

## **Your Health Unlocked Podcast Episode 46**

### **Living With Rheumatoid Arthritis - Erin's Story**

Hi There, I'm Adele Scheiber, the host of the Your Health Unlocked Podcast and the Director of Communications here at the National Women's Health Network.

Are you feeling unheard in your health journey? If so, you're not alone. Many face the crushing weight of chronic illness only to have their concerns dismissed or minimized, leaving them to fight for their well-being alone. Erin's pain was dismissed as anxiety for over a year until she was diagnosed with rheumatoid arthritis, or RA. RA is a chronic autoimmune disease characterized by inflammation of the small joints, usually in the hands, and women are two to three times more likely to develop it than men. And, contrary to popular belief, RA can hit at any age. This episode of Your Health Unlocked uncovers the often fraught process of obtaining an autoimmune diagnosis, the expense of autoimmune medications, and the challenges that come with living with RA. Despite these health obstacles, Erin continues to find joy with her partner and cats and is continuously learning to choose rest over pleasing others. Don't miss this insightful and moving conversation with one of our very own staff members.

0:00:29 - Adele Scheiber

Okay, so introduce yourself for the masses. We can also pull from your bio but tell our readers about you.

0:00:39 - Erin Evans

So, let's see, my name is Erin Evans. I am the Director of Operations at the National Women's Health Network. I've been working here for a number of years now. I'm originally from California, moved out here after college, live with my partner and our two cats, who I love and adore. I love to travel. It's my number one favorite thing. I wish I had more time and money to do it. Let's see, I'm not sure what else.

0:01:22 - Adele Scheiber

Well, what do you specifically? What do you have? What is the full name of what?

0:01:26 - Erin Evans

Got it, got it. Okay. So, I have rheumatoid arthritis. I was diagnosed with it in October of 2017. Although I started having symptoms in early 2016 that slowly got worse and worse over time. I went to my doctor in November of 2016 just complaining of pain in my hands and I have anxiety to begin with. So, I think that my doctor did not take my complaints about pains in my hands very seriously. He thought that I was just anxious and imagining things. The symptoms progressively got worse. I-actually the first symptoms that I started having early in 2016 were pains in my neck and shoulder and upper back area that I thought were just stress, because I was at a job at that point in time which was extremely stressful, and so I just thought it was stress. Then things just kind of progressively got worse. So, I went to the doctor saying I don't think this is just stress, I don't know what's going on, my hands hurt, my neck and upper back hurt. He initially diagnosed me with something that he called uh "blackberry thumb", telling me that I was spending too much time on my smartphone, using my thumb. You know, kind of like a carpal tunnel sort of thing,

0:03:32 - Adele Scheiber

Blackberry thumb, that's so, that's so outdated, like come on [Laughter].

0:03:46 - Erin Evans

So, I made a conscious effort to be on my phone less um you know, plus, it was 2017. You know I needed to take a break from the social media just so it didn't do my head in right? But using the phone less didn't decrease the pain. The pain just got progressively worse and worse. I – he had me go to physical therapy in the summer of 2017. And I quickly realized that the physical therapy wasn't the solution, that there was something else going on, [Adele - mm-hmm].

So by the time I was due for a physical in 2017 on my, the pain was so bad I could barely hold a hairbrush just washing my hair hurt like I would touch my scalp to kind of rub the shampoo in and I would get these sharp shooting pains up my fingers and up through my arms and, you know, it was just very debilitating and the pain kind of fluctuated throughout the day, so it would be the worst first thing in the morning and then it would kind of ease up a little bit in the later morning and afternoon. So, I was able to do work.

I was able to type and stuff, but, you know, a lot of other things I wasn't really able to do. Um, so finally, you know, had this physical. I was literally crying to the doctor saying like I'm in so much pain, I can barely wash my hair, I can't. I can barely hold a hairbrush. And so, he was like, oh well, let's run some tests.

0:05:43 - Adele Scheiber

And that's the third time, the third visit. [Erin - Oh no, this was probably the seventh visit], oh my gosh, [Erin - over the course of like a year.] Yes, yes.

0:05:53 - Erin Evans

And so, he finally ran some tests and I got a call from him like two days later telling me that I had tested positive for rheumatism, that he wanted me to come back to do a couple other tests. And so, like the next day or a couple of days later, and he looks me in the eye and says, oh no, this is not all in your head, this is really real. And it was so infuriating because it's like, yeah, I know, it's not all in my head, this is really real.

0:06:32 - Adele Scheiber

Yeah, you never said that exactly.

0:06:35 - Erin Evans

It's like you didn't take me seriously all these months right because you thought I was just a hysterical hypochondriac or something, right, right, right, yeah, yeah.

0:06:45 - Adele Scheiber

Yeah, it would be one thing if you had been like I'm just not sure, but that is not what you were saying.

0:06:49 - Erin Evans

Yeah, exactly. I'm not imagining this.

0:06:55 - Adele Scheiber

So, okay, you were diagnosed finally. [Erin – Yes], you know what, what's the treatment protocol and what are some other ways you mitigate the effects of rheumatoid arthritis.

0:07:07 - Erin Evans

Sure. So, you know, when I first, when I was first diagnosed, they needed to kind of get you know, really tackle the pain. So, I was put on steroids for about six months.

Oh goodness, what is the? What's the common steroid that they put everyone on? That's something my grandmother and everything. And then they initially put me on the steroid and methotrexate, which is a drug that suppresses the immune system. It's also apparently, I believe, a common drug to treat cancer. It's used in treating cancer. So, yeah, it suppresses the immune system because basically, what the rheumatoid arthritis is, is it's my immune system is attacking myself.

It's attacking, you know, my immune system is like gone loopy and doesn't recognize that healthy cells from I guess you know, invasive cells, and so it's attacking like healthy cells and so it's attacking um my joints, and so the methotrexate kind of turns the immune system down a bit so that the kind of the attack on the body is reduced. I was on the methotrexate only for a couple of months and it definitely helped, but my rheumatologist didn't feel like it was doing enough, so he has put me on Humira as well as methotrexate.

So, I take Humira every other week and I have to take a dose of the methotrexate weekly so that's kind of the medicine I'm on, as well as, you know, ibuprofen if I'm feeling a little sore. And I'm also on folic acid to kind of help mitigate some of the effects of the methotrexate and Humira.

0:09:43 - Adele Scheiber

So that's, that's quite a hefty treatment regimen and I, as I understand it right there, a lot of that regimen and I, as I understand it right there, a lot of that has to be like refrigerated and stored very carefully.

0:09:51 - Erin Evans

Yes, the Humira has to be. I have to get it through like a specialty pharmacist. It has to be refrigerated and you have to be really- you have to keep a pretty strict routine with it. So, you're supposed to be taking it the same day every other week at the same time.

So, you know I try to schedule it. I work from home on Mondays, so that's usually when I, that's when I take it and I have it on my calendar to do it right as I'm wrapping up from work. So, it's like finish work, take my Humira, and then I can relax for the rest of the day.

0:10:32 - Adele Scheiber

Right, Well, and you know, I know you work here at the National Women's Health Network, which has great health insurance, but I mean any idea what the costs are and the copay. Can you talk about that?

0:10:57 - Erin Evans

It's an insanely expensive drug. I will say that the network's health insurance is amazing, and it makes a very expensive drug much more affordable. I cannot remember the exact price that I was quoted. But if I didn't have insurance, or if I didn't have good insurance, I would be paying something like several hundred dollars a month for this, and with no insurance, it's thousands of dollars. [Adele - Oh, my goodness], luckily, it's about 5 dollars for six doses, so it's very affordable because I have health insurance, or good health insurance. For people that don't have good health insurance or no health insurance at all, I don't know how they survive having this condition because it's extremely painful if you're not treating it with medication.

0:11:57 - Adele Scheiber

Well, and so much of our health insurance is tied to our jobs here in the US. And then this is one of those conditions where the chronic pain can interfere with your ability to work, and that I mean, wow, it's almost like the game is rigged, okay, so, other than these medications, is there anything non-medicinal that helps mitigate rheumatoid arthritis?

0:12:25 - Erin Evans

So, you know I like to take like hot baths will oftentimes help kind of relax the, the muscles and the joints, because it's it affects the joints, but it also has this kind of carryover effect of, like it, it makes me more prone to muscle fatigue and muscle weakness and things like that. And I haven't been as physically active because of the pain and then, you know, coupled with the pandemic, my exercise routine has almost been non-existent. So, but I, I do try to get out and walk so that I'm not, so things aren't atrophying. Um, but yeah, like, warm baths, heating pads really help, just remembering to stretch out at the end of the day, like, especially like my back and neck, because, again, like sitting at a desk all day, you know it's, it's bad for everybody but, when you have this kind of condition, it just makes what is not great even worse.

0:13:51 - Adele Scheiber

Right, right, well, and so it sounds like you've got you've got this pretty well under control, um, but I mean, it's still a chronic condition, right? So, what are some common challenges even when you're managing this to the best of your ability that you experience as a result of rheumatoid arthritis?

0:14:09 - Erin Evans

Stress is a big exacerbator. I find the biggest challenge is managing my stress and a bit of anxiety you know, that predates all of this.

0:14:29 - Adele Scheiber

Right.

0:14:29 - Erin Evans

So, I have a tendency to get more stressed out about things. So, the biggest challenge is just- has been learning to manage my stress levels, learning to manage my anxieties. Because I do. I have had some flare ups in the past when things have been particularly stressful. You know I do have more pain, or you know flare ups.

0:15:05 - Adele Scheiber

That's an interesting, you know, illustration of like the mind body connection, right? So, because I know, I know you like we're friends, so I know that like, for instance, sometimes like work stress which has nothing to do with your ability to use your hands happens all the time, but you're saying that that flares you up like there's a direct relationship.

0:15:22 - Erin Evans

Yes, yes definitely I can think of particular examples of either stress at work or stress at home that has led to flare-ups and in those times, depending on how acute the flare up is, I just need to take a sick day from work and rest, or you know, I will actually have to call the doctor and he'll prescribe a small dose of, like a six day dose of steroids or something to kind of bring it back down. So, with managing the stress that kind of again goes back to taking a nice warm bath. Or, you know, taking a walk, playing with my cats is a nice stress reliever. I think that again, the challenge is trying to find those things that can alleviate the stress. I've just started physical therapy to help with some lower back pain and with the goal of trying to get back into a regular exercise routine, because I think that the physical activity of working out does help with the stress and I think that over time it will help with just feeling stronger and you know, helping with the muscles and everything.

0:17:05 - Adele Scheiber

I'll go on short, sad little runs with you the next, the next time we're in DC [laughter] little water buffalo trots, Um, yeah, well, and it's also. You know, you're echoing a lot of things we hear from other people who suffer with chronic conditions. You know, not just stress, but you also have to really carefully manage your energy, Is that right?

0:17:24 - Erin Evans

Yes, right, yes, oh yeah, I get very, very tired. I've always had, I've always had issues with sleep and I'm a very light sleeper. I've had insomnia in the past, and so I already kind of have like this predisposition to like being tired and the arthritis definitely exacerbates that. Like if I don't get enough rest, I find that I have to - I can't do as much in the day that I used to when I was younger. I mean that's probably just the aging process, but um

0:18:10 - Adele Scheiber

And so, you're familiar with, like spoon theory and all that. Yeah, how good, would you say? I mean, how good have you had to get at figuring, like, are you pretty good at figuring out when you're going to tap out, when you're going to hit the wall, or do you like find yourself out on the freaking metro, like with zero spoons?

0:19:15 - Erin Evans

So, I'm better at being able to recognize when I need to rest-when I need to take a break. I'm somebody that has generally pushed myself, maybe more than I should just over my life. Again part, probably part of the patriarchy is just like we have to work harder. You know we can't- don't want to appear weak and all of that stuff. So, you know, a lot of it in the past few years is just being able to learn and recognize the signs of my body being like you need to rest, like you're not being lazy. You're not just not pulling your weight.

It's like you need to rest, you know, you're not going to be good to anybody, especially yourself, if you're not taking care of yourself and letting yourself rest. And you know that is very difficult because we live in a society-we live in a hustle culture society that tells us that we need to be going, going going. hustle, hustle, hustle, get that coin, all that stuff and you know any sort of I need to rest can be perceived as lazy by some people, and you know

0:21:00 - Adele Scheiber

Well, we're all tired, Erin, [Erin – yeah (laughter)], that's a subtweet, only if you know, you know [laughter]. Oh well, so you segue me beautifully to my next question, which is have you ever experienced discrimination or ableism due to your arthritis or what you perceive as that?

0:21:12 - Erin Evans

I mean definitely, sometimes when you know - because these medications that I have to take are very hard on the liver. So that means that I really, I can't really drink alcohol anymore.

0:21:38 - Adele Scheiber

That's a problem in and of itself. I'd be so miserable.



0:21:45 - Erin Evans

You know, I really enjoy a nice glass of wine. So, you know, I am able to have a alcoholic beverage like once a week, so it's not like it's completely off the table, but you know. That means that if I'm in some sort of work event and you know alcohol is there has been pressure in the past from people like “well, why aren't you drinking?”

0:22:22 - Adele Scheiber

Which is so bizarre to me. Like you don't know someone's life, like what if you're in AA?

0:22:30 - Erin Evans

Exactly. And it's just such a weird thing to have to. You know, it's like I don't feel like I need to explain or reveal something about myself to somebody because they're being weird about like “why aren't you drinking?”

0:22:52 - Adele Scheiber

It's not your job to live up to someone's expectations of how you should socialize. Basically, exactly, that's a weird one. I haven't heard that one. I thought you were going to talk about other things. Interesting.

0:23:02 - Erin Evans

Yeah, it's weird. And I definitely – you know again with people not understanding exactly how tired I can be or just ow much you know, even my family and loved ones, don't really? You know it's like I'll say like, “oh well, I'm just feeling tired” and they're like “well, you know we're all tired” and it's like, but you don't really understand, just like. I really am tired, like it's really hard to do more than what I'm already doing.

0:23:46 - Adele Scheiber

Resting becomes not an option but a necessity. Like your body - it's hard to describe to anyone who doesn't deal with it. I'm telling you, yeah, yeah.

0:23:56 - Erin Evans

And it's difficult because it is an invisible thing, you know.

0:24:00 - Adele Scheiber

Right.

0:24:01 - Erin Evans

You know. So, for example, I take the bus to the office and luckily, it's a pretty short bus ride, but still if the bus is really crowded, I usually need to sit. I usually need to sit, and you know it's, but I don't look, necessarily, like somebody that maybe needs to sit or, you know, holding onto the rail.

0:24:29 - Adele Scheiber

I can see that being really painful.

0:24:31 - Erin Evans

It actually can be very painful. So, it's like it's just a couple of times being in situations like that where it's like, I don't look like I have anything wrong with me, but I can't do some things. I don't feel like I should have to announce, "I have a chronic condition." It's just, I guess this is just. You know. I wish that there was more compassion, well, and just less snap judgments.

0:25:14 - Adele Scheiber

You know what I'm saying. Do you have the tag on your car? Have you ever been challenged for being in the parking space?

0:25:24 - Erin Evans

No, no. Luckily, I don't. I mean I don't drive right now, so I don't have to worry about that [Adele - that's good.] But, yeah, I can only imagine how, if I do get a car and having any sort of like disabled thing.

0:25:40 - Adele Scheiber

No, that's, that's the common one. But the bus thing is interesting, you know. You always see that there's that cliché moment in like movies and sitcoms where, like, the pregnant person's always offered a seat, but that's because there's a whole bowling ball right there. It's very visible and it's not like, no shade. I'm glad they get to sit down, but they don't have to say anything, whereas - that's interesting. So, what advice do you have for others who either suspect they might suffer from rheumatoid arthritis or who have been diagnosed?

0:26:10 - Erin Evans

So, anybody that suspects I would just say, just from my own experience of dealing with a doctor who was not listening to me. It's just, if you're in the same situation, to just keep going back and going back. In hindsight I wish I had been a little more forceful earlier on saying like, "hey, I know you think that this is all in my head, but I'm in a lot of pain and I don't think it's a pulled muscle, I don't think it's stress. I think there's something really serious going on and I need tests done." I wish I had the confidence to say that earlier on, and not wait until it became so debilitating that I'm like crying in front of the doctor. You know because, that's the only way he'll take me seriously.

0:27:07 - Adele Scheiber

Well, and it's like, at the end of the day, it's like: trust your gut, trust what you're feeling. You know you're the expert in what your nerves are telling your brain. Yeah, he can't feel that, and I think some people undervalue that. That you know, and it's easy to undervalue our own perceptions because we're conditioned to, especially as women

0:27:30 - Erin Evans

Exactly. Yeah, I would also say just listen to your body. You know if you're feeling tired, rest. If you're feeling like you can't do something or it's or you've kind of hit your bucket for the day, or you know your bucket's full for the day like just kind of tap out, and you know try I

mean tap out, and you know try I mean try not to be so apologetic about it or feel bad about it.

That's something that I'm getting better at, just being like, "hey, I just can't do this right now. I need to rest. Yes, I want to do this thing, but I can't do it right now, let's do it later, or something"

0:28:26 - Adele Scheiber

Are you too part of the recovering people pleaser posse?

0:28:30 - Erin Evans

Oh, I yes.

0:28:31 - Adele Scheiber

You got your membership card, amazing.

0:28:33 - Erin Evans

Yes, oh yes, that has been, that has been quite the challenge saying no to people when my like first instinct is always to be like okay, yeah, what do you want me to do and should I do more

0:28:45 - Adele Scheiber

Yeah, no, I hear that. "No" is a complete sentence. Uh. Some of my favorite phrases are "I am unable to" just don't even say why "I am unable to do that." The other thing is, we always assumed as people pleasers that something needs to get done tomorrow. So, ask the question, "when do you need this by?" And half the time they don't need it when I think they do.

0:29:25 - Erin Evans

Exactly like most of the time it is not an emergency. I need to stop thinking that every time I'm asked to do something, that it needs to be done right now. I am getting better at, you know, being like okay, "when do you want this done by" Or, "I have x, y and z to do. You know, I need to prioritize things. Where should I fit this in?"

0:29:33 - Adele Scheiber

Well, and you're articulating something that is rarely articulated. I think people like people pleasers, people who have limited energy, and we're so used to being on hyper-alert for managing energy, we make a lot of assumptions, right, we make a lot of snap like oh God - because we're just so we're on high alert all the time, like, "oh God, my plate's filling up, how am I going to deal with this?" And I think that there's there often is more room to move than we realize, you know. Um, the other thing is I want to shout out to uh, one of my mentors, Jackie, she used to say, "Instead of saying I'm sorry, say thank you for your patience." Yes, oh, that is so good, isn't that so good? I still try to do that. I say sorry like it's my second name, but I have to remember about that phrase.

0:30:21 - Erin Evans

Oh, I need to write that down on my computer screen so I can instead of like "I'm sorry, I haven't gotten back to you soon enough," like, yes, thank of your patience as I navigate competing priorities.

0:30:34 - Adele Scheiber

Yeah, it really makes you feel better. And people like being thanked. They've done studies on this. People. What are they going to say? "No, thank you!" like that's not a thing. Um, all right, Erin. Well, this was great. Is there anything else you want our readers and possibly listeners because I want to put this on the podcast to know?

0:31:01 - Erin Evans

Just that there's not enough research being done. There's really not a whole lot of information out there as to what causes this. You know, I asked my rheumatologist, "What caused this? Why do I have this?" And his response was "we don't know." He's like you could have a genetic predisposition, it could be a result of a virus, it could be, we just don't

know. And you know, the fact is, I think the reason we don't know so much, we don't know more about this condition is because it predominantly affects women.

0:31:35 - Adele Scheiber

Yeah, back to the old disproportional research dollars problem. Also, I've noticed this is a trend in most autoimmune diseases too. They're understudied, maybe because they're hard to study. I don't know. But we're going to do a little series on that. I want to learn more about that.

0:31:53 - Erin Evans

They're understudied. I think they're underfunded, understudied.

0:32:01 - Adele Scheiber

In proportion to their incidence in the US, especially my gosh. That's interesting. Well, thank you so much for your time and your story today. Erin.

0:32:10 – Erin Evans

No problem!