Episode 3: Shilpa's Story

Narrator  00:00
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Shilpa Venkatachalam  00:14
Goals change through the course of our lifetimes, right? We might want to attend graduation of a niece or a daughter, we might want to go to a wedding, we might want to hike and I think it's important to constantly update your rheumatologist.

Daniel Hernandez  00:30
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 Dr. Shilpa Venkatachalam, a scientist who has rheumatoid arthritis, but her treatment has not been a clear path forward. Shilpa will share with us ways to work with your doctor on finding the right treatment for you. And also the reality of what it's like to go through these unknown moments and who to turn to when you're feeling alone or frustrated.

Shilpa Venkatachalam  01:22
I was diagnosed back in 2017. But prior to that I had a lot of symptoms that now in retrospect, I wish I had picked up on. It didn't even occur to me that this might be something to do with an autoimmune disease, much less rheumatoid arthritis. And so when I did get diagnosed, a lot of things started to make sense. And so there was a sense of relief at the diagnosis because it all made sense. And so there is a long with relief, a lot of dread, a lot of anxiety, a lot of fear about the future. And so I think you know, for someone who's newly diagnosed, and now looking back to that point in 2017, I have a better understanding of all these conflicting emotions that that that were present at the time of diagnosis. Now added to that I was already working in CreakyJoints. And I must give credit to to some of my work because I don't think I would have recognized some of these symptoms as being connected to an autoimmune condition if it weren't for my work and my work, I mean, not just the research work, but anecdotal conversations I was having with other patients in our community as well, who helped me along my pathway to diagnosis. And so I bring to the table I think this conflicting, constantly conflicting sides of me, one as a as someone who does research in this field, and who knows the evidence, who knows that I should be taking the medications, who knows that the benefits far outweigh the risks in most cases. But there is also the patient in me, who has the same fears, the same anxieties about the side effects, about starting out a new medication, about taking an injection, giving yourself an injection, about being on those medications for a lifetime, possibly. And so there's there's a constant sort of a battle or negotiation that goes on between the researcher and me and the patient in me.

Daniel Hernandez  03:26
I'd like to touch a little bit more on that duality of emotions on how you mentioned that you felt relief in 2017 when you first got diagnosed, and you also felt this anxiety and dread. Does that go away now
that you have been diagnosed, and you have been in constant contact with a rheumatologist? Does that go away? Or does it just change from the diagnosis to the treatment process?

Shilpa Venkatachalam 03:57
That's a great question. I don't think it goes away, but it does come and go. So you know, rheumatoid arthritis is a condition that sort of ebbs and flows. So there are good days and bad days, there can be good weeks and bad weeks, and so on and so forth. And so in your worst moments, and by worst moments, I mean, if I'm in a flare, the dread does come back, the anxiety does come back, the fear does come back, because in those moments when you're in the grips, or in the throes of severe pain and severe fatigue, where you can't do your everyday tasks, even things like laundry, standing and cooking, chopping vegetables, holding a hairdryer, there is a sense of dread that comes along with the inability to do those everyday tasks, you know, so your thoughts are along the lines of oh my god, what is this flare lasts forever. What if there is no medication that can help me? What if my pain continues and I'm not able to do the things that I love to do? But that you know, also gets back winced every now and then with hope, and the hope and the positivity. And the optimism comes with reminding yourself that there are options, especially today, there's a range of medications, cutting edge treatments that were not available 10 to 20 years ago. But there is a support community whether you know, you can draw on both your family and friends. And you can draw on in, sorry, draw on a community like CreakyJoints. And honestly, I draw on CreakyJoints still, because I have a lot of friends who are people who've been living with these conditions, who are part of the community at CreakyJoints, in Arthritis Power. And so I think speaking out your fears, voicing your concerns, talking to your doctor, for example, talking to a mental health professional or therapist, these are your support tools that you have to draw on, especially in times of dread, anxiety, fear, when you're going through a flare, etc. So it's really a balancing act, that that you're constantly that you learn to become very good at, you know, balancing the fear and the anxiety with hope and optimism and reminders that there are solutions, there are really a range of solutions that are available and people to support you to help make the right decision for yourself.

Daniel Hernandez 06:21
Immunity, advocacy, advocating for yourself as well, for others, educating yourself, they're so important and we've been hearing this from everyone that we're speaking to about how instrumental it has been for them in order to keep going. What other things do you do personally, in order to keep that hope alive to keep moving? Especially if a treatment isn't working the way that it should or if a flare suddenly comes up? What is it that you do in order to keep going forward?

Shilpa Venkatachalam 07:00
That kind of question makes me reflect on several things. And I think I want to start answering that question by first saying that it's okay to feel the fear, it's okay to feel dread. I think vulnerability is absolutely fine. You don't have to be in quotes strong all the time. So it's okay to fall apart and have those days when you think I'm not going to be able to do anything. And that happens to me too. So there are days and on my worst days at the worst times of my flare, where I have had breakdowns. And I have had moments where I feel like, I can't deal with this pain. And that's fine. I want to put that out there first. But I think you know, at some point, you have to also pick yourself up. And there are very many ways in which you can pick yourself up. And sometimes that's by resorting to things that might be in your toolbox, but also outside of you, right? So your support system. Do you have a good support system, friends and family, they can help you give you courage give you hope at times when you need it. I do a lot of meditation and mindfulness as well. And you know, it's really difficult to practice these
things during a flare. So it's easy to do to practice meditation on good days, because you feeling good, but on really bad days, when you wake up in pain, you really have no energy to do anything else. And so those are the days when you have to tell yourself, sit down for 10 minutes and practice your mindfulness. And that's what I do. I also play you know, pursue hobbies. I think that's that also helps me mentally and emotionally to stay strong. So for me, it's music. So I practice, I play instruments, I practice my music, if I'm not able to go out, for example, I have friends come over. So there are several different things I think to do in order to keep your courage, give yourself courage. And those tools, I think it's important to always remember those tools are hard to reach out to at your worst times. But that's exactly when you need to reach out to them. And so you know, whether it's pursuing of hobbies, talking to a therapist, practicing mindfulness, yoga, if that's what works for you, doing things that you love, being around people, watching something funny sometimes on TV helps as well, listening to music. So it's not something out of the ordinary here that I am sharing. But I think, you know, based on what works for me and for others, I've borrowed from others. I've learned over the years to borrow from other people as well, their tools. And so this constant sort of communication, sharing exchange. I think that's what really helps you to keep going.

Daniel Hernandez 09:46
Shilpa, what is the end goal? What does successfully treating your RA look like? What does that feel like to you?

Shilpa Venkatachalam 09:54
A treatment working, first of all means symptomatic relief for people who live with a condition. And by that, I mean reduced levels of pain, reduced levels of fatigue, so that I can do the things that I love to do without pain interference, without interference, fatigue interference. So I can go out, do things with my friends and family, I can continue to do things that I love, whether that's cooking, or playing an instrument, working, you know, being productive at work. So when your RA treatments work and your symptoms calm down, there's a domino effect. You're able to do other things that you love doing, and that you have to do in your everyday life. The other thing that I think is also to pay attention alongside your doctor and clinician, and, you know, it's really important to encourage these kinds of conversations, and I encouraged myself to have these conversations with my doctor, is what is the goal? What are we, what are the numbers we're looking at? And where do we want to get to? And by that, I mean, you know, people who live with these conditions, and I speak for myself, we get our blood drawn regularly, we do lab work regularly. And those lab works and those blood tests have indicators, you test your blood for certain inflammatory biomarkers. And so part of a treatment working is making sure that your blood work looks good as well, your lab work looks good as well. So I think it's really a combination of the patient lived experience, the everyday lived experience of the person, and on the one hand, and then making sure that your counts, your bloodwork looks good, alongside, you know, conversations that you've had with your doctor. So whatever looking good means for you, as a specific individual with a specific condition. Combine those two, and if you hit your goals, your targets that you set for yourself, I want to be able to walk five miles without pain, and I want to get my CRP levels reduced to such and such levels. When those two things come together, and you've achieved your targets, that's when you know your medication is working well.

Daniel Hernandez 12:06
It's a testament to that persistence that one has to have. It's such an individualized condition, that you really do have to define your own goals, make sure that those goals are being met and making sure that that is what your your physician and yourself are working towards. On that same vein, Shilpa, what
do you recommend for those listening, when do you recommend that they should start speaking about these goals with a rheumatologist? Is it once a year? Is it on every visit? What is what is the best approach in order to figure these things out with your rheumatologist?

Shilpa Venkatachalam 12:47
So my answer is always and every time you see a rheumatologist, there are two sets of goals. So my goals are probably things like I want to be able to travel to California on a six hour flight or to India on a 20 hour flight without feeling too much pain, unbearable pain, I want to be able to be productive at work. I want to be able to invite people home and stand at the kitchen and cook without feeling pain in my feet. Those are my goals. Those are everyday lived experience goals, targets that I set for myself. My clinician or my doctor or my rheumatologist might have other goals that he's thinking about to do with bloodwork, to do with lab tests. So every time I go into my doctor's office, my rheumatologist office, I make sure that I voice my targets so that he knows what I'm trying to achieve. When I start on a new medication, when I switch on a medication, or when I'm on a medication that I've been on for a while. This constant re-evaluation of goals, because goals change. Goals change through the course of our lifetimes, right? We might want to attend graduation of a niece or a daughter or a sibling. We might want to go to a wedding of a friend. We might want to hike, etcetera, etcetera. So our goals keep changing, and I think it's important to constantly update your rheumatologist about those goals, and to integrate it into the goals that the rheumatologist thinks are important to achieve as well. So to answer your question, I have these conversations, even if it's just a five minute conversation, write down maybe five points you want to convey to your rheumatologist before you go into the office, but convey your goals because those are really important for your rheumatologist to know as he or she thinks through what kinds of kinds of treatments you might need, what are the next steps etc.

Daniel Hernandez 14:45
Goal change. That is very, very true. Very important to keep in mind. Can you tell us a little bit about the research you're doing around precision medicine, Shilpa?

Shilpa Venkatachalam 15:00
I'll start by saying that I see that sometimes there's a lot of confusion around the term precision medicine because it's something that's only now being talked about in the rheumatology space. Whereas in oncology, it's been present for a few years now. The research that we do is patient centered and anything that's patient centered, starts off with education. So we're talking first about educating and creating awareness about what this term really means. The first step is to educate, to build awareness around what precision medicine is. You know, people who live with these conditions, obviously know that they get their blood drawn every now and then, they get lab work done at many of their in person visits to their doctor. The doctor looks at these blood tests for indicators in a disease like rheumatoid arthritis, those indicators could be referred to as inflammatory biomarkers, which then help and guide your doctor and you to make shared informed decisions about things like what medication, is a medication working or not, what medication can I try if a particular medication isn't working? Is there active inflammation in my body? Is my area very active right now? Is it possible for me to get to a low disease, and so on and so forth. Along these lines, what we're doing currently within the research sphere of the organization, is we're about to launch a study in the form of a survey to gain insight into how patients with rheumatoid arthritis firstly, perceive their RA related bloodwork. So what do they know about the bloodwork that they are getting done? Do they understand the blood work? Do they understand the different panels that they're getting done and looked at by their doctor? How does this interaction then inform treatment decision making? So do you as someone who lives with the condition,
do you understand your blood tests enough to talk to your doctor about these blood tests? Do you use them to make decisions about your medications and your treatment, and the management of your own disease? If you don't understand your blood test, you ask your doctor, why they're paying attention to these particular parameters in your blood work in order to make decisions. So we start off the study there. And then we want to also try and understand RA patient preferences. So rheumatoid arthritis patient preferences for a blood test that could help predict whether an RA medication would work well for them. So if there was a test, that could help predict whether or not a medication could work for you, and you know, could work for you could mean many different things, would you consider getting that test? That's what we're trying to understand. And this is in line with precision medicine, which really looks at an individual's sort of genetic makeup, or some kind of, does some kind of molecular or cellular analysis, in order to understand which treatment might work for that particular person.

Daniel Hernandez 18:05
Last question that I'd like to ask you. You've given us so many sensible, very easy to follow advice on how to motivate yourself in moving forward and having these discussions with your physician and advocating for yourself, continuing to communicate with your community. Is there anything that you'd do differently, or you tell a patient that may have failed on multiple treatments, and is feeling discouraged about their prospects for getting better and achieving remission? There any advice for that person?

Shilpa Venkatachalam 18:42
So I reframed how I think about this. And so I don't ever say that I failed on a medication, to start with. I just flipped it and said, "You know, I need to now find the right medication, because I'm currently not responding to a specific medication." So that reframing of thinking really helps, because it puts the spin on what you need to do, not what you haven't achieved. And so that really gives you some kind of motivation, it empowers you to a certain extent as well. The other thing that I can share is that again, you know, I'm not going to lie, there are moments when you feel a range of emotions. It's not always black and white. So you feel emotions at the same time, that have to do with fear, anxiety, frustration, hope, because there's more medications to try, etc. So in those moments, I try to remember that there again, that there are lots of options today. There are cutting edge treatments because of ongoing research, and that my rheumatologist is as invested in me as I am in myself to find the right medication. That I have the support that I have, I'm lucky to be working in an organization that also provides me with a lot of support, especially in times when I am going through a flare, etc. I think the advice is to not give up, really. And I think, you know, it's easy to say that when you're in a good in a good place, but it's not easy to remember that when you're going through a flare, it is those moments when you feel like it's nothing's going to work and I have these thoughts too. "Nothing's gonna work, I can't find the right medication, why isn't the medication working? Is there something else wrong with me? Is there something else that's going on?" These are those thoughts that that, you know, bubble up, especially in times of flares and times of heightened pain, etc. And I think, you know, go back to my previous point, to have your toolbox ready for those times, especially. If it means writing post it notes and sticking up in around your house do that. If it means doing meditation, mindfulness, practicing yoga, do that. But whatever it takes, I suppose my point is, do whatever it takes, first to allow yourself to feel that sense of vulnerability, but then to say, "I'm not going to stay here, I'm going to find the treatment that works." And then it happens, you find the right medication. Takes time, but you find it. And so just keep reminding yourself about it. And never let go of your targets. You know, keep your targets front and clear. Always talk to your rheumatologist, keep channels of communication open. I think the crux of this is, take charge along with your rheumatologist and have other people help you take charge in times when you're really down with a flare.
Daniel Hernandez  21:37
Do whatever it takes. You're not alone. Thank you for sharing your story and time with us, my friend. We really appreciate it. Be well.

Shilpa Venkatachalam  21:48
Thank you. And thank you for giving me this opportunity to share my experience and I hope, you know, a lot of other people have shared their experience with me. And so this is sort of returning the favor of paying it forward. I think this kind of sharing and exchange of ideas is really important as we all support each other as we live through conditions that are chronic, so thank you.

Daniel Hernandez  22:14
Thank you, Shilpa. 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  22:31
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