Episode 2: Alexis' Story

Narrator 00:00
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Alexis Mobley 00:13
Being flexible and fluid, and just really trying to be in tune with my body as well, which I thought I was before, but with RA, you definitely have to really tap into that communication a lot stronger.

Daniel Hernandez 00:26
Welcome to Let's Get personal, a podcast that shares a 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. In this episode, we'll hear from Dr. Alexis Mobley, a scientist who has rheumatoid arthritis. But before she knew this was her diagnosis, she really had to put on her investigator hat to figure out why she was experiencing her symptoms. These investigative tools have helped her along the way, even after she has been diagnosed. And she's going to share with us a bit about it today. Let's start. Welcome. Alexis, thank you so much for joining us.

Alexis Mobley 01:22
Absolutely. I'm excited to be here.

Daniel Hernandez 01:23
We would love to first spend some time and hear a little bit about your journey. What spurred you to start looking for an answer to your symptoms? And how long did it take to get diagnosed? Could you walk us through that?

Alexis Mobley 01:35
For me, it was the fact that I was no longer mobile. I've always been very active up until this point and around the symptom onset, play tennis like four to five times a week, I was walking everywhere, just out always doing stuff. And you couldn't really find me ever sitting down. And that was very swiftly taken from me around the start of the pandemic. So yeah, it did start in around late 2019. But really right around when the US decided to go on lockdown that was about when my body decided to lock down at the same time. And so it was really hard for me because I was literally going like I said, playing tennis walking. I mean, I was averaging a minimum of 10 miles a day, you know, my fitness trackers. To now I can barely sit up, I can't walk, I'd fallen in the shower several times, I was on a lot of pain, things just weren't adding up or making sense. And so that just started a very long journey between tens of doctors, probably eight or nine specialties of just trying to investigate what was wrong with me. And why was I feeling this way. Countless blood tests at this point, just trying to figure out what's going on. My inflammatory markers were always really high. And you know, everybody was like, "Oh, just do physical therapy for a few months, and you'll be okay." But I mean, I did 30 to 50 sessions of different types of physical therapy, physiotherapy, and I just still wasn't really getting better. In the process, I was like,
well, if my inflammatory markers are high, and these things are going on, why don't I see a rheumatologist and maybe figure out if there's something else that's going on. And so I still have had to go through a series of rheumatologist but December 31st, 2020 is when I got my definitive diagnosis of rheumatoid arthritis and having to then change my life around that and understanding what my body is doing and, and trying to get everything under control. So it's been a very persistent journey, but I'm very hard headed. And I don't like to be patient so I really did press on the accelerator and just said, "No, we're going to figure this out. And we're going to figure this out now because my life isn't going to stop and I refuse to stop. So let's try to figure out what this is and what we need to do to fix it."

Daniel Hernandez 03:52
I love the word persistent journey. It sounds like if it weren't for you and your persistence, you might still be in the process of getting diagnosed right now.

Alexis Mobley 04:03
Yeah, I definitely agree with that. Because like I said, every doctor I went to, I mean, I saw all the specialties. You know, all the orthopedics, the surgeons, the spine specialists, just neurology, cardiology, just you know, my body just kind of crapped out all at once. It was just too much and a lot of stress. And like I said, I refuse to again, I that might also be the scientist in me, it's just like it's okay that you don't know but point me to somebody that might know. And so it was just a lot of networking and hopping around until we figured it out. But I still have the willpower to want to know what this is. Even though there were some times where I'm just like, "I'm just tired and I need like a month or so. Or a couple of weeks of just like not seeing a doctor, not hearing 'I don't know,' not hearing this." I definitely had amazing support from family and friends just helping me balance the okay let's be tenacious but like it's okay if I rest right now because I've done a lot. Just whether it be networking in the community, my own research, you know, trying to find doctors, things like that. So that was wonderful to have their support as well.

Daniel Hernandez 05:08
Great to hear that you did have a support system. We hear that from a lot of our patients where it's, it's so important to surround yourself and educate those around you about what you're going through. Could you talk to us a little bit of the ways that you that you tried to bring the community in with you to help you through these tough times?

Alexis Mobley 05:29
I've always been a very kind of closed off person, just like, oh, I always got this together. So I did have to have several therapy sessions of just like, "Alexis, you need help. Like, you can't do this, you can barely stand for 30 seconds, like, how are you going to do anything else? Like people need to know? How are they going to accommodate you?" I also have a very high pain tolerance. And my mom and I have discussed that because she's like, "Most days, I don't know you're in as much pain as you say you are. Um, she's like, I don't doubt that you're in pain," but she's like, "You hide it. So well. It's once you start getting into, you know, levels of pain that you can no longer handle, that's when I see your personality change." So a lot of it took just me breaking down barriers within myself, first of all, so that I could ask for the help and let people know from day to day just like, "Hey, I'm alive, but I have no energy. So I'm just going to be sleeping all day today. I have my snacks, I have my this, I have my that." Being open to my mom, just saying, "Hey, I have four to five hours of MRIs today, can you come in so I can get all of this imaging done and come down and support me? Here's this leading diagnosis and all the paperwork I found, you know, all the websites I found, let's sit down and talk this out." It was just me

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mainly learning how to open my mouth and ask for help or say exactly what I need or am feeling in that moment. But then also giving adequate feedback that if something that somebody did wasn't right, or didn't make me feel comfortable to also have that space, and let them understand, like, we're all learning, you know, we all didn't know what the outcome was going to be, you know, we're used to, to one set of parameters, but things are changing from day to day. And so having that flexibility and fluidity has also been really important. And then just also finding other disabled people. And so I also had to find, find those perspectives as well of just, "Hey, I'm just feeling like a potato today." And other people are just like saying, "We're just all you know, vegging out right now. And that's okay," but still friendly reminders of like, "Oh, you know, if you decide that you're gonna get up, make sure you grab your bag, and you know, grab all of the stuff that you said you're going to or make sure that you have doubles of this," or, "Oh, I found these cool pillows that are really helpful." You know, just stuff like that just like little tidbits that other people may not know, but other people have already gone through it and figured out ways to make their life comfortable. So a lot of learning, a lot of deconstructing from the entire community and just being open to trade secrets, I guess I don't know. Just like how to survive, being disabled and chronically ill, especially with rheumatoid arthritis and as hard as it hit me and very suddenly.

Daniel Hernandez 08:09
A diagnosis alone can bring on a whirlwind of emotions, and then having to learn about treatments can be a lot to take in. The good news is you're not alone. Your rheumatologist wants what's best for you, and will work with you on picking the right treatment plan that fits into your needs, preferences and lifestyle, a process known as shared decision making. I asked Alexis about the first time she took on medication and what that was like for her. She mentioned how doing her own research helps her in conversations with her doctor. Could you tell us a little bit about how that first time you took a DMARD, disease modifying antirheumatic drug, or that conversation that you had with your rheumatologist of what demarche you would start with? Could you walk us through that?

Alexis Mobley 08:57
It was a pretty simple conversation. I had been on steroids for quite a long time. You know, it wasn't putting the disease in remission, it was helping, it was taking the edge off, but I was still nowhere near where I should be in my life. I had just kind of generally looked up autoimmune disorders just to figure out like, are there just kind of general medications that you can take that might help and so I had seen methotrexate being a very common one, which kind of blew me away because I've only ever known methotrexate as being a chemotherapy drug, you know, for cancer. That's when I started really digging into methotrexate and how it works and its mechanisms of action. Then I realized, you know, it's a lower dose, it's different, the dosing is different. So I was like, okay, that's understandable. And like, quite a bit of science. We don't really know why it works, but it works like alright, like, that's fine. You know, so what do we do to mitigate some of the side effects, what does this mean my life would look like on any of these medications, and so we did actually end up starting me on methotrexate, but at first I was definitely kind of overwhelmed, because I never thought I would have to, like, you know, give myself injections at home. And so that's always kind of scary, like, is it gonna hurt today, but thankfully the injection doesn't hurt. It's just usually the medication afterwards, as I call it, the slow burn. But I've been able to kind of come to terms with that and having a simple conversation with my doctor. "Okay, how long will I have to be on this before we know, you know, maybe we might have to change his medication? What do you expect for other people, you know, similar to me? Is this gonna make me feel better or worse? Like, you know, what other things would we change? And what's the, the final line of okay, you're not responding? Or I'm doing really poorly on this with side effects, like when do I call back,
you know, before I have to come back," type situation. So that was more of my discussion since I had really done a lot of research on the back end myself. I'm just trying to figure out how we can get this treated and get me back to, at the time I was reaching for normality of what I'd known before, because that's kind of what I was promised. But now just how can I get to a pain free life at this point.

Daniel Hernandez 11:07
What do you hope would have been different before getting to your rheumatologist? What advice would you give those that haven't gotten there yet?

Alexis Mobley 11:16
I really hate that the doctors just kind of kept giving me hope for something that they thought they understood and they knew, but we all knew we didn't know what it was. For me, that's really frustrating. I am definitely more of a realist, I wouldn't say I'm pessimistic, I wouldn't say I'm overly optimistic, I just want you to tell me how it's going to be because then I can better prepare myself. And so I can understand that as a patient, if you just keep hearing, "Oh, just three more months, or just six more months, or just this amount of time, or just this amount of time," and you keep holding on to that and things aren't working. To prepare yourself for whatever you need to prepare yourself for. You know, for me, it was like, okay, at the six months point, you know, what are my next six months going to look like then if you keep saying that this is what's going to be good? Like, what are you expecting the timeline to be? What are we expecting this to look like? Because if that's not the case, we need to be prepared for the other six months afterwards, you know, the emotional toll that's going to happen. And so I had to be very open and honest with my doctors as well of just like, "I get that you want to give me the optimism and I can give that to myself. I have a community that can give that to me. Like you're the professional and I need you to be honest and upfront with me about what I should be expecting, you know, immediately what are we looking at six months out? What are we looking at two years from now? What are we looking at? Be honest and upfront, you know, are my joints to the point where like, yeah, you're probably gonna have to have surgery and like, you know, five to 10 years? Or did we catch it early enough that it's, it's still okay, and it's not progressing as badly as we think it is. It's just that there's these other these other issues that are going on." And so I've had to have just very blunt conversations with like, I won't be upset if your bedside manner is not up to par, like, I just want you to tell me straight up how it's going to be so that I can prepare myself and I have the support I need to get through whatever that tough news is going to be. I think just being again, honest with the people around you, your doctors, your friends, your social networks, of what level of commitment do you need from them? You know, what words do you need to hear from them? Or what words do you not need to hear from them, so that you can ultimately thrive because it's, you know, it's your life, and you're the one that's living it every day.

Daniel Hernandez 13:30
Precision Medicine is part of a patient's individualized treatment plan that takes into account objective data like labs, and individualized genetics, and it can help in the RA treatment journey, by finding the best treatment for an individual based on their unique characteristics and needs. I asked Alexis about her experience with precision medicine.

Alexis Mobley 13:52
I've mainly heard the terms in my own research. We haven't really discussed them, I would say, within the office, or how these medications, maybe precision or personalized medicine or ways that we can make it more personalized to me because I definitely wish that were the case. But looking more in to
the medications and the things that were out there it was it was really cool, just to see the options and
the different cytokines that they're trying to target. I know we talked about the way that my symptoms
are presenting and some of the other other molecules that could be produced because of, you know,
some of my blood tests and things like that, that we talked about. That's mainly been our discussions.
I'm thankful that she is honest about the science, I'm able to discuss, you know, some of these other
things that are coming up, but she's also open to trying things as well and just like, "Okay, we'll try it and
see what happens. Like this really won't hurt you," you know, so gonna go ahead and try it. And so
that's really been the extent of our conversations. I hope that it becomes more common for all diseases
because I mean disease presentation really is Is individualistic, everybody's illness is different, the way
you feel it is different. And so we just kind of have blanket terms for a bunch of symptoms, if you will,
but it's still going to present differently for each person.

Daniel Hernandez 15:17
You wrote an article for CreakyJoints, and I reread it, I had already read it, but I reread it last night. And
I just want to share with our audience a quote, it's a strong quote, but it's very fitting for what we're
speaking about, where you have to push through a lot of these adversities in order to find the solution
for yourself. So I'd like to read this quote, and if you could just explain to us a little bit of what you were
going through when you wrote this. So you said, "As a mother, I felt it was my fault. If only my
body would have cooperated. If only I hadn't been diagnosed with this disease, maybe we could do a
little bit more." That's so strong.

Alexis Mobley 15:59
Like I said, with me being active, me and my child, we were always doing stuff. We would just get in the
car to go somewhere. I'm in Houston. So we would get up and go to Galveston. We would, right before
the pandemic, there was a Lego exhibit that had come in, we took the rail, I had to do some
experiments. So we took the rail to my job and I was like, "If you go to work with me, we'll go to the
Lego exhibit." And I mean, we just walked all of the area of the museum district. Going there, getting
food, playing at the park, meeting random people, getting on bikes, you know, just being able to do
random fun adventures. During the pandemic, you know, I tried to maintain as much activity as I could.
So we would try to spend some time just walking around the neighborhood and just talking, um,
because that was something we used to always do when I would walk them home from school, they
would just talk about whatever they wanted to for an hour, it was just time to talk to Mom. Mom's not
distracted, I was distracted. But while I wasn't distracted, I could talk about anything, any problems. I'm
having my aspirations, random, silly thoughts that I thought throughout the day, and so I tried to
maintain that as much as possible. But it's really hard when I felt like those things that we usually did
were pretty much taken from me. And I didn't know how to accommodate that, like, I didn't know, okay,
"What do I need now to be able to try to walk around the neighborhood?" Or, "What do I need to do
now?" So like I said, at one point, my legs weren't working. So it's like, I can't drive, you know, how do I
modify my car so I can still drive? Like, how can I do these things and make my life accessible. So we
can see something similar to the life that we had. And that was just very hard and overwhelming for me.
And it still is, from time to time, because, you know, we're used to having dance parties, we're used to
just randomly singing. I've had to change a lot of my clothes. So we've we've done fashion show lately
of me just like, okay, I can't go to the store. But I'm going to do the size chart. And hopefully it'll fit and
like, let's see if this will be like, you know, my new fashion sense and how that adapts. And so we've
definitely had to be more innovative, not only being at home, but now with the accessibility issues that I
that I deal with. And it was definitely a mourning. And it's still a morning that I go through from time to
time of just like, "Oh, I'm really excited to do this. But what will this look like?" You know, I would love to
go out on a cruise at some point, I would love to get on a plane, but what is that going to look like with my walker? You know, are they gonna break my walker? If they do that, what am I going to be able to do like, how am I gonna get around? Like, you know, just all these little pieces that I didn't have to think about that now it's completely shifting the mindset. Like said since it came so suddenly it was like, "Okay, how do I navigate my house? How do I navigate my car?" Just all these little bits and pieces, how do I how do I brush my teeth because half the time I can't stand up that long? Like do I'd get a little chair for the bathroom? Like how do I make this fit in my space.

Daniel Hernandez 19:01
This is really common for people diagnosed with a chronic illness. There is often a sense of grief and loss that comes with living with a lifelong condition as you realize you can't do things like you used to. Alexis told me about how she's accepted a new way of life.

Alexis Mobley 19:19
So it's been a lot of adapting and mourning and just understanding that my life looks different now. And I may not know how to do everything that I've wanted to do before, but there are ways to do it. And I may not always be able to afford the things that I want to do with some of the things that I'm wanting to do. But there are options. And as long as I continue to do well or again just voice like, "Hey, I want to do this or I want to go about that." I'm sure that between myself and my support system, we'll figure out a way to make it happen. And so it's just balancing all of that every day and understanding how that will manifest or how that will work with my body. You know, like I said, today it's supposed to rain. So I know later, my, you know, my joints are already a little stiff. I'm like, okay, yeah, like, I'm just gonna get under my heavy blanket with my heating pad. And today, it's just gonna be watching TV, but maybe tomorrow will be a little bit nicer. So maybe I'll walk down to my mailbox. Being flexible and fluid, and just really trying to be in tune with my body as well, which I thought I was before. But with RA, you definitely have to really tap into that communication a lot stronger.

Daniel Hernandez 20:34
Thank you so much for sharing your story with us. Thank you so much for being an inspiration to those listening to us today. And for those that you, you touch with all of the work that you do. Any last words of advice or encouragement for those listening?

Alexis Mobley 20:50
I know for me, like said the mourning, I think was the hardest part. So if you're in mourning isn't a linear process, you know, one day you might be absolutely fine. And then another day you might not be and that's okay. Just like you have to listen to your body from day to day, you also have to listen to your emotions and how much energy you can give to that. And sometimes you just don't have the energy to mourn and I also understand that. So just in all things, just honor your body, it's yours. Again, you're the only person that has to live with you every day at, you know, every moment. So just ensure that do what you need to do. So hopefully, maybe that'll be something that you can hold on to as well as you move forward and go about your life.

Daniel Hernandez 21:34
Thank you Dr. Mobley. This was great.

Alexis Mobley 21:37
Absolutely. Yeah, it was a pleasure to be here.
Daniel Hernandez 21:40
And thank you our listeners for listening to Let's Get Personal, where you hear about the RA treatment journey. If you 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 21:56
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