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# The Effects of EDS and HSD in Males: Identifying and Addressing Unique Issues, Needs, and Concerns

Adam Sherman, RN, BSN  
Webinar—July 10, 2019

Video <https://youtu.be/HZvhvToukBO>

[00:00:00]

[00:00:05] **Sarah Jo Ritchie:**

Hello, everyone! I'd like to welcome you to today's webinar, "The Effects of EDS and HSD in Males: Identifying and Addressing Unique Issues, Needs, and Concerns" with Adam Sherman.

[00:00:16] **Adam Sherman, RN, BSN:**

Hello!

[00:00:17] **Sarah Jo Ritchie:**

My name is Sarah Jo Ritchie, and I am the Volunteer Coordinator at The Ehlers-Danlos Society, and I am your moderator today. This webinar is part of our ongoing series, "Living with EDS and HSD." This is how today's

webinar is going to work. Webinar attendees will be muted at all times during the webinar, however, you are able to type any questions you may have throughout the presentation, into the question box at any time. Adam will not be able to see or respond to any questions until the Q&A portion at the end of their presentation. Please do not send your questions more than once. It will not increase your chances of having your question answered, it will only make it harder for us to sift through the questions, to make sure we are able to get as many of your questions answered as possible.

Adam Sherman earned his associate of Applied Science degree in Nursing from Oakland Community College, in Waterford, Michigan, and continued on to complete his Bachelor of Science degree in Nursing at Oakland University, in Rochester, Michigan. He has been licensed as a registered nurse since January 2016, and strives to contribute as much as he can to patient care, within his limitations, living with hypermobile Ehlers-Danlos syndrome. He explains, that otherwise, it would be a complete waste of a BSN. His passion and knowledge for helping others led him to the creation of this webinar, in hopes to synthesize research, standard knowledge, and common sense, to explore how biological, anatomical, environmental, and psychosocial differences, can create unique challenges for males built with the connective tissue of EDS or HSD. Adam's goal is to raise awareness, trigger greater discussion, offer suggestions for improving patient and self-care, and perhaps make our male zebras feel a little less alone. Adam grew up in Glendora, California, and feels honored to currently reside in Bloomfield, Michigan, with his cats Sasha and Shlomo, who graciously give him the privilege of living with them.

Thank you, so much, Adam, for putting together this webinar.

[00:02:20] **Adam Sherman:**

Thank you. So, we're gonna start – I'd like to make some – let you know some basic assumptions. Obviously, everyone's experience with EDS/HSD is their own, and everyone has their own experiences, and some symptoms, maybe not others. So, for this webinar, we're just going to assume that, that the males are going to have some reduced proprioception, weakness in various sphincters, autonomic dysfunction – which despite not being a diagnostic criteria, is certainly very prevalent – pain, fatigue – “the youzhe,” and of issues with – with the vascular system. Especially in this case, and certainly, there's vascular EDS. I'm going to be focusing on the, more the

venous system, which can cause things like venous insufficiency and dysfunctional valves, that cause blood pooling.

Obviously, there's going to be some reduced muscle strength with hypotonicity. And most this webinar, unfortunately, because it is applicable to a greater majority of the population and because there already is so little information, it's going to be focused more on cisgendered men, or males – people who are assigned the male gender and sex at birth and still continue to, to find that congruent. I'm also probably going to end up using "EDS" when referring to EDS/HSD, just for simplicity, but know that when I'm saying "EDS," I am acknowledging everyone in our group.

[00:04:00]

So, I saw this picture through my Facebook feed, and it just seems so perfect in terms of how I feel, and I imagine others feel, with EDS. And in a way, it doesn't make too much sense, because really, with Ehlers-Danlos, the, you know, Tin Man would be everyone else and you know, you'd be the flexible one. But, I can see it the other way. For example, that oil can, that can be the bottle of water with you, you know, when you have POTS and try to keep your blood pressure up, and you know, this is how you're built and you're born, and you're just saying – and you're looking everyone else doing things and you can't understand why you can't, and you're just very, very frustrated, because no one ever tells you that your body actually might be a little different, and no one ever tells you that, that there are things that might be more difficult. You're just, you know, a lot of times it could be one of the more invisible disabilities and people don't really acknowledge it as such, and you're just, and it's just, it's very invalidating, really. We're just looking around, and you can't figure out what's going on, and hopefully this webinar will also shed some light on those things to help people know what's going on. And that's Sasha [*inaudible*].

[00:05:10]

Alright. So, why don't we talk about why EDS/HSD would even be diagnosed less in males. The ratio—I mean it's a genetic illness, it should be affecting both sexes equally, so there has to be something else going on. Probably hormonal factors, biological factors, possibly even prenatal factors, and other genes that are all affecting each other to create the phenotype where males are probably going to have a little less severity and, and less likely to be diagnosed. For the biological factors that actually do decrease severity, we can see why. If you look at, you know, throughout the hunter-gatherer times, and you think about the differences in the sexes, and different functions throughout the animal kingdom,

that males are generally meant to hunt, fight, move things, achieve erections – otherwise known as my bucket list – and to do these things, me...males are generally going to have to be a lot more stable, lot stronger, a lot more muscle mass, dermis is generally found to be about 30% thicker, easier to build muscle, and of course, when – with EDS already the muscle can be compromised with the collagen, and then the ligaments and tendons tend to be – the muscles are needed to compensate for their lack of strength.

So, all these factors are already being very protective. If you almost think of more like a baseline, and then you look at, you know, where this might be genetic. I don't if you can actually see this. And then it sort, you might almost see it almost like a separation of male and female, because of the protective factors, and the factors that can worsen it. And then of course, there's hormonal factors like testosterone which, which increases muscle mass, increases strength and, and does all that, whereas – and these hormones are found in both sexes, or all sexes, you could say – estrogen, progesterone tends to cause more of a relaxation of connective tissue. Which doesn't make sense, when you think about the necessities of childbearing, but we're going to be talking about males, and we also want to know why...

[00:07:30]

Even if there are protective factors, why is the diagnosis rate still so much lower? I think some studies show that really, the ratio tends to not be too skewed in most of them, but in hypermobile EDS, the most common and the one without a clear genetic cause, is probably more heterogeneous, there's probably several genes or maybe different subtypes within it, but for right now, we know that the ratio can be as high as nine to one, and since there's not a clear genetic test, and it is made more in clinical grounds, than it wouldn't – it would seem to make sense that there's probably that bias, and other factors can come into play, in terms of diagnosis.

So, when we think about males, one thing we certainly know – look: one thing we learn in nursing school, is that males tend to be less likely to seek health care services, just for the sake of being males. And for that matter, when it comes to EDS – and we'll talk about this more – all the problems can be related to things that could impact sexuality and, and other issues that relate to a sense of masculinity. So, there can be some shame, embarrassment, some self-blame, and, and other things that might just, that might make a male less likely to seek healthcare.

There's also possible that, as we know, Ehlers-Danlos tends to accumulate damage over time, because of the greater range of motion, the micro damages, and it's certainly possible that a male might take a little longer to develop some complications, and then when they actually do reach the healthcare services, it's possible the Beighton score might just not be positive anymore, and might have some historical joint mobility which they never learned about. And for provider bias, I mean, unfortunately health care professionals are still very, very much guilty of bias as anyone else. We try our best to learn tolerance, and, and learn about other cultures, and everything like that, but at the end of the day, there's still probably going to be some- some bias in terms of the stereotype of, "Oh, you just need to man up." You – the pain might not be taken as seriously, and actually, that's something I do want to mention specifically, because a lot of times females, there's, there's an issue with female pain not being taken as seriously, and generally, what that means more so, is that the overall cause and – will not be looked into as much.

So, whereas a male would complain about the same pain, they might be taken more seriously in terms of diagnostic testing, and, and more evaluation. With EDS, especially considering that it might be less likely to be diagnosed, the pain that might be reported could actually end up being, when all is said and done, and – and maybe tests come back negative, it might even end up being worse, because the idea of, oh, the pain being all in your head or being dramatic, is so at odds with societal expectations of masculinity, that it could actually take on its own set of problems. And of course with ED- and of course you know, is a catch-22 because of the under diagnosis and skewed ratio than a lot of these conditions of and comorbidities like, like POTS, can be seen as female diseases, and so unfortunately, providers, professionals might take in the gender – the sex into consideration when even considering certain diagnosis, and that's certainly one thing I hope that will, will change.

[00:11:21]

So, now that we understand some reasons why EDS might be diagnosed less in males, I want to discuss the effects it does have on those who are affected. And I went out – I did want to mention also, that the studies recently shown that when EDS is actually, especially hypermobile EDS, it's actually looked for in family members of females who are diagnosed, they generally will find the ratio being more around 70 to 30 when it's actually evaluated. So, there's a huge under-diagnosis situation anyway, so we're evaluated so there's a huge under-diagnosis situation. Anyway.

So, we're gonna talk about some anatomy: testicles, penis, prostate, bladder, pelvic floor, and the rest. I like the rest, because you know, sorta like the Gilligan's Island, you know, "the movie star and the rest..." Anyway, that's the rest.

[00:12:10]

So let's start with the testicles. Why not? It's a very good place to start. So, as we talked about, we're gonna assume that there's going to be some autonomic and vascular dysfunction, and unfortunately, with already there being so little research into EDS, the research for males in particular are, you know, quite scant. So, we're gonna have to just extrapolate from other research and make some assumptions here, and hope it turns out all right. But one way, one thing we do know, is that with dysfunctional blood flow backing up, there could be issues with congestion within the test-...within the testic-...testicular circulation, which can end up creating decreased size in the testicles and which have also been shown to be correlated with a reduced testosterone level. Since this would be expected to be more chronic than another, than someone in the right, in general population without EDS, and probably more bilateral, it might make sense that you might not see that unilateral, smaller testicles you might see in someone else. You might see a generally decreased size, and this might actually have an effect on a male sense of masculinity. If you think about a society, how often we associate testicles in our testicle size with, with bravery, and bravery. If you think about how many times we hear the term, "Oh, she's – he's got some big balls there." Something like that.

So, this unfortunately, if this does end up decreasing the size can, can affect a man's sense of identity, and it also has shown that this reduced testosterone level, or there's a risk for a reduced testosterone level. Some studies have shown that, and when you can say that testosterone is so relevant for strengthening connective tissue, strengthening tendons, muscle mass, and so on, and when you can say that these vascular issues can happen very early, there can be issues also potentially during puberty, during growth and development of secondary sex characteristics, and of course if that ends up happening, there could be a cycle going on. I was going to make a slide with a cycle, but I got kind of lazy there. Where you think of, where you think of the lower testosterone leading to lower connective tissue, leading to lower to even more blood flow issues and, and creating catch-22 situation.

That along with everything else, can create reduced fertility. Another reasons potentially for reduced fertility is with autonomic dysfunction

causing problems with scrotal retraction and, and changes with distance for the body. When it comes to fertility in males, sperm has to be kept, I want to say about three degrees lower than the rest of the body, which is why they're even outside of the body. They're there to have a lower degree, so that they're you know, getting cooled down. Well, if it also needs to be retracting to compensate for temperature outside it, it could end up causing issues with temperature in the sperm. So, we just want to think about – of – that if a male with EDS is having a problem with fertility, there might also be an issue with that, that are affecting things. And, as already mentioned, with testosterone providing so many factors, that catch-22 happening. There's just so many issues, it's just hard to keep up.

[00:15:52]

Speaking of things I can't keep up, the penis can also be affected in Ehlers-Danlos syndrome, in ways that you might not think about. For example, if you look over to this diagram here, a lot of times people will just think of the penis as being something like an appendage outside of the body, just some skin that fills up with blood and becomes erect. That would actually be really difficult to achieve an erection that way. To think about just only things happening on the outside of body. In reality, the penis is very well anchored from the inside. In fact, the penis- about as much as half of it is inside of the body, anchored by various ligaments, and tendons, and the pelvis, and everything else.

You'll notice the one thing, one ligament in particular. The suspensory ligament is responsible for holding the penis up during an erection. So, it can fill with blood, it can get harder and larger, but something actually has to hold it up and anchor it, and oftentimes hold it up in a, you know, upward angle. Much like every other ligament in EDS, that can become weak and which can cause a whole host of problems – for example, if, if the ligament stretches out, the penis can potentially hang out more outside of the body. In some ways, some men might find this good, because then it's you know, more is outside. There is a problem though, in terms of the lack of stability there, so that can affect sex, and we'll talk about sexual activity a little later, but it can certainly cause a lot of problems there. Maintaining an erection could be more difficult if, you know, if there's not- if it's not well-anchored. Which especially then, can put pressure on the venous system, and it just again. cause a catch-22 all the way around.

What we know with EDS, if there's – that the skin can – is already stretchier. You're more elastic and can droop, and become lax, so it's

certainly possible that many men might find the pubic skin becoming looser, hanging down and creating what people might call a hidden penis, and considering much like testicles and probably even more so, penis size has so much relevance for sense of masculinity for so many males in our society, that this can definitely have some psychosocial effects. We also think about – and one of the – another big thing here, is talking about that skin. With the – there's a higher risk of impaired skin integrity. It's certainly possible to get abrasions much easier with the weaker connective tissue. Cuts, scrapes, abrasions with you know, rubbing...which is what happens during sex. And that, those breaks in the tissue can create a higher risk of genital infections, and for that matter, STDs, which we'll talk about.

And we also to think about, with anything, impaired wound healing. So, in this case, when it comes to the penis, we have issues with circumcision, and, and it does make you wonder, because since infants are generally circumcised, as much, within a week of being born for the most part, if males aren't being diagnosed with EDS until later it does make you worry and wonder about, about what that might mean for any infants, in terms of healing there. So, that's another reason to bring greater awareness.

And, while this is actually a slightly different problem, priapism, which, which is an erection that does not go away. You remember those erectile dysfunction commercials: "Call your doctor if erections lasted for more than four hours." So, while it's probably less likely less of a risk, with EDS there is still an issue with autonomic dysfunction, because the blood flow, even the valves and the venous system might be weaker, there's still going to be the issues with, with the neuro hormones and the autonomic nervous system in creating that erection. Which might end up decreasing the amount of venous return, causing the erection to last longer, which itself can cause complications.

[00:20:18]

And the rest. Well, you know the rest is later. Alright, so well, for right now: prostate, bladder, and pelvic floor. So, one thing, this is really kind of theoretical at this point, there's more and more recent studies looking into the cause of prostatic hypertrophy – enlarged prostate – and one thing they're finding is that, well, one of the questions they wanted to figure out is why is a, why is an enlarged prostate going to be more common in older men, yet it's the, who probably have reduced androgens, reduced testosterone, reduced male hormones, yet, why is it enlarging in them, and the way to treat it is by blocking those same hormones that they have less of? Why wouldn't it be happening in younger men. You would think

the risk would decrease. Well, one of the things we're finding recently, is that it's probably because it, the testosterone any – really most – most sex hormones are in the blood, they're floating around, they're connected to serum proteins, and for the most part, they're inactive. I think one percent of the testosterone in the blood is even active at any time. So, when they're measuring testosterone levels, they're generally finding – they're, you know, including them with the serum proteins. However, when it's cut – however if you look at how close everything is the v – in the testicles, it hasn't gone in the blood and been diluted yet. So, if there's venous insufficiency, if there's venous congestion, backflow, that testosterone that's being originated directly from the testicles, can back up directly into the prostate, completely undiluted, so it ends up being as much as – so, if there's 50 percent less in the blood, there could still be essentially 50 times as much coming from the testicles because there's no dilution, and that's one of the things that they're finding.

Again, this is very brand-new, very recent, but what is interesting is that they're now in trials for surgical procedures that involve ligating and cauterizing what are essentially varicose veins in the system there, in the same way that they oblate varicose veins in the legs. They're finding that if, that if they blocked that backwards blood flow, they've actually been able to treat BPH. The reason that's, and that's in trials. It's of course something to consider when you're discussing with your doctor various surgeries, because again, wound healing – any surgery – any surgery of the prostate, it's going to have greater risk to it.

It also makes you wonder with, with those anti-andro, Finasteride, Proscar, Dutasteride, Avodart. Those are used to reduce the prostate size, because they block the conversion of that testosterone to its more potent form of DHT, that's mostly active in that prostate there. Now any medication is – and again this is not medical advice – any medication, especially when it's more preventative like Finasteride, often is...would be the doctors going to, or provider rather, is going to be doing any kind of evaluation of the risks and benefits, and decide for a person individually the factors, why this medication might be appropriate, why it might not be. So, while this certainly isn't a suggestion that, that someone with EDS should be taking something, what is it, what it is saying, is that it might be something to mention the doctor. It's just one more factor when they're considering the right treatment plan for you.

With alpha, with other medicines for the prostate, they involve alpha-1 blockers. Most famous one's Flomax. There's anticholinergics and Cialis, which is also an erectile dysfunction med with – the problem here is that all these are – well, alpha-1 blockers in Cialis are vasodilators. So, what – and then the anticholinergics, well they're not so much vasodilators, but they do cause some orthostatic intolerance. So, and we'll get more of the medications later, but an issue with, with worrying about men with enlarged prostate and the medications they might be taking, not that they shouldn't take these meds, and certainly they might be appropriate, but again with the factors that the doctor or provider might be weighing, it's just another factor when deciding on the right treatment plan.

Another issue, is that a lot of males without EDS, it doesn't matter, are diagnosed with what they would call chronic prostatitis. The other term for it is lower urinary tract symptoms, and what I find interesting is that there's also diagnoses of interstitial cystitis, which I also believe is somewhat common in EDS, but interstitial cystitis is generally associated more with females, but when you're actually – and this is what studies have been evaluating recently too – is when you look at it, the symptoms are pretty darn similar. Is it possible – is it possible just because men tend have a prostate gland and those symptoms are often seen in prostate issues? Is it possible that there's even, either a misdiagnosis going on, or that there's a shared pathology that no one's really evaluating during the treatment? Because quite frankly, the treatments for all of us is pretty disappointing as for right now. But the reason that's important to bring this up, is because interstitial cystitis does still have a different treatment. So, for males with EDS who are being diagnosed with chronic prostatitis, it might be something else that the doctor may want to evaluate in terms of, in terms of what's going on. It similarly – any medications and they want to take that into account. One reason is that often times people with chronic prostatitis, even if it's – and they're finding more and more that oftentimes, it's not bacterial – but a lot of times males will be diagnosed bacterial prostatitis, given antibiotics, empirically, which is basically, there was no real proof of it, but we're going to give you antibiotics because we assume that's what's going on. The problem there is, that there's a lot of toxicity with antibiotics, especially they're finding more and more lately, and this is, a lot of times you're there finding some mitochondrial dysfunction with EDS, which might be responsible for some of the fatigue. So we worry about the mitochondrial effects that we're now finding with

antibiotics, and also especially things with like Cipro, the fluoroquinolone antibiotics especially are now being associated with tendon rupture and other effects that will be especially important for people with EDS. So, again, I'm not saying not to take antibiotics. I'm not giving you medical advice. What I am saying, is that consider, that consider this diagnosis. Consider these, consider this with your provider when evaluating the right treatment plan, when evaluating the right medicines, because there are, there are factors here that are going to be affected, that the provider might be, might be good for them to have knowledge of.

One other thing I wanted to mention, and this is, is just like with the penis size, testicle size, I personally imagine that there's a strange it is – strange as that is, a bias, against sitting down to urinate as if recumbent urination is somehow a problem to masculinity. But if you really think about it, I probably actually heard the term like suggesting that in, when trying to make a blow against the male ego, you might have even heard of, "Oh you probably have to sit down to urinate." I've actually heard that. But what they have found is that doing that actually is effective for relieving those symptoms with prostate enlargement. Sitting down to urinate can create a lower post-void residual, which means that it empties better, might be more comfortable to urinate. So, even though it's an effective intervention, unfortunately it's also something that can have unique effects for male identity.

[00:28:21]

And the rest. Now we're getting the rest. *[Inaudible]*...Alright, so one of the things that we're noticing, or that you'll notice in the slide, is that many of the effects of EDS on the body effect what you might consider a sex, secondary sex characteristics, and this is probably one of the biggest reasons that it can be difficult for men beca – or males, or people who have a male gender identity – because some of the effects, when you think about the sex, a secondary sex characteristics going back to the hunter-gatherer times, you realize how much – well, let's just go into it. On the skin, we all know velvety, doughy, those are one of the, you know, it's one of the criteria. Well, velvety, doughy skin, soft skin, it's generally more, it might feel more what some would describe as "feminine." Someone who is feeling your, their own skin that might be – they're more fragile, it might actually feel less masculine and have an effect that way.

Speaking of the thinner skin, this doesn't necessarily mean that the that body hair is any thinner, so you might have a level of body hair that would be more average for males, but very thin skin, so it might be causing a

lot difficulty when it comes to shaving. Skin might be much, much more sensitive, higher risk of abrasion, especially on the face, which already has thinner tissue, and if you think about that, since most males on average have 30 percent denser dermis than females, already the shaving supplies for, for males are probably going to not take that into account, or no, they are taking that into account. So, you have to take that into account when you consider you're buying shaving supplies and looking at possibly the most sensitive shavers, ones that mean – you may just have to have some stubble and especially during puberty when this – when a male's skin is, is hopefully getting somewhat thicker, and if there have – it might be especially difficult. So, you think about, you know, teaching your son to shave or something, you know, there might be more to it, and as we'll get to later, it might be possible that the son might not want to say anything, and find it very uncomfortable.

Then we're talking about acne. Now, when we think about acne, males and females can have the same severity of acne, yet males are having much higher levels of androgens, testosterone, that are, that generally drive that semen production and drive that acne. You would normally think that males would, that would have significantly worse acne, yet, it doesn't necessarily mean that, and one of the reasons is probably to do that – due to that thicker skin. So, again, if you're having that, that thinner skin with levels of androgens that are in the male range, it's certainly possible to create a much more painful, severe, cystic type acne, and then of course the with the thinner skin, the treatments, especially concerning that you would want a stronger topical for example, well, actually Accutane works. But when you think about the treatments, again skin is thinner, much more irritating. So, it's just – puberty wasn't pleasant for me, I'll just say that much.

*[Laughter]*

Anyway, you might also have issues with a feminine fat distribution. A lot of times with hypermobility, there's lipedema, which is because of issues of the lymphatic system, much like the vascular system being stretchy, and the lymphatic system might have more drainage issues for reasons they don't quite understand, can actually affect the deposits of adipose tissue, and since the lymphatic system would generally be in the lower body, and – and what they might call the gynoid regions, it's certainly possible that males might be more prone to developing a less masculine fat distribution, a kind of distribution that's more focused on hips, thighs,

buttock because of that reason, and certainly it's all theoretical, again there's so little research on everything, but – and then, but also go – and also going to cellulite, because again, weaker connective tissue, cellulite is, is not really, you know, be – it's not really obesity, what cellulite is, is the – a break, a weaker fascia, weaker connective tissue that's holding the adipose tissue in. That's why weight loss can even make cellulite worse for some people. So, for – so it's certainly possible, and there aren't really any studies into this, but again, having to extrapolate, it's certainly possible that males could, might be more prone to a more feminine fat distribution, which in itself can again, lead to difficulties with a gender identity, gender identity and self-esteem.

We talked about hormone issues from before, with the lower testosterone levels potentially, and with, with fat the way – again, males and females both have estrogen. Estrogen is created by the enzyme aromatase, which is created – which is mainly found in – I mean it's found other places, but a large source of it is adipose tissue. Fat tissue. So, generally the more fat someone might have, the more aromatase they have, which means the higher estrogen levels they have. So – and that aromatase activity can differ in different places, but with gynecomastia, it's certainly possible to have male breast development. And with gynecomastia, there's a tremendous amount, and this is where I'm extrapolating everything else; gynecomastia, there's a tremendous amount of studies and research into its effects on male self-esteem, especially during puberty and adolescence, when, when that often will happen. So, and we know from all this research that gynecomastia, male breast tissue development, which oftentimes isn't even, you know, not as striking as it might be for a female, we – it caused a significant distress. So, if you're – and that's just for gynecomastia – so, if you're looking at all these other things, that's why I'm able to offer as a possibility, that this research is relevant to so many other issues that a person with EDS might face.

When we think about how much athleticism is involved in a male gender identity, we can see why poor muscle size, definition, and tone might affect male self-esteem. We – and one of the reasons for this aside – aside from the actual structure of the collagen, the, of the muscles, aside from the actual energy and fatigue, there's also that issue of not knowing how to properly exercise and move, and getting strains. You can – which is one of the reasons it's so important to understand – well, we'll get to that later, but for PT, because it might not even be possible to build muscles to the best

potential, without knowing how to actually do it which might not be taught in the same way, which might not be relevant in the same way to someone with EDS, and it might be to people in general. Going to the gym and just starting to pick up things might not have the same effect if a person with EDS has no idea that their joints are loose, and that they need to hold them differently. And proprioception. So, physical activity, lack of coordination, difficulties with, you know, football. I mean, geez, how many times to always have we seen those parents fighting at a little league games. That's how it – the point is that – that – that can have an effect on it.

And another thing, and personally I think this is what: vocal cords. Vocal cords are connective tissue. They're there and they can be weaker, or more fragile, or more flexible as well. When we think about males having a more – a voice that tends to be more monotone, it might be, you think about those – the stereotype of the boy going through puberty and his voice changing, and you know, going to different registers, and it's certainly possible that might continue, or at least have greater variance, which can also- I mean for me, it caused some teasing, I know that much, but the upside is that there's also a greater ability to sing potentially, so consider that. I personally have a four-octave singing range, so...I couldn't go to show choir because of the proprioception, but the point is, I enjoy singing. And as the only person willing to listen, it's been very well received.

[00:37:10]

Now, this slide doesn't really have much relevance to me because I am celibate by choice. *[Inaudible]* ...but for those who find it relevant, let's talk about sexual activities. One thing, and again, this goes back to definition of masculinity and side, societal ideals of masculinity, we think, even going to back to biblical times, look up, look up the story of Lilith if you ever have a chance. When you think about the idea, the missionary position, the sex position of a mate – of the male being on, you know, with the male and female – the male being on top, I'll just say, that's a lot of work on your, on your cardiovascular system to maintain all that blood flow while you're fi – while you're prone, you're facing down. So, when there's a lot of autonomic dysfunction going on with EDS, with let's say POTS, a lot of times the most comfortable position is going to be supine. So, if a male with EDS generally prefers to be supine during sexual activity, that can – that actually has a connotation that could – that first, for some, that might be a connotation of a problem with their masculinity, not to mention the pain, and fatigue, and other issues, and then going back to before with the ligament laxity and the penis, now you're having two issues going on,

for – it might be more comfortable to be supine or lining, lying down, lying on your back for any sexual activity, but then it isn't very well anchored, so – so, then you're – so then it's not being held up. It's just, it's just a lot. It's a lot of, you know, darned if you do, darned if you don't.

We talked about erectile dysfunction and since, when it happens a lot younger, and especially in someone with EDS, it's more likely that it'd actually be more of a venous issue. Most erectile dysfunction in general, and certainly the meds that are made to treat it, are looking into the idea of reduced blood flow into the penis. Most – that's why most meds for erectile dysfunction are vasodilators, and you'll see that's why it can be associated with things like diabetes and heart disease, because of atherosclerosis and impaired blood flow. When it happens, well...the young, the younger it happens, the more likely it's going to be a venous issue of the blood staying in the penis. So, it makes you wonder, especially with the issues that vasodilator medicines can, that can create if, if device and procedures to hold the blood in, might be more effective. One thing that's very well recognized as a treatment, that I don't think the really use or talk about mu – very much anymore, and actually I'm not sure if this is still the case. I know that at one time they that it was even covered by Medicare, are penis vacuum devices. Which is, which is putting it over the penis, and then suctioning, you know, making like a vacuum pulling blood into it, and then you would put some kind of ring around, to hold that blood in there. It makes you wonder if that might- if that might be a an option for some people to talk with their doctors about, especially if they're – if there's concern, or if they're having issues with the more common drugs like Viagra and Cialis, which I assume that's why it doesn't work for me – others. Anyway.

Then there are surgical procedures for erectile dysfunction. Now this, much like the prostate procedure, procedures, is also in trials, but much – again, like cauterizing veins for varicose veins, they are now finding that they can potentially treat erectile dysfunction through surgery that – that blocks, that – that reduces what might be varicose veins in the penile circulation, and they've been finding trials, at least right now, some effectiveness with that. Most, most surgical procedures for it, would involve some kind of prosthesis that I think you would like pump air into, which in the case of EDS again, has wound healing issues. And so again, this is in trials but, maybe in a year for now, when someone's watching this, maybe they'll have this as more standard and something to look into.

But again, everything's to do with your doc – your doctor, your provider, and just including these things in the conversation when evaluating what's best for you.

And going back to autonomic dysfunction, and – and when you think back to – I don't want to go back to the slide. We could. Eh. When you think back to the whole structures there in the autonomic system, there can be issues with ejaculation. That's a very well-coordinated event. Seriously, it's like an orchestra. When that thing happens. A lot's going on down there, and so you can see why if something's a little bit off, it can cause problems. One thing that can happen, is if you think about the, the sphincter that's locking when ejaculation happens, of course the bladder has to be blocked. Sort of like the trachea, you know, when you're swallowing, the air pipe is going to be blocked. Sort of like that. You're gonna block the bladder when ejaculation is happening. If that's weak, then you can get what we call retrograde ejaculation, which God I hope I'm right in this. I'm now doubting myself as I say it. But anyway, the point is – well this happens. Whether it's retrograde ejaculation. It'll back up into the bladder, which can be quite painful, or – or lead to issues with fertility problems, or – or at the very least, not have much ejaculate coming out and, and leading to less pleasure. For various reasons, they can also have ejaculation without an orgasm, orgasm without ejaculation, but just the, the complexity there can cause a lot of these disorders, which as we'll talk about a little later, can be worsened by many medications.

And again, we talked about the higher risk of abrasions, so it's definitely important to, and it's always important, talk about safer sex and risks of STDs. It's just something to maybe especially remind someone, to give them that little extra incentive to really make sure they, they practice it.

[00:43:19]

Now, most of this webinar has and, and we'll talk about the psychosocial aspects for males who were also assigned male at birth, which is majority of males, but let's not forget the, the LGBTQI, and I'm sure there's many others, community, because unfortunately the treatment of these individuals have been historically very shameful really. If you look back in literature from even just a few dec – decades ago to see how, how gay men, or in the literature they still call it male – men who have sex with men, is the proper, is the literature term, since it's, since gay is more an identity issue – but you'll see back in the 70s, before they even called HIV, or before they, before they came up with word a for AIDS, since it was first identified in the gay community, they would call it – the very first term

was GRID, which was gay-related immune dysfunction, which no one in their right mind would ever do for any other population group. Even in illnesses that are predominant in some, in a certain population.

Of course, you look in the history of psychiatry, in the history of – they even had this one diagnosis called gay bowel syndrome. It was just really, just – it's just really upsetting, and, and of course, even nowadays, you're still gonna have bias from providers and healthcare professionals, which I think is probably the most important thing to be mindful of, especially since so many of these issues already, as we discussed, affect ge – systems that are related to gender.

So, anyway, getting back there, getting off on that tangent. When we look at the gay community, men who have sex with men, we now have something called prep, call – in this case, Truvada, there might be more approved later on for the same purpose, but at least for right now there's Truvada. That will, that can be taken by a person that does not have HIV, and prevent them from becoming infected if they were to be exposed to it by a, by a person with, that was HIV positive. We also now have shown from studies, that people who have HIV and are virally suppressed – having undetectable levels because of their medication regimen – that they found it literally impossible to, for them to transmit it to of someone. So, we have a situation now, where, and it's real, where it's actually unfortunate that anyone would still become, come – would still be a newly-diagnosed HIV. A lot of it has to do with our healthcare system and everything else, but the point is, that again, there's no studies to really validate this. This is all just potentials and theoreticals, that there could be a decreased – vigil – decreased vigilance in in protecting oneself and, and from, and in utilizing safer sex.

And even if that worked, even if it were to be almost okay, one of the problems is that because HIV had become such an issue in the, in the gay community, a lot of other STDs may have gone by the wayside in terms of cognizance. The – and there's other STDs that are – many of which could be permanent, many of which can be resistant to treatments. There's now – for everyone, there's now becoming drug-resistant gonorrhea, syphilis, all these other all these drug-resistant bacterial infections that were once curable. There's now – there's HPV and all that, which there's a vaccine for most HPV strains, but we can see that there's gonna be issues that you still want to mention, and the primary reason for that – well, not the primary reason, but one thing to be especially concerned about – is

that much like every other tissue, the rectal tissue might be thinner and weaker, and in general HIV – what other, whatever STD we're talking about, it's – the risk goes up astronomically whenever there's any kind of impaired tissue. That's why if there's already an STD going on, like, I don't – any – any STD that might be going on, the risk of acquiring HIV goes up astronomically, because of that break in skin integrity. We, with Ehlers-Danlos, it's possible if the skin might be thinner. That there might be a greater risk of transmission for various things.

And going back to Truvada, I mentioned before, the mitochondrial issues, potentially. We do know that Truvada does have an effect on bone mineral density and kidney function. Already with Ehlers-Danlos, you're going to have, potentially, issues with bone density, which can start younger and potentially it will cause osteopenia. So, while you're considering the idea of prep – prep, which with Truvada, consider that, those issues for the EDS.

Just let's see – sexual practices. Now, this is – we're tou – we already talked about rectal tissue, and all that. Now of course, any person of any sexual orientation can engage in any number of, of sex acts, including receptive anal intercourse, whatever it might be, and I think the studies even shown that – that of the surveys they've done, I think it's only about the 50% of men identifying as gay, even engage in any kind of anal sex, but – and so, I don't want to make it out like, you know, "Oh, you're gay. You must be having anal sex." Let's talk about this. What I am saying, is that it's probably gonna be something that, be a little more likely to encounter with increased frequency in that population. So, we already know that there's already going to be an increased risk of rectal prolapse. In fact, rectal prolapse in men or females that have they're non-child- they haven't given birth, that that in itself, can be a diagnostic criteria. So, if men are already at a greater risk- and there's no scientific evidence, I just want to put that out there – that there's not really much research to go by, to actually show this. It just seems intuitive that there might be, that it might increase that risk further, if there's going to be receptive anal intercourse. I do remember – I was able to find one study from a while back, and of course, you know how great historical studies are when it comes to the treatment of gay people, so who knows that this – if there's any truth that frequent anal receptive intercourse caused a decrease in anal sphincter pressure, but even then, it was showing that it wasn't terribly significant. But, with EDS, if there's already an issue, then it's just something else to keep in mind.

And with, with oral sex, again, anyone can be engaging in, in this, and certainly don't want to single out two gay males, it's just that, much like everything else, with the Tin Man, I go back to the Tin Man, it's all you've ever known. So, they might not understand that their jaws might naturally open wider than the average person. So, when performing something like oral sex, there might be a greater tendency to stretch- stretch the jaw, which might create TMJ problems, that could end up, that could be ended up, that could have been prevented had there been greater care taken while engaging those sexual practices. Transgender males and females – I actually had the opportunity to talk with some transgender, transgender men. So, people born assigned, the people assigned the female sex at birth and, but found their gender identity incongruent and transition to being of the male gender – that they have found that the *[inaudible]* when it's the testosterone, the direct – the reduction in the more female hormones, has increased their muscle strength, and has actually helped decrease their symptoms of EDS. Which would be what you might expect.

So, so, there is evidence, that for females that transition to be male, that they actually do get a benefit out of that transition with the hormones. Which actually does make you then wonder, does that mean when we're having this debate about when to start hormone therapy, and when to start that transition for adolescents and children that identify that way, it almost might be a consideration, again, as part of the many factors in a treatment plan, of whether it would actually be beneficial for, let's say a female transgender child, when you're deciding whether to do hormone therapy. Might be something to consider that it might end up improving the overall course of EDS. So, just something to keep in mind. On the other hand, if you have – if you have a male, a person assigned by male sex at birth, and transitions to be female, so a transgender woman, then there's also that issue of – even perhaps if they had, I don't know, maybe might call latent EDS, or, or subclinical, or symptoms that weren't particularly severe, that they might be expected to get more severe, or to become prominent with that reduction of testosterone, with that increase in those other hormones, that you might want to take that – consider that – when designing a treatment plan, and when preparing them for that transition, that they might actually have other underlying health problems that might actually worsen, that aren't related, that go beyond just average risks of hormones, that are actually related to the underlying illness and how they're affected by them.

With non-binary individuals, I, I don't have much to say. Unfortunately, there's already so little information here, but really, I mostly just want to say you exist. You matter. And please give us your experience, because I'm not too sure where to go with this. All I know, is that so much of the effects can already have an effect on, on the gender identity and the sense of self, that for a non – for a non-binary person, I imagine that might have some effects. And please, let them, let us know what they are. Be heard.

Same for intersex individuals. Now, with intersex individuals, there's a lot of misconceptions. It used to be that people that were born intersex, at the very least, with ambiguous genitalia, or, or genitalia or secondary sex characteristics that aren't, that are more variable – there are more variants than the average, a lot – it used to be that they were just given surgery immediately. The doctor – they came out, the doctor decided what they'd be, and that's what they were. And it was unfortunate, because oftentimes it, because it led to surgery that was oftentimes just unnecessary. And who knows that the doctor made the right choice. It doesn't consider them, and it's been caught – shown to just cause a lot of problems. And research, and, and especially the WHO and the national organizations, are advocating to delay or, or just not perform any kind of procedures, at least until that person can make a conscious choice. And instead, to be – instead, giving validation to them as an individual, and potentially, and hopefully, and I'm glad this is finally happening. A third sex or gender option on things like birth certificates and other areas, but anyway. When you, when you think about intersex individuals, there's already so much going on with gender identity and society, and I just imagine that this might add one more complication. It makes you wonder. I mean, I mean some – when you think about the effects of EDS on secondary sex characteristics, it does make you wonder: is it, could you even potentially look into the help that, and advice, being given to intersex people, and possibly even extrapolate that and apply it in, for the psychological needs of males with this syndrome. It's just a thought. But the point is, that while this the only one slide, and I hope I covered some things, and hopefully someone will pick this up further, I just mainly want to say: You matter. That you exist. And we want to hear you, and – and you matter.

[00:56:09]

I feel like that came out sarcastic. It wasn't, I promise. So, there are certain meds that you might expect males to be using more so than others, but may also be using more than, let's say females, or well – and at present everyone's using them. But they're certainly gonna have effects on the

autonomic nervous system. Almost all of them do. Since the autonomic nervous system is using the same neurohormones that are used in the brain. Whether more – one of the most commonly complained about side-effects, is the effects on ejaculation, and orgasm, and erectile dysfunction. Already have the EDS going on, antidepressants, you might just want to think about, might have even more of an effect. You may want to consider, as part of your treatment plan, when you're discussing with your doctor various issues, maybe include your EDS. And one more thing. When choosing the right medicine, if sexual dysfunction is an issue. Then we talked about erectile dysfunction meds, where most of them are vasodilators, but not all. Cialis, Viagra, Levitra – they're all, they all work by blocking the breakdown of nitric oxide, which itself is one of the most powerful natural vasodilators in the body. So, increases the, you know, artery and venous diameter. More blood flow gets through, compensating for any kind of blockages, or any other reasons.

They – then there's all – there's also, ones you can insert. I think one is called "MUSE." It's actually insertion into the penis. Problem is, often times again – there's oftentimes so many, so much autonomic dysfunction happening in, in EDS, that this might end up being a problem. And it might, it might even end up being ineffective, if the problem is keeping the blood in.

We talked about prostate meds. Alpha-1 blockers are very, very common. Again, Flomax. Just to, just as a, example of why it's so – why it can be such an issue – if you think about Midodrine, which is a very commonly prescribed and well-established treatment for orthostatic intolerance and POTS, it works, that works by, you know, agonizing alpha-1. So, you're taking – so, would be taking something that the opposite. So, this isn't to say you shouldn't take it, I'm just saying that it's something to consider when discussing with your doctor.

Reglan, if there's gastroparesis, which can be common in EDS, then Reglan is very well known to cause hormonal problems. Especially increased prolactin, which in males has much more of a significant effect – which is generally have – have much more of a significant immediate effect, than it would in females. Especially Reglan has been shown to cause more gynecomastia, male breast tissue growth, and even lactation.

And finally, Rogaine. And I'm just assuming, naturally, men are more likely to use Rogaine. And Rogaine for men, in – compared to the female

version, is 5% versus 2%. And it just makes you wonder, if there is thinner scalp skin, would there be a greater systemic absorption. And remember that Rogaine is the, the same active ingredient as – just the br – well it's Minoxidil, which is also used as an oral blood pressure medicine because it's a vasodilator. So, it is something – again, vasodilation potentially for systemic absorption.

[00:59:25]

So, what are the implications here? I think that it's been well discussed how these issues can be, can affect men. Not just with their unique anatomy, but also just with a societal ideals of gender roles, and, and secondary sex characteristics, and what it means to be a male, and just, and that identity and self-esteem. And there's so many things that, without having more awareness, without understanding better, could potentially affect males on a psychological level. In ways that many, many people not consider. So, what I think that one of those important things is – and this could go – is remembering the potential for shame, embarrassment, lack of access to healthcare, and it being all anyone's ever known, it's certainly possible that they might not say anything. They might just think this is either natural, or just, or something's going on with them. Or, or not realize any – or not realize it's something to bring up. So, that's why it's important to have that awareness. So, that as a member of the support group or, or a support system, or healthcare team, to know that these issues are possible, and that there's things you could take from that, and potentially there might be other issues. Certainly, there has to be a lot I haven't addressed so far, but just to think about that.

So, instead of waiting for a male to, to mention, let's say they're having issues with maintaining erections and they just don't understand why their med's not working, and you might want to discuss, "Well, you know, it's possible it might be hard to keep the blood in there, and might this, might be a better option." Or, they might not think to say, "You know, I'm having difficulty with these sex positions."

Or, I feel – or for that matter, just thinking of saying that they're having issues with their gen – with their sense of masculinity, or lack of – and I think one of the biggest, well not one of the biggest: one issue is, that again, going back to how much athleticism is associated with masculinity and sense of self. So often providers and professionals will recommend exercise and say, "Oh, just diet and exercise, and, and take on this sport, or whatever it may be, and again, not knowing that there's anything different, and with all the, with all the advice out there given to the general

population that might not have these hypermobility issues, it might not end up being effective. So, it might end up being where there are, where they're trying to exercise, even despite fatigue and pain that they assume everyone else has, and, and they're not holding themselves correctly, because they don't know they need to, and it just becomes very, very futile and very, very setting up to fail, which only worsens the self-esteem. Assumes that there's something wrong with them and there's – and at a certain point, there have to, there has to be realistic expectations, where – so that it isn't just, where it's not just feeling like it's your own fault all the time. "Oh, if I only exercise more, only if I worked out more, or if I eat this food and not this food." And after a while, you have to accept, for your own sanity, that there's a very significant genetic underlying condition that you're gonna have to work a lot harder on. Oh – we have to work a lot harder, and it's still not going to be as great of an outcome as some without it. And I think that providers need to understand that connotation of exercise and working out, and everything like that, on the male gender identity, and how – and that self-esteem that, that may not be thought of.

So, much like we began, I'd like to say my major piece of advice, is that when evaluating for Ehlers-Danlos, EDS and HSD, especially if it's – especially if it's more of a hypermobile variety without any genetic factors, and aren't female, which, the point is, don't consider the, the gender. Don't consider the sex. Don't consider if there's male and female when, when deciding whether to even think about EDS or HSD, or their associated comorbidities like POTS, because it's most likely already underdiagnosed, for that same reason. We don't want to perpetuate that catch-22, and we don't want to – and assuming that only contributes to the difficulties males have with – with the identity there.

[01:04:19]

One thing I—and I will end on this, with environmental factors, because we do know, that despite EDS/HSD being genetic, that there's a lot of other factors influencing those genes and how they end up presenting itself. So, we talked about how testosterone can be protective. We know that studies have been showing that globally, testosterone levels have been decreasing on average. We know that fat tends to increase estrogen, which relaxes connective tissue, and we know that there's certainly an obesity epidemic going on with – and with sedentary lifestyles, you know, there is something to say about, about, at least my – I mean, there is still deconditioning going on, so there – so even if it might be harder to build muscle with EDS, it's

certainly going to be – you're still going to have less muscle mass if you're not, you know, out and about. Then there's environmental estrogens. They're finding that certain intersex conditions – I can never say this word right, I want to say hypospadias, or the urethra on the underside – is on, it's not at the end of the penis. That's generally associated with environmental estrogen exposures, for example, and that's been increasing. And so all those factors could increase biologically, at least the severity of males who are affected, and we also know that with changing, and that society is changing their attitudes about gender. We hear – so much of this webinar has been – you could almost associate with what might end up being what they call toxic masculinity, because so much of – really it is. But because it is so ingrained, it's still something to address. But with our changing attitudes, hopefully males will be more likely to seek health care and providers who will have less biases that might increase the rate of diagnosis, and the greater awareness that we're trying to get across. So, I'd like to thank The Ehlers-Danlos Society for giving me this opportunity to provide you this information.

[01:06:34] **Sarah Jo Ritchie:**

Thank you, so much Adam. The webinar was fantastic and extremely informative. We already have a few questions in, but before that, I just want to say we have a lot of thank-yous from everybody, whether it's men, whether it's moms. One of the comments we received was, "I just want to thank Adam for addressing these male-focused issues, even when it could feel awkward to discuss some of the topics. As a mom with a teen son with hypermobile Ehlers-Danlos syndrome, I'm planning on sharing this link with him once the recording is posted, in case there are things he has, or will experience, that he's not comfortable with talking to me about."

[01:07:07] **Adam Sherman:**

That's very important, yeah.

[01:07:09] **Sarah Jo Ritchie:**

That's – that is phenomenal and thank you so much for that. Just a reminder: If anybody else has any other questions, you still have some time to get them in, but, our first question comes from... "As a mom with a young male zebra, what would you recommend for how to broach some of these subjects with him as he grows and matures. I know everyone is different,

but what approach, or what way should I go about discussing this with him? What would you like to have discussed when you were younger?"

[01:07:37]

**Adam Sherman:**

I would have just liked to know – I would just like to have known it. To have known any of this. I would have liked to have – I wasn't even diagnosed until, actually, just a few years ago. Before that, I was just diagnosed with it, with what many, what happens to many people: fibromyalgia, chronic fatigue, depression, all that stuff. I was – because of the lack of awareness, I – it wasn't until I...well I won't go too far into it. But my point is that all, none of these things were ever even considered as, I was – I never really brought these issues up, because I didn't know that they were issues. I just know, knew that I saw everyone around me and I'm wondering, you know, much like the Tin Man, "Why is everyone else able to do this? Why is no one else having problems with this? Why can other people work out and build this muscle? Why is it that with me, you know?"

And now, of course, I know it's because I'm not even holding my myself correctly, as I were to do it, but I just never – I just wish I had known. And I guess as a parent, you may just want to be the one to, to tell them what's to be expected, because if this is all you've ever known, then all that's gonna happen, is you're just going to be very frustrated and confused, and looking around you not understanding what's going on, and I think that also, it probably would have helped had I been diagnosed with it earlier. So, certainly you know, being aware of EDS, and being aware and – and – and I guess also respect the experience. Respect the child's experience with their EDS, and with any symptoms, to not just dismiss it as, "Oh, everyone feels self-conscious. Oh, everyone has problems their body. Oh, everyone feels this way."

Or, "Stop being dramatic about this." Or – or something like that. It's a – that – to not to invalidate someone's experience, especially as they're, as they're growing older, and not to – because you might find that you probably are going – that without realizing, you probably are treating a male that might present with this, or present with certain concerns differently than a female that might, without even realizing how you might. So, just give them the information. Just let them know that some of this stuff isn't normal. Some of this stuff is normal. And some of this stuff might be experienced differently, and – and that it's okay, and not to give those unrealistic expectations of, "Oh, things..." Especially, "Oh, things will

turn out fine. Oh, you'll grow up and, and you know, this is just something to deal with right now, or whatever it may be." Validate the experience. Validate the identity issues that make – that it might be affecting, and – and hopefully again, with greater awareness support from others, or for that matter, support from any mentors. But just – I think the biggest issue is just letting them know they're not alone and, and what they're experiencing is valid.

[01:10:43] **Sarah Jo Ritchie:**

Thank you. This is a question we had from a couple of attendees: "Do you have any tips on stabilizing the SI joint during sex, especially when the male is the one that's supine."

[01:01:55] **Adam Sherman:**

Well, when supine or prone? Because supine will be on your back and prone will be on, being facing down. But, regardless, well – I, I don't have too many ideas. I mean, my guess – my guess would be maybe an SI belt? I would imagine it might, again, be easier if it was lying down, because then, you know, there's more support to the hips you can use. If you're prone, being on top, it would probably just have to, just be a lot, probably more conscious effort into it – and I would just try the SI belt, see if that does something. I don't think it would get in the way when you consider where you're actually putting it.

[01:11:39] **Sarah Jo Ritchie:**

Alrighty. We have another question: "I experienced increased issues with EDS after age 45. Do you think this might be related to testosterone levels, or other things?"

[01:11:51] **Adam Sherman:**

It could be. There certainly – connection issue is very, it's surprisingly responsive to small changes in hormones. When you think about all the studies showing, at least in females, the joint laxity and a greater risk of, of joint injury in sports, based on where they are in their monthly cycle, you can see how, just how responsive tissues can be to those hormone changes. So, that's certainly possible. That could play a role. It's certainly a reason that you might want to discuss with your doctor. It might be a reason to get your hormones checked, and it might be a reason to – another factor to put in there for, for when your provider is considering any kind of hormone therapies. Not that I might – not that

you should get it because of that, but one more factor. Another issue just has to do with age. Remember that EDS, with the weaker connective tissues, there's more wear and tear. There's less resistance to damages. So, there's going to be more, it's just going to be a more...I can't think of the word. But the point is, at a certain age, and the age is different for everyone, a lot of these things just sort of come together, and they reach like a critical mass, and then function can decline. When everything comes together, and you haven't been working on PT, and a lot of times, unfortunately, this is when people end up being diagnosed, is when that happens, and they weren't given that chance to prevent all this stuff. So, I would say that – so, to answer your question on hormones, I would say that it'd be a good reason to see your doctor and get your hormones tested, and be something to consider as part of your treatment plan if – when considering hormone therapy. And also to consider that it just might, just – it just might be the course of the condition, as your – as damages build up over time.

[01:13:43]

**Sarah Jo Ritchie:**

Thank you! We actually had a few questions about vasectomies and EDS. One was, "I had a vasectomy before I was diagnosed with EDS. Do you have any ideas how this can relate to your discussion on testicular prostate crosstalk, and does it have an effect on hormones and EDS?"

[01:14:02]

**Adam Sherman:**

It can. I think there have been some studies showing in correlation with hormone changes in some men that have had vasectomies. I – one big thing that happens, is that the sperm are still being produced. All that's happening is, you're, is they're just not going anywhere. They just – so they – but they end up building up. They have to be – and to take care of that, the body often will create anti-sperm antibodies, so – which creates almost like a little bit of an autoimmunity there. So it is certainly possible that this could end up affecting other tissues, and with EDS, there's already an issue with increased autoimmunity for various reasons, but if, but that could end up causing an immune reaction, potentially causing inflammation. That might affect the testicles, that could affect hormones, that could end up causing a catch-22. And again – and then if there is inflammation down there, which would be expected, at least somewhat, then, then yeah, that can weaken things all in the area. Then speaking of a vasectomies, of course, you're going to – for anyone considering it, of course there's always the wound healing issues.

And I mean, it's certainly possible that that the surgical procedure itself might have affected some connective tissue, connective tissue sphincters, all that, but I would definitely say that it is possible that there could be a correlation between the two. I can't really think of any advice in terms of treatments, or really what to do about it, but – and I certainly wouldn't say that you shouldn't get a vasectomy because it could worsen your, your issues, but yeah, it is something to consider. It is something explore.

[01:15:45] **Sarah Jo Ritchie:**

Awesome! Thank you, so much. Do you have any general recommendations for males with hypermobile Ehlers-Danlos syndrome and an alpha-1 deficiency?

[01:15:54] **Adam Sherman:**

Which one was alpha-1? Is that – let's see. Are you able to look that up real quick, 'cause I know what that is, and I just forgot real quick. *[Inaudible]* Hold on. Let's see if I can find it.

[01:16:10] **Sarah Jo Ritchie:**

Alrighty. While Adam's looking, if anybody has any last-minute questions, we're going to start wrapping this up very soon. So, get your questions in now.

[01:16:20] **Adam Sherman**

Alpha-1 deficiency, right?

[01:16:22] **Sarah Jo Ritchie:**

Yep.

[01:16:27] **Adam Sherman:**

Oh, okay. Alpha-1, it – wait. Sorry...wait – wait. Was it alpha-1 antitrypsin?

[01:16:36] **Sarah Jo Ritchie:**

The question just said alpha-1 deficiency.

[01:16:40] **Adam Sherman:**

Well, assuming they mean antitrypsin. Mainly what I know, is that it has to do with deficiency of the – of a hormone that blocks the action of another hormone, which is alpha-1, and it has to – it honestly, not, not much. I just know that when it comes to EDS, that there is an increase in lung capacity, which can be coupled with a weaker diaphragm. So, if we're talking about

lung issues, then I honestly not really sure if I could think of anything, unless – other than that, there might be an issue with, with, I mean, with diaphragm strengthening being important for it.

[01:17:30] **Sarah Jo Ritchie:**

Yeah. The question was clarified.

[01:17:32] **Adam Sherman:**

Oh?

[01:17:33] **Sarah Jo Ritchie:**

Antitrypsin.

[01:17:34] **Adam Sherman:**

Antitrypsin?

[01:17:34] **Sarah Jo Ritchie:**

Yeah.

[01:17:35] **Adam Sherman:**

So, I'm not – I mean, I know what that is. I'm a little familiar with it. I'm not aware if there's any complications outside of the lungs. I know that like I was saying, with – and this would apply with anyone with really any kind of lung issue – is that with Ehlers-Danlos, because the stretchier tissues, lungs tend to have a higher capacity and the diaphragm tends to be weaker. So, that can obviously affect conditions both, actually, both ways. So, the only thing I can think of, is to strength – is to do diaphragm strengthening, which incidentally, can be helpful singing. And there's, and there's other devices that can be used. I don't know if that's specific to males, however, unless there's something that I'm forgetting about in terms of how the effects that, that alpha-1 antitrypsin can cause. Are there any specific issues that related to that diagnosis that you'd want tips on? If they're still there.

[01:18:35] **Sarah Jo Ritchie:**

I'm not seeing anything yet, but we can always come back to that, if they clear it up.

[01:18:39] **Adam Sherman:**

Alright.

[01:18:40] **Sarah Jo Ritchie:**

Another question: “My son has EDS. His symptoms began at puberty. He’s very disabled by it. Will some of his symptoms decrease as he gets older? He’s currently 17.”

[01:18:55]

**Adam Sherman:**

There, there’s not really a short answer to that because intuitively, because of the way the EDS works with the, with higher wear and tear, one would think that it would actually potentially get worse. However, there’s also – especially at that age, especially into your 20s, there’s greater opportunity and incidence of building muscle strength and growth. Many males continue to develop musculature and other secondary sex characteristics well into their 20s. So, in that capacity, it can certainly, there’s certainly opportunity for improvement. Especially if there’s knowledge of proper training forms – forms of training, PT, how to hold one’s self while building that muscle. The reason that it probably got so bad at the start of puberty, is because just unfortunately of how development works in during puberty and in the staging of it.

For example, it might take the skin a little time to thicken up, but the hair might be coming in first. So, so shaving can be extremely sensitive. It can be – there can also be issues with, when – for all adolescents, there’s difficulty of proprioception, just because their bones and, and body are growing faster than their brain can keep up. So, so, you’re having that issue where the brain hasn’t even started to keep up yet, and yet your bones are growing. So, hopefully by the time that the brain catches up as best it can, despite the EDS, then there should be – it should be easier to develop that stability and – and, and control over your joints, and that should, that should help decrease symptoms. So, I think a lot of the – to answer your question, is just learning how to live with it: the body and brain; nervous system catching up to that sudden growth; and the continuing muscular development, which considering that the greatest opportunity to build that muscle and build that strength is probably, you know, now into the 20s, to get some very good PT and, and education in starting now. So, yes. I think that it can improve, and I think that there’s a lot of likelihood to improve. That’s, that’s the best I can answer.

[01:21:28]

**Sarah Jo Ritchie:**

Alrighty. Is there any experience with testosterone intake?

[01:21:34]

**Adam Sherman:**

Well, I know the experience with – well not – from what I have discussed with transgender men, men assigned the female sex at birth, and, and transitioning male, I've heard them often comment that the hormone therapy – taking that testosterone – did improve their symptoms. So, certainly it's possible that males that might either like increase their own levels, or especially if they're hypogonadal or anything like that, it's certainly evidence, at least from there, that treatment with testosterone, or levels that are, you know to bring them up to normal levels, could have an effect on improving the symptoms. So, in terms of experience, I can only tell you what I've heard from transgender women that – or transgender men rather, that have taken testosterone – have had improvements.

[01:22:35]

**Sarah Jo Ritchie:**

To tangent off that question, “Are you aware of any research that is specifically looking at experiences of trans people with hypermobile Ehlers-Danlos syndrome? *[Inaudible]* ...effects, surgery, pelvic floor issues...”

[01:22:47]

**Adam Sherman:**

I can't find research on my own on cisgender men with Ehlers-Danlos. And I wish there was, and I wish and I hope that there will be, but I'm not aware of any research. And I did try to look very hard into it. The best I can do, it, what, much like with what I've had to do, it's just a matter of extrapolating the research that's already – the small amount of research that's already there. But hopefully, this will spark some.

[01:23:13]

**Sarah Jo Ritchie:**

Another example, is chest masculinization. If someone who has already had chest masculinization with EDS, is there a greater risk of essentially needing to redo the same procedure?

[01:23:23]

**Adam Sherman:**

There's always, for any plastic surgery, or for any surgery, for any wound, there's always a higher risk of needing to – of there being impaired wound healing issues and needing to redo it, to have it redone. One would assume that there'd be a greater risk drooping, with all body tissues, the same way with the lax tissue with the penis. Relaxed skin there. There could be lax, there could be a greater propensity for skin and the chest to droop down, which would create possible need for revision later. I mean, obviously, that risk would, would exist with anyone, but it's just something

that would be more likely in someone with EDS. Not sure if that answered the question, but I would just say, that for any surgical procedure, including the male masculinization surgery, that there's a going to be a higher risk that it would have to be revised, or are repeated in the future.

[01:24:26] **Sarah Jo Ritchie:**

Alrighty! Unfortunately, that's all the time we have for this webinar. Again, thank you so much, Adam. Your webinar was extremely informative and if anyone would like any more information about anything that was presented today, please check out our website for more resources and information. Feel free to give our helpline a call or an email, and definitely consider signing up for our newsletter if you haven't. It's a fantastic source for the most up-to-date information and upcoming events. Our next webinar will be on July 24th at 2:00 p.m. Eastern Time. We will be having Lauren Puryear presenting on "Genetic Testing and Diagnosis of EDS and HSD." You can look out for the sign up for our next webinar shortly. Technology permitting, this webinar should be available on our YouTube channel within the next week or so. If you found this webinar helpful in any way, please consider hitting that like button once the webinar is available on YouTube, and also subscribing to our channel, so that you can be alerted to when we're uploading our newest videos. There is also a donation button on our main YouTube page. It's thanks to donations, that allow us to continue to provide programs like our webinars, along with other great projects and research we're undertaking. Once again Adam, thank you so much.

[01:25:34] **Adam Sherman:**

Thank you for having me.

[01:25:36] **Sarah Jo Ritchie:**

I hope that you've had a great impact, and you've started a wonderful conversation on the effects of EDS and HSD on males. I hope you have a great day, and I hope all of our attendees have a wonderful rest of your day as well.

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