



The
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The Mind-Body Connection

Marisa Bergfield

The EDS Global Learning Conference 2019 Nashville

Video coming soon

[00:00:00]

[00:00:09] **Offscreen:**

Woooooooooooo!

[00:00:11] **Marisa Bergfield:**

Oh wow! Thank you! I appreciate that! Alright. Okay, good morning everyone. I'm so happy to see you all here. So, as the lovely Miss Bloom has said, my name is Marisa, and I'm a training clinician. I also have hypermobile EDS myself, and I have first-hand experience of having very real physical symptoms being dismissed as mental health, but I also in turn, have dismissed my own mental health symptoms in response, or just because I didn't have the information that was needed. So, my goal today is to share some of the current literature with you on mental health and EDS, as well to empower you, to get you thinking and feeling as if you are, in fact, the own driver, for your mental and physical health. So, in our, in our next slide that's going to be coming up here, we have a wonderful depiction of—if anyone could click that for me. Do we have a...

[00:01:15] **Lara Bloom** (Offscreen):

There's a clicker up there...

[00:01:16] **Marisa Bergfield:**

Oh! Fabulous. Let me see. Oh, it was hidden. Give me a moment to see if it—hmmmm. Ah! See, now I'm the driver of my own presentation, too! This is working out lovely. Alright. So, fabulous.

[00:01:28] So this slide right here, documents all of our current, that we are aware of, types of EDS—and that my, my lovely colleague, Jack, made for us. So, while all of us are zebras, not all of our stripes are the same, and one of the things that I absolutely love about this conference is that for some, this is the first time that you're meeting other individuals that also have EDS, maybe even specifically your own type. And this gives us an idea of different experiences, unique and, how sometimes we can differ from each other. So, today I wanted to make sure I can kind of capture as much information as possible, but I recognize not everything will apply to you right now, but maybe in the future, and maybe you know someone that it does apply to. So, when we're looking at—

[00:02:16] Skip through—so when we are looking at research, one of the big things that we see, is the prevalence of anxiety. So, when you're looking at mental health research, we—this is the number one thing, that it's likely that you're going to find. So, Bulbena et al. actually found that 70 percent of individuals with EDS had anxiety, versus a significantly lower amount than what is in the control group. And since this landmark study in 1988, there have been a handful of other studies that have done similar research, that have found almost identical numbers. That really solidifies this prevalence of anxiety within our population. More specifically, a meta-analysis was done, and that just looks at all the different literature that existed at that time in 2011, and it specifically found that there was a greater perception of fear, as well as a greater fear intensity. In addition, we also saw there was a higher probability of a diagnosis of panic disorder and agoraphobia. Agoraphobia, being a fear of, or avoidance of situations that would cause significant panic.

Additionally, we've seen quite a few pieces of research come out on depression. I think one of the most significant findings is the fact that those who are what we would consider on diagnostic wandering, are—that do not know where exactly some of their symptoms were coming from. Those individuals are more likely to have a higher rate of depressive

symptoms. There was also a 5.8 relative risk increased of being diagnosed with a personality disorder, and within that there was a specific elevation related to this- this type of anxious compulsive personality disorder that was found.

With regards to potential for addiction, some new research has come out, and—but one of the first ones was at Dr. Bulbena's group, who found that we are more likely to drink alcohol potentially, and smoke tobacco as well, but a really rich piece of research has come out just recently, in 2019, on prescription medication. And that actually found, that if you have EDS, you're more likely to prescribed medication, most likely pain medication, that might be highly addictive, and if you are being prescribed that medication, it's likely going to be at a higher dosage than someone else who does not have EDS. So, if I go to get a tooth extraction, right, there's a potential that I am going to be more likely to be prescribed medication, heavier medication, at a higher dosage, than perhaps someone else that was getting the same tooth extraction that did not have a connective tissue disorder.

[00:04:54]

And that brings up lots of questions. It's how exactly does that impact us? But I think it's important for you all to know that, so you can be empowered when you are in that seat, and having these things considered. An absolute door opening has happened as far as research on eating disorders. We have seen absolute new, new studies going on, currently in research that is ongoing. That indicates that there's some type of overlap in presentation between specifically, anorexia nervosa and EDS. So, that means that some of the symptoms that we're seeing in EDS also coexist with symptoms of eating disorders. These are things like fatigue, orthostatic intolerance, the ectomorphic appearance that sometimes we see with EDS, and there's new research that's been done by, and I—forgive me if I mispronounce her name—but Dr. Baeza-Velasco, who actually has a wonderful map that theorizes how EDS might contribute to the presence of an eating disorder. So, this is something that continues to come into fruition, and I look forward to sharing this more with you as we have new research that comes out.

An area that we absolutely need more research in, is both psychosis and neurodevelopmental. So, Dr. Bulbena and his team looked at psychosis, and they actually found that there—in individuals that have schizophrenia, they looked at those that had EDS and, and those and that did not have EDS—that had been diagnosed with schizophrenia, and there appears to

be a specific subtype that was found that had joint hypermobility as a key finding, to the point of considering it almost as a separate type. So, there seems to be some type of relationship here that we don't fully understand yet, but that's something that's definitely on the radar that we need more research for.

In addition, another area, as I mentioned the neurodevelopmental conditions. So, a literature review has found a very high co-occurrence of EDS and attention deficit hypermobile, hypermobility disorder, ADHD, hyperactivity disorder, that we're looking at finding out more information on. We also saw a prevalence of children being diagnosed with developmental coordination, having additional joint hypermobility symptoms, which perhaps means that there could be some type of relationship there. And then we're seeing new research, and this is one that continues to be published and has ongoing studies currently, is the potential comorbidity of EDS and autism spectrum disorder.

And, specifically, right now there's research going on about proprioception and how that might be a piece that we need to look at. Proprioception being: knowing where you are in relation to where everything else is and how we process sensory information. So, next year at the conference, when you come back, I hope to have more information on this one, because I know that we've got a lot of research that's ongoing.

[00:07:48]

So, all of this to say, we have a higher likelihood of being diagnosed with anxiety disorders, eating disorders, ADHD, development coordination disorders, autism spectrum disorder, as well as bipolar. Now I want to be clear. I, in no way, can confirm that we actually have increased experiences of these things, but what this says is, we're being diagnosed with it more. So, either we are having these experiences more than others, or this is the way that we're being perceived. Either way, it's really important that we know this information, so we can be empowered as we walk this out.

[00:08:27]

And this isn't just for EDS. And this is one of the things that I'm really, really passionate about, as we see similar numbers and similar prevalences of diagnoses with individuals that have a variety of chronic illness conditions, as well as chronic pain. So, as you can see, cerebrovascular conditions, 23% of those individuals are dealing with major depressive disorder. We see that with cancer, there's a 42% of them are dealing with major depressive disorder. So, it's not just EDS. This isn't just isolated to what we're experiencing. And then we look at chronic pain generalized, not as related to any specific condition, we see that about 50% are

struggling with depression. Twice as likely of being diagnosed or having a mood or anxiety disorder; 3.5 times more likely to deal with depressive symptoms. And what's really interesting is we see that these depressive symptoms have a tendency to increase with the presence of pain. And this is particularly important when we don't know where that pain comes from. I think perhaps that's kind of a, that makes sense, right? But when we see the numbers and we see that it's not just EDS that deals with that, perhaps there's something here that, you know, we should be looking at, and tracking our own symptoms as well. I know for me, when I saw this, I really started to think. "Hmm...on my bad days, what's my pain doing?" I'm just giving you education and things to think about for yourself and your own journey. This might—you might be like, no that's not me, but maybe it is. Maybe that's something that contributes and you see yourself in this, this slide as well.

[00:10:06]

I think the heaviest part, for me, is this study that has recently come out of the University of Waterloo. So, they looked at adolescents that had self-reported chronic conditions, and what they found was if you have a chronic condition and you're an adolescent, your odds of suicidal thoughts increased by 28%. Your plans to die by suicide increase by 134%. And the one that absolutely I can't wrap my mind around, is your odds of a suicide attempt increase to 363%. 363%, that is an absolutely alarming number, and that's not just for EDS. We know specifically within this research we found, that there is a spike in that risk soon after someone is diagnosed. So, we see that there is this critical window, in which we can act and have preventive measures in place, and I don't know about any of you else, or anyone that's on the livestream, but my diagnosis of EDS was just the beginning of diagnoses, and it seems that they—I just keep tacking them on to my diagnostic list. So, this is something, for me, has been particularly important and I know that when a new diagnosis comes along, that I need to be extra careful.

And this is this is actually particularly important to me, and I created this presentation because a dear friend of mine, by the name of M'Lynn Hope Tyler, took her own life at the age of 18. Just this past year, she was diagnosed with EDS, syringomyelia, and Chiari malformation, and she was overwhelmed with her physical experience, and the psychological distress that went alongside it. And the last thing she asked, was that we would share her story. So that no one else has to walk her path. And so, I bring

this up today, because these aren't just statistics on a screen, these are earth-shattering experiences that people go through.

And I'm not gonna ask anyone to raise their hand to say if they've had any of these experiences, because I know you know. I know that you that, you're doing some internal searching, hopefully to see if you've ever been there. But it happens. And I love life, right? I absolutely have a rich life and I love where I'm at, but even in some of my darkest points, these have been things that I've had to deal with. Wondering, you know, what is my life going to look like and where I'm at now, you know, I absolutely love it, but I recognize if I—I describe myself as being bright and bubbly—if I can experience this, these dark, deep, nasty places that my illness has brought me, I know that other people can experience it too.

And so, after we lost M'Lynn, my dear friend Julie and I got together, and we said we've got to do something. 363%—we've got to do something. And my friend Julie actually herself, has had multiple suicide attempts that have all come after she has changed her medications. So, we started having this conversation about safety planning and what can we do to prevent this? And one of the tricky things is, a lot of this is preventative and occurs when we're feeling great, and when things are going well, but when we need it the most it's a really important that it's already in place. So, one of the things I really want to encourage you all today, is to just start thinking.

So, for my friend Julie, her safety plan: she knows that she has a particular reaction to changing medications. So, she has someone go along with her when she picks up that medication, and then for a strict period of time, which can be anywhere from a week to two weeks, she's not allowed to be alone. And this is something that she's created on her own. I certainly wouldn't want anyone to push this on someone else, this is an individualized thing that we're creating. But she's decided this is what works best for her. And during that period, items in the house that she would consider as being dangerous, are secured. So, this is something that has helped her be able to navigate new medication changes over the past couple of years.

I myself have not had any suicide attempts, but I completely think it's important for everyone to have a safety plan. As well to have a therapist. Maybe I'm a little biased because I'm a mental health clinician, but I think that means maybe, maybe that's the best thing to hear, is that I have my own therapist.

And so, my triggers, if you will, are isolation. My triggers are invalidation and new diagnoses. So, those are three things that really, really kind of shake me up, so I have a plan for these things. If I know that I've got a new doctor that I'm going to go see, I make sure I've got an appointment with my therapist beforehand, and we go over exactly what I'm going to say, how I'm going to present it, and we talk about it. So when I walk in that door, I feel confident. I've already gone to a professional. I've spoken about it. I've gotten her concerns, and then if someone does say, "Oooh—I actually think that's just in your head"—I can say, "Oh, I was just talking to my therapist about it, and she disagrees." So, if you would like to get an author of release, you can absolutely talk to her, and that works out pretty well so far, but then it—on the flip side, if I know that I'm going to see someone who, and maybe in the past I've had experiences that they have a little bit of a harsh tone with some of what they're saying, or if I'm not sure what's going to happen, I'll call up my therapist and I'll say, "Hey! I've got an appointment with someone new on the 23rd, do you have an appointment on the 23rd or the 24th?"

So, after that appointment, I can sit down and I can process, and I can unpack all of the stuff that was said with someone whose whole job is to be there to support me, and to listen to me, and to encourage me which is wonderful. And I deeply would encourage that for other individuals, as well, if you think that was something that would work. The other thing that I mentioned, is isolation, is something that, that, that's a sign for me, that I know things maybe aren't going so well. When I start to isolate from others, I go, "Oh, that's, that's not very good." And I've been called out by my family and friends on this one. So, now my new plan is when I have something that's come up, I tell a parent, partner, friend. I've got three people that I go to that know what's going on with me. So, when they haven't heard from me, they can check in, because they know where I'm at.

But this is just my plan. That's just Julie's plan. But the beautiful thing of this, is it's individualized. So, if you look at, "Hmmm. What would be a situation that might bring me additional stress, additional psychological discomfort?" It might—it's going to be different for you than it is for me, but that's so great, is you're the one that's creating it not me. And you can tailor it to exactly what you need and you continue to edit it. So, I share this with you today, because I and my own experience, have seen how safety plans can absolutely benefit people. How having this information and being empowered changes how we feel when we walk into those

doors to see new clinicians. And I hope perhaps, that you might be able to have a similar experience as well, and benefit from this. or at least just to get you thinking. Maybe you're like, "Hmm, not for me." But hey, if you're thinking about it, that means something. Because on your journey, you are not alone. You are in fact the driver of your own mental and physical health. And I know sometimes it feels like EDS can take over and be that driver, but it's you. You have that power, and we are here to come alongside you, to help you feel that, especially in those moments when you're not sure who's the person that's driving, if it's you, or if it's EDS, or somebody else. So, we at The Ehlers-Danlos Society, we want to share this literature with you, because it continues to come out and like I said, I can't concretely say what the, the incorrect diagnoses are that are occurring. We're working on it. Hopefully I'll have that research for you soon, but this is up to you to do some individual thinking, to see what you feel applies, and if it doesn't apply to you now, maybe it'll apply at another time.

[00:18:10]

But what I want to do, is I want to leave you today with some resources. So, these are wonderful things that we have on our website. We have a mental health toolkit, toolbox, that is absolutely wonderful and has lots of different things. So, if the safety plan isn't your cup of tea, that's OK, we've got lots of other things on there that you may find beneficial, or maybe someone you know would find beneficial.

We have support groups: online, in-person, all over the world. And I don't know about you, but my experience working in support groups: it's a powerful thing. And maybe here in the conference you've met people; this is kind of a support group in and of itself, right? We're all sitting together. We're having I don't know how many, eight, eight hundred zebras in one building? That's the largest support group I've ever seen, right? So, if you could have this regularly and take a chunk of the conference home with you, where you can get on your computer, in your pajamas, in the comfort of your own bed, and have that support right where you're at. We want that for you.

We have our online communities, and then another link that is actually not on this slide, is our help desk. This has been an incredible new resource that we've implemented over the past year. We have email address that you can send in, and we also have a phone number that you can call, and if you're in one of those places where you do feel like you're really at risk, we have other resources that can provide more immediate responses. And we

won't be able to answer at all times, but we have other resources as well, that can help you if you're feeling like you're in one of those places.

So, today I want to leave you with a piece of inspiration: that you do have so much more control, and there are so many other people that are willing and excited to come alongside you, to jump in the car with you, to join you on your journey, to help you repair and feel fueled up, to continue to lead your own, and drive your own experience, as far as your mental and physical health. And if you have any questions on safety planning or what you can do to feel more confident and being in control, please seek me out. I've been in the HEDGE room. You know where to find me. There's the thing, this is the only time I've ventured outside of that room the whole conference. As well, my email is there. My inbox is open to you, and I would be more than happy to be a supporter and a cheerleader for you on your journey. And with that I'm turning it back over to Miss Bloom. Thank you, so much.

[Applause]
