

Your Health Unlocked Episode 021: A Generational Story of Living With Ehlers-Danlos Syndrome

00:00:16 [Adele Costa](#)

Welcome to Your Health Unlocked, a podcast that empowers you to make better healthcare decisions by elevating accurate, unbiased information about today's most pressing health topics. This podcast is produced by the National Women's Health Network, a nonprofit group of activists fighting for better access to high quality health care across the nation. We do not rely on big Pharma, medical device companies or insurance companies, meaning we answer only to science and healthcare consumers like you. If you'd like to support us in our work, head on over to NWHN.org/donate and make your contribution today.

00:01:03 [Adele Costa](#)

Hi there. I'm Adele Costa, the host of the Your Health Unlocked podcast and the director of communications here at the NWHN, also known as The Network. Ehlers Danlos Syndrome, or EDS, are a group of rare, inherited chronic conditions that affect connective tissue. This connective tissue provides support for skin, tendons, ligaments, blood vessels, internal organs and bones. And because it does so many things in the body, symptoms of EDS can be widely variable, making diagnosis challenging. Roughly one in 5000 people have EDS, and 70% of those identify as women. Today we're interviewing parent and child duo Lorie and Carter Ringo. Carter (he/they pronouns) is a trans masculine nonbinary advocate and artist and the current multimedia communications lead here at the network. They recently graduated with a BFA and worked throughout college to advocate for better accessibility on their college campus. They were diagnosed with hypermobile Ehlers Danlos syndrome in 2014.

00:02:09 [Adele Costa](#)

Lorie Ringo (she/her pronouns) is Carter's amazing mom who did not receive her Ehlers Danlos diagnosis until the age of 45, despite living her entire life with symptoms. An artist all her life as well, she worked as a pottery teacher for 15 years and assists other local ceramicists regularly. She is active on online EDS support groups and assists as an admin for one.

00:02:30 [Adele Costa](#)

Keep listening to learn how this incredible family unit navigates daily life treatment and EDS advocacy. All right. Welcome, Lorie and Carter Ringo to the Your Health Unlocked podcast. Carter, we know you, but why don't the two of you tell us a little bit about yourselves, how you're related, and some of the chronic illnesses you've been diagnosed with.

00:02:57 **Carter Ringo**

Okay, I think I should probably start. Hi, I am Carter Ringo. I use he/they pronouns. I am currently employed at the National Women's Health Network as--

00:03:07 **Adele Costa, in a sarcastic tone**

Wait, you are?

00:03:10 **Carter Ringo**

I am as, the multimedia communications lead and also the editor of this podcast. So, hello. It's nice to meet you.

00:03:15 **Adele Costa**

How Meta

00:03: 18 **Carter Ringo**

Ha- Meta

00:03:20 **Carter Ringo**

This is my mom, Lorie Ringo, and we both have a genetic disorder called hypermobile Ehlers Danlos syndrome, and a couple of the comorbidities that come with them. So I'll let my mother introduce herself.

00:03:34 **Lorie Ringo**

Yes, I'm Lorie Ringo. I have been living with this a lot longer than my children, but I didn't find out till I had it till I was 45.

00:03:47 **Adele Costa**

Wow. Okay, Can we, can we, so just for my bad ears, can we say the name of that one more time for me?

00:03:54 **Carter Ringo**

Hypermobility Ehlers Danlos Syndrome. It is a connective tissue disorder.

00:04:00 **Adele Costa**

Okay. Yeah. So what is a connective, follow up question? What is a connective tissue disorder? Tell us then we'll put it in the show notes, too, what exactly this encompasses.

00:04:11 **Carter Ringo**

So Ehlers Danlos syndrome is essentially - we like to use the rubber band imagery, where it's like all of your connective tissues, which are the things that hold your body together, are like rubber bands on normal people; They stretch. In people with Ehlers Danlos syndrome, it's like they have holes through them. And you know what happens when you stretch a rubber band that has holes through it? It just snaps or it goes too far or it breaks. So this is the tissue that holds your entire body together. It supports your organs, supports your joints, all of these. So frequently, people with specifically hypermobile Ehler Danlos syndrome will have hypermobility in their joints, which is kind of like being double jointed, but - not, and frequently will experience dislocations or subluxations. And then all of the fun stuff that goes with your organs not being held up properly.

00:05:03 **Adele Costa**

Oh, goodness gracious. Okay. Lorie, is that kind of your understanding of it, too? Is that a good summary?

00:05:08 **Lorie Ringo**

Yes, very good summary. Some of the things that can happen to people with Ehlers Danlos syndrome, even if they don't have the specifically joint hypermobility, I know very young people under 30s that will never eat food again because their innards are not supported well enough, and they have to be fed by a tube.

00:05:28 **Adele Costa**

Wow. Okay.

00:05:30 **Lorie Ringo**

Because all those internal organs need a structure to pull against so that you can digest food and eliminate waste, all of those things.

00:05:43 **Lorie Ringo**

And so- you could, You could never have a dislocation, but you could have that portion. So this thing presents in so many different ways that doctors can't recognize it. And that's why you get to some people wait 20 - 30 years. I waited 45 years for a diagnosis.

00:06:03 **Adele Costa**

Wow. Yeah. We are going to get to that because that sounds ludicrous to me, but.

00:06:08 **Lorie Ringo**

It just shows up in so many different ways. People can't - the doctors, they're just not trained enough in all of them, to know.

00:06:15 **Adele Costa**

Right.

00:06:15 **Carter Ringo**

We also get great skin.

00:06:16 **Lorie Ringo**

Yes.

00:06:17 **Adele Costa**

Is that sarcasm?

00:06:21 **Carter Ringo**

It's a genuine, like it's part of Ehlers Danlos. You get, like, the collagen in your skin - For some reason, it just ends up -- being like your skin is soft and generally clear.

00:06:30 **Adele Costa**

Yeah, she's born with it. Maybe it's Ehlers Danlos. *(To the tune of the Maybelline jingle)*

00:06:34 **Lorie Ringo**

That's exactly.

00:06:35 **Adele Costa**

We'll edit that out. That's interesting.

00:06:38 **Carter Ringo**

Absolutely not. I'm keeping that in.

00:06:42 **Adele Costa**

Wow. Okay, so we talked a little bit, so okay, let me summarize. So we've got the hyper joint party trick thing, but then the not so chill organs might not work. Great skin. What are some other really common you talked about comorbidities. Is that everything? Are those the main features?

00:06:59 **Carter Ringo**

There's a lot.

00:07:00 **Lorie Ringo**

Tons.

00:07:02 **Carter Ringo**

Some of the ones that I've been diagnosed with or expected to be diagnosed with are mass cell Activation Syndrome. It's really common in people with Ehlers Danlos. It essentially means that-

00:07:11 **Adele Costa**

That sounds ominous, what is that?

00:07:14 **Carter Ringo**

It's like your body is allergic to itself and randomly has allergic-like reactions to seemingly random triggers. Sometimes it's heat, sometimes it's stress, sometimes it's random foods you might have eaten your entire life.

00:07:30 **Carter Ringo**

IBS is really common with people with Ehlers Danlos, things like neuralgia, specifically Occipital and trigeminal neuralgia, because of cranio-cervical instability, which is like your head is on a Bobblehead. Chiari malformation, which goes along with cranio-cervical instability. And its - this is a little bit graphic. It's like your brain starts falling out through the back of your skull.

00:07:57 **Adele Costa**

Oh, my gosh.

00:07:58 **Carter Ringo**

It's actually like an incredibly treatable thing. Unfortunately, in the States it's not. They generally wait until you are knocking on a death door to fix that one. But over in countries like China, it's actually really common. And so it's something that's fixed really early.

00:08:15 **Adele Costa**

Interesting. So before you go on, remind me, because you actually educated me on what neuralgia was. Can you explain a little bit about what that is? Because that's words people don't know.

00:08:26 **Carter Ringo**

Neuralgia is misfiring of the nerves or the nerve endings being frayed in kind of like a fibromyalgia sense. But it's targeted. People who experience Occipital and trigeminal neuralgia generally have - oh, there's a cat. Sorry. People who experience trigeminal and occipital neuralgia generally will have pain in their face and their head and their eyes. I have both. And it does feel like someone is stabbing you through your eyes, which is not - ten out of ten could not recommend, but -

00:09:04 **Adele Costa**

Doesn't sound great.

00:09:05 **Carter Ringo**

It's not great. But it is something that's a common thing that people with Ehlers Danlos experience.

00:09:11 **Lorie Ringo**

So what happens there is that nerves, all of the rest of your body stretches a little bit, except for, like, bones. Right. So you're designed to stretch, but nerves don't stretch. It's one of the tissues that won't stretch. So, if you dislocate or whatever, those nerves are stressed, and that's when you get tingling in your hands and feet, anywhere along the nerve path, all the way up to the brain. If the nerves get stretched, you can wind up with tingling, numbness, and neuralgia pain. In your feet--

00:09:52 **Adele Costa**

Right, Right. The more stretching everything else does, the angrier the nerves get. That makes sense. Makes sense. Now I'm starting to understand why those gymnasts need physical therapy.

00:10:02 **Lorie Ringo**

Yes! Absolutely.

00:10:04 **Carter Ringo**

Another thing that happens with people with Ehlers Danlos is that the Vagus nerve, which is the central nerve that controls the autonomic nervous system, which is the nervous system of things you don't think about. So your heart rate, your blood pressure, all of these things that your body controls without you thinking, gets very messed up. And so people can get things like POTS or

Dysautonomias, which are dysfunctions of the Vagus nerve, where people with POTS will be like, sitting down and have their heart rate be 140 beats per minute, or standing up, and then you pass out.

00:10:46 **Adele Costa**

This is a co-occurring issue. I know somebody with just POTS and not Ehlers Danlos-- And I mean, POTS alone is a rough diagnosis. So this is co-occurring - a lot of people.

00:10:55 **Lorie Ringo**

Yes, and that can happen. You can have the tendency towards dysautonomia of any sort and be perfectly fine running a marathon and you get just a minor virus or you eat a bad scallop and you have a little bit of an illness, and then all of a sudden, boom. Now you are living as if you have end stage congestive heart failure.

00:11:22 **Adele Costa**

Oh, my goodness. Wow.

00:11:24 **Lorie Ringo**

You can't stand up, you can't breathe. You can't- You're just like, oh, my God, what happened to me? I just had a cold. Or I just ate something that bothered me. And all of a sudden you are down into this rabbit hole. And the doctors don't necessarily know how to take care of you because it's not rare. It's just rarely diagnosed.

00:11:48 **Adele Costa**

So that's helpful. So my takeaways are this is incredibly complex.

00:11:52 **Lorie Ringo**

Yes.

00:11:53 **Adele Costa**

And incredibly unpredictable. Would you say that that sounds about, right?

00:11:58 **Lorie Ringo**

Very much so.

00:12:00 **Adele Costa**

Wow, wouldn't want that. So let's start with you, Lorie. You said you weren't diagnosed, so you were 45. I'm assuming you're older than that. Now, I'm going to make assumptions. When do you first start experiencing -- take us back. When did you first start experiencing symptoms and what was the path to diagnosis and treatment like for you?

00:12:21 **Lorie Ringo**

Okay, so I had birth defects, and there's no way to prove that my birth defects came from the Ehlers Danlos at this point. Might have been able to prove it back then. In 1972, when I had the surgery, they fixed the urinary system that was wrong. And I've been fine ever since in that regard. But from that point on, there was just a bunch of weird things that happened. I was asking my mom, how old was I when I sprained my ankle sitting down?

00:12:56 **Adele Costa**

Wow.

00:12:57 **Lorie Ringo**

The first time I sprained an ankle, I was sitting down. So you know how you sit at a chair with four legs and you kind of wrap your feet around the bottom of the legs, right?

00:13:09 **Adele Costa**

Yeah. Like a lemur. Absolutely.

00:13:12 **Lorie Ringo**

I mean, some people do this and for the EDS-er you're trying to support this body that wants to flop over. So I was sitting like this and we were playing a game, and I was very into the game as a child, and I must have been six or seven, because it wasn't all that long after the surgery that had fixed my innards, and the phone rang next to my head. And I don't know if you're probably much younger and you don't remember the sound of a phone in the 70s.

00:13:40 **Adele Costa**

Oh It was jarring. I had a grandma, yeah. I remember.

00:13:45 **Lorie Ringo**

I jumped out of my seat, but my foot was still attached, and I dislocated my foot sitting down. And it was good -Six weeks. And my father was a welder, and he had this little stool on - sorry, my cat. He had this little stool that was on wheels, and I scooted all around the house on that, literally for six

weeks. And thank God he brought that thing home from work. And so they would carry me all over the place because I was still little enough. And then a couple of years later, I sprained an ankle again, the same one. And then a couple of years later, I rolled the ankle and fell down the basement stairs and broke two bones. And then a couple of years later, I did it again, and I wound up having the first orthopedic surgery. Excuse me- At 15 years old, they went in and rerouted tendon to act like ligament.

00:14:53 **Adele Costa**

I see. Yeah.

00:14:55 **Lorie Ringo**

And the doctor came out and said to my mother, how is it she's walking? There's no ligaments in there. There's nothing but gossamer. Those were his words. There's nothing but gossamer.

00:15:10 **Adele Costa**

Well, that's the title of the episode, y'all. Okay. Wow. So gossamer. I think it's like that like Lacey gauzy material.

00:15:19 **Lorie Ringo**

Imagine your wedding veil instead of a rubber band.

00:15:22 **Adele Costa**

Rubber band, instead of there it is. Yes, that's exactly right. That's rough. Oh my gosh, that's serious. That's a great visual too.

00:15:29 **Lorie Ringo**

Right? Now that I have had multiple orthopedic surgeries, every doctor that goes in there and does some repair work on me, it's like I have to go to the mechanic all the time. Every doctor that goes in there says there was no ligament in there. I had to whip stitch the whole length of that ligament just to make it stay together.

00:15:53 **Lorie Ringo**

Here's the worst thing about all of this. My level of Ehlers Danlos is considered to be mild.

00:16:00 **Adele Costa**

Really?

00:16:01 **Lorie Ringo**

I have mild Ehlers Danlos syndrome.

00:16:05 **Adele Costa**

So hashtag lucky to have the wedding veil. Is that what I'm hearing? Sounds terrible.

00:16:09 **Lorie Ringo**

Yes.

00:16:10 **Adele Costa**

Oh my gosh. Okay. Wow. So you've had a bunch of orthopedic surgery. They realized something was like a five alarm fire after this first surgery. Did they know it was Ehlers Danlos? Like no, right.

00:16:23 **Lorie Ringo**

No.

00:16:25 **Adele Costa**

What do they think? What was the original?

00:16:25 **Lorie Ringo**

I think the diagnostics are taking a very big leap right now. There are certain doctors that will say to you, oh, don't go to Dr. Google this, that, and the other thing. But because there's Dr. Google now, and people can look up their own symptoms, they can approach the doctor and say, wait a minute, you're missing something. Now I might not be right, but you're not allowed to drop the ball anymore. And that's what happened in my younger years. So many doctors were not trained well enough in this, and they dropped the ball. So that's why I didn't get a diagnosis till I was 45, when Carter was a little one, and I was just diagnosed with it. And we're in pediatrician's office, and I said to our beloved pediatrician, who is now retired. I said, I have hypermobile Ehlers Danlos. We have to be on the lookout. And she just went, oh-.

00:17:34 **Adele Costa**

Boy.

00:17:36 **Lorie Ringo**

And I said- Oh? Because I could. And she said, you know, you're going to be my resource on this. And I said, Why is that? I went to medical school in the 80s and I got a total of one paragraph of education on Ehler's Danlos syndrome. She goes, I remember reading it.

00:17:59 **Adele Costa**

Wow.

00:18:00 **Lorie Ringo**

But it was one paragraph in all of my medical education. So here we go to all these doctors, and we're pleading to them for help. But they weren't educated either, right?

00:18:13 **Adele Costa**

It's funny you say that. We just had a guest. They were a trans masculine identifying person, and they said that their doctor told them, you are the data. I don't have data. You are the data. Right. So it sounds like for a lot of - I mean, that's scary, right? And just to kind of return to something that you said about Dr. Google, I love the way you summarize that. I might not be right, but you're not allowed to drop the ball. And I've heard that from doctors. You know, The good news is we had one of our board members and doctors on the show, Dr. Julie Thai, and she's like, I welcome patients bringing me their Google printouts because it is in line. Like, I think, as you said, Lorie, with this new kind of cooperative, collaborative care model that a lot of doctors are adopting. And you're right, I think it's an extra layer of information and it's an extra layer of accountability to have that information at everyone's fingertips.

00:19:12 **Adele Costa**

And clearly, if people are getting a paragraph, you know what I mean, in the 80s, that's something - that self advocacy is important. Right? So it sounds like it really was in your case.

00:19:19 **Lorie Ringo**

It really, really is right now. And you read books all the time. I'm reading a new book that I just got called The Dysautonomia Project. Basically, on behalf of my child who doesn't really have a lot of time, I'm reading this book. And right in the beginning of this book, it says, we are going to flip the clinic. Now, you've heard the term flip the script. And this is basically they want - this Dysautonomia Project set of doctors, wants their patients to come to them, being able to give the full patient history that so many of us have learned to dismiss so much of it because our doctors weren't capable of handling it.

00:20:07 **Adele Costa**

But you get the ten minute visit, the 15 minutes visit, no one reads the notes. I mean, that's unfortunately a typical experience, especially when you go primary first line, right?

00:20:17 **Lorie Ringo**

Yes, What they're saying is, even if it's overwhelming, we want to hear it all. But that's doctors who are specializing in this, if you show up to average GP with all of this, they still send you to the psychologists.

00:20:36 **Adele Costa**

Really? And that's been your experience?

00:20:40 **Lorie Ringo**

Multiple times.

00:20:40 **Adele Costa**

Wow.

00:20:41 **Lorie Ringo**

I like to say that I spent 30 years on the wrong treatment bed.

00:20:46 **Adele Costa**

Wow. So you're telling me, Lorie, before the age of 45, when you got your diagnosis, people were just like, are you sure this isn't all in your head? Really?

00:20:55 **Lorie Ringo**

Yes, From the time I was, I don't know, twelve.

00:20:58 **Adele Costa**

Wow.

00:21:01 **Adele Costa**

And and they were saying even after they looked and they saw no ligaments, even after they saw that?

00:21:04 **Lorie Ringo**

Yes. The same doctor. The same doctor when my wrists started to go, because that was an ankle, and then my wrist started to go, he's like, she just doesn't want to go to school. Take her out of here.

00:21:15 **Adele Costa**

Wow. I'm so sorry. That's clearly not acceptable. Okay. Wow. Well, so you did eventually get a diagnosis. How did that happen?

00:21:25 **Lorie Ringo**

Okay, so I kept going back to my GPS and back to whoever I could talk to, and I kept getting sent back to therapists, mental therapists, and literally for years and years and years. And finally I'm teaching at camp, which was the best thing I ever did. And I accidentally got a case of fifth disease.

00:21:54 **Adele Costa**

I don't know what that what is that?

00:21:55 **Lorie Ringo**

Fifth disease is human parvovirus. Okay.

00:21:58 **Adele Costa**

Oh, jeez.

00:22:00 **Lorie Ringo**

Well, it's very common among children, and when they get it, they get a little rash, they get a headache, maybe a tiny little fever, but they feel fine, so they go on with their day. But when a child brings it to an adult - so camp is almost over, I'm like, I have a fever. It's terrible. So I finally get to the doctor, and I said, it's as if someone gave me rheumatoid arthritis overnight.

00:22:26 **Adele Costa**

Oh, gosh. That hurts listeners.

00:22:30 **Lorie Ringo**

And he's like he's like, you work with kids, right? I'm like, yeah. He goes, I don't think it's rheumatoid arthritis. And I think I know what it is. We'll do the blood tests to confirm, and it was parvo. And I literally couldn't hold a teacup without two hands. I couldn't do with the one hand for - for six weeks after. And then after that subsided and I was recovered and I would go back to him, I'd say, Doctor, remember how that happened? This is kind of the level of pain. I've been in - about half of that - for all this time. And he's like, okay, well, that's weird. So he ran the ANA series, which is the test that - antinuclear antibody tests, and they're looking for all the rheumatoid concerns because my aunt had terrible rheumatoid issues, and it showed up very slightly over the line for Lupus.

00:23:29 **Adele Costa**

Right, okay. I was going to ask about lupus because of that autoimmune thing you were talking about. Yeah.

00:23:33 **Lorie Ringo**

So it's another connective tissue disorder, but I didn't have Lupus. I was just dehydrated enough to show that there was something wrong with my connective tissues. So go to see rheumatology. So I go to Rheumatology, they repeat all these tests, they come back negative. One of the issues with this set of disorders is you constantly come back as healthy. All of the paperwork, all of the X rays, all of the - I don't see it.

00:24:01 **Lorie Ringo**

Okay? And you almost can't blame the doctors for saying they're staying in their lane. They don't want to jump to some other specialty lane.

00:24:08 **Adele Costa**

Sure.

00:24:09 **Lorie Ringo**

And they're like, I don't see it. I don't see Rheumatoid. I don't see lupus. I don't see what's wrong.

00:24:14 **Adele Costa**

They don't see what they tested for. Exactly. Right.

00:24:16 **Lorie Ringo**

So finally I switch Rheumatologists, and I go to another one. She's like, oh, you have fibromyalgia. And I'm like, okay. And then she wants to give me a medication, and she keeps pushing it at me and so forth, and I'm like, But I don't really want to be on this medication. I hear nasty things about this medication. And she's like, no, you really have to try. You have to do it. And I'm like, But I'm not even sure that that's the right diagnosis, because you keep saying it's in the muscles, but it's literally every small joint in my hands. It's my wrists, it's my elbows, it's my hips, it's my knees.

00:24:48 **Adele Costa**

Right, Your history does not support that.

00:24:51 **Lorie Ringo**

Right?

00:24:52 **Adele Costa**

Yeah.

00:24:52 **Lorie Ringo**

And she goes, well, wouldn't you rather it be fibromyalgia? There is something else it could be.

00:24:57 **Adele Costa**

Okay, wait a minute. That's not how this-

00:25:01 **Carter Ringo**

That's not how the medical field works.

00:25:03 **Lorie Ringo**

Right?

00:25:04 **Adele Costa**

It's not a crystal ball. So what did you say to that?

00:25:07 **Lorie Ringo**

Well, I said, but listen, I'm going to Disney because the high school band is going to Disney. We're going to Disney. What am I supposed to do while I'm in Disney? She goes, Take the medication, damn it. So I go and I fill the medication, and then the pharmacist calls me, and he says, you shouldn't be on this medication. I said, what do you mean? He said, well, with the other medications you're on, it can cause congestive heart failure.

00:25:31 **Adele Costa**

Oh You know, a small side effect.

00:25:34 **Lorie Ringo**

So he says: Listen, you might not get it, but these are the circumstances under which you should not take it. If your feet start to swell, stop taking it instantly. So here we are in Disney, and my feet start to swell, and my feet don't fit in my shoes. I think Carter remembers me trying to buy shoes inside Disney, too.

00:25:57 **Carter Ringo**

Yes I do.

00:25:57 **Adele Costa**

Oh, my gosh. Right? Because you're like, a mom with, like, kids and obligations in addition to that, like, a full time job.

00:26:03 **Carter Ringo**

Yeah I was in 8th grade.

00:26:04 **Lorie Ringo**

8th grade, yeah.

00:26:09 **Lorie Ringo**

So the symptom that the pharmacist warned me about comes upon me, and now it's like, okay, I have to put this down. And all along here, I'm taking massive doses of Ibuprofen to deal with pain that no doctor is even recognizing.

00:26:25 **Adele Costa**

Right?

00:26:26 **Lorie Ringo**

So I'm starting to get all kinds of gut issues just from taking massive doses of Ibuprofen for the last 20 years.

00:26:36 **Lorie Ringo**

So I do this to get through Disney. But in Disney, I have decided - I have just fired that Rheumatologist.

00:26:43 **Adele Costa**

I think that's fair.

00:26:45 **Lorie Ringo**

That lady will never see me again. So I get home from Disney and I start calling around to Rheumatologists. And one on the other side of where we live, different town, actually has availability in two weeks, and that's really rare. You usually have to wait six months. And so I'm like, okay, I'm going to go to her, and I just make an appointment. And never before have I had this happen. This doctor was very smart, and she reminded me very much of my grandmother, who was a brilliant diagnostician as a nurse in the 30s. So this doctor comes out to the waiting room to get me. Never had that happen before. It was always a texh.

00:27:28 Adele Costa

Yeah.

00:27:31 Lorie Ringo

And she watched me walk into the exam room, and I sit down and I wrap my little feet around the chair like I always do to hold myself up. And she said, you don't have fibromyalgia. I know what you have, and you're not going to like it because there's nothing anybody can do about it. I said-

00:27:49 Adele Costa

Wow.

00:27:50 Lorie Ringo

And I said to her, okay, well, I think I ought to know. And she tells me, this is what you have. You have to eat two or three times the amount of protein you're eating now. You have to take in more vitamin C. You have to do physical therapy. And that's really it. That's all there is.

00:28:09 Adele Costa

Wow. So, I mean, what was going through your mind when she was telling you that?

00:28:15 Lorie Ringo

Actually, I immediately flashed back to a conversation I had had with my grandmother, my brilliant diagnostician grandmother's sister, who was also a nurse - back in the had had a conversation with her, and I had had another surgery. And I said, Aunt Dot, I just feel like there's one diagnosis that's going to explain it all. How come I can't get up and I don't have the energy to go to school like the other kids? And there's one diagnosis, I just know it. And that side of the family thought I was the bee's knees. And she's like, oh, no, Lorie, you're perfect. And I'm like, thanks, Aunt Dot.

00:28:51 Adele Costa

There are some KPIs here that would beg to differ, but all right.

00:28:56 Lorie Ringo

And I'm like, thanks. I'm so glad I'm so perfect in your eyes. You love me so much. But the fact of the matter was, my inkling as a *teenager* was right, that there was one thing that tied all of my symptoms together. And here this doctor that looked like my grandmother, who had been long dead, handed it to me, and I was shaken. And then over the next few weeks, I went through all kinds of mental distress, like, oh, my God, I was right. And nobody listened to me. And I still kind of have

PTSD when people don't listen to me now because I kind of like, listen I could be wrong, but if you don't consider this, you're a fool.

00:29:43 **Adele Costa**

Yeah, well, it's interesting. So there's a couple of takeaways from that. I mean, you just got this devastating diagnosis that's going to affect you for the rest of your life. And what is sticking with you is the emotional trauma of getting there. I mean, that is a testament to just how devastating it can be when you're not listened to, when you are medically gaslit, when you are put on the sidelines. Ehlers Danlos, this is no joke, right? You have PTSD. Not the disease necessarily-

00:30:11 **Lorie Ringo**

Little Bit-

00:30:12 **Adele Costa**

But of the way that you were treated on your journey there. So thank you for that. What year was your diagnosis, Lorie?

00:30:19 **Lorie Ringo**

Ten years ago.

00:30:20 **Adele Costa**

Ten years ago, okay, so my question now let's switch to (Carter) Ringo. So you got this diagnosis around what time, Ringo, did you start experiencing symptoms? And what was it like kind of watching your mom go through all of this? For years, basically.

00:30:40 **Carter Ringo**

So one of the things she likes to say about me is that she knew I was also in the same boat from the first time I started walking. She tried to hold my hands up, like when you hold your little baby's hands up to have them walk. And my wrists came apart in her hands.

00:30:58 **Adele Costa**

My God.

00:31:00 **Carter Ringo**

So she knew right from the jump, she was like, you also have this, you need to like as soon as she found out, she was like, we are getting you into a geneticist, we are getting you into all these

doctors. I was 14 when I got the official diagnosis, which was helpful because I was able to get prepared for a lot of stuff. But it was definitely rough watching my mom go through all of these and it was I because you start to develop like a personality and a brain at around eleven, I feel like. And so I had watched my mom go through all of these really rough things and have doctors be like, oh, it's this one, this will kill you eventually. And it wasn't- multiple times, it was scary. But I also didn't think I had anything.

00:31:48 **Carter Ringo**

I knew I was in pain and I knew that I was exhausted all the time and all these things, but I didn't think that I would end up being in quite the same boat because kids think they're invincible. But I think her getting her diagnosis and then becoming a medical advocate, not only for herself, but for me, and being like, I am not going to let you have doctors tell you that you don't have this. I'm not going to do all of these things. We know you have this, we know we need to get you proper treatment for all of these things. Definitely set me up for the better, for sure.

00:32:28 **Adele Costa**

Right So, I mean, Lord, we know 45 years doing diagnosis. How long did it take you to really get officially diagnosed?

00:32:38 **Carter Ringo**

It took less than a year from mom getting diagnosed to me getting diagnosed, and I was 14.

00:32:44 **Adele Costa**

Right.

00:32:44 **Carter Ringo**

Really not very bad.

00:32:46 **Adele Costa**

So I just want to put, you know, that self advocacy saved, you know, your child, Lorie, all those years of what you went through. So way to go, mama bear. And we talk a lot here at the network about the importance and how we need to honor lived experience. Right. And all throughout your story and throughout Ringo's story, you're having things be told to you, but then you're having that very visceral lived experience moment of the wrists coming apart. Do you know what I mean? And just know you know when something ain't right.

00:33:19 **Lorie Ringo**

Absolutely.

00:33:21 **Adele Costa**

Okay, you got it's today. Now it's what? 2023. January 2023. You both have your diagnoses. Doctors know that they're on notice when you come to their office because you're going to advocate for yourselves. Let's talk about how Ehlers Danlos affects you guys today during your everyday life. And you guys could switch back and forth on this one.

00:33:43 **Carter Ringo**

All right, I suppose I will start on this one. Well, I could tell you right now I'm having a very rough pain day.

00:33:53 **Carter Ringo**

We like to um, Ehlers Danlos is all about symptom management and not about treatment of the actual source because there's not a lot of treatments for the actual source. Full body like stem cell treatment has been researched, but it's not as funded as it should be. And all of those things, it's not available and it's not there yet. So every doctor that you go to as an Ehlers Danlos patient will focus on specific sets of symptoms and managing those symptoms, sometimes they do a great job, sometimes they don't. One of the things that both of us do as patients with Ehlers Danlos is that we go to physical therapy at least once a week, if not twice. We are constantly - for different parts of the body. Like, I am currently focused on my upper half right now. I am getting physical therapy specifically for my neck and my shoulders because those are probably my worst parts.

00:34:49 **Adele Costa**

Sitting like a golem all day here.

00:34:51 **Carter Ringo**

Exactly.

00:34:52 **Adele Costa**

At our desks

00:34:53 **Carter Ringo**

Exactly.

00:34:59 **Carter Ringo**

Sorry, I'm getting off track a little bit.

00:35:00 **Lorie Ringo**

That's okay.

00:35:03 **Carter Ringo**

Point being, all of the things that we have to do is not only symptom management but self management. It's like a learning curve to be like: I really can't do everything all in one day. We talk about the spoon theory being that you only have a set amount of spoons in your drawer at any point in time and every single time you do a task, you take a spoon out or four spoons out, depending on how big that is. Brushing your teeth is a spoon. Going grocery shopping is four spoons.

00:35:30 **Adele Costa**

That's a lot of spoons, yeah.

00:35:33 **Carter Ringo**

And it's like, how many spoons do you have for the day and how can you manage how many spoons that you're going to have so that you don't overdo it and cause yourself more harm later?

00:35:42 **Adele Costa**

Well and for those of you who aren't familiar with this, we'll put in the show notes. But the spoons in this analogy are representative of your daily energy, right. And when you're out, you're out, especially when you have a chronic illness. And unlike somebody like me, who sometimes I get dead tired at the end of the day, but where that stops for me is I go to sleep, I wake up, and I'm fine.

00:36:06 **Lorie Ringo**

Right, and you're allowed to have spoons, too, and run out of them as well.

00:36:09 **Adele Costa**

Well, right, but I feel like the folks with chronic illness, what I'm getting at is, like, the spoons are like, you don't want to take credit from the next day. You know what I mean?

00:36:19 **Lorie Ringo**

You do all the time, you borrow

00:36:20 **Adele Costa**

Is that fair to say, Ringo?

00:36:22 **Carter Ringo**

Yeah, 100%.

00:36:24 **Lorie Ringo**

Yes.

00:36:24 **Carter Ringo**

I took all of my spoons for today, this weekend. I cleaned so much. They are *gone*.

00:36:31 **Adele Costa**

Yeah, that's all right. Well, I know you're a really hard a** boss, but I think she'll (Laughter)

00:36:42 **Adele Costa**

Lorie, like spoon theory. I think people know it. But you talked before we started recording about something called fork theory. Can you talk about that?

00:36:48 **Lorie Ringo**

So just love the flatware analogies, evidently. There was a response to that. So Christine Miserandino was the blogger that put forth the spoon theory, but then someone took that. But no, it's forks for me, because stick another fork in me and I'm done. And basically, every little thing that you do when you're walking around the world in pain or using your wheelchair, going around in the world in pain, whatever it is that you do to get through your day - because those are just tools. You wouldn't try to write a paper without a computer anymore, would you? It's just a tool. Use your cane, use your wheelchair, use your whatever - But anyway, back to the forks, because that saves you forks and spoons to use those tools. Okay?

00:37:57 **Lorie Ringo**

But in any case, the forks are okay, so oh, my God, I'm late for this appointment and the traffic, and my neck is tightening up, and that's like a little tiny shrimp fork stuck in your neck, and my back is killing me, and I didn't sleep well, and maybe that's a barbecue fork stuck in your back. And if you stick me with one more thing, I'm going to blow up. I am going to *literally* go supernova, because I just can't take another thing, and I'm going to scream at you, and I'm going to have a fit.

00:38:17 **Lorie Ringo**

And the best thing that you can do as somebody who's dealing with metering out this tolerance for all of these normal, everyday problems is know when you're getting close to blowing up, detach from the world, and what do you call it, Carter? Bubbling. You go into a bubble.

00:38:38 **Carter Ringo**

Yes, yep, separate.

00:38:40 **Lorie Ringo**

You separate, and you just, okay, I need to go and recover for my own self, because I'm not going to be fair to you if you have an issue because my issues are -

00:38:50 **Carter Ringo**

Because I've got a fork in my back.

00:38:54 **Lorie Ringo**

I've got, like, 19 forks stuck in me, and I can't even handle your little paperclip next to me.

00:38:59 **Adele Costa**

Right? That's a really cool riff on spoon theory, right, because where spoon theory is all about energy management, fork theory is all about your tolerance management and kind of like your relationship management, too, to yourself and to others. Right. And when you don't have good energy and we're dealing with chronic pain, self and relationship management is hard. Right?

00:39:20 **Lorie Ringo**

Even the people that you love the most, you will scream with them, and it's not necessarily their fault for needing you in that moment.

00:39:28 **Adele Costa**

Right.

00:39:29 **Carter Ringo**

Its something also heavily used by the neurodivergent community for indicating sensory overload. Like, how many things can you have going on at once before you explode? Kind of thing.

00:39:43 **Adele Costa**

Yeah, well, it reminds me of kind of like, honestly, more people should be doing these self check ins and these communicating of their needs right. And this building of systemic resilience, which is what

you're really talking about with fork theories and the bubbling and like, okay, I can tell the forks are about to pop me. How do I make sure I don't get popped? And I think that's really - I mean, would you say that thinking about it that way is empowering?

00:40:11 **Lorie Ringo**

Maybe it's empowering, but it's also a matter of growing your self understanding, Right.

00:40:22 **Lorie Ringo**

It's that whole, If you're a pitcher and you're trying to pour out your blessings on anyone else, if you're empty, you can't - there's just absolute limits to human beings. And when you go into the job of motherhood like I did, and you choose that path - because it really does have to be a choice there. When you choose that path, you think that you're going to be able to pour your blessings on your babies and your family forever, like Snow White, but you can't. You're still a human being. And-

00:40:59 **Adele Costa**

Desire and your capacity do not always matter.

00:41:01 **Lorie Ringo**

Exactly. We think, okay, well, I always must provide what my children need. Yes, you do. You need to do that. But what do they need versus what do they want? Take back a little bit so you can give yourself what you need, and then later on, you can give them what they want.

00:41:21 **Adele Costa**

Lorie, hearing you talk about this, I really feel like I'm sitting with a Ringo clone. Because one of the things, no, one of the things and you taught them well, because one of the things that I super appreciate as a supervisor let's talk about this. You said you deal with it in motherhood, right? Ringo, you deal with the same thing at work, right?

00:41:42 **Carter Ringo**

Oh yeah

00:41:42 **Adele Costa**

I mean, you will message me, and I love this about you. You'll be like, look, it's a low spoon day. I'm going to do what I need to do today, and it will get back to you tomorrow. And because you do that I know. Okay, I'll shift that on Carli. You're like, all right. So a lot of times people are like, oh, Ringo is

so busy, I'm afraid to ask. I'm like, no, don't be afraid to ask because Ringo would tell you if it's too much.

00:42:07 **Carter Ringo**

I will.

00:42:08 **Adele Costa**

So would you say that you practice that? Did you learn that from your mom? Let's talk about that.

00:42:14 **Lorie Ringo**

I think you learned that from watching me fail at that.

00:42:17 **Carter Ringo**

I think so. I could agree to that. It was definitely learned by watching someone else struggle with it and then realizing as I went into college and started doing advocacy things for other disabled students on campus and being like, yeah, no I know where my limits are.

00:42:39 **Lorie Ringo**

There's nothing like being the mom of the second grader in the scouts meeting and the scouts leader looking around the room saying, I'm going to shut down this group because I don't have any help. Who's going to do it? And then having your baby just lock eyes with you from across the room saying, you have to do this. You have to do this, Mom. You have to do that. You can read it in their eyes and you're like, *ugh* you want me to do it? And then you do it. But then they do watch you overdo yourself to the point where you can't cook dinner. They watch you overdo yourself to the point where you can't actually run the meeting and they go, oh, look at that.

00:43:28 **Lorie Ringo**

Watching me fail, I think was maybe the best learning experience for my child because you need to learn to manage yourself. And I wasn't doing that because I didn't have my diagnosis yet. I didn't right. Everybody was saying to me, there's nothing wrong with you. Just keep going. And that's exactly what I was doing and I was failing.

00:43:50 **Adele Costa**

Right? And I mean, not to be the thera- I hear a little self-judgment and I encourage you to reframe the word failure there. It sounds to me like this has really been evolution, right.

00:44:03 **Lorie Ringo**

Very minor failures. And it's okay to say I failed at making dinner today. I totally failed. I called instead, totally acceptable failure.

00:44:17 **Adele Costa**

Yeah. Oh, this is freaking fascinating. Okay, so I'm going to first Ringo then Lorie, what has been like the single most helpful tool you talked about, tools that you wish everybody had access to when navigating this illness.

00:44:33 **Carter Ringo**

A really good primary care doctor, who knows about what you have. I recently found one who I had one conversation with and she's like, oh, yeah, I know what Ehlers Danlos is. I did my clinicals on Ehler Danlos and I was like, **gasp** oh, my God. And I immediately got referred to every single specialist I would ever possibly need. Because you have to go to Cardiac and you have to go to Urology and you have to go all of these different things because you have such a complex disorder. That's on the medical side just a really good doctor. Just at least one. On the personal side community. Other people who can tell you what's going on and other people who are like, I've had this. Keep an eye out for it. Not every person who has Ehlers Danlos is the same. Like, there's different ranges, degrees, but also people who are like: I went to this doctor, avoid them. I went to this one, and they listened to me. I went to a place, and it was not accessible. I went to a place, and it was-

00:45:38 **Carter Ringo**

All of these different things that you can only get by talking to other people with the same sort of situations and same sort of lived experiences.

00:45:46 **Adele Costa**

And where do you find that community? Do you have, like, a recommendation?

00:45:49 **Carter Ringo**

There's a lot of support groups on Facebook, but also just in there's a lot of people on Instagram who have Ehlers Danlos that post about their experiences or people on YouTube who have Ehlers Danlos and post about their experiences

00:46:05 **Adele Costa**

Hear that folks- Social media isn't all video games and kids on their phones. It's invaluable tool.

00:46:12 **Carter Ringo**

Exactly.

00:46:14 **Adele Costa**

What about you, Lorie? Things -The absolute most helpful things for you.

00:46:20 **Lorie Ringo**

Yes. Those things that Carter mentioned. Yes. But what I wish I had, I'm going to go to what I wish I had and what I wish everybody with Ehlers Danlos had free and open access to mobility devices that wouldn't cost you your left lung. So to get a very small powered wheelchair that you could travel on an airplane with will cost you about \$2,500.

00:46:53 **Adele Costa**

Really?

00:46:53 **Lorie Ringo**

And insurance won't pay for it because it's considered a luxury to go on an airplane and go someplace. But you might have to travel to Minneapolis or something for a doctor.

00:47:05 **Adele Costa**

I got to go to work every quarter.

00:47:07 **Lorie Ringo**

Yeah, right, but that's not important- your life isn't important to the insurance companies. So the doctors also are afraid to even ask for those things for you and so-

00:47:24 **Lorie Ringo**

having not just a doctor that knows about it, but it's an advocate for you when you go into the doctor and you say, I can't stand on a line in a store that's more than two people long because I start to get dizzy. So because of that, I need a wheelchair. Not because my legs don't work, but because I get dizzy.

00:47:46 **Lorie Ringo**

They don't know how to advocate for you under those circumstances.

00:47:54 **Lorie Ringo**

And I think we're in an upswing. Like back in the 90s, nobody knew what autism was. Now everybody knows what autism is. I think we're on an upswing with Ehlers Danlos- with all the connective tissue disorders because Ehlers Donos is not the only one. There's Lupus, which comes on you later, but there's Marfans, that's also genetic. And there's Loeys-Dietz. There's a whole bunch of things that give connective tissue disorder as doctors are becoming more aware of it. I think that's going to change the script. Oh, you need a roll later that's got a seat in it. So you can sit down when you're standing on the line. Let's get you a roll later. Your insurance should pay for that because you need it instead of having to pay the \$200 out of pocket, whatever it is.

00:48:38 **Adele Costa**

Yeah. You want to see the self advocacy and the heightened awareness lead to the systemic expanded access?

00:48:45 **Lorie Ringo**

Absolutely.

00:48:46 **Adele Costa**

Yeah. That's the hope for everything. That's why people- that's why everyone -Why is awareness raising important? Is because it's not awareness that the thing exists. It's awareness necessarily. It's awareness of how it impacts folks and what they need. Right? Yeah, that makes sense.

00:49:01 **Lorie Ringo**

And for us, when we go to physical therapy, if you sprained ankle had to go to physical therapy, you would go for, I don't know, six weeks, whatever, till the muscles built up, and then they figure you're well now and you're done. So your insurance company says, okay, this is how much time you get for physical therapy, and then you're done. For us, it's a lifelong process.

00:49:24 **Adele Costa**

You need it's a maintenance, thing.

00:49:27 **Lorie Ringo**

And we use it partially to get out of pain. Some of the pain that we're in, it doesn't take care of all of it, trust me. But that is also, for some insurance companies, not a valid reason to go to physical therapy. So they'll reject you. So what we do is we say we're trying to build the body back. Even though my physical therapist does -I do exercises, Yes. But there's - what's it called? Baby?

00:49:56 **Carter Ringo**

Myofascial release.

00:49:57 **Lorie Ringo**

Myofascial release that my physical therapist is doing on me now, and I'm gaining a little function back because of it because I'm not in so much pain.

00:50:11 **Adele Costa**

Right, so less songs and dance with the insurance companies about what we need. Yeah, that sounds about right. All right, guys, is there any final thing you would like our listeners to know? Usually people use this advice for others struggling or things you want folks to know about you.

00:50:30 **Carter Ringo**

Do not deny yourself aid or treatment - if you obviously have reasonable access to it. But if you think, oh, I'm not disabled enough to use a cane. If you're thinking about using a cane, use a cane. If you're thinking about needing a wheelchair, use a wheelchair. If you think you would benefit from it, do not deny yourself something that would benefit or improve your life because of people looking at you. If you're young and use a cane - I started using a cane at 16. Use it. It will help, and it will make you feel like more of a person.

00:51:06 **Adele Costa**

Yeah. Hear that, guys? All right, what about you, Lorie? Any final thoughts for our listeners?

00:51:10 **Lorie Ringo**

I'm just going to riff on that just a little bit. You wouldn't deny yourself your eyeglasses?

00:51:15 **Adele Costa**

No, I would not.

00:51:16 **Lorie Ringo**

They're the tool that lets you do the work of reading. So those assistive aids are the tools that allow you to do the work of living, right? The other thing I can say is don't feel bad about firing a doctor.

00:51:37 **Adele Costa**

Right? They they work for you. It's true.

00:51:40 **Lorie Ringo**

You're paying them. Your insurance company is paying them. Somebody's paying them on your behalf. Don't feel bad about firing a doctor if they are not doing the job that you're paying them to do, find a different one. Because I got to tell you, if you work for XYZ Company and you don't do the job well enough, guess who gets axed, right?

00:52:06 **Adele Costa**

It's person at XYZ company listeners. Absolutely.

00:52:12 **Lorie Ringo**

Apply the same standards that someone would apply to you, to your medical team. I have great physical therapists now, and I got to tell you, the current set of doctors I have, except for my GP, by and large, are women younger than me. And I think that age of person is flipping the script on the medical school education thing.

00:52:38 **Lorie Ringo**

They're starting to say more about this.

00:52:40 **Adele Costa**

It's a new generation of students, right? It's a new generation of practitioners. Right.

00:52:46 **Lorie Ringo**

And some of my doctors are old men and they're very good at their work. When you're looking for a doctor who's going to fully listen and understand if yours is not doing it, find a different one.

00:52:58 **Carter Ringo**

You deserve good medical treatment.

00:53:02 **Adele Costa**

Well, and you deserve to feel heard too, right? So even I would even say the NWHN strongly believes that if there's something in your gut, get a second opinion, right? If you're not feeling respected, if you're not feeling listened to, even if you think the treatment you're getting is good, there's no harm in seeking a second opinion, right?

00:53:19 **Lorie Ringo**

Absolutely.

00:53:21 **Adele Costa**

Well, I can't think of a better note to end on. So thank you both - my favorite parent and child duo here for being on with us today.

00:53:32 **Lorie Ringo**

Thank you. I hope this helps somebody.

00:53:52 **Adele Costa**

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