Academy of PHYSICAL MEDICINE

# Transcript

# 368R- Hypermobility EDS with Elisabeth Davidson

DRAFT TRANSCRIPT

Steven Bruce

Good evening. I hope you're well. It feels like ages since we've been on here. In fact, it's only two weeks, but we've been so busy. We've had a lorry Hartman weekend a first aid course in London a vestibular rehab course here in the studio. And only a few days ago we had Robin Landsman functional Active Release course. All of them went down really, really well. So we will definitely be running more so keep your eyes peeled for dates for those courses. We also had quite a few new members over the last couple of weeks and I've no intention of trying to list them all but a couple did catch my eye this morning. Teresa in Bournemouth, my old stomping ground, nice to have you on board. And Carol in New Zealand. I'm not actually sure if you're watching at 630 in the morning, but it's been a while since we had any Antipodeans. Join. So great to have you with us. And then there's Pamela. Pamela isn't actually a member. She's a friend of his evenings guest speaker and she asked very nicely if we let her join in. So of course we did. Pamela welcome. Obviously, we know that once you've seen the quality of what we do, you'll be joining straight away and never forget, we aren't just about CPD here at the academy. Great to have you with us. As I said, I can't list everyone who's joined in the last few weeks but you are all very welcome. Do make the most of the evening ask lots of questions. Now the subject of hypermobility is always a popular one. And I have Elizabeth Davidson with me this evening to give us the latest on the topic. In particular hyper mobile, Ehlers Danlos Syndrome was trouble saying that hypermobile Ehlers Danlos Syndrome, which is of course one of the 13 types of Ehlers Danlos it was what's qualified as a chiropractor she did that 30 years ago. She specialised in pregnancy and paediatrics, so the MSc in paediatrics. In fact, she's still a Fellow of the Royal College of chiropractors, specialist faculty of pregnancy and paediatrics, having previously been its director. However, she was diagnosed with H EDS some nine years ago and now spends a lot of her time on connective tissue disorders. Elizabeth, welcome to the academy.

Elisabeth Davidson

Thank you for having me.

Steven Bruce

Now we're gonna start we're gonna go off on a tangent I normally take at least 30 seconds before I go off on down a rabbit hole. But we're going to start with the rabbit hole straightaway. What is it with you and ancient Greeks and in particular whispers of Aphrodite? Well,

Elisabeth Davidson

the idea has always been floating around in my head. whispers of Aphrodite, of course,

Steven Bruce

is the novel that you how long ago is that? Right? I

Elisabeth Davidson

published it last year. I spent a couple of years writing it while I was waiting to get my licence to practice in Denmark, I had lots of time on my hand. And I thought this was the ideal time. But since I was a child, I was 12 years old when I first visited Delphi where it takes place the ancient temple, and it just caught my imagination. What's

Steven Bruce

the what's the thrust of the book, I have started the book. And I apologise because normally when someone's got a book, and especially if it's related to the topic, then I'll have a copy here and I will have tried to have read it before the show, but only a couple of chapters in and I'm and I love historical novels. I love the fact that I can be entertained and learn something about ancient history at the same time. Just quickly, what's the

Elisabeth Davidson

story, the hero and if you like the entire protagonist, she's a priestess in learning when we when we first meet her, and she's learning to become the Delphic Oracle. So the prophets the priestess, which was a prophecy, and it was actually an incredibly important site. It was the most important site in the ancient world. And I always just wondered, how do you become, you know, this sort of Oracle. And I also wanted to explore women's lives in ancient Greece because we hear about all the heroes and the wars and the men and yeah, so. So I did a deep dive into the rabbit hole of ancient Greece and discovered an amazing

Steven Bruce

research number I absolutely love it. Yeah. And I must point out to people you said, getting your licence a little while ago, you've been qualified for 30 years qualified at the Anglo European college here. But actually, you are Danish historically, although the Scottish accent belies that slightly. So the licence was just returning to Denmark and

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Elisabeth Davidson

actually returned to Denmark until 2021. I graduated in 94. And practice in Scotland till till then, till I saw my clinic and then so yeah, so it took a little while there was a combination of the delays of Corona and, and Brexit and Danish bureaucracy, but so I had time on my hands,

Steven Bruce

but you'd like to relive the place, don't you? I do remember South Africa earlier. Oh,

Elisabeth Davidson

yeah. I was in South Africa in March. Yeah. It was keynote speaker at a big paediatric conference in Johannesburg, which was very flattering and very amazing. I've never been down on that before. And I've been in in all over Europe, really? And and also Israel a couple of years ago before COVID.

Steven Bruce

We're not going to talk about paediatrics today. Well, we probably will a little bit I suspect that I was interested in what you said earlier on when we were having lunch that actually you can talk more freely about what you as a practitioner can offer offer to babies in Denmark than you can in this country? Because although they have similar rules to us in terms of advertising, nobody cares over there.

Elisabeth Davidson

Well, pretty much yeah, we we have rules about what you can say and what you can't say. But people don't make outlandish claims, either. And, actually, I find that both the the health care professionals and the parents are very well informed about what chiropractic can do. There's always been lots of research in the field and Denmark. So, yeah,

Steven Bruce

so hypermobility, then, like you it's a bit of a worldwide problem isn't evenly spread, or it

Elisabeth Davidson

is not evenly spread, it is more predominant in certain populations. I've actually got a slide that we can perhaps look at. Yeah, which shows that it is. The latest figures that I saw last week was that it's it used to be thought it was one in 4000. But now we think it's one in four to 500 that actually have hypermobility. And as we can see on the slide, it's varied. It's more prevalent in the African continent, and also, for some reason in Greenland. I

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Steven Bruce

was gonna ask you about that. I mean, it doesn't seem to be much overlap there in the population phenotype, if that's the right word, we

Elisabeth Davidson

don't know is the answer. And we've only really started looking into it in great detail in the last sort of five to 10 years. And we have the genetic background of 12 of the 13 subtypes, but not the hypermobile one, yet. They're looking at it at the moment.

Steven Bruce

So Carol over in New Zealand and all of the others in Australia and Western we're most of Europe and UK, we're looking at about what 5% According to your scale is yes,

Elisabeth Davidson

yes, roughly. Although I always find that when I go out and teach a workshop. There's it's yeah, it's probably Yeah, one in five is probably right that you find that the people when when they go through the test, they go Oh, actually, that applies to me.

Steven Bruce

In five. Yeah. That's a bit more than 5%. It is it is.

Elisabeth Davidson

But that's perhaps because we are in a profession that maybe are drawn to.

Steven Bruce

Yeah, I was going to say that the number that comes through our doors will be much higher because actually you're gonna go to people if you've got problems and one of the things that I have to say it really has confused me about hypermobility is first of all, I used to think Ehlers Danlos meant hypermobility, but hypermobility is just one form of Ehlers Danlos. And perhaps you can elucidate on that moment. But also then I started looking at it. And there's also hypermobility spectrum disorder. So we've got another spectrum that can people that people can be on now as well. And clearly, there's got to be some overlap overlap between all of these things. And there's there's an acute confused patients as well as the conventional medical world. And you

Elisabeth Davidson

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can be globally hyper mobile and all your joints. So you can just be hyper mobile in one joint or in a couple you can have to in order to qualify for the ILAs danlos. There are a set number of very strict rules that you have to qualify which we can we can cover later. Things like skin tissue, stretch ability, you have to have a lot of comorbidities that that are correlated with it. We don't really know why. But we do see that there are higher incidence of anxiety and depression and things like Potts syndrome. So there's lots of physical comorbidities that you don't necessarily have if you're just type immobile. So and also women tend to be affected by it by a factor seven more than men. Okay.

Steven Bruce

When you list all those possible complications, if we were to test the whole population, do you think that there would still be a high incidence of those things or was it only the ones that were coming to Your clinic because obviously they're coming because they've got a problem that demonstrates who's

Elisabeth Davidson

I asked that question, actually one of the expert groups that I'm a member of, and I said, you know, are we becoming more aware of it? Or is it more prevalent? And we dancers? We don't know. We simply don't know. You know, we are more likely to see people who have issues in our profession. Yeah.

Steven Bruce

Yeah. Yes, you're right. And I suppose well, we'll, we'll talk about, you know, how it affects people doing Can we talk about you, you were diagnosed? Nine years ago? 10 years

Elisabeth Davidson

ago? Yeah. In my late 40s. Yeah.

Steven Bruce

So your hypermobility came on suddenly?

Elisabeth Davidson

No, no, I've always been hyper mobile. In fact, I was quite proud of all the interesting stats that I could do as a child that other children couldn't do. On the other hand, I was also clumsy and fell a lot and sprained my ankles a lot. And but because it was in the family, and it was just considered Well, that's just how we are so I guess back in the 60s and 70s people just didn't go to the doctor for things like a sprained wrist. So

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Steven Bruce

no, perhaps no, we have done long ago now. So long before COVID. We did a show on juvenile hypermobility, but I mean, that can bring with it, some very nasty effects gone to a young young lad we had on the show, then he was kept away from school a lot of the time because he was just in such excruciating pain that you couldn't he couldn't function.

Elisabeth Davidson

You didn't have that. Not to that degree. And I also had a mother who was a nurse, so I didn't get away with you know, trying to get off school. He

Steven Bruce

wasn't trying to get away with it. He wanted to go to school was Yeah, genuine, painless. Boy was Yeah,

Elisabeth Davidson

yeah. I mean, I suffered pain as a child, I had growing pains, I had headaches, I had gut issues, I but it was just well get on with it. You know, and I, as a consequence, didn't really go to the doctor with it until because it became a chiropractor and, you know, get treatment and managed quite well until my mid 40s. And then then everything, I managed to tear both cruciate ligaments and both knees over time. And the instability and the pain just finally made me go and get diagnosed.

Steven Bruce

Okay, and you know, we didn't get quite the way through your life story. Yes, you were diagnosed with this. You are now what we would call disabled you had an assist to have assistance. you've travelled from Denmark for this show, you have assistance to get to the passport control from the from the airport. How else is it affecting you now.

Elisabeth Davidson

So it also means I can only work part time, I now work three days a week seeing patients. And at the time when I was first diagnosed, and I was really, really in a lot of pain, I was worried that I wasn't going to be able to continue practising as a chiropractor, but I managed to get some treatment that helped and modify my lifestyle because I get my head around that this was a disability that wasn't gonna go away was probably the hardest thing. Right?

Steven Bruce

And does it affect you in other ways? I mean, clearly, when you arrived in the studio here, going up the stairs was not a not a comfortable thing for you was it? So

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Elisabeth Davidson

I use a crutch but it's mainly because of my instability because of my tendency to fall. And but nearly 10 years ago when I'm when I was diagnosed, I used to crutches. So I consider that a improvement progress. And it's partly through exploring all the different treatment options available and and modifying my lifestyle. But yes, it does affect me. I mean, I'm still in pain every day, I still can't dance like I used to I can't track up the mountains like I used to, you know, so yeah. But you you kind of you come to terms with it eventually. And that's a big part of actually having the lowest mo syndrome is learning what you can and what you can't do.

Steven Bruce

Does it help your practices? It's to a large extent devoted to children. That means you can sit down for a lot of treatment. Yes,

Elisabeth Davidson

absolutely. Yeah, I treat a lot of babies and a lot of children and sort of the seven to 10 year age group. And that does make my life a lot easier, as opposed to a big rugby player.

Steven Bruce

We have a question from Simon come in a few minutes ago. He says he treats a number of hyper mobile payment patients some with EDS. And anecdotally, he says he finds a lot of them have a Mediterranean, he says Safadi background, is he going down a rabbit hole? Does it really matter what their background is? If they're hyper mobile?

Elisabeth Davidson

No. Apart from as we saw on this slide earlier, there is a high predominance in certain phenotypes, and no, not necessarily. I mean, we see it all over the world in all races and all types.

Steven Bruce

But in terms of the people coming through your clinic door doesn't really matter. They're either they're either hypermobile or they're not only and it doesn't matter what their background is no, not really. Which are there any differences in how people respond to treatment? Depending on their background?

Elisabeth Davidson

I don't think so. I think that's more of a mindset. I think that's more in terms of how willing are they to accept that this is something they have to maybe change their lifestyle or do

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Steven Bruce

well now's your chance to be rude about certain groups of people. populations, who are the ones you find most resistant to change? Don't say the English.

Elisabeth Davidson

No, no, not so much thing is I do find the Danes, interesting, more active than the than the British. I mean, we cycled everywhere we walk everywhere, we tend to have more of a lot outdoor lifestyle, certainly than they did in Scotland, where I practice for many years. And so therefore, the ones that I see now in Denmark, are more adversely affected by it by the ILA stemless. So these are the more heavy ones that have real problems with day to day life. And I see a lot of children with it as well, not not a lot. But I see some ways very clear that this child is going to need intervention, not just what I can do, but a whole multidisciplinary intervention. Denial, maybe some others are more thankful that they finally have an answer that they finally have a diagnosis that they can go, Ah, now all my strange symptoms make sense.

Steven Bruce

Yeah, odd, isn't it? So curious psychological factor that people like to have a name for the thing that's going wrong with them? Even if that doesn't change anything at all? Yes, yes.

Elisabeth Davidson

But I think it's also about being validated. I think quite often people go, Oh, no, you're fine, you're fine. Just get on with it. You just have to work through the pain, which I don't believe is a good thing when you have less than less, because you can actually do more damage to yourself. So it's about learning what you can do and what you can't do and what your limitations are.

Steven Bruce

So tell us about your stand loss generally, yeah. Rather than hyper mobile EDS. What? Why isn't one of the 13 categories? Well,

Elisabeth Davidson

that's a good question. It's one of the connective tissue disorders, and the 12 of them are at quite severe, one of them carries high mortality and morbidity. And that's the vascular one. So whenever I see someone where I suspect that they may have either classic or vascular Ehlers Danlos, I always send them for genetic testing, because we can test for that. And those are people who are at risk of rupture of internal organs at a young age,

Steven Bruce

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as a cellular level, what's going on, was basically the

Elisabeth Davidson

the matrix of everything in our body is made up of collagen, and the collagen is faulty, and people will eat less than No. So I often explained to patients that it's like the glue that you have in sticky notes, it just doesn't hold very well. And once you've damaged the ligaments or the muscle tissue, it never grows back together the way it was. And it'll always be weaker than before. Whereas normal people have super glue in the in that collagen. So

Steven Bruce

when we're talking about vascular or general generalised what's being vascular, I understand what's being affected, does this mean that the blood walls are lower the blood vessel walls are less robust, they are very

Elisabeth Davidson

thin and very much at risk of rupturing. So these are the people that have spontaneous rupture of for example, in an already aneurysm at, you know, at a young age. Okay,

Steven Bruce

so the obvious question from that is, then well, how would you recognise it?

Elisabeth Davidson

Well, that you couldn't necessarily they have more like blue sclera in the eyes, and they have more see through skins, you can see the veins extremely clearly. That's one of the things that point out, and then they have the extremely hyper extendable skin where you can pull classic iList animals can probably pull their skin in the neck out about five centimetres from your normal people can't do that. So

Steven Bruce

so someone comes to your clinic, you think they look a bit thin skinned? Would you do that you tell them to pull the skin out from the right, and at what point do you say I'm not going to treat you you need to go and get genetically tested immediately?

Elisabeth Davidson

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If I suspect I mean, I would do the full testing and you don't check like the beaten syndrome. That sorry, the beaten scale, you would look for all the the skin issues and the bowel issues and the heart ache and

Steven Bruce

and because presumably, you can have more than one category of EDs again. Yes.

Elisabeth Davidson

Well, no, you can't actually no, you're either you're one of the

Steven Bruce

if I've got vascular EDS, and the baby's going to be relevant. Yes,

Elisabeth Davidson

very much. You're gonna score nine out of nine. Vascular? Yeah. Okay. Pretty much. Yeah, they are much more hyper mobile than pretty much any of the other subcategories. Most of them are really rare, I think really? Okay.

Steven Bruce

So sorry, I thought you said I couldn't be hyper mobile and vascular. I think you're either one or the other.

Elisabeth Davidson

Well, you will have hypermobility. Right. So hyper mobility is something that your body can do, but the other is a genetic condition that's caused by it. So every single ILAs Danlos Syndrome are hyper mobile. Right.

Steven Bruce

So then why is that a specific category H EDS. If everybody radiates See, this is the sort of thing that's confused me. Yeah. If you were lucky, that's a specific type of EDS.

Elisabeth Davidson

Well, I think they used to, I mean, they used to be six categories back until 2017. They change the criteria and they realised that there were more categories. So now there's 13. And I'm not sure I think either the age EDS is the one that they don't really understand yet. And yet, it's the biggest

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category because there's clearly some issues, it's clearly some comorbidities, but we haven't actually found the gene that codes for it like we have in the other categories. So, but hypermobility is just one of the signs that you see. Yeah.

Steven Bruce

So with classical EDS, what distinguishes that from

Elisabeth Davidson

they are much more flexible as well then then, then other sort of normal people or even HGVs, when they also have a lot more comorbidities, they will often have heart issues. They will often have gut motility issues they will have the parts or they'll have the there's a lot of people that have associated gluten intolerance or or various allergies.

Steven Bruce

Okay, I got a question here from Alia, who says he finds chronic fatigue is a huge issue with his son. We're now homeschooling which has helped a lot not sure it's just the fatigue from the condition but also anxiety. I'm assuming that his son has hypermobility.

Elisabeth Davidson

Yes, there's a high incidence of people with EDS of any kind that has anxiety and depression, which is understandable when you consider that they're almost always in pain. And that will also we know that there's a high correlation with chronic fatigue or even me and we actually there's some experts that believe that Emmy is really people that have not been diagnosed properly. That is sort of a catch all. syndrome. And if you check a lot of these people, they probably have some underlying tissue disorder.

Steven Bruce

Do you mean that me doesn't might not exist as a separate thing altogether?

Elisabeth Davidson

syndrome, isn't it? So it's a collection of symptoms. And sometimes Emmy can be triggered by a viral illness. And we also know that the expression of the symptoms in H EDS in particular, can be triggered by either trauma or viral illness.

Steven Bruce

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We do have some persuasive speakers but at least one persuasive, persuasive speaker on the show who was arguing that Emmys quite probably viral and hence long COVID could be part of that whole that whole picture. So it can says I'm part of a Facebook group called Send carers united and incidentally it has been discussed that many children with ASD ADHD etc. Also have hypermobility and or EDS. Is that what you find? We

Elisabeth Davidson

know that there's a link, and we don't know what it is. So yes, people with hypermobility doesn't necessarily have ADHD, but there's a high percentage of them that do. But we know that most everyone on the autistic spectrum are also hyper mobile. But we don't know why. So there is a link. And that's definitely been noted in the literature

Steven Bruce

that complicates the picture doesn't bear in mind that just treating one affects the other is one cause the other? We don't know, but we don't know. So what is the state of research? I think you said you discovered a new paper recently,

Elisabeth Davidson

I did there was one published that I didn't actually get to send to you because it only came out on May 15. And this was new guidelines by Sally Pizarro at owl. I'll send you the link, you can send it out. And it's guidelines to managing pregnancy in hyper mobile women. And they did it's basically a collection of expert witnesses and expert expertise and all the latest research and they've collated everything that there is and I just issued new guidelines. So it is very handy and it's full of all the latest research.

Steven Bruce

How much of a problem is hypermobility and pregnancy? It's

Elisabeth Davidson

a huge problem. Because they are much more prone to bleeding, they're much more prone to potentially losing the pregnancy. They're much more prone to early delivery, or complications during delivery. And really, I think the main thing is that the if a woman is sheduled for a C section, for instance, her birth care team has to be aware that she may not react properly to local anaesthetic. So for instance, an epidural, she may not it may not work well for her. So they need to be aware of that. I

Steven Bruce

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remember years ago when we brought this up on the show before that, it came as a huge revelation to us that that that effect occurs and that a lot of people going to the dentist, don't respond to Novocaine or whichever the anaesthetic was they were using and dentists wouldn't accept it. You must be numb because I've given you half a pint of Novocaine or whatever it was, like squirted into them. Well, when

Elisabeth Davidson

I told my dentist that I had been diagnosed, he went oh, that's why you always need to be injections instead of one. He said that totally makes sense. As

Steven Bruce

I mentioned now, it must be more more better known

Elisabeth Davidson

now. Yeah, but in the past, yeah, they would they wouldn't necessarily understand it.

Steven Bruce

Okay. We were you were talking about the actual scale earlier on, based on scale. So I keep I don't know why I keep calling it back back till internet providers in my mind or whatever. They're the beaten scale earlier on. What use is the beaten scale? It's

Elisabeth Davidson

a screening. And it's part of the diagnostic criteria, part of the diagnostic tool set. And it's, it was designed originally for adults. So in 2021, I think there was another modified version of it that was designed for children from the age of five, which I'll, when your child 18 Roughly, yeah, so there's gonna be some crossover? Absolutely. Yeah. I mean, all children really, by definition are hyper mobile in the in the first decade, they should be, and, and then they gradually become less so during the teenage years, but some people remain as they, you know, have a mobile all through their lives. You can you can score 99 on the beaten scale when you're 10. And then perhaps for when you're my age 57. And but the good thing about the new criteria is that it also counts what you scored in the past, not just what your score presently, because we know that things can change with time, we become more stiff with age, but we're still more flexible than most people.

Steven Bruce

Right? And there's does that increasing stiffness with ease? Does that cause a reduction in symptoms of any sort? On

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Elisabeth Davidson

the contrary, in my case, certainly, I I find that I get more pain the older I get. Whether it's a combination of just age and wear and tear and haven't been a chiropractor for 30 years has definitely taken its toll on my joints. I can tell that but yeah,

Steven Bruce

who were the worst affected them? It's not just chiropractors, osteopaths, physios who use the house, you physios. Poor things don't get used their hands as much these days, do they? But you know, there must be other professional

Elisabeth Davidson

anyone who does manual labour? Yeah, very much so. But we see it in all professions.

Steven Bruce

I suppose then it's it's fortunate that a lot of manual estimation, most manual labour is done by men, because most of it involves

Elisabeth Davidson

they're not as badly affected by it.

Steven Bruce

I was gonna say, because men are a lot stronger and less clever.

Elisabeth Davidson

Now, I didn't say that.

Steven Bruce

I can say, yes, we've been asked to run through the beaten scoring. We're going to run through that in a little while. But before we do that, I just I still want to just get to the bottom of the beaten scale. You said it's a screening tool. So okay, fine. It's a screening tool. At the point where I meet the threshold, then what happens? Well,

Elisabeth Davidson

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then you look at the other criteria. So you look at do they have the comorbidities? Do they have things like headaches? Do they have things like irritable bowel syndrome? Do they have heart issues? Do they have chronic pain? Do they have recurrent dislocations, or subluxations, or chronic repeated sprains and strains and soft tissue issues. And dental problems, dental anomalies are quite common. So such as you often have a narrow plate or narrow palate with crowded teeth. But you may also have actual dentin issues or nerves that sit crooked or so you look at that as well, you look at are they symptomatic, they must have been in more than figures three sites for more than a year in order to qualify. So there's actually something called the GP EDS toolkit that you can go in and download from the EDS website, where you can see all the different criteria

Steven Bruce

or at least things that you were screened or test for showing for in your own clinic, or you're going to say, based on you, you've passed the threshold, we're gonna send you off to someone who can look at this. And the problem

Elisabeth Davidson

is there isn't many places you can send them. The GPS don't really understand it particularly well, the rheumatology clinic which is where you would normally be sent don't want to know because they can't do anything about it. So what I tend to do is run through the GP toolkit and take off and if you have enough tics then you then I'll write to the GP and say I think this person should be screened by either rheumatologist or perhaps genetics if I suspect or something or if I want to rule out things like vascular EDS, right.

Steven Bruce

Again, I mean, you talked about some things which are not not obvious in terms of vascular EDS. So if you think they've got thin, transparent skin Ain't no bluish clearer. Are they likely to bruise easily?

Elisabeth Davidson

They're much more so than then even HDDs. Yeah. Look at them and they

Steven Bruce

and obviously you're now out of the UK is medical system but you haven't been out for very long. So you know what the NHS at least in Scotland would do for people like this? Does your average GP when he gets a letter from someone like you or like me, and things that I would call sort of warning flags like hypermobile EDS, vascular EDS, eds, things like that, comorbidities all those things ought to be making him think, well, you know, what you're talking about, perhaps how to look into this and do something is the response good,

Elisabeth Davidson

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in my opinion, it or in my experience where I worked, we had great response from the DPS when we wrote to them, they would take it seriously. And they would, they would act on it. I also found that once I had the diagnosis, my DP was did a complete turnaround and says, Well, what can we do to help you whereas before it was, oh, you need to lose weight, you need to act, you need to exercise more, you need to just get on with it, you know, so they suddenly understood that there was a real, a real condition that they could help with.

Steven Bruce

Interesting, they only GP says, What can I do to help? What can he do to help?

Elisabeth Davidson

So a GPU can give painkillers? It is very much a multidisciplinary, if you don't mind meld, please slide. Yeah. We'll go through the beaten score shortly. But if we look at this slide here, we can see that it is a multidisciplinary treatment. So you need you need counselling to learn about your condition and to learn to accept that you need painkillers that is very important, because people have to have a good quality of life. That was one of the things that my GP had a long chat with me about was, you know, you need to take painkillers, I wasn't very happy about it. But it did make a difference. Did

Steven Bruce

painkillers work equally well, with no EDS, patients, that's

Elisabeth Davidson

the that's the big problem. It doesn't work particularly well. So we through trial and error came to a combination that worked for me, but that doesn't mean it's going to work for the next person with EDS. So right now I'm waiting for the pain clinic in Denmark to to come up with a with a plan, because unfortunately, the medication I was on in Scotland is not available in Denmark.

Steven Bruce

What's the pain mechanism?

Elisabeth Davidson

Second question, isn't it? I mean, we know about the pain gate theory, we know about how chronic pain changes things in your brain. And when you have pain or your life, you become more susceptible to small nociceptive input. So yeah. So but who know Is it painful? It's painful because of the injuries. It's painful. Because you constantly injure yourself. You overstretch the tissue, your muscles work harder, because your ligaments are not holding everything together. clumsiness was my biggest problem as a child, even as an adult. I mean, it was a running joke when I was at university that oh, here goes Elizabeth down the stairs again. And they heard they heard me for

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many times. And so I probably sprained my ankles 50 times, you know, and eventually the the decide that that's not fun anymore. Yeah.

Steven Bruce

Okay. Let's just go back to that slide that we had up a second ago. Because as I looked at earlier on, I'm not entirely sure where you enter this, this cycle.

Elisabeth Davidson

Yeah, as a chiropractor, I would think we probably go under the physical treatment.

Steven Bruce

Right. So somewhere down here is where your patients muscle strength

Elisabeth Davidson

muscle, and during the proprioception, when we can help we have to be a little bit careful with spinal manipulation because it's actually contraindicated in the WHO guidelines, although I think the new guidelines are from 1995. So these

Steven Bruce

are the WHO guidelines? Yes, yeah. The NICE guidelines are different.

Elisabeth Davidson

I am not sure they've been updated, to be perfectly honest. Yeah. So spinal manipulation is a contraindication and ILAs Danlos Syndrome. However, you can use non force techniques, you can use mobilisation, you can use lots of good techniques. I mean, I've benefited extremely well from cranial sacral therapy and osteopathic type treatments. But now and again, when joints lock up, best thing is to get them get them loosened up, but you have to be careful because they don't have the same anatomical end range as normal people do. So your your specificity in the adjustment needs to be very, very spot on and capital.

Steven Bruce

You heard me mentioned Laurie Hartman's course earlier on and I'm always amazed and impressed when he comes along to teach it, you know, because he uses so many different levers to to look up a joint the actual range of motion of the manipulation is very small, indeed, very fast, but very small, which presumably is helpful because you're not trying to stretch

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Elisabeth Davidson

and that's how I practice as well. Yeah, yeah.

Steven Bruce

What else is going on in this chart here? We got Behaviour Therapy. Yes, yes. So

Elisabeth Davidson

I think Learning to understand how to control your, your anxiety. You know, there's lots of tools you can work with a psychologist or psychotherapist about, you can do breathing exercises, or you can do mindfulness. I mean, there's lots of things, learning to accept that you have a chronic disorder is probably the number one thing and that's hard to get your head around, you know, you because you want to keep finding a cure, you want to believe that it gets better. And I'm very much a believer in that and I are better than I was 10 years ago, because I've learned to modify my lifestyle and my behaviour, your

Steven Bruce

what your medically trained you, you've done a lot of research into this. And while it can't be much fun to realise that you you can understand that for a lot of patients, I think it's very hard to understand that medicine doesn't have an answer. Absolutely. Yeah, yeah, let alone a one click answer. Absolutely.

Elisabeth Davidson

Yeah, I that's one of the things I always talk to patients about is you know, we you know, medicine is not an exact science, it's very much a trial and error. And let's see if this works. And if it doesn't, we'll try something else.

Steven Bruce

So a part of part of your role and is communicating this to patients in a way that they will take on? Do you typically refer to some sort of behaviour or certain psychological psychotherapist?

Elisabeth Davidson

If I Yeah, if I feel that that's what they need, then, then I think that has helped me enormously. I had the privilege of working with an amazing psychologist who really taught me some good tools. And so I think that can be very beneficial. But it is something that they mentioned in literature as well how important that aspect of managing the condition is. Because we know there's a higher incidence of anxiety and depression. And yes, you can treat that medically. But sometimes it's more important.

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Steven Bruce

There's any need for the the psychological therapy, the counselling, talking therapy. Do you think there's any need for that therapist to be experienced? Or at least to understand hypermobility? Oh, absolutely. Yeah. That many of them around?

Elisabeth Davidson

I don't know, to be honest, I think it has become much better known than it was even five years ago, the Ehlers Danlos organisation worldwide set up a programme called EDS echo. And five years ago, which was basically a platform where all kinds of healthcare professionals could come together and learn more about EDS. And it's free to join you. They've got conferences in North America and in Europe, and I think they're working on setting something up down under as well. And a lot of it is done zoom or electronically and it's extremely worthwhile being a member if you are a professional, they work with either either spineless people, right?

Steven Bruce

This This one might be right up your street, if I may say so. Sarah says Do you have an opinion? Also not serious? maioria was she's just mission somebody else? 99 That's the one that I thought was yours. What are your thoughts on the microbiome relationship to EDS,

Elisabeth Davidson

we know that that has a huge impact on it as well. We know there's a big issue with permeability of the of the membranes in the guts and people tend not to absorb nutrients particularly well. So we know that people tend to be anaemia have anaemia, they tend to not absorb the vitamins particularly well. So there's there's that whole aspect of it as well. And I've certainly found a big difference in cleaning up my diet that we know that is a strong link with gluten allergy. We don't know why that exactly. I mean, you're gluten free Yeah. And again, it's something that I probably was as a child but didn't realise it. But yeah, I just that was actually diagnosed before I got the either stand loss diagnosis so but and that made a massive difference. I also need to take vitamins and minerals because I simply don't absorb it enough from the food that I eat. So I need to supplement I am

Steven Bruce

intrigued that you mentioned people don't take up B vitamins properly because we've had a couple of shows about vitamin B 12 deficiency deficiency and the the lady who spoke on those shows was quite adamant that the normal response of the conventional medical system is inadequate and that if you if you are Beto deficient then you need injections it's not it's no good just taking supplements by mouth or if you don't absorb

Elisabeth Davidson

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it from like that then yeah, pretty useless. We've also got the issue that so many people are on stomach acid reducers so like you're yes

Steven Bruce

the proton pump inhibitors which apparently and they actually have all sorts of crimes. They

Elisabeth Davidson

did this if you're on them for more than six months then you tend to become vitamin B 12 deficiency.

Steven Bruce

I'd recommend to anyone watching the shows with Tracy witty was came on the show. I mean, she's just MC she's fantastic about Beethoven. And there's some wonderful resources that she shares with people.

Elisabeth Davidson

You need to give your body the building blocks to rebuild itself. If you don't eat properly, then then it's going to struggle. Yeah,

Steven Bruce

we're gonna get onto the base and score in a minute. So we'll get over into a practical bit in a couple. There's a couple of questions I want to go through before we get on to I'm gonna call it the Bechtel score because that's because that seems to come off my tongue more easily. He says 80% of diagnosed anxiety states have hypermobility and he's quoting Jack, Jennifer Jessica Eccles, from Brighton. I think you mentioned Spreckels earlier

Elisabeth Davidson

on was one of the team was Sally Pizarro that published the late

Steven Bruce

80%. That's high, isn't it very

Elisabeth Davidson

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high. Yeah. And we don't know exactly what the link is. But it makes sense that if you're if you feel like you can't trust your body, it would make you feel anxious. So there's probably both a neurological link, I think, and a psychological.

Steven Bruce

Yeah. I mentioned my earlier on, she was asking whether any dietary changes could be beneficial. In your case it was gluten preserve, are there other we talked about V. 12, as well, are there other particularly high profile dietary components,

Elisabeth Davidson

and there was a paper by Mark a story from I think it was 2012, where they listed all the dietary nutritional sort of values that genuinely helped the symptomatic things that people experience in EDS, but they say we don't really have the research to support that this is what you should be doing. But it's worth trying. Okay.

Steven Bruce

And one more before we go into some practical stuff. Sarah wants to know, if you have an opinion as to which painkillers are most effective, and you could say earlier on that it may vary, but varies from

Elisabeth Davidson

person to person. Yeah. I mean, you really have to speak to the, your own doctor and try and see what works. So um, for some people, the ones that they're trying to ban, like codeine, and that works really well for other people. They can take Gabapentin or some people use low dose naltrexone, it just, it's so different from I can't really

Steven Bruce

regulate nonsteroidals. Do they have a beneficial effect?

Elisabeth Davidson

They do? Yeah, they do. If you can tolerate them for your gut issues?

Steven Bruce

Yeah, of course. Of course, everything has consequences. Yeah. Jordan, should we have a quick look at a slide on baking scale,

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Elisabeth Davidson

we can learn to eat. So I've included note, let's just go back to so here's the Beighton score, not the back. So remember this, this was initially done for adults. And it doesn't really take into account the like the shoulder girdle at all. It doesn't test that. So there's been a lot of criticism, but it's the best that we have at the moment. And so basically consists of five things that you that you check, you get one point for each side, that is positive and, and one point for being able to touch the floor with your hands flat. Most people can't do that. I can just about reaching still. I used to be able to do the splits, but I can't do that anymore. That's not on the beaten score. But but it probably should what you

Steven Bruce

said if you suffer from hypermobility disorder, doing the splits is not going to do you any good. It's going to it's going to make life miserable.

Elisabeth Davidson

Well, it's if you're a gymnastic can be beneficial. If you're a rugby player, it's not particularly handy. So yeah, it depends very much on what kind of sports that you do. People with hyper mobile problems should probably avoid contact sports in the greater light of things. But like anybody else, you can train your muscles to be stronger. And so it's really, really important from a preventative point of view is to get people to do exercise as early as possible, but it has to be modified to their tolerance. Okay.

Steven Bruce

That's gonna look a great show.

Elisabeth Davidson

Yes, let's do that. I'll follow you.

Steven Bruce

Grace, thank you for coming in again and being on.

Elisabeth Davidson

Yeah, so we're gonna start with having grease touch with straight knees, touch the floor, with flat hands if you can, or as far down as you can. So that's pretty good. It's not quite hyper mobile. So I wouldn't actually score that. Because yeah, how far can you go school? So I mean, I used to be able to put my hands right flat.

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Steven Bruce

That's not far off. Now. It's not far off. And that's with your knees straight.

Elisabeth Davidson

Yes. With me straight. Yeah. So I also used to hyperextending my knees, but we'll we'll get you to lie on the bed for a second. So the other next thing we check is the hyperextension of the elbows. So we can actually see here that you do over extend beyond 180 degrees in the elbows, on both sides. So that's the point for each of them. Now the one with the some. So you pull your thumb to watch your forearm. So two minute writing, which just kind of turn it around. So you want to go that way. There. So if you hold

Steven Bruce

other than the camera can see how far your thumb can go and you're spending the entire phalangeal joints as well, isn't it? Yes,

Elisabeth Davidson

doesn't happen to me. So what we're really looking at is kind of the thumb touch the forearm. I used to be able to do it. But again, I'm getting older now a little stiffer, not quite, that's not normal.

Steven Bruce

With nails this.

Elisabeth Davidson

Can you do on the other hand as well? Like that? So you know that way? Yeah, pretty much. Yeah. So that's the point for each of them. So you've got four points already. So the next one is extending your little finger with a flat hand.

Steven Bruce

So again, at right angles,

Elisabeth Davidson

let's do it that way. Yeah. And you can see that not only does she hyperextend in this joint here, but she also hyper extends in that in the PIP joint as well. Let's try the other one. So we'll bring it right back as far as you can, so you're just about 90 degrees. So interestingly, you're a little bit more on one side than the other. So there's one point there. So that's five. So that already sets you on the hyper mobile border, if you like, but you don't really have any of the other symptoms. So now let's

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check your knees. So this is passive stretching of the knee. So I'll get you to lie down on your back. And then I lift your legs up. Now just relax your knees. And let me do it. So in this case, yes. When I actually push it, there was a little bit of hyperextension. But it's a few degrees. It's minimal. Yeah, that's pretty normal at her age. Yeah.

Steven Bruce

What is what is abnormal them?

Elisabeth Davidson

So, so big, and that one isn't actually you're more stiff on that knee than the other. So beyond the 180 degrees, so I mean, I used to stand like this with my knees. And I can't do that I make a point of not doing that anymore, because it's actually very unsettling. I've had to learn to use my muscles instead of just hanging in my joint. So I'm very conscious of the way that I move now. Thank you so much. Great, really appreciate it. So that in a nutshell, is the beaten skills, she scores five out of nine, which is borderline. So that is

Steven Bruce

only significant if she has she has any other issues. Yeah. Or symptoms. Yeah. So if you if you don't come around to find out, we did talk briefly about the sort of things that you might do in terms of exercise for someone with hyper. And

Elisabeth Davidson

so because a lot of the instability happens in the legs, we focus on strengthening the lower limb, particularly the hip flexors, and the knee extensors. So I would use, like elastic bands, for instance, give them strengthening exercises, I would use balance, like cushions for children, or little mini trampolines. And so that we improve the proprioception, because we know that the proprioception feedback from the particularly the ankle joints, but also from the knees is faulty. And they just people have a different gait when they have you started loss.

Steven Bruce

And we need what are the best exercises for improving proprioception?

Elisabeth Davidson

Well, that would be your vestibular rehabilitation.

Steven Bruce

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I was gonna say so we've, we've just run a course on vestibular rehabilitation. So we weren't thinking particularly of hypermobility. Yeah.

Elisabeth Davidson

So for little toddlers, for instance, if I find that they are behind in their development, I'll get the parents to not necessarily go out and buy lots of equipment, but just take like the cushions off the sofa and have them have them walk, you know, so that they can walk on different surfaces like sand or grass and barefoot particularly I give them particular exercises to develop the arch in the foot by getting them to maybe lift little pieces of Lego with the tools from one bed to another. I mean simple things like that. It needs to be a game for children. For older children, you can you can direct it more towards the sort of more normal types of exercise, but it's really about strength, right?

Steven Bruce

In terms of an adult patient rather than a child, would you send them off to a strength and conditioning expert at the gym? And so you're gonna be somebody we

Elisabeth Davidson

knew what they were doing. Because I think a lot of very good trainers aren't aware of the risks that someone with EDS have overextending. And so, posture and core strength is extremely important. And like I say, I've worked hard on trying to improve my general awareness of how I use my body when I'm just walking because otherwise I could be walking across the floor and all of a sudden, I've gone over my ankle or I've just done a

Steven Bruce

only given the principle of strength training is that you're going to, you're going to lift the weights to the point of failure within a very few repetitions, that is going to tear tissue, which is

Elisabeth Davidson

better off with lower weights and more repetitions. So I tend to work from the principle that if you can do 20 reps, that's your goal. If you can do more than 20, you need to up the weight. And if you can't do 20, then then you need to lower the weight. So that's kind of my principle for strength. But it also has to be done in the correct form. It has to be done controlled. I mean, you see so many people, you know, using momentum when they when their strength training or not training the right muscle. Yeah,

Steven Bruce

you're allowing that allowing a dumbbell or barbell to bounce at the elbows?

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Elisabeth Davidson

When I see that, yes.

Steven Bruce

Okay, so how many personal trainers do you think are even aware of hypermobility?

Elisabeth Davidson

Very few, unfortunately.

Steven Bruce

Right. So we need to be careful to read is there anything else? That was great,

Elisabeth Davidson

thank you so much for

Steven Bruce

your cameo appearance this week. So

Elisabeth Davidson

I don't think we should worry about you. But you do have one or two. And that's normal. I mean, that's common, we see that a lot. One or two joints are hyper mobile. And then hopefully, that'll never be significant for her. One

Steven Bruce

thing does occur to me that one on a previous occasion, when Grace was in here, it's clear that she has quite a bit of over pronation that the ankle Do you ever use in schools and

Elisabeth Davidson

I wear orthotics, yeah, make a huge difference. I want to go up around the heel, which actually stabilises me immensely. So yeah, and you can use, in my opinion, you can use orthotics from about age six onwards. And then even more important in young children. I mean, you can get joint support specifically for Ealer standards that are much more rigid than the ones that you normally use. But if you can start building up the muscle strength from an early age, and hopefully you'll not need those types of A's at a later age.

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Steven Bruce

Thank you again. Great. We'll get back to our seats.

Carrie has asked what your opinion is of Pilates for EDS. She says she's had great results with a patient who was in constant pain and struggle with walking. With walking to walking for pleasure, when he was just a great success with a combination of osteopathy and Pilates is that common?

Elisabeth Davidson

I think Pilates is amazing. Yeah, absolutely. It's one of the best forms of exercise. Yeah, definitely a lot of room to say that because you're working on conditioning the core. So it's all about building the strength without over exerting yourself and actually one of the UK members of the iList danlos sort of group of therapists is is I think she's a physiotherapist who does have Ehlers Danlos herself and she's done a lot of videos that which are available free on YouTube, on particular types of exercise for people with Ehlers Danlos Syndrome.

Steven Bruce

I suppose one of the cautions that people will have one of the worries we'll have is that you can get videos on anything on YouTube that you don't know the quality of the evidence behind what you're being told. And I'm assuming that this lady she's a physiotherapist is probably quite cautious herself in what she says. But I hope she makes it clear when you know this might work for one patient it might not work for another. She's excellent.

Elisabeth Davidson

Her name is Jeanne de Pon and she has done videos for just about any kind of exercise, but most of it is plot is based on the D bond the IBO and right? Okay, well, my

Steven Bruce

team will be beavering away in the gallery at the moment trying to get a reset a reset link that they can put up on the screen but we'll do that a little bit later on. Will has asked whether or when he has a patient with hypermobility type EDS who also has lumbar rotation of s one and S two. She regularly experiences SI joint dysfunction for which she relies on a walkingstick chiropractic management is a lifeline but despite its benefits surgical stabilisation of the size was considered. However, orthopaedic surgeons don't want to touch her. Is there any surgical joint stabilisation procedure that are effective? Or are warranty Ross safe in EDS? Well,

Elisabeth Davidson

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I've had a few patients that have had their SI joints surgically fused post pregnancy they've all ended up with crutches and not been able necessarily been better off so yeah, you're right. I mean I remember speaking to an orthopaedic surgeon a few years ago and Aberdeen and he said we don't really like touching your people because you know the outcomes not particularly well we you know we know we scar really badly we heal very poorly from from surgery. So it should be a last resort. Okay,

Steven Bruce

so the name of that physiotherapist you mentioned earlier on was Jeanne Jeanne divan right the link the link is up on the screen now. So that's something that people I'd like to pursue after the show hope. Just says I think there's a link between people with the MTHFR and different reductase gene variation, then we should try and say that it's too long at people keep doing this to me, they're sending great long words, and I haven't had time to practice them. So I'm gonna stick with MTHFR. Yes. And she says that gene variation and EDS hypermobility and how it affects B, vitamin and folate absorption, but not sure there is a folate dependent EDS, she says additional info from Claire short DHFR is getting attention due to genetic mutation thresholds. My wife, as you've known. Me, for MTHFR is getting attention due to a genetic mutation that may lead to higher levels of homocysteine in the blood and lower levels of folate and other vitamins while they were Yes.

Elisabeth Davidson

And you're right. There has been very much in the news. Or in the in the research papers in the last two, three years. I was actually reading one last week on that. And I thought, That's really interesting. It's still hypothetical. But it actually got me thinking, I wonder if I should start taking that particular type of folate, that you absorb better when you when you've got this, you know, haven't been tested for the gene, but it makes sense. And there's also I mean, there's a lot of theories out there, but we don't know. But it kind of makes sense. I think when you think about how, how many people are affected by that gene these days.

Steven Bruce

There's an awful lot of questions about this. I told you, hypermobility was really fascinating, interesting, what is it? And maybe it's the fact that we all hope that we can do some good for the patients or the sufferings, even though there's a lack of real science behind what we're doing, or I mean, in many areas. Robin asks about lifting weights and says you lifting weights in the mid range to avoid stretching? Yes.

Elisabeth Davidson

Okay. So it's really important not to overextend any joint when you're when you're training, it's really important to do it slowly and control so you're actually using the muscle. And because we just people with EDS don't have the same end range, you can just keep going. And so it's very easy to overstretch and actually damaged the ligaments so lower weights, more repetitions. So always my go to

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Steven Bruce

swimming is always a good go to pastime for everything. That's presumably good for EDS.

Elisabeth Davidson

That was the only thing I was good at as a child. Every other sport. I was miserable. doing

Steven Bruce

the splits. You were a gymnast? Yes, I was a gymnast. Yeah. Helen says what are your thoughts on cranial cervical instability as a complication of EDS?

Elisabeth Davidson

Yes, that's something that you need to be aware of. It's a very real thing. And so I always advocate not to do any kind of rotational type adjustments in the upper cervical spine, I tend to use other techniques, if that is warranted. And it's, it's I mean, some people are so badly affected by instability that they end up with surgery to stabilise them. So it's always something that needs to be in the back of your mind when you're treating someone with less than a loss.

Steven Bruce

And I suppose there were all sorts of reasons why you might want to adjust someone's cervical spine, let's say headaches. For example, if you haven't spotted a link between hypermobility and headache, maybe you're thinking somebody the spine is connected there. That's surely it's still it's still going to be even you might feel this joint is less mobile than the others. But you're immediately going to recognise that it's hyper mobile,

Elisabeth Davidson

aren't you? Not necessarily? Yes, exactly. So I mean, I remember when I was going through university, I had had a car accident a few years prior and was had severe head injury. And I had chronic headaches every day for eight years. And chiropractic helped, but only temporarily for a couple of days. And was that with manipulation with the neck? That was neck? Yeah, yeah. At that point, it wasn't recognised that yeah, we knew I was hyper mobile. We knew I could bend more than the most people. But yeah, it was it was the 90s it was like, Yeah, let's crack that neck. And it wasn't until I graduated. And then I think my the principal I was working for got tired of cheating me. And she said, Oh, why don't you try cranial sacral therapy, and I thought I'll try anything. And it was the first thing in eight years that took away my headaches. So that led me down to explore that technique. And I find it extremely useful for hypermobile people. Because you can go in and without rotation of the spine, you can go in and loosen things up much easier and make a big difference. So

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Steven Bruce

I was just thinking, as you said that actually maybe the the neck isn't hyper mobile. Well, if it's not hyper mobile, is it still at risk?

Elisabeth Davidson

Yes, you are more at risk for injury in any joint. Right.

Steven Bruce

Okay. Now I've got a question from Ashling. Here. Ashley, very nice to hear from you. I'm coming down to see you in a few weeks time when we take the first day roadshow down to Winchester. If I remember correctly, and somebody is taking the question of my screen. Ashley wants to know, how do you know that a child is abnormally hyper mobile? When you said in the first decade all children are hyper mobile.

Elisabeth Davidson

Yes, what's abnormal and what's normal so I I had a little boy in, for instance, who was seven the other day who was extremely clumsy. He had very soft, dewy skin. He could see his gait was on on abnormal he he was he was kind of humble, hobbling around a little bit the parents did. He was he was limping, but I don't think he was. He just didn't have any stability in his ankle joints. And he had this sort of soft, dewy muscle, they have a subtle lower muscle tone than other children as well. So it's not hypotonia, but it is less than normal. And I think that's something that you become proficient at recognising through time. So when we took him through all the tests, I mean, he scored like 110 on the beaten skill pretty much. And he had every single classic symptom. So for me, that was very obvious. I've also seen babies with hypermobility where well, you can feel this every joint clicks. And now this one baby I had was actually a baby of someone with known EDS. So it was, you know, we expected to find it, but you could tell this baby just I mean, all babies have soft skin, but this baby had extremely velvety, soft skin. And their joint range of motion was abnormal, even for that age that her tone was abnormal. So you have to sort of really, you know, most children are hypermobile until they're about 789 10. They start sitting at school and their core reduces and all that sort of stuff. So but it's very obvious with these children that they have the history of clumsiness, maybe delayed development, they may have the anxiety issues as well or ADHD or, yeah, so there's, again, you're looking at all the hype, the older comorbidities is not just about the hypermobility.

Steven Bruce

And how common is it that the parents would predict would also have

Elisabeth Davidson

we noticed genetically linked, right, but it's not always recognised in the parent? That

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Steven Bruce

was my next question. Because they might not know. Yeah, yeah. Does that mean that you would start would you say to the parents, who would you? If the parents stay with their child? Would you ask them to do the bacon school?

Elisabeth Davidson

This young boy that I had in the other day, neither parent had a history or knowledge of it? So for whatever reason, you know, it was obviously a gene that became expressed in this boy or not the other children, which can happen as well? Yeah. Okay.

Steven Bruce

Sam says, Do you do the Bateman score as well as the brightness score, as well as the Beighton? I was taught to do both, but that was several decades ago. To

Elisabeth Davidson

me, it's out of date. So the brightness, the brightness, so I don't really use it. How does it differ? That's a good question, because I haven't used but I'm you

Steven Bruce

can tell us how important score differs from the Beighton scale. But what

Elisabeth Davidson

we did a little I'll just change the slide because there was actually a couple years ago, an update where we recognised that the beaten isn't appropriate or wasn't appropriate for young children. So this paper came out in 2021, where they looked at the beaten in children each file and here you can see that the beaten score must be a minimum of six. Normally, it's for an adult's right, in order to be relevant. And then you have to have all these or some of the minimum of three skin and tissue abnormalities. You got

Steven Bruce

to have a degree in English to understand just some words in there that I've never seen in my life. He moves so direct scars, which we're not going to get drawn down to at this point.

Elisabeth Davidson

Pires Setia scars is mostly seen in classic and vascular they have really, really thin, almost papyrus like scarring and white scars. I mean, we're talking where most people get a scar that's maybe a

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millimetre or two there'll be centimetres. The bilateral pyogenic papules in the heel, a little extrusions of fat through the fascia in the heels. I've got that on both feet. Hernias, very common. And they can be in guano, hernias. It can be stomach hernias, it can be hernias, pretty much anywhere. And then you also have to have minimum to have the muscular skeletal complications where you have the pain and the dislocations or subluxations. Not necessarily with trauma. It could be something as simple as a woman going to the gynaecologist and having an examination, and then her hip joints will dislocate, which, you know, doesn't normally happen. Many doctors actually doubt that it can happen, but I've seen several women that were did happen, right. So you have to have all these other issues too, in children in order for them to be classified as he was demos. Okay.

Steven Bruce

We will obviously send these out later on because it's hard to make sense of them over an iPad or a computer screen so they'll come out as a handout tomorrow. Amy has asked whether it counts on the beaten scale if the person is hypermobile at the elbows and knees in flexion instead of extension. Okay, have a patient who has a new stock point on the elbow, we can get the wrist behind the shoulder and the feet in front of the hip with knee flexion was not

Elisabeth Davidson

part of the beaten skill, but it's probably part of having mobile, because the beaten skill doesn't cover every joint. Like I say, it doesn't even mention the shoulder joints, for instance.

Steven Bruce

Okay. Is the beta scale of a wrong then? No,

Elisabeth Davidson

it's just not adequate. Right?

Steven Bruce

How would you improve it?

Elisabeth Davidson

Well, that's a good question. I would I would bring in things like rotation of the hip and rotation of the shoulders because those are two major joints that are difficult to stabilise. And that we often see problems with, I mean, I've got chronic shoulder issues that I've had since. So

Steven Bruce

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out of curiosity, then how would you measure an abnormality in that regard without actually putting the joints at risk? Because if someone is that as vulnerable, as you described a moment ago at the gynaecologist, you don't actually want to dislocate someone's shoulder or hip through testing.

Elisabeth Davidson

No, you don't. You I mean, you know what the normal range of motion should be. So if you can go beyond that, without the patient being particularly bothered, then you know, there's an issue.

Steven Bruce

Yeah. Okay. So then you do the Beighton scale, and you've got something you put on paper for the GP or the rheumatologist to look at and take into account. Robin Robin is our single issue fanatic on the subject of barefoot running and barefoot shoes, but he makes a very good question here. Would you recommend barefoot shoes given that apparently they give you massively improved?

Elisabeth Davidson

So I don't know. I love going barefoot myself. I think it's good to be barefoot. I think it's important to stimulate you know, the, the proprioceptors in the foot and the muscles in the foot properly. But I don't know enough about barefoot running to be honest.

Steven Bruce

I'm sure if you if you have the time, Robin will sit down for hours and tell you about barefoot running. Robin. I'm only teasing of course.

Elisabeth Davidson

But I know that I need insoles to support my my. Yeah,

Steven Bruce

they don't fit well in and I

Elisabeth Davidson

don't think they would. Yeah.

Steven Bruce

So Jury's out Robin, trying to get an answer to you after some more research is done. And no fear is asked a question about core stability. And you talked about core strength earlier on. I sometimes

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think that the term is perhaps misused. And I only say that because I don't know if you know of Professor Al Leatherman, who's an osteopath called qualified as a physiotherapist as well, he's done quite a lot of research into core stability, and is a sceptic about the value of specifically training the core, because one of the things he points out is that whatever exercise you do, you will be you will be strengthened. And you will be training those muscles, which we think of as the core, but none of them operates in isolation, they all operate in massive groups, you've got

Elisabeth Davidson

to consider things like pelvic floor, the diaphragm, and of course, the stomach in the back muscles all together, they all work as a unit. And I think a lot of issues is that we sit too much, you know, our modern lifestyles mean that we sit and so I

Steven Bruce

guess if you are hyper mobile, then probably do it more than others. Because actually, it's painful to do. It

Elisabeth Davidson

can be painful to stand for a long time. Yeah. So I give everyone pelvic floor exercises, everyone, regardless of age, I get people belly dancing, I get people using their cores enough so that you don't have to sort of go to the gym and do sit ups but but just becoming aware of using your core in your day to day life. I think that's part of the problem, that we don't use it. The minute kids start school and sit too much. They lose their core. Right?

Steven Bruce

You mentioned their pelvic floor exercises as well. And, again, we've had a small team of people come in to talk about hyper pressive training. I don't know if you've heard of hyperbaric you

Elisabeth Davidson

have heard of it. I'm the jury's out on that one.

Steven Bruce

They seem to think it wasn't out in terms of what they were dealing with, which was incontinence, particularly in women after they've had babies. And at least that genuinely, I mean, pelvic floor training might work. But when it doesn't, then hyper pressive training is more likely to work. And I just wonder whether

Elisabeth Davidson

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I mean, I've been to a class and it was interesting. I didn't feel it was for me. But that doesn't mean that it won't work for some people.

Steven Bruce

But also, I mean, they were the group that came in here we're talking about it in terms of incontinence, they've not even considered it as being beneficial for someone who's hyper mobile. So no,

Elisabeth Davidson

exactly, no. So it may well work very well. I mean, at the end of the day, all techniques and all exercises work to a degree. You just have to find what's right for you as an individual.

Steven Bruce

And it says is there an increased incidence of hip dysplasia with EDS? So I guess that can be Yeah, we've talked about instability in the hip, but but actually malformation of the hip joints, rarely

Elisabeth Davidson

malformations, but we do know that there is a link between circles survived or destroyed. shared during labour and, and hip issues. And women with Ulis danlos are more likely to have all these complications. So yeah, it is something that should be borne in mind, but I'm not sure that the actual genetic incident of it is any higher. It's more of a space issue.

Steven Bruce

Okay. Spike says would claiming be good or not recommended for a patient with a H EDS.

Elisabeth Davidson

Personally, I wouldn't do it, I would be too scared of falling. And that's partly because that might be

Steven Bruce

nothing to do with EDS.

Elisabeth Davidson

Didn't want to go don't have the muscle strength, they don't have the muscle strength to claim. If you can build that strength, then I'm sure it's fine. And I think contact sports in general is not a good idea. So things like rugby boxing, you know, because you have the inherent instability, potential

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instability and potential for for damage. Much higher in the sports. So, you know, if you have the strength to do it, then I'm sure it's fine. But personally, I would be, you know, not for me.

Steven Bruce

And it might not be the thing thing, you recommend it to a patient. You've never done it before. If they're already doing it, and they're getting away with it, you might say great, keep up. Yeah, absolutely. Okay, so, Spiker, we have to make your mind up on that. 199. We had a question from 99. Earlier on, who says have you come across Kimberly Kitzur row who has created a biochemical network map which connects neuro divergence with comorbidities such as EDS?

Elisabeth Davidson

I've heard about it? Yeah. Not in any great detail. But yeah, I have come across it. So I think that's something that they're exploring at the moment in in the research, and I can't wait to hear more about it.

Steven Bruce

Yeah, I've just seen one over here, actually, from Sam, because we were talking about strength training. Earlier on, we talked about PTS sounds as he's recommended, Tom Morrison, who's an online personal trainer, his business partner is hyper mobile, and his programme is apparently geared towards strengthening for EDS. We'll try and get a link for that and send it out on the show. But Tom Morrison, an online personal trainer might be worth excellent knowing about for patients, as you said, certainly worth having someone if they're going to give you advice, if they understand EDS, and always

Elisabeth Davidson

asked to meet up with them and explain, you know, what the, what the problem is for this particular patient. So if you can find a great personal trainer that understands Yeah, then that makes a big difference. You get a lot of

Steven Bruce

compliments already from the people watching, not least from my aura who says this is a brilliant session, but she also wants to know whether collagen supplementation is of any use?

Elisabeth Davidson

Yeah, that's a good question. Because there's the they're divided about that. And because you don't necessarily absorb it particularly well, you wonder, but then my argument is, well, if you don't absorb it from food, either, you need it from somewhere. And I have taken it for probably the last 15

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years. And I wouldn't like not to take it. Is that all in my head? Maybe? I don't know. Possibly. I think it's worth a try.

Steven Bruce

Yeah, and it's all in your head that doesn't really matter. Does it not really matters is the better

Elisabeth Davidson

visual, because it could be the placebo effect. But so what if it's working? That's what matters? Yeah. I mean, the research will say no, there's no, there's no evidence that it works. There's no evidence that it can help, but it can't harm either. Yeah.

Steven Bruce

Lottie says is it recognise that shortened hamstrings in adolescence during fast bone growth can skew the flexion test in the beta scale? Yes. Okay. That was a nice easy answer, wasn't it? So it makes logical sense. Where does that take you then? I mean, other other things, it might you might then still say, No, I'm still convinced this person

Elisabeth Davidson

or you're looking at all the other joints. Really, like, like we saw in our lovely test subject. I mean, she had extremely extensible PIP drugs. And, and so it may be that because she's, we're eating it. I'm not sure how old she is. And, and a student and, you know, work that she's just not particularly flexible, but she could become more flexible if she worked on it possible. So yeah, that's not the only you again, you've got to look at the whole picture. It's not just one thing and not just the beaten test. That's really important. You've got to have all the other comorbidities as well. Okay. Are some of them.

Steven Bruce

Interesting one here from Sam, Sam says, What can you tell us about pelvic floor spasm with women with EDS?

Elisabeth Davidson

Not a lot.

Steven Bruce

Great question. But we know that there

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Elisabeth Davidson

are a lot of women with EDS that have painful intercourse and that have issues but it's not really my area of expertise. So that's where you would look to someone like Sally Pizarro And Jessica aquest, who are the two main researchers in women's issues? And have a look at what the research says about that.

Steven Bruce

Often thought that life isn't much fun for women. So many shows you

Elisabeth Davidson

seem to be dealt a tough hand sometimes.

Steven Bruce

D says what exercises you got to recommend? Would you recommend to strengthen the cervical spine to help away stability? Hmm,

Elisabeth Davidson

that's a good one. I'm not sure that you can because it's its genetic instability. It's a genetic fault in the soft tissue in the in the collagen. But obviously having a good posture. I don't particularly like cervical exercises. I have done them. I've been given them before, and I don't find them helpful. I'm much more about my posture in general, my core, my keeping the shoulders back. And I always when I work, I always sit on a saddle chair so that my posture is good. And that keeps the spine back. But I still end up sitting like this when I'm on most people. Yeah, but I correct my

Steven Bruce

posture 50 times a day. So Alexander technique would be good.

Elisabeth Davidson

I think that would probably be really good. Yeah, I've not really explored that myself. But yeah, it was very popular when I was a new graduate. Yeah.

Steven Bruce

And we've had a couple of very good speakers about Alexander technique on your show in the past and in quite some time ago now. But again, maybe worth exploring. Rachel says is there a link between EDS and other spinal abnormalities, such as rotating Atlas, Klippel file, etc? Not I'm hoping you know what those

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Elisabeth Davidson

people file syndrome know, that's another genetic issue that isn't necessarily linked with EDS. You have however, herniation of the cerebellar tonsils into the cervical spine back can be associated with EDS, but not liberal file syndrome,

Steven Bruce

which maybe Lindsey said are swallowing problems and choking more prevalent in EDS

Elisabeth Davidson

is yeah, all kinds of gut motility issues, okay.

Steven Bruce

And says that she's read research to suggest that the genetic mutation associated with EDS is sometimes manifest with unattached ear lobes. She herself has EDS and has unattached ear lobes, which might also be something to look at when assessing patients that have come across

Elisabeth Davidson

that. Yes, I have come across that theory. Um, as far as I'm concerned, it's just a theory. And I don't think that I've not seen that in the in the proper research, but it is suggested in a lot of Facebook forums and people, you know, sort of look at people's ear lobes and,

Steven Bruce

but it might actually be one of the things that says, a better job

Elisabeth Davidson

more associated with one of the more rare syndromes not necessarily

Steven Bruce

but it might make you test it might make your unbeaten school testing,

Elisabeth Davidson

not just the elope know

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Steven Bruce

an Amazonian tree frog is sending this. I have many patients who take collagen who are hyper mobile who benefit from collagen or type two liquid as far as that goes, Okay, well, you said that as well. So well done for the Amazonian treefrog Robin has come back into bang on about barefoot shoes again. I do like Robin, Robin Robin is a very, very intellectual contributor. And he says he had some really good results with barefoot for EDs, even in a patient who thought they couldn't do without their insoles. Like anything new it was about incremental loading published that year, well, yeah, maybe you should, like anything new. It was about incremental loading to get them conditioned before using their feet that makes everybody who's talked about barefoot, so you can't just go from running in normal trainers are in orthotics.

Elisabeth Davidson

And by doing that incremental strength training, you know, you would be improving the proprioception and the strength anyway. So yeah, it makes sense.

Steven Bruce

D says she has a friend with EDS, who suffers very badly with headaches and dizziness. That friend is seeing an OA specialist chiropractor in Shropshire called Ian Smith, who specialises in cranial cervical issues. He gets specific and directed manipulation to the OA joints. And he's using scanning equipment to achieve the angle and it really helps him now. First of all, is that something you're familiar with?

Elisabeth Davidson

I've heard about it. And I don't know the technique particular. I think all techniques work to a degree, but there are certain ones that we should be very careful of, and that's particularly the rotational ones in an upper cervical spine, and I'm not saying that we shouldn't adjust them at all, we should just use modified treatments. So that particular treatment is modified to be safe. And let's

Steven Bruce

be careful what I say here because I don't want to offend any of my chiropractor colleagues who are watching nor any of them who might be in the studio with me at the moment. But I did go to some CBD probably 15 years ago. It's a very famous osteopaths practice in London. And there was a chiropractor was presenting the CPD and she was part of a an organisation for the APUs FICO complex, something like that. And what she told us was that that's the only joint that they manipulate and that everything stems from that. And that they did a huge amount of training so that they could take their X rays, which they took frequently. And get them just right and diagnose the angle of the joints just right. And so that they could stand in exactly the right position to get their adjustments just right, is, again is that sounds as though this the Ian Smith that we were talking about a moment, it sounds as though he might be one of those upper cervical complex specialists.

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Elisabeth Davidson

It's funny, isn't it, people have very specific ideas about, you know, feeling that their technique is the best one. And their technique is, you know, most appropriate, and I think that depends on the patient. To be honest, it may be the best technique for certain patients, but I'm not convinced that it's the best one. But I don't know enough about it to say, and, you know, I, you know, my background is so T sacral occipital technique and cranial sacral. So I tend to use those non force techniques. And they work really well for me, and they work well for the patients that I see. But that's not to say that they work for every patient, I

Steven Bruce

think, possibly, you'd have to be a very, very confident practitioner to work on the cervical, specifically the upper cervical, as in someone where you know, the joints might be vulnerable? Because, yes, it might work. But you only need one where it doesn't work.

Elisabeth Davidson

Absolutely. I mean, I don't let anyone touch my neck. And I know that I have to have my neck in a very certain specific position in order to get the correct line of drive. And then it doesn't take much to release it when it's joint when it's stuck. And so, but that's through trial and error, you know, I've had a lot of adjustments over the years, I thought, Oh, that wasn't good. But it does help. And you know, you learn, you become proficient, you become confident. And I wonder if

Steven Bruce

we're slightly off on a tangent here. But I just wonder if that is the case with the modern output from the osteopathic and chiropractic colleges? Because the sense I guess, is that many of them are being steered away from manipulating because they're frightened of the possible adverse consequences. And actually, if you don't train in it at that early stage, how do you ever get to that level of expertise?

Elisabeth Davidson

You don't know. It's, it's yeah, it's a conundrum that we see. I mean, I think when I trained 30 years ago, we were overconfident. And we thought chiropractic or, you know, osteopathic could treat anything and everything. And then that was clearly wrong. You know, but we became really good practitioners. And, and, you know, these days, I'm very careful about who I treat and how I treat them. And, you know, after 30 years, yes, I'm a good adjuster, when I can do things with very minimum effort. But it does take time, and it does take practice. So yeah, but I don't know that that's just where the profession is headed. I mean, there are all the contextual factors that are important to definitely.

Steven Bruce

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But Hannah says, Have you ever used modifying cranial cervical flexion test as a stabilising exercise?

Elisabeth Davidson

Nope. It's a short answer.

Steven Bruce

You just say you were very sceptical

Elisabeth Davidson

about exercises for I just don't feel that people do them. Well, yes, there is that of course. Yeah. Because I know I don't do them.

Steven Bruce

Why don't you do them? You said you haven't found it effective. But if you don't do them, you can't

Elisabeth Davidson

know. Well, I did do them after I had my car accident when I was 19. And I was set to physio for four months. And I just did not feel that they were helpful at all at the time. And so your own experience, you know, most who you become, you know, and so I just found them useless at the time, and they might have been good if I had had proper treatment first, but it was a long time. Three or four years before I saw chiropractor. Right?

Steven Bruce

I'm gonna get a couple more questions because we're running out of time. Sam says if you suspect a child with EDS, and has linked comorbidities to support that, do you go to the GP if they find it difficult to diagnose, or is there any other organisation that you would recommend?

Elisabeth Davidson

Yes, that brings me to the last slide I want to show you here. There's a couple of websites hypermobility.org and ILAs danlos.org And they are amazing. They have lots of resources for families and for children and for schools. To understand the condition you can join as a as a normal person, you know, parent or you can join us professional member both they have a lot of good resources. You can also if you struggle to get diagnosed, they do have the London hypermobility unit, which is the best in the country with all the best experts. It is private obviously, but they will take people from I think the whole of the UK and then I also recommend that you look into Alan he came he's, he's the main guy behind a lot of the research in the UK. He's the guy behind him in the UK, the echo

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programme, and he's, he's not really a practitioner anymore. He does mostly research now these days, but he's he's got a lot of good information. Alan Hakim, he's a rheumatologist, Professor, rheumatology.

Steven Bruce

I did look him up earlier on before we came on. But then of course, we will share these resources is Alan mentioned on any of these areas? Yeah. Yeah. So we will, we'll make sure everybody's got

Elisabeth Davidson

that. But I think particularly the hypermobility.org they have a lot of good resources for schools, parents,

Steven Bruce

too quick resources that have been sent in by our audience today Amazonian tree frog says there's a legal Susan Douglas on Facebook who has been working with people for years as excellent specific control positions programme for hypermobility. And Sam says the other online person that's Sam recommends is Tracy Rodriguez, who is a hypermobility coach. She talks about the link between ADHD hypermobility and tongue tie. I've heard of both actually. Yeah. So we'll share those as the things. What's the message for our practitioners? Should they be dealing with this? Should they get specialist training to deal with this,

Elisabeth Davidson

I think the best thing you can do is read learn more about the subjects learn how to recognise it, learn what your role as a practitioner would be in supporting that patient. We can't cure it, nobody can because it's a genetic condition. But you can do an awful lot to improve that patient's life. And and then join the echo network join, you know, the hypermobility Association as a professional member and become part of the network of amazing people across the world now that are working really hard to improve the knowledge about this condition. Because if it was called the most under diagnosed condition in the world, up until a few years ago, I think we are getting better, especially in the UK, I'm really impressed how much more awareness there is a bit than when I was diagnosed nearly 10 years ago.

Steven Bruce

Yeah, that is that is harming? Where is the? Where is the research going? I mean, presumably they're looking for

Elisabeth Davidson

happening in the UK, particularly, I think Bristol University and probably in London as well.

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Steven Bruce

Looking for genetic modifications they can make to try and they are looking

Elisabeth Davidson

at things like that. I mean, I know they've had a lot of good results with that in for instance, in. In other conditions, I think we're not at that stage yet. But it would be nice to think that maybe in another generation, or do we have to understand the genetic link in order to make genetic modifications. Yeah,

Steven Bruce

sure. Yeah. And what do your patients get from coming to see you those with ADHD? It's not ADHD, sorry, Ehlers Danlos, eds? Well,

Elisabeth Davidson

I think they Well, first of all, they get support, they get someone who understands what they're going through, they get

Steven Bruce

to this communication element and this, which is very, very massive part of it. Yeah,

Elisabeth Davidson

I think they get an understanding of their own condition by someone who has lived through it. And they, and I can give them links to other practitioners and other resources where they can learn more about it. I'm a member of the ILA Standards Association in Denmark, which is really good. I am of the UK associations as well. And I'm actually listed on the.org site as one of the people with special interest in Denmark. So recently, I had a referral from the States, from someone who was moving to Copenhagen and wanted care so So yeah, you can you can do all that kind of stuff. So I think you can support people. And I think understanding how complex it is and how difficult it is, have an empathy, having the experience or having lived through it makes a big difference. It

Steven Bruce

was with we've had 604 people watching, which is quite a sizable audience. It is always an interesting, popular topic. One of those was your friend Pamela, who hasn't asked the question. So I'm very disappointed about. Thank you for giving up your time, and lots and lots of useful information. A really great stuff, I think from Elizabeth and hopefully that's going to be really helpful to you in your own practice.

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