

Ep #36: Hypermobility MD Linda Bluestein



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Susi Hatelty

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Male Announcer: You're listening to *From Pain to Possibility* with Susi Hately. You will hear Susi's best ideas on how to reduce or even eradicate your pain and learn how to listen to your body when it whispers so you don't have to hear it scream. And now here's your host, Susi Hately.

Susi: With this podcast episode, I am delighted to be interviewing Linda Bluestein. And Linda Bluestein is with Bendy Bodies. She's the Hypermobility MD. And she is a part of the upcoming course that we are running on hypermobility disorders.

And I am delighted. Delighted to have her here to share her take on hypermobility, the experiences that she has working with the clientele that she serves. And we're just gonna get right into it in and dig in. So welcome, Linda.

Linda: Thank you so much for having me, Susi. I'm really happy to chat with you.

Susi: Super. So the one big piece of this is, as many of the people who follow me know, is that I've been working with people with hypermobility for a long time. It's not that people with hypermobility have come to me saying, "Susi need help with this particular scenario." Usually it's some other pain scenario and then in the conversation with them, they talk about hypermobility.

And interestingly, more people are talking about hypermobility these days, which is a reason why I wanted to create this course. And there's more talk about the spectrum of hypermobility. Can you share a little bit more about what is meant by the spectrum of hypermobility?

Linda: Sure. So when we talk about joint hypermobility, it's important to know that that is not a diagnosis in and of itself. That when we say joint hypermobility, that just means that a given joint has a greater than average range of motion as would expected for that person's age, gender, etc.

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And a person can have one hypermobile joint or many. And a person can be at a variety of different places along the spectrum. When I'm giving talks, I have a slide that I show where, you know, if this is the basket of all people that are hypermobile, inside of that basket, you're going to have people that have one hyper mobile joint, you're gonna have people that have lots of hypermobile joints.

Amongst those people that have lots of hyper mobile joints, those people would be called that they would have generalized joint hypermobility. A subset of those will have Hypermobility Syndromes or hypermobility disorders. And they can be from a variety of different causes. In fact, there's literally hundreds of different things that can cause hypermobility disorders. I should rephrase it the other way. Hypermobility itself can be caused by hundreds of different conditions.

So when we talk about hypermobility disorders, oftentimes we kind of now are breaking it into the subset of Ehlers Danlos Syndromes, which are a type of connective tissue disorder and the hypermobility spectrum disorders.

So when they brought in this new term, it is nice because to think of it as a spectrum is, I think, a very, very helpful concept. When someone's younger and their connective tissue is stronger, they have a lot higher content of collagen in their bodies. They're much more resilient, and they have a lot less wear and tear on their body, they are going to be functioning at a different level than somebody who's a lot older or has had a lot of injuries.

So people can be at different places on the spectrum, either because they have a different etiologic cause of their hypermobility and or because of other factors along the way, such as injuries, nutrition, trauma, different programs that they've participated in. Like the ones that you're doing, where they're working to build strength and developing things within their bodies may help keep them at a different place along the spectrum.

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So I think another interesting thing is to know is that people are not going to stay at the same place along the spectrum over the course of their lives. That it's very normal to move kind of up and down that spectrum. So I hope that helps, kind of just give a little groundwork for that.

Susi: And so when someone has EDS, for example, how does that then correlate to what you just said around moving up and down through that spectrum?

Linda: Okay, so EDS, which is the abbreviation for Ehlers Danlos Syndromes. That is a group of, we now know, 14 different disorders. There are 14 different subtypes of Ehlers Danlos Syndromes. And amongst those 14 different subtypes, 13 subtypes can be diagnosed by genetic testing. Okay? The last subtype that cannot be diagnosed by genetic testing is called the hypermobile type.

Well, unfortunately, the hypermobile type is by far the more prevalent of the subtypes. The hypermobile type literally accounts for between 80 to 90% of cases. So at this point in time, we have not yet identified a single gene or a group of genes really, that explains this grouping, this hypermobile EDS grouping. So at this point, it is a clinical diagnosis.

In 2017 new criteria were introduced by an international consortium that tried to help really solidify the nosology and make it much more clear what does it mean when somebody says hypermobile Ehlers Danlos Syndrome. Because prior to that, there were a lot of different terms that were being used. And maybe some of the listeners will be familiar with terms like joint hypermobility syndrome or, my least favorite one, benign joint hypermobility syndrome.

I literally still see providers that either send patients to me or the patient will self-refer to me. And in their note, it will say benign joint hypermobility syndrome. And they removed the word benign very, very intentionally because there's nothing benign about these conditions. People have a lot

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of pain, or they can have, excuse me. They can have a lot of pain, and a lot of impact on their quality of life.

So the Ehlers Danlos Syndromes are, collectively those 14 different subtypes collectively, are the most common connective tissue disorders. So that means that they are the most common type of condition where our bodies have a genetic code that is faulty for making our connective tissue, which is literally present everywhere in our bodies, it's in our tendons. Boy, I just combined ligament and tendon into one word and created a new word, tendoment. So whether it's tendons, or ligaments, or muscle, or fascia, or the walls of our blood vessels in our gut. Connective tissue is everywhere.

Everywhere in our bodies, it's one of the only four types of tissues that we have in our bodies. So it makes sense when you really think about it, if a person has in their genetic code, if their genetic code is writing for improperly formed collagen, or one of the genes that codes for something related to collagen, that then they could have problems anywhere in their body. That they could have problems in multiple different systems of their body because of the fact that connective tissue is so diffusely present.

Susi: Now, what I find fascinating with a lot of my clients is that there is a pattern between their mental health, anxiety predominance, and more of a lack of proprioception. Now, they also can be very sensitive to their external world. And they can be very sensitive to their internal world, but this idea of proprioception seems to be lacking. And this mental health piece of anxiety seems to be very present. Can you talk about that correlation?

Linda: So first of all, I have to tell you, when you emailed me and asked me some of these specific questions, I was pretty blown away to be honest. I was really amazed at your depth of understanding of these issues. So first of all, I was extremely impressed because you're spot on with all of this.

So, first of all, we could probably spend two hours talking about any one of these topics. But let's first take the anxiety piece. Anxiety is extremely,

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extremely common with hypermobility. We know that if you take a clinic of people that have anxiety as compared to other diagnoses, and you look to see how many people are hypermobile as compared to the control group. So the control group has a different diagnosis than anxiety. You are going to see more hypermobility in the anxiety group than in the control group.

And you can do the exact same opposite or corollary step with looking at a clinic of people that have hypermobility as compared to a different rheumatologic condition. And you can see that the people who have hypermobility have a greater prevalence of anxiety as compared to the other rheumatologic condition.

So we know the overlap between hypermobility and anxiety is absolutely huge. Why is that? No one knows 100% for sure. But there are a number of interesting things that have been found through research studies, including larger amygdalae I think would be the right way to say. I'm going to make up another word here. The amygdala in the brain of the person with a hypermobility disorder can be bigger than in a person who does not have a hypermobility disorder.

And the amygdala is the fear center of the brain. That's the part of the brain that you know makes sure that we run away from the tiger that's chasing after us. So it's not surprising in a way that we would have... I believe there's only been one study looking at this because, you know, they had to do MRI, they did functional MRI testing on these subjects. So it's not like they looked at hundreds and hundreds of people. But it was a big enough sample size they did find statistically significant differences in the size of the amygdala in these two groups.

And we also think that part of this difference with anxiety could be due to the differences in proprioception. So, for people who don't know what proprioception is, proprioception is knowing where your body is in space without looking. And so that's a very important tool to have, or skill to have. Knowing whether or not you are hyper extending your knee, as you're

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standing on it is very, very helpful. Because ideally, we are standing on a knee that's not hyper extended.

If we have “normal” range of motion and our knee doesn't back bend, then our knee stops at a “more normal” place. And we don't have to put in that effort engaging our muscles in order to make our knee have like a little micro bend. You know, is kind of what I try to explain to people, you want to stand with a little bit of a micro bend in people that have hypermobile knees.

People that have hypermobility, they're going to go to that end range oftentimes, and they don't have the correct type of relationship with their sensory receptors in the joint in order to get that proprioceptive feedback. And so we think that that may also contribute to anxiety. Because if you don't even know where your body is in space, that can increase anxiety.

So there's a lot of theories about the proprioception piece and how does that relate to anxiety. And then the third factor that can be important when it comes to anxiety is adverse childhood experiences. Have you heard about those?

Susi: Mm-hmm, yes.

Linda: Okay. So we know that adverse childhood experiences, or other type of traumatic experiences can greatly impact the amount of anxiety that a person feels. And a lot of people that have hypermobility disorders, they may or may not have had adverse childhood experiences, like illness in a family member, or divorce, or emotional or physical trauma, something like that.

But if they haven't experienced that, a lot of them have experienced some other type of like traumatic medical experience, for example. They went to the doctor in extreme pain, and the doctor said to them, “There's nothing wrong with you, you're perfectly fine.” That is one of the absolute most devastating things that you can do as a healthcare professional. And it's

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something that I think a lot of people don't realize, that if a person is coming in pain, they don't want something wrong with them, but they want an explanation.

And rather than saying, there's nothing wrong with you, it would be much better to say the test came back normal, I don't see an explanation at this time. You could even say I don't really know where to turn to next. But don't lead the person to believe, number one, that you don't believe them. Number two, that you're not validating their experience. And number three, that they should be doubting their own experience.

So these types of experiences can be very traumatic, these experiences with healthcare professionals that a lot of people have had. A lot of people with hypermobility disorders have had these experiences. And these can lead a psychological scar that can be difficult to work through and can increase a person's anxiety, you know, for some period of time. It's not that they can't, in many cases, improve that. But they need support, they need our understanding, they need our compassion. And again, we can say we don't know. But we need to be saying we don't know rather than making them feel like they're crazy. So that's the anxiety piece. Do you want me to go on about interoception exteroception?

Susi: Yeah, before I go there though, I think what's so validating listening to you speak is it's what I find, like a big piece of my work, because I see so many people who have a persistency in symptoms and that they might gain some positive gain. But then that tends to be occasional, and they're kind of running after and chasing this thing.

And when I work with them, a big piece of it is how can I help them regain or just gain an internal locus of control? And when I help them do that, initially through their body, invariably we see it as well in their mind. And there's this sort of sense of ground.

And what I hear you saying is it's like, which happens unfortunately a lot within a lot of arenas of our life, not just in medicine. But it's like when we're

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saying to someone, "What you are feeling does not exist." Then if they're little or if they are somewhat, I'm not sure how I want to say this. But there's a power dynamic that is out of whack. And so then they believe the authority figure. And then they must say, "Well, whatever I'm feeling must not exist." So then there's that lack of internal control.

And so when I help them bring that back, then it makes complete sense why their pain can go away although the condition doesn't change. Because the condition is the condition, the physiology is the physiology, the anatomy is the anatomy. And how they live inside of that is what is changing.

Linda: Yes, I'm glad that you pointed that out because you're absolutely right. The power differential is very, very significant and can definitely play a significant role. And that is true, not only with, like you said, outside of healthcare professionals, but within family relationships as well.

Susi: Yes.

Linda: So that is a very, very important piece, yeah.

Susi: Super fascinating. So yes, now let's play around with this notion of their increased interoception and exteroception, and what you have seen in that realm.

Linda: So this is so interesting. So again, for listeners who are not aware, interoception is awareness of what's going on inside of yourself, inside of your body. And exteroception is awareness of what's going on around you. So like reading a room, for example.

And I remember, gosh, it was probably only 10 years ago or so that I was talking to someone and they asked if I thought I had a good... What was the word that they used? Because they didn't call it interoception or exteroception, but they asked... I'm going to have to make up another word again. But they asked me if I thought I was like, you know, well tuned into

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those kinds of things. Intuitive, that's what it was. They asked me if I thought I was an intuitive person. And I was like, not particularly.

We only know what our body feels like, we only know what it's like to be us. We don't know what it's like to be anybody else. And they helped me to realize that, like, I thought my husband could read my mind. Because I pretty much could feel like I could read his. But he was completely clueless about, you know, maybe what I was feeling. And likewise I would be in a boardroom with people, and be much more sensitive to the air changing and things like that. Sometimes I've joked that I can feel every cell moving around in my body.

People who have connective tissue disorders do tend to have increased interoception, awareness of what's going on inside their bodies, and exteroception. Or again, that being super intuitive type of sensation that they walk into a room, and they can really tell that something is off, or that someone is, nervous or anxious.

Which, I think, leads me back to the anxiety piece. Which is that we know that we are energy beings, right? And we know that if someone else is depressed, we are likely, if we spend time with that person, especially in more close physical proximity, we may start to feel depressed. Likewise, if someone else is anxious, and we're spending time with them, we are more likely to be anxious. We pick up on each other's emotions and mood and things like that.

So if we're more predisposed towards anxiety anyway, and then we have this greater awareness of what's going on around us. These are genetic conditions, so we have family members that have anxiety, usually. So that is going to increase our anxiety in many cases.

So I love what you're doing with the grounding and internal locus of control. Because I think it's so, so important that people have tools that empowers them and gives them back some of that sense that they lose with the poor proprioception of, you know, "Where am I in the world? Where do I fit in? I

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don't even know where my joints are, much less what my role is or where I'm headed.”

You know, anxiety is all about the future. And people who have a lot of hypermobility have a lot of anxiety or connective tissue disorders, somewhere on that spectrum. You know, we tend to worry more about the future than a lot of other people who are, “Eh, whatever it's going to be.” Part of it is we've learned from being injured. And having all of this sensory and nociceptive, or painful input into the nervous system, that people can become fearful of movement. Because oftentimes people have injured themselves doing very simple things.

I was speaking with a very, very highly ranked professional dancer, current professional dancer. And he was telling me that he tore a bunch of ligaments in his wrist picking up a dumbbell. And, you know, if you can injure yourself doing something that simple, you know, your nervous system remembers that. And that makes you more anxious because you don't know when the next thing might be coming.

So really when you start to really put it all together, it really starts to make a lot of sense.

Susi: I love that whole mind body connection because the other symbolic piece that I also see is many of my hypermobile clients are also very adaptable. Right?

Linda: Yes.

Susi: They can be very flexible, right? Which I always find so fascinating. And I often will say to them, initially, those who their hypermobility has been one that has been more so trained, as opposed to genetically acquired is they tend to go for certain kinds of sensations. So for me, it's helping them. And even for those who have genetically arrived with hypermobility there's another sensation inside of them that I'm helping them find, that is distinct

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from going after that big stretch sensation. Which tends to enable more hypermobility than less.

Linda: Definitely. And that reminds me of a paper that, I think, the abbreviation was EAET. It was a paper about fibromyalgia, and they looked at the different psychological strategies with people with fibromyalgia. And they compared CBT, cognitive behavioral therapy, versus this other therapeutic approach. And I think it stood for expressive something, and it had to do with people that had fibromyalgia were not as assertive and were not as likely to really say what they thought. You know, they were more likely to be people pleasers. And like you said, that flexible, go with the flow, you know, I don't want to rock the boat kind of a thing.

Well, you know, I often will tell people that if you don't listen to your body, if you don't listen to the messages that your body is telling you, it will keep screaming louder and louder at you until you finally listen. And then once you start listening, you can really learn to tune your ear into your body, into a way that is really helpful. Because I think what ends up happening is oftentimes, then we start listening to our bodies, and then we start to get anxious with any little sensation. And then we are aware of so much, and we're like bombarded with sensory input.

So it can be hard to sort all of that out. Because psychological pain and physical pain are both processed in the brain, and are processed in the similar areas of the brain. So we need to be able to sort through these things in order to have the most healthy psychological and physical life.

Susi: I love that. I utilize an analogy with a traffic light, and that the whispers or indicators in your body are like the yellow lights. And the yellow lights let us know the reds coming. And to help people discern between a fresh yellow, which often people speed through and go faster, and put the gas pedal down harder. Versus the stale, which is when they might, and where I help them learn how to brake a little bit and slow down.

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But then that yellow light becomes so important because they're sensing into what those yellow lights actually are. What those whispers are that are ones to pay attention to versus ones that are not maybe necessary to pay attention to.

Linda: I love that. That's a really great visual. Also I feel like another huge advantage of that is it kind of takes out the judgment piece. Our society, we are so, you know, the way we put certain people up on a pedestal. You'll hear about a football player, you know, not to put down any particular football players, I won't mention any names. But you know, you hear about somebody who, oh, they broke a rib and they continued to play through the whole thing. Wow, what a hero. It's like, well, but was that really the best thing for them to do?

So I love that nonjudgmental approach, just observational type approach.

Susi: Yeah, that's great. So let's move the direction now towards the yoga world. And I think some key questions, given that a lot of the people who are listening to this have a foot solidly in the yoga world, many of them are yoga teachers. With your experience, what, as yoga teachers, and even like fitness leaders and Pilates instructors, like any really within that spectrum. What can we notice and what can we improve our ability to see, to help work more effectively with our hypermobile students?

Linda: So, a few things. The first one that I would say is, it's really super important to remember, no matter which way you want to think about it, N equals one, or owner specific diagnosis, or highly heterogeneous conditions. Those are three different ways, basically, of saying that these conditions are highly variable in different people.

So, we always want to make sure that we are... You know, there might be two students in your yoga class who they both may come to you before they start the class and say that they both have a hypermobile EDS diagnosis. And they both have, you know, say for example, a POTS diagnosis, postural orthostatic tachycardia syndrome. Which is where you

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have difficulty tolerating upright posture. So they get dizzy, lightheaded, their heart races.

So they've told you that they have the exact same two diagnoses. Let's say that they're the same gender, and that they're the same age even. But they probably still have vastly different bodies. Now, of course, experienced yoga teachers are really going to already know that, and experienced athletic trainers, and physical therapists etc. But I think it's just always important to remember that some conditions are more uniform than others. And these conditions are not uniform at all. So that's the first thing.

The second thing is to remember that, or to know that yoga can be hugely beneficial for people with hypermobility, if it's done in the correct way. And the person needs to be given permission to, again, like we said, like you said, with the green light, yellow light, red light type thing. That they need permission to not do certain poses and things like that. And to really make it so easy for them to not do it. Because a lot of us don't want to stick out, right? So even if you say that, like they still might try to do it. And they might be thinking, "Oh, I'm not sure if that feels right."

I know I went to a yoga class maybe 15 years ago. And they told me that before I started, they said if something doesn't feel right, don't do it. But I was kind of embarrassed to not be doing what everyone else was doing. Now, of course, at different points in time people have their eyes closed, so why should I care? But I still didn't want to stand out.

So I think, you know, really make it very, very comfortable for someone to listen to their own body. And that it's completely normal for people to be making modifications during the class. That modifications are not only accepted but they're expected, you know, for people to be incorporating these into their yoga routine.

And lastly, I would say that there's a huge difference between joint hypermobility and joint instability. So these conditions under this umbrella that we're talking about, that can be referred to as hypermobility disorders

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or hypermobility syndromes. We use the word hypermobility, not joint laxity or joint instability, because hypermobility or increased range is easier to study. But joint laxity is probably the more important feature.

So I have patients that are more like Gumby, which you know, I'm probably dating myself, maybe some of your listeners know who Gumby is and some will not. But Gumby is this green creature that you could kind of mold into different shapes and was very flexible. A little like toy that when I was a kid you could have. And other bodies are more like Raggedy Ann. And Raggedy Ann is a floppy rag doll.

And so some people might be very hypermobile. But yet, they don't have a lot of problems with joint malposition. And other people might not be as hypermobile, but they have a lot of laxity. They have a lot of difficulty with maintaining joint alignment. And then you're going to see everything in between.

So it's very important to be working with, I would say if they're on the more extreme end, then they probably would benefit from at least some one-on-one work. As compared to people that are more stable, you know, doing better from a pain standpoint, they might be safer in a group class. But I think a lot of people that have hypermobile bodies, they really would be best served with a considerable component of, if not one on ones, like small group and that kind of thing.

Susi: That's terrific. What's so lovely about that answer is there are a lot of physicians who don't either understand enough about hypermobility or they don't understand enough about yoga. That they'll simply just tell their client patient to just stop practicing. So that's a really great way of arming, if I could say the word arming, the person as they go into their yoga practice, whether it's in person or whether it's on Zoom these days. That they can start that process of listening.

And it could actually be the Zoom classes may actually be that much better because they're not amongst a whole group where someone can actually

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see them move. And they can actually start that listening process for what sensations to pay attention to.

So that's great, because I know there's a lot of people who love yoga and then are told they can't do it or shouldn't do it. And then it's like, "Crap, now what?"

Linda: Right. And the really ironic thing is that, for example, like for me when I was 16 years old as a dancer, and I was already having joint pain. I went to the doctor and they told me to stop dancing.

And number one, that's the worst thing you can tell a person. Because number one, psychologically that is so damaging. I identified myself as a dancer, like, first and foremost, before anything else. All I wanted to do was dance. I wanted to be a professional dancer more than anything else in the whole wide world. And somebody telling me not to dance was just, you know, it's like they tore the rug right out from underneath my feet.

And then three, if you tell someone not to dance, don't do yoga, or something that they're doing for their bodies, that if they modify it and do it in a different way they can retain as much strength as possible. And be incorporating movement strategies in a way that will actually help them be able to move better for longer. Now you've just taken that away from them. And if you don't give them something else to do instead, which usually they don't, it's really yeah, that's a really harmful approach. And unfortunately, it's one that exists in many, many places.

Susi: So, what I want all the listeners to get here is that Linda and I are really about changing that. And how as you're able to listen to those quiet nuances within. And sometimes that might sound a little bit difficult, but once you, as you mentioned, you used a great phraseology actually, which was when you tune your ear to it, not only does it become beneficial. And I would even add that it becomes quite powerful. Because then you've got information that is yours and yours alone that you can then measure

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against and measure for relative to like choosing whatever activities that you're doing.

And so when we're looking at the course that I'm hosting beginning of this April, it's really helping you come into this place of feeling rather than fixing. And this idea of you have, or your clientele has a unique connective tissue and what does that mean for you. And discovering really and being a scientist and being curious about what that actually means in terms of what you can do. And so it becomes very, very powerful in terms of stepping into your own uniqueness.

And then as a teacher or a healthcare provider, you get to become a trusted advisor. You become one of those who's not saying, "Well, you just can't do that." You're one of the ones who says, "Well, you know what, I don't know. And here are some resources for you to explore. Here is a pathway that you can follow." So that you're not letting the person just leave the office with some with despair.

Linda: Absolutely. And what you're doing is you're teaching them how to fish, not just giving them a fish.

Susi: Yes, I love that line. I love it. But you know what? If someone is actually saying, "I don't know." Or if they're saying, "Don't do something." They're not even giving them the fish. They're taking the whole tackle box away.

Linda: Right. Right. Yeah, that's exactly right. They're taking the whole tackle box away. The approach that you're taking though, is teaching them a very special skill that they can use for the rest of their life.

Susi: Yeah.

Linda: Extremely valuable skill.

Susi: Yeah, and so important for anybody, but particularly in the context of hypermobility. So important in terms of really understanding your own

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unique nature and the individual characteristics of what this is for you. Because as we've been speaking about, I mean, there's such a huge spectrum. Some hypermobility is something one trains for, some people are born into the world with it. And so you get to explore what that is for you.

I think where I'd like to finish up is if someone is working, or maybe they're going in for surgery. I've got a number of clients who've had to go in for surgery for something else that might be related to their hypermobility. And some of them might have white-coat syndrome. Like they're really nervous because of scenarios that have happened in their past within the medical community.

So what would be some like little tactics that they could go in with? More physicians, I know, know more about hypermobility, it is becoming more mainstream. What would be something that a client who might be nervous going into a medical appointment or they know they're going into surgery, that they could say to the physician and say, "Hey, listen, I need you to listen to me on this one. This is what I..." Like, can you give some ideas just to arm them with some tools?

Linda: Right, so from a practical standpoint, I don't know if you know this or not, but I am an anesthesiologist. Did you know that?

Susi: I did not know that.

Linda: Yeah. So I trained as an anesthesiologist. And then I worked in the operating room for over 20 years. And I have EDS, I have hypermobile EDS. And my own EDS caused some medical problems that led to a change in tactics, and ultimately led to my not being able to work as an anesthesiologist in the operating room anymore.

But that's when I opened my pain practice. Because I thought, well, I've learned so much about how to take care of my own body, having been only

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diagnosed in my 40s, that I might as well help other people with this as well.

So I have many, many, many years of experience. Not just as a physician but working in the operating room specifically. Working with, you know, all of my friends were anesthesiologists of course. And hanging out with surgeons all the time, because that's where you live. I mean, you spend more waking hours in the operating room that you do anywhere else. So I definitely understand the surgeon's mindset. I also happen to be married to a surgeon, so I definitely understand their mindset.

And it can be very challenging, because your question is multifaceted in my mind. One is, you know, is this person going to take seriously your medical situation? And from a medical standpoint do you feel like you're in good hands, that they will be incorporating properly the potential risks for you?

So for example, some people that have Ehlers Danlos Syndrome, they might not heal as well from surgery. So they may have more issues with breakdown afterwards. So like the wound might break open, for example. Now, some people would have that anyway. But that doesn't all by itself mean that you for sure do or for sure don't have that condition. But there are certain types of scarring on the skin that you might be more likely to have.

And so there are a lot of surgical factors that are important for the surgeon to know. And there's also a lot of important things for the anesthesiologist to know.

So for example, say you're having back surgery. After you go to sleep, the team actually... Say I'm your anesthesiologist, I put you to sleep, I put the breathing tube in. Well, now you're completely asleep, we're going to roll you from your back onto your stomach onto the operating room table. Well, if you have joints that dislocate, now I just paralyzed you and took away your muscle tone. And so when I roll you onto your stomach, if I don't know otherwise, I potentially could dislocate a joint.

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And it wasn't until after I was no longer working in the operating room and learning more and more about Ehlers Danlos Syndromes that I realized how little I knew, when I was practicing as an anesthesiologist, how little that I knew about EDS.

Now, in fairness, we're learning more and more about these conditions with time, right? So a lot just wasn't known back then either. But I didn't know about necks and how necks can be unstable. Even if there's not like a diagnosed unstable condition in the chart. If a person has neck pain, they have certain features that would be worrisome, this is a potential problem.

Anyway, so I created, I wrote a paper first of all with Dr. Pradeep Chopra. He and I wrote a paper for anesthesiologists and surgeons to be aware of potential complications for this group of people having surgery. And that paper is open access.

So people could go to my website, so hypermobilitymd.com. And then if you go to in the media page, and then you click on the, I can't remember what it's called exactly, but it might be perioperative care in the Ehlers Danlos Syndromes, I think is the name of the paper.

So if you click on that link, then you'll find the paper. And you could print that and take it to your surgeon and say either, "I've been diagnosed with this condition." Or "I suspect that I have this condition. And I heard about this paper and was wondering if you'd be willing to read it." Or at least go through it yourself and maybe highlight a few things that you are particularly concerned about.

So say you've never had an issue with your neck, great. But you have other particular things that you're concerned about. You're better off really focusing on those two or three things, than just handing them the, I can't remember how many pages it is. 10, something like that when you print it out on paper.

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But I also created a card, a wallet card that has compacted a lot of the same information from the paper. I think I created the card before we wrote the paper. But anyway, the card is also available on my website, and you can print that from my website as well.

And that's, from a practical standpoint, giving your surgical team some information that you know, "Hey, I think this might apply to me. You know, I would really appreciate it if you'd be willing to take some of these precautions." Most of them are things that are not going to hurt you if they take these precautions and it turns out that you don't actually have EDS, for example. If that makes sense.

Susi: Yeah, I know that's really, really terrific because it gives them either the wallet card or the paper and some scientific meat that is often useful to go into an appointment with. So that then when they're talking with the surgeon it's coming from a place that they're familiar with, and that's a paper.

Linda: Right. And Dr. Chopra is also an anesthesiologist by the way. And he also practices pain management specifically in the Ehlers Danlos Syndromes.

Susi: That is fascinating.

Linda: And we're the two co-authors, yeah.

Susi: That is fascinating. Well that has been terrific. I mean, we could talk and talk and talk about this all day long and in part we have an opportunity to listen to more of what Linda has to say in the course that I'm running from April. And you can find the link in the show notes. It's functionalsynergy.com/hypermobilitydisorders.

If you want to check out Linda more specifically you can find her at hypermobilitymd.com.

Thank you so much, Linda, for today.

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Linda: You're very welcome. It was great chatting with you.