my rheumatologist just to make sure that my medication was working. She was not insulted at all that I got a second opinion. She was actually like, "Definitely, I was I know exactly who to send it to." And she sent me in for an ultrasound on my hands to make sure you know, I wasn't being inflamed. And he said, "Yeah, my medications were working for me."

Daniel Hernandez 08:35
I think that's very interesting. I think it might be very daunting to a lot of us to speak to a physician or a rheumatologist about getting a second opinion. How do you broach that subject? What advice would you give someone that wants to get a second opinion, but they're being a bit hesitant to communicate to their physician about that?

Eileen Davidson 08:57
Definitely intimidating asking your doctor for a second opinion. And so I guess I'm lucky in a sense that my rheumatologist is very open to them. And I have found quite a few rheumatologist who are open to them. And it just takes, you know, asking, "Hey, I would like a second eyes on this. It's nothing against the way you're treating me or I just want to take the advantage of being able to see another specialist plus the second opinion, just so I can have some reassurance." It's not necessarily that you want to go against what they're saying. It's maybe you want the reassurance or if you're not comfortable and you have feel like you have, like a difficult rheumatologist, you might be able to ask your primary care physician to send you in for a second opinion to someone.

Daniel Hernandez 09:51
As you mentioned, you have to take control over your disease. Does it get to a point where you just don't want to take control, you want to give the control to someone else? Or is that not something that's possible when you have rheumatoid arthritis?

Eileen Davidson 10:08
Yeah, definitely. In the first year and a bit of my diagnosis and going through a whole slew of different medications. And right when I started biologics, I gave up. I stopped medications. I didn't go to my see my rheumatologist for a good six months. Because I was scared of them. I was scared of having more side effects and the risks. And you know, there's so many people out there that kind of shame you for taking medications or you get so much unsolicited advice. "You just need to cut out all meat, all sugar, all dairy, you need to eat nothing but kale and do yoga 24/7, basically." And so, in my first year, I got so frustrated, and I stopped medications for a period, but then the disease got so bad. And I went to Dr. Google and started reading about what happens when you leave rheumatoid arthritis untreated. And I was like, "Yeah, I think it's time to call my rheumatologist." And, you know, when I did, and I was so embarrassed, was so like, "She's gonna get so mad at me for you know, hiding for six months." And she was like, "I'm happy to see you." And I told her, you know, I was just scared. And she's like, "Don't worry, almost all of my patients do this. But the problem is, a lot of them don't go back." They don't go back to medications because they failed some and they refuse to go on to more.
Daniel Hernandez 11:39
Being disappointed in the way that you react to medication just makes you not want to try another one. And that is not the case here especially with rheumatoid arthritis. But also, if you do stop seeing your rheumatologist, knowing that it's okay to come back, no one's going to be angry at you is very important. Have you found success on a therapy as of right now?

Eileen Davidson 12:10
Before the pandemic, unfortunately, I was so close to remission, that was words from my rheumatologist. But the problem was, I had to stop going in to my infusion clinic. Ever since then I kind of haven't been able to kind of pick myself back up as much. Mind you I've had various other health things kind of come up because that's kind of life with chronic illness. Chronic illnesses are like chips, you can't have just one. However, don't totally have relief is because I still need to exercise and take care of myself to feel my ultimate best. And I also need to accept that I have irreversible joint damage. I also have fibromyalgia. I also have endometriosis. I have anxiety and depression which have very physical symptoms, too. So is my inflammation controlled? Yes. Am I in remission now? No. And I really hope to get there again soon.

Daniel Hernandez 13:09
I really want to thank you for taking the time and just being very open and honest about this, this disease that isn't cut and dry. Any last words of advice to those listening to us.

Eileen Davidson 13:22
As much as your rheumatologist can help you the only one who can really help you is your taking yourself taking the steps that you need to to get healthier, whether that is you know, going through the treatment journey, being vocal about what treatments you want and need. And when it is time for change, but also understanding that these medications do take a long time. And that there you have to take care of yourself in between those times as well. They do work better if you are taking care of yourself. And it is really important to get treated right away as rheumatoid arthritis does better when it is treated earliest. I really hope that we're able to kind of highlight that the changes in medications over the last decade or so have you know really shown progress for people living with rheumatoid arthritis, particularly biologics. My aunt never, she wasn't she wasn't you know, diagnosed in time of biologics and I have friends who weren't either so, you know, they're not seeing those curled hands anymore. They're starting to do less joint replacements and so that's that's really great. And I think that's an important thing to highlight. And you know, the rheumatologist like my rheumatologist know she's like, "You need biologics right away." So precision medicine is really important to me because it could help me live a better life.

Daniel Hernandez 14:44
Thank you so much, Eileen.

Eileen Davidson 14:46
No problem. Thank you.

Daniel Hernandez 14:48
And thank you, our listeners for listening to Let's Get Personal, where you hear about the RA treatment journey. If you'd liked this episode, please give it an honest five star rating and subscribe so you never miss another one. I'm Daniel Hernandez and we'll see you next time.
Narrator 15:03
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