



The  
**Ehlers  
Danlos**  
Society™

**The Ehlers-Danlos Society**

P.O. Box 87463 · Montgomery Village, MD 20886 USA  
Phone: +1 410-670-7577

**The Ehlers-Danlos Society - Europe**

Office 7 · 35-37 Ludgate Hill · London EC4M 7JN UK  
Phone: +44 203 887 6132

[ehlers-danlos.com](http://ehlers-danlos.com) | [info@ehlers-danlos.com](mailto:info@ehlers-danlos.com)

# The Mind-Body Connection

Lara Bloom

The EDS Global Learning Conference 2019 Nashville

Video <https://youtu.be/HlxGFRPq-YO>

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[00:00:06] **Lara Bloom:**

So, I'm going to kind of talk to you about the, the mind-body connection, and how important it is to have that concept, and to more importantly, really grasp what it means.

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Okay, so we have some pictures here. we've got Laura Sylvester in the room? She in here? Laura here? So, Laura runs Mind Body EDS, which is the stand just outside there, and one May Awareness Month, we—a couple of years ago, we started a May campaign, "It's Our Time," and we asked everyone the average time to diagnosis, and it was averagely around 12 years. And I think it was a year later, that Laura turned this into more of a visual campaign, and asked everyone to raise their hands and show how many years it took. And you can see from this picture, some examples of that here. And I think, you know, one thing that unites so many people living with EDS and HSD, is just how long that journey is. And not how long it is, but how harrowing it can be as well. And I think that that is

something for, not just our community to take like—take into their—their minds, but critically, healthcare professionals. When someone living with these conditions walks into your room, they have been on a diagnostic odyssey. And it's been hard. And it's been long.

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And these are some of the things that you stumble along on the way, some hurdles that I think consistently, no matter where we, we are in the world, whatever conferences we attend, you just seem to hear the same things. The US always think the UK have it better. The UK think the US have it better. They think that it's better in Paris. Where should I move to? Where's the best place for me to go? And the answer is, right now, there is nowhere that's got it right completely. There is a lot more to be done. Everywhere you go, in the most progressed countries around the world, these hurdles are there. People are called hypochondriacs. They're not believed. There's child protection fears because of Munchausen's by proxy, and we call it FII in the UK. Over-medicalizing. Sometimes the physical side of things, with the bruising, the bleeding with the rarer types.

It's deconditioning, you know? When I see people in chairs, often that's, that's a really positive thing, and it gives you better quality of life, but often it's because these people have been neglected and left to decondition, and get sicker and sicker every single day, and it is simply not good enough. And so, people are just left to get worse, physically and psychologically.

You have multiple doctor visits. There's no one that understands what this is. There's some people that don't know what it is, so you go, and you seek the next person that might be able to give you something. Some answers. A reason. Sometimes, you'll get in the room with the person you've been waiting a few years to see, and you still don't walk away with what you hope for, and you know that you can't easily go back to them because you'd have to wait another two or three years. Sometimes you get in that room, and you have a decade of questions to get through, and symptoms, and you've got 60 minutes to get a decade over and across. And you lose your, your words, and you forget, and you get emotional, and you're fatigued, and you might be having a bad day anyway; and you walk out and you go, "Oh my god! I didn't mention that one thing!" And it's hard and people don't realize that. And I think that people have to be mindful of that as well.

People aren't believed. And not just from professionals. By your parents. Your friends. Your husbands. Your wives. Your siblings. When you want to go out, you might have had a really great night, you're at the bar, you're

dancing, you're jumping around, and the next day you can't even lift your own head up. And you even sometimes got your mum going, "I just ask you to do the dishes. You were out clubbing last night." Now, sometimes that just might be because you don't want to do the dishes, but often, it's because you just are having a bad day. And there's no rhyme or reason. You could have had a day on the sofa just watching Netflix, and the next day you can't lift your head. It's not because you might have gone hard—I mean, we're all gonna need a hell of a week of downtime after this, right? So, sometimes there's, there's very real things that cause that the ups and the downs, but sometimes it's nothing. There's no reason. You're like, "Why am I feeling so terrible?" And you don't have the answers to it. And that's really hard, not just for you to comprehend, but then imagine the person watching in on it, to comprehend.

And so, I think for us as patients, the people living with this, sometimes it's important to be mindful of that. That this is hard. Sometimes give people a break. It's hard to be a zebra, but it's quite hard to love a zebra too. And I think a lot of parents and partners in the room will feel that. So, it's about communication. Saying, "You know what? Right now, I'm having a bad day, and I don't know why, but just allow me to have that day. Make it a safe space for me to have a bad day." But most importantly, make it a safe space to have a good day. Because what I see time and time again, and I mentioned this at the end of, of the documentary "Issues With My Tissues," is that it becomes much harder to have the good days, because then people don't believe them because of your bad days. So, people then kind of revert to a safe space of just being in that bad, bad day space because it's like, okay, people will just get this. It's consistent. It makes sense. So, I'll just stay in this place, because if I maybe get up off of the chair and I'm able to walk 5,000 steps one day, the next day when I need my chair, no one will believe me or understand it. And we need to get to a place where you can run, you can walk, you can roll, you can do whatever you need to do, on whatever day that is, and people won't question it. People understand it.

And we're desperately trying at the Society, to educate in that way. To have webinars. To have talks. To have these events. So, that not just people living with this understand, but your support systems around you understand as well. There's also very real insurance concerns. I'm very blessed to come from the UK, where we have the NHS. I mean, it's not perfect, but I you know I don't take for granted that if something's wrong, I

can go to the Accident Emergency Room and be seen for free at any time. See specialists, there's often long waits, and often in the UK, people who want the best care having, have to end up going the private route anyway. But in the US, I know, that you're scared to almost get the diagnosis, because that might impact insurance, or not get the diagnosis, because then you won't get the care, and it's a really mixed bag of fears. So, it's another thing to think about on that really long journey.

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And this is what I want the take-home message to be for everyone. All 3,000 of you tuning on, on livestream at the moment. All the people that are going to watch this back. It is not in your head. Don't let anyone ever make you think that it is. But most importantly, please, do not feel threatened that we are sitting here and very actively telling you to remember to build a bridge between your mind and your body.

It doesn't mean we're saying, that after all these years, after that long road with all the hurdles, that we're now saying the way to cope with it is in your head. We're not saying that's because it's in your head. [inaudible] ... from how you move. When you breathe. Moving your hands, your legs. Everything comes from your mind, your brain. It controls everything. If you imagine anyone, anyone in the world—old, young, healthy, sane, insane, whatever you want to call it, every single person in the world. If you imagine that they have spent years, decades sometimes, seeking an answer for the reason they're feeling everything. Having chronic pain, chronic fatigue, myriad of multi-systemic issues. Being accused of being a hypochondriac. Being questioned constantly every day. No validation. They finally get a diagnosis, and they're told they've got something that has no cure, very little treatment options, very little management, and then you're left back out there in the wilderness.

How do you not need psychological support to deal with that? I don't know anyone that would be able to go, "Cool! Thanks, I'm good."

*[Laughter]*

"I'm gonna go off and live my life." It's impossible. So, don't be threatened by the fact that we are pushing hard that psychological support should be offered to everyone diagnosed with EDS, HSD, and every single chronic and rare disease. I don't just speak publicly about EDS and HSD, I represent as many rare conditions, chronic conditions as I can, and it's the same everywhere. This isn't special for EDS and HSD. When you go and you get diagnosed, I mean let's, let's not even discuss about the amount of physical options that are not offered. We know we have that

issue. People should be offered a full MDT team. They should be offered all the physical care and management they need. but they should also be offered the psychological management they need, to be able to take on what they have to deal with every day, for the rest of their life. So, don't be scared. that is the biggest message I want everybody to take from this. Don't think that if you need psychological support, CBT, mindfulness, meditation, counselling, whatever option it comes in, that that doesn't [in]validate your very, very physical, real problem. It is not in your head.

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The long journey leads to multi-systemic issues physically, but also it leads to even more fatigue: fatigue of the body, the mind. Fear. Petrifying fear. Will I end up in a wheelchair? Will I have every comorbidity, associated symptom/condition that there is? Will I ever find someone that will love me? Will my parents understand? Can I go to college? Can I go to school? Will I get a job? Real fears that you have to deal with. Pain. Physical, emotional pain. Anxiety. Depression. And something that we're talking about more and more, and I'm really excited that we've, we've brought over Dr. Chad Shepherd from the UK to talk about this concept of PTSD. This diagnostic odyssey is a battleground, and we are wounded from this journey, and this PTSD is real. We are seeing people living with PTSD because of that journey to diagnosis. So, when they get to the point where they're diagnosed, the symptoms of that, which again, are very real—no one would tell a soldier that his PTSD or her PTSD is not real—and shouldn't be [in]validated. It is real and it needs to be focused on, and talked about, and not feared.

And what I see time and time again on forums and on social media, is this reluctance of this being discussed. "Stop saying that because it means that when I go to my health care provider and they hear your talk, that they'll think it's in my head." Well then, you're not listening to this talk properly, because that's not what this means. There were some recent published researches, reached—research that states, "Invalidation of a person's most basic feelings, is one of the most psychologically damaging things one person can do to another. Empathy is both healing of wounding and the prevention of it." I would like every single healthcare provider that ever watches and listens to this, to really remember that. I'd like you to all remember that. And try it and get as much validation as you can through education, through the resources that we provide.

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And reach out to us. Reach out to me personally. These are our contact

details: [helpline@ehlers-danlos.com](mailto:helpline@ehlers-danlos.com). We have an incredible helpline team. We have 28 free phone numbers for people to dial. We have an incredible infrastructure in place now to help as many people around the world as we can, to really be believed. Be treated. Be managed. Be cared for. The validation needs to happen everywhere. And remember, it is not in your head. Thank you.

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