[0:00] Welcome to Fat Chicks on Top. This podcast contains frank discussions about the body, sexuality, and occasionally uses swear words, which may not be appropriate for people under the age of 18.

This podcast also uses facts, statistics, and mathematics, which may not be appropriate for liberal arts majors.

And this podcast relies on science and reality, which may not be appropriate for evangelicals.

[0:25] Music.

[0:30] Outro Music Welcome to Fat Chicks on Top.

You are here today with your host, Auntie Vice, and it's good to be back.

Happy April, everybody.

I am here with a writer, an editor, a journalist that we met through some writing assignments, Tabitha Britt.

And the more I found out about her, the cooler it was. She runs a site, Do You Endo? And it's all about endometriosis.

And I know a number of my listeners and a number of my own friends have had experience with endometriosis.

And there's not enough information out there about it.

And it's more women living with a chronic invisible illness that really affects so many parts of our lives.

So I wanted to invite Tabitha on to talk about her experience. Welcome to the show.

Thank you so much. I'm so excited to be here and talking to you because it's so important to reach as many people as possible.

[1:54] So for folks folks who aren't familiar with endometriosis, right?

It's one of those medical terms.

And if you have it and you've been diagnosed, you know how painful and devastating it is.

But for folks who are less familiar, what is endometriosis?

The easiest way to describe endometriosis is just abnormal cells growing in the body outside of the uterus.

Something that a lot of people don't understand is that endometriosis does not grow inside the uterus at all.

Adenomyosis grows inside the uterus, not endometriosis.

And it's actually been found on every body part, I think, except for the spleen.

That's crazy. And that is a real understatement to the amount of havoc it can with a person's system.

So if somebody has, like when you thought something was wrong, you initially thought it was like this ongoing UTI, correct? Correct.

[2:55] Yes. So one of, well, first of all, I always knew I had endometriosis because my mom had it and I had all the same symptoms that she did.

I went through like seven doctors.

It took me 14 years to get diagnosed, even though I was telling them I have endometriosis. But when I was in graduate school, I was having what I thought were really bad UTIs and I was urinating blood.

I was in the worst pain in my entire life.

It took so many doctors, a very incompetent urogynecologist.

And then I finally found Dr. Leamer, who is my urologist now.

And he's like, oh, you have interstitial cystitis, which is often considered like an evil twin of endometriosis.

It flares up with inflammation because endometriosis is also an inflammatory condition. So my endometriosis was causing these symptoms and terrible problems with my urethra.

[4:01] I didn't realize at the time that the endo was growing around these areas either.

So it was, for me, so difficult because I just thought, man, I'm just having UTI after UTI.

I don't know what's going on. on um but when he told me that he finally prescribed me um something called urobel it's like peridium it's just what you would get at the doctor if you've had a uti it's the stuff that numbs your urethra because i didn't have an infection it's just this i see um which i think now they're calling bladder pain syndrome was ruining my life but that was a big part of my my endometriosis diagnosis, because that year, right after I talked to the urologist, he's like, I really think you need to go to, you know, find another specialist and not a gynecologist.

So I had to continue my search for the perfect surgeon, perfect doctor.

[5:02] So there's a couple of things I want to touch on there to start.

And your experience is like so much with those of us who are female bodied.

When we go to a doctor and we're like, this is what is wrong.

And you knew what was wrong. wrong and you were completely dismissed multiple times by multiple doctors so let's talk about how was it to keep going back knowing you knew what was going on with your body for a little bit i got so discouraged i thought i was just going crazy i was like nobody's listening to me because they were doing blood tests they were doing all this stuff that i was like i don't need blood blood test.

Like, I need you to take this out, please.

[5:45] So it was just, it was really discouraging. And I would just call my mom like crying, like, I don't know what to do.

And she also, I feel so bad for her because she didn't know what was wrong with her. I knew and still couldn't get help.

And that was years and years ago. So I can only imagine how frustrating it was for her.

I don't know for a while I just felt like I was quite literally going crazy um and at the time when I was so sick I was in graduate school and it was it was a lot trying and I was working too so it was just it was a lot on me at once and endometriosis is so stressful in itself because of how painful it is and how it makes you feel just kind of you know it's just it's painful and Some days you can't get out of bed, and that on top of people not listening to you isn't the best combo.

[6:39] And gaslighting is so much of the experience folks have, especially femme-presenting folks, have in medicine.

Is doctors just right you are, talk over you, tell you you don't know what's going on?

How did you finally come upon somebody who would listen to you?

So I found Dr. Nizat, who was, he started the worldwide endometriosis march.

I went to that march, I think it was 2017. It might have been right around 2018.

And I met him and told him, you know, these things are happening to me, can I please get an appointment with you? you.

And so I got an appointment within like the next week, talk to him and finally set up a surgery.

Cause he's like, what you're telling me is endometriosis.

And just hearing him say that, I was like, you know, like, thank you for saying that out loud.

Thank you for believing me first of all. And so that's, that's how my first.

[7:45] Diagnosis situation went, I had to have surgery again.

So the biggest problem with endometriosis, I would say is that it never goes away.

It's a chronic condition. And my mom has had four surgeries and you just have to keep getting it taken out.

And even if you get a hysterectomy, like I know a lot of people will say, I'm getting hysterectomy to take care of my endometriosis. But the problem with that is that endometriosis doesn't grow in the uterus.

So even if you get a hysterectomy, you're still going to have those lesions and you're still going to have that pain.

Now, a lot of people who do get it, though, also have adenomyosis.

So it takes care of that because that's how you get rid of adenomyosis.

So, you know, everybody is completely different. And that's very important for people to stand up for themselves and know what's best for them instead of just listening to a doctor or whatever.

But I don't know. And it was just such a complex disease.

I always say, I always tell people it's like cancer, except it never goes away.

[8:48] The thing is that people are like, oh, it can't kill you.

But recently they're finding in research that women who've been in chronic pain their whole lives and stuff, and they do these autopsies and everything, they find so much endometriosis inside of them.

So while it can't kill you, if you had it as bad as I did, you would feel like you're dying.

And, you know, in 2022, I had my second surgery and I had it with a different surgeon and that man saved my life because even though I was so happy for my diagnosis in 2018 and everything, after that surgery, my recovery was really hard.

I didn't feel immediately better.

I later found out that there was some endometriosis left inside of me and everything just wasn't exactly done how it should have been. But it's really hard to find.

It's really hard to see. So it's no one's fault, really.

And it grows back and everything like that. But when I finally met with Dr.

Sechkin, it took me months to get an appointment.

But when I finally met with him, he is the co-founder of the Endometriosis Foundation of America.

[9:59] And when I met him, I just felt the most relief I'd ever felt in my life because he was just so on it.

He listens so intently to every word you're saying.

And he, he ordered immediately all this imaging and everything, because we were worried that it was, that I'd have to cut my bladder basically, because I was still having so many problems.

And when I finally did have surgery, there was some superficial in my bowel and things like that.

I guess back to what I was saying is that like, it's.

[10:38] It's just these cells that grow and grow and grow so in 2022 when i finally had surgery they realized that my ovary my left ovary and everything was literally glued to my stomach and they're like no wonder you were in so much pain all of these things all these organs and everything inside of you were glued together in a ball and i was just like thank god i had surgery because had i left left that and just kept living that way. Who knows what else would have fused together?

It was already affecting my bowel and my bladder and then all this was stuck on the side.

So it's just so important to piggyback off of what you were saying.

Even if you feel discouraged and you feel like you're crazy and everything, don't stop until you get help.

Because if If you don't, it's just going to ruin your life.

I was in such a dark time and a dark place because the pain, I could not get out of bed.

I couldn't live my life. I took my mom to a concert for Mother's Day.

I had to sit down the whole time. I couldn't even stand up. It was that bad. And I'm a young woman.

It's not like I'm actually going to be 30 on April 9th. So, you know, it's not like it's just I was in pain that I shouldn't have been.

It was like I was like 100 years old, you know.

[12:05] And pain is so dismissed, right? Anymore, the fear of the opioid epidemic, like I live with multiple autoimmune disorders that cause severe amounts of pain.

And the immediate assumption is you are a drug seeker.

And what you want to do is you just are looking for a way to get high.

[12:23] Before you had this diagnosis and doctors that would listen, was there anything that relieved the pain or could you get any help?

Well, so for the IC problem, for my burning urethra, people thought I was crazy.

My best friend would look at me like I was insane.

But I would go to CVS and get those like little azo urinary things.

But the problem is they made me really nauseated.

But it was the only thing over the counter that would numb the urethra pain.

So like my urine would be like pure orange for like months at a time because I'm taking all these little over-the-counter peridium pills.

And as far as the endometriosis pain goes which is completely different i i would not be surprised if later on in life my liver has some kind of problem because i took a lot of motrin or like ibuprofen this is the only thing i can get i will say though phoria has um little like suppositories that are have like cbd and stuff in them that helped my back pain and um i would use those, and i like that and i i would smoke weed but i just that was all i could do like those were the only things i could have to help me and you know heating pads for the endo ice bottle water in case i have an ic flare like just whatever i could get my hands on to make it feel better.

[13:48] Well and pain really affects quality of life right so i was living in jersey um i had to move so i could pay for the surgery which is a whole nother problem of endometriosis but like some days when i was just in so much pain and my it was a lot of pain in my lower back it was just and i think now because everything was so fused together and my bowel was involved in everything i think that was a lot of that but i would just lay in bed and be like, why even get up today?

Like, why do anything?

Just the...

[14:25] Amount of loneliness and like just pure agony that I was in.

Like some days I would have to like lay on my shower floor and just hope the hot water didn't stop working.

I will say I'll never forget one time I was, it was during my menstrual cycle, which those times are most of the time the worst.

But when I got really sick, I was hurting every day, but I was laying in the shower.

I have have two beagles and um at the time I only had Biscuit I think but she was laying outside the shower door and she would just lay there and sit with me and I think she knew that I really was was not feeling well but yeah it's it makes you feel just really discouraged and and like Like, you know, I was having a hard time with work and trying to do well as a journalist and do things that I love in life.

And when I was living in Jersey, I was always getting invited to events in New York. And it was like, you know, I love doing that, but I had to keep canceling.

And the more you cancel, the less you get invited.

[15:37] And so it was really affecting every little part of my life, like social life, my just home life.

Just every piece of life was affected.

I couldn't work out. So I was just lounging around like, you know, it was just affecting every part of my life.

[15:57] And I think that's what a lot of folks don't get when you're chronically ill, is that it's not just the days you feel bad, right?

It impacts every aspect of your life.

You talk about how it impacted work and when you feel like crap a lot of us go to work when we feel like crap and for those without a chronic illness and without severe pain i don't think they understand this is not like going to work when you have a cold how was it impacting your work life, when i was younger and trying to get diagnosed when i was in grad school i was working at this little uh college magazine for women it was ironic because only men work there i was like the only woman who worked there and i remember i came in late like twice and like a certain period of time i don't know like two months or something and i will literally never forget this but um also precursor whenever i was there i had to run to the bathroom a lot because i was in pain and and just just having problems with my IC and that was before I knew what it was, I guess. And I'll never forget.

I came in and the boss called me into the conference room, but he also called everybody else in there. And he was like.

[17:20] You came in late several times.

He's like yelling at me in front of everybody. And he's just like, do you have a drug or a drinking problem?

I was shocked.

I have never had that happen to me before at work or anything. I'm a hard worker.

I really take pride in what I do. And I just didn't know what to say at that point.

And I was just like, no, sir.

I'm in grad school. school. I have a lot of homework. I'm really stressed.

I did not tell him I had been going to the hospital on and off for the last month and a half.

I did not tell him, by the way, I'm pissing blood every five minutes in case you wanted to know.

What do you tell to a room full of men like that? What am I going to do?

And I was shocked. So I went back to my desk.

But then once I thought about it, I was like, I fucking quit. So I did.

And I was like, Like, I'm not going to do this and I can put myself through this. So I did quit, but I'll never forget that.

[18:24] And I think that's kind of a common reaction, especially if you're dealing with older men in the workplace.

I know when mine started presenting and it was very severe and very rapid onset with my autoimmune stuff. of.

[18:40] Without a diagnosis, it's really hard to say it's a health thing, you know, especially when it's because that feels kind of private, right?

Especially when you're involving anything with the GI system and with gynecological stuff, you don't really want to say to a group of men, this is what's going on, right?

Once you got your diagnosis, did it change how you approached and And what you let people at work know?

Yes. So when I was finally like, okay, this is officially endometriosis and I have this, like I have proof now, I would tell.

So I'm mostly a freelancer and have been. The only times I've ever had a full-time job was so I could get health insurance.

So when I went to work at Bauer in 2018, I straight up told them in my interview, I have endometriosis.

I'm scheduled for surgery within this amount of time because when I was applying for new jobs, I hadn't had surgery yet.

And I just was very honest with them. Granted, I was interviewing with two women.

Even had they been two men, I think I would have told them I'm having surgery for this condition because after that experience, I was just like, there is no way I'm going to let somebody make me feel as small as that man did.

And so I just made that promise to myself because, you know.

[20:06] No matter what anybody else thinks about what you do or whatever, like the job you choose to do, that's something that's important to you.

Like I care a lot about my job and the work I do, and I know I do a good job at it and I shouldn't allow anybody else to make me feel a certain type of way because I know like only, you know, what you've been doing, like that whole room didn't know what I've been going through.

And I was like, I can't be hard on myself because because these people like think all these things.

I was like, just look at what you went through the past two weeks, like running back and forth to the ER and everything else.

I just told myself never again. I'm never going to let that happen ever again.

And so any time I ever got in a position to have a full time job again, I'd be like, you know, especially that one, because I was having surgery soon and they were totally fine with it. They still hired me. I worked with them for a while.

So I'm just I'm very honest with it now. If I have any kind of full time position.

[21:06] So I know with the rise of the gig economy and all of that, lots of people are freelancing, working for themselves.

You know, I do the same thing. How much of your decision to freelance and not work full time for an agency was influenced by the needs of your health care?

I have been a freelancer for 14 years.

I started as a journalist when I was like 16. It was all I ever wanted to do.

Honestly, I just hate being on somebody else's schedule.

I like to get work done on my schedule, so that's just always been who I am, but having the freedom to take a nap when I need to or to lay in the shower if I have to is really nice.

[21:54] Just sticking to freelance has just been a goal of mine.

Like I said, the only reason, like I had a full-time job when I had my second surgery, because if I didn't know that the insurance bill was absolutely.

So I got a full-time job so I could get that health insurance.

And then shortly after my surgery and everything, and I got better, I quit, which sounds terrible.

But like, I mean, I was unhappy there. They were working me way too hard.

And I don't like that. I don't like being on the computer 24 seven for, for things like one of my best friends always say, like, we're not curing cancer.

You can write this description tomorrow.

Like it's not, you know, and sometimes when you're in the corporate environment, they like, you know, even when I was working with the people who were very understanding of my condition, um, especially in media, you know, I was staying there seven, eight o'clock at night.

I lived in Brooklyn at the time. Took me an hour to get home.

I was working in Midtown.

It was like, it was exhausting.

And also when you're sick like that, you don't want to ride the train for an hour to go to work or whatever.

I'm very familiar with that train ride. I lived in Brooklyn while I was working in Manhattan.

And it's, especially after rush hour, it feels like you're on there for an interminably long period of time.

[23:17] But I want to talk a little more about work environment because with COVID and And with long COVID, we're looking at a significant percentage of the population having an inflammatory long-term condition that impacts their ability to work.

So what type of accommodations would make it more reasonable for you to work for a corporation, since we're not getting healthcare uncoupled from work anytime soon in this country?

[23:45] Well, there have been some full-time roles that I really, really wanted, but I didn't apply for because they were hybrid because now a lot of places are going back to hybrid and because I had to move away there's no way I can just have those positions anymore because they're requiring three days in the office so I think it's just honestly makes no sense at all why companies can't just be remote like before if we did it for that long and it it worked.

Like, why are they going back to how it was or whatever?

So I think, you know, I think the hybrid thing is definitely a barrier between that, and just not allowing remote work at all.

I did hear something that there's going to be like, either a four day work week or some kind of something I don't know, I saw it running around in Instagram or something.

But, um, you know, also, working beyond nine to to five, because a lot of companies, you know, they won't, they'll say in their contract, you're nine to five.

But when you actually go to work, they'll be like, Oh, like.

[24:51] I noticed you weren't logged on at like 8.30. Like, you know, just like you have to be on all the time.

And it's just such a toxic environment for your health because you have to constantly be at work.

You can't, you know, you can't eat lunch. You can't be with your family.

And it's, I just think America needs to calm the fuck down.

Like, I think, you know, we need to prioritize what's more important.

And it seems like during COVID, people would have realized that.

And I think during the time they did, but for some reason, we're now reverting back to that corporate culture, that always on culture that like, oh, I'm more burnt out than you.

Like, it's not good to be burnt out. It's terrible for your health and stress will kill you. It will give you an ulcer.

It's literally in studies like years and years that stress ruins your health. It just destroys it. it.

So especially for somebody with endo or something, you know, there was a recent study that said chronic pain can actually change your brain.

And it's like, why do we need more stress on top of all this, you know?

[26:02] Well, and you bring up a good point because a lot of these companies like, yeah, it's a 40 hour week, but it's not right.

It's the, the expectations are well and And above, especially in journalism now, because you have to have so much social media, so much, you know, interaction and engagement beyond just what you're writing.

And they don't necessarily count that time as time at work.

And you mentioned the importance of being able to take a nap when you need one and stuff.

You know, just having how much of it would if they gave you flexible work hours and stuck to no more than eight hours a day with that, you know, you could log on it.

10 and off at two take a nap come back at five and go would that work as an accommodation.

[26:50] Yeah that would sound nice if they were giving me health insurance you know um I think I like the way I have life right now Tuesdays and Thursdays I kind of have easier days and I just hit deadlines on those days and then Monday Wednesday Friday I have like shifts and meetings Um, so it's, it's just for me, I like having, um, the flexibility, you know, to, to go to the grocery store to, you know, to take a nap, even after surgery, like I feel 1000% better, but I still get tired sometimes.

So like I was, I nap during the day when most normal people probably don't, but it's nice to be able to do that.

Well, it would make the workplace a more enjoyable place because people get nasty at work and petty.

And some of that is stress and dealing with things outside of the workplace.

The other thing that I think that a lot of people miss is when you have a chronic illness, you go to the doctor more than once a year.

And most doctors are open between nine and five.

[27:53] So it really impacts your ability if you have to have you know, all of these times off to go to the doctor.

How did you manage that before you got a diagnosis?

Just up before, like I said, I was in graduate school and I was, I was freelancing them.

Um, but whenever I did have like in my next job that I got immediately after the, um, chaos of what I went through, I was a copywriter for a beauty brand.

Um, And I had to go to the doctor a lot, which they weren't mad about, but it was like, you go to the doctor a lot.

It wasn't like you can't go, but it was definitely like elephant in the room kind of thing.

And I just ended up quitting that job because at the time I just could, I was like, I really need to focus on getting help.

And I was like, I can't handle both this job school and trying to find a good doctor. So.

[29:02] It was then that I was just like, okay, I need to full on commit.

I mean, for the most part, I can write online and I have been freelance, but anytime it's been full time, it's definitely been an issue.

Right before my second surgery, I was working full time for a digital agency.

Luckily, my manager, I'd known him before and he knew about the endometriosis and everything. thing.

And if I didn't feel good, all he would need is like a Slack message.

And he'd be like, you know what, you can just work different hours some other time. So it was really nice that I had that.

So I think the most important part is if you have to have a full time job, to try and find allies within work who you can trust and talk to.

Because unfortunately, sometimes you can't trust everybody.

And if you tell someone, look, I really need this accommodation, some nasty people will use it against you and try to take your position or get over on you or whatever unfortunately that's just how life is but if you can find somebody or if you can find a manager who you can talk to i mean i think during the interview process it's very important to pick up on cues of somebody's.

[30:14] Emotional intelligence how they're acting during you know your interview with them and whether you think that they would be pay attention to the vibes right like good gut feelings um Because most people who are genuine and kind will understand, hey, you have to go to the doctor. That's fine.

But in New York and stuff like that, it's really hard in the corporate world to find somebody who's kind and understanding.

[30:42] And I think that's really critical, especially for people in management positions to hear, is that health is, if your employees aren't healthy, they're not going to be giving you the best they have anyway.

So the more you can help prioritize it. I know when I was onboarding my employees, when I was the head of a state agency, you know, we'd go over all the benefits and I'm like, you have this much sick leave and I don't care why you use it.

There's no justification, right? It doesn't have to be, well, I need a mental health day.

Just take your sick days as you need them.

And there's no glory in banking your vacation days.

If you need them, take them.

But I don't think, and I know from my own experience, that's not a general accepted corporate culture, right? It's work yourself into the ground.

So you go through this, you get your diagnosis, you start getting help, and you start up your endo. So let's talk about that project for a little bit.

[31:40] Yeah. So do you know, it was so important to me, I, I started it in grad school.

So I was about to graduate. And one of my last projects I had to do, it was a design class.

And they were like, you need a final product at the end of this class.

And I was like, well, this is something I've always wanted to do.

Let me just create it for this class.

And at the time, it was just for the class. Like, I didn't think it was going to be anything more than a project.

But when I was creating all the like the social court and everything, because you had to like create something real, I started to get messages from people on Instagram and Facebook.

And they were like, oh, my God, thank you so much.

Thank you for doing this. I love reading this. Can I write something?

And, you know, just I love this one story.

That was exactly me. And so many people were like.

[32:34] I needed to read this today or like I needed to see this. And I just got so excited that that's something that I was just doing as a project in school was was, you know, becoming like so important to some people.

So after I graduated, I was like, there's no way I'm stopping.

So I just kept kept going with it and getting more writers and having some friends of mine make up my editorial team.

And, you know, I was really working on it a lot when I wasn't constantly trying to work. Or I will say one terrible thing that happened is that over the years, we got like over 11,000 followers on Instagram.

Instagram shut us down for period content. And...

[33:20] I didn't even want to restart Instagram. It took me forever to decide to do it. I finally did.

But now we have like no reach because of what we talk about.

So it's, it's really frustrating being censored all the time.

Because that's the main point of do you window is that, you know, yes, there's medical information on there.

But the main point of it is, is to bitch to have a voice to actually speak I mean we have a section called ready to rant and that is just like literally you can rant away and and we will publish it because when you write things down like that when you're so upset and you're in so much pain you feel like nobody's listening if you write it all down you feel better but if you write it all down and it's published for people to read that's a little different too you feel like an extra you know validation that like this this is how I'm feeling in the read it world.

Like, you know, and a lot of my writers love that they can just say what they want.

I do not censor them, you know, cuss all you want, say how you feel.

You'll feel better after you do. So the whole point of Do You & Do is just to help.

[34:31] I call them individuals, to help them just really feel heard because for so long, I knew what it was like to not feel heard and not be heard, even though I was, basically metaphorically screaming and no one was listening to me.

So I just really don't want anyone to ever go through that.

So if they can come to me and talk about their life and their experiences, if I could just help them, that would be great.

One day, I would love to pay for one surgery a year but we're just not we're not there yet but later in life like maybe 10 years from now or something i really hope it's like a huge huge thing and that i can help fund surgeries and do events and stuff but that's gonna have to be when i'm older and i can afford to do so but um for now it's just a place to talk about your feelings and um, just get validation and find a community as well.

[35:31] What have you gotten out of finding this community?

[35:34] There are so many more people than I ever realized who have endometriosis.

And I know all the statistics say like one in 10 people.

That is really true because once I started this and everything, people started coming out of the woodwork, like just constant.

And then I found this huge group on Facebook. I'm not on Facebook anymore.

The Do You Endo page is still up. but um there's just there's thousands and thousands of people who have endometriosis who are just like and some of their stories like i know i was in a lot of pain but there are some stories out there that are just absolutely devastating like thoracic endometriosis gets in your lung this one lady had her lung collapse like some other girl had a honey on her brain like it's it is just like one of the worst conditions and for there to be like no talk about it ever except for in march when it's endometriosis awareness month is just beyond me like i have no idea why nobody's talking about it when when thousands and thousands of people are like dealing with it every day if we had one in ten men have something wrong with them you know it would be all over everything and not censored by Instagram.

Let's talk about that censorship for a minute because you write on a variety of topics.

So where do you find you're shut down the most by social media?

Because you spend a lot of time having to promote different things on social media.

[37:02] Well, I mean, a long time ago, we did great on Facebook.

We were getting thousands of reach by the day, like, things were really doing well there.

But now it's like, anytime I try to post, okay, so really good example, the other day.

So sometimes I post things I write on LinkedIn. The other day, I posted an article that I wrote for in style about underwear.

It got like no reach at all. And I think that's because it had underwear in it. because the last in style article I've posted had so many impressions, so many views and stuff like that.

And I was like, this has got to be because the word underwear is in it.

Anytime that I have like menstrual anything or anything to do with sex.

That's why people on Instagram are putting like S3F or SEGG or, you know, it's just, it's getting ridiculous.

Um, and I went to sex tech school, which was amazing.

And everybody there was having the same problem. Um, it's, it's, it's really hard and the worst part about it is is like okay.

[38:07] I don't know if you watch the new sex in the city i absolutely hate it but i hate watching, so um carrie bradshaw is nothing like she used to be but in one episode she's supposed to go on a podcast and talk about vaginal dryness like a thing for vaginal dryness she refused to do it and i was like this is absolutely insane even carrie bradshaw can't talk about vaginal dryness like she completely refused to do it and um i was pissed first of all because it's completely different or whatever than than the original show and then in like the next episode there was a penis pump and i'm like so we can't talk about vaginal dryness but there are ed commercials on the radio on the actual radio in the public that even children can hear are playing non-stop ed TV commercials every day, but God forbid we talk about vaginal dryness.

I mean, are you kidding me? Like, it's just, we're just going to be censored for the rest of our life. Like Unbound just did a whole study.

Unbound is a sex toy company. They just did a whole study where they rebranded everything for men and found that those posts didn't get censored, even though it was the same products and everything.

So it's like, Like, it's ridiculous, and I don't know when it's ever going to be fixed. I don't know.

[39:29] Well, and it is ridiculous because more than half of your population menstruates at some point in their lives.

Like, this is a physical thing that happens.

Why can't we talk about it? Well, and that's one of the problems with getting information out about endometriosis.

This is a medical problem. We don't censor information on diabetes.

We don't censor information on heart disease, but all of a sudden, oh, it's got girly bits in it, so we must censor.

[40:00] And that makes no sense to me because while endometriosis does affect life, or it does get worse during your period, endometriosis is a whole body disease.

Even men can get endometriosis. It's very rare, but there's been like 12 cases, I think, that there's studies on.

But endometriosis is an inflammatory condition.

It's literally abnormal cells growing in your body.

Scientists don't know why yet, because they haven't researched to find out why because there's other more important things to do, I guess.

But the whole thing is that people often market endometriosis as like, either an infertility disease, it can cause infertility.

And I feel so bad for those people who are going through that, but that is not the only thing that endometriosis does.

Endometriosis can literally ruin your life. It's, it's an, a whole body disease. It, it.

[41:00] Everything in your life is affected by it but i think people just market it as like a reproductive disease or whatever which makes no sense because it doesn't even grow on the uterus so it's like they just i don't know i don't know it's i can i can get so enraged about it i don't know well and this is one of the rants we have on an ongoing show is diseases that that predominantly affect ABFAB people, you know, you're assigned female at birth, are the ones that don't get talked about, are the ones that get censored, are the ones that don't get studied.

And there's literally millions of us living with things that we don't have.

Your experience, you knew what you had.

You went to doctor after doctor and told them, right?

You know, my common line when I talk about my stuff is you can lead a doctor to a diagnosis, but you can't make them think? Because they don't.

It's immensely frustrating. And so to have that community, like you've started with Duendo, is critical.

So for folks out there who think, well, this kind of sounds like what I'm going through and want to connect with your community, how can they connect?

And do you offer like, you know, group sourced, these are adequate doctors in your area?

[42:20] Yes. So eventually I'm working on a new thing on the site where we're going to have a whole section for doctors locally.

But the most important part about finding a doctor is finding an excision specialist, not somebody who does ablation, not someone, not a random some gynecologist, someone who is an excision specialist.

The reason for this is because if you go through the whole process and you get ablation, which I may be pronouncing wrong, but it basically just burns it off.

The root of it is still in there.

So it's not gone. Nothing has gotten better.

It's just been the top of it's been burnt off, which isn't going to help no one it's going to be very expensive you're going to be in a lot of pain for recovery and then nothing's going to get better because it's still infinite so.

[43:14] I 1000% always tell people like, please just talk to Dr. Suchgang.

There's a form on his website. He is so understanding.

Even if you can't get to New York for surgery, he knows other surgeons who may be able to assist you where you live.

He also offers funding for low income families and and programs.

Dr. Sutchkin really is the real deal. I don't know what's going to happen.

And Dr. Chu helps them as well. She was also a part of my surgery.

And I just hope they continue doing what they're doing over there.

He's getting up there in age, but I think he's training Dr.

Chu and everybody to follow in his footsteps.

So I 1000% recommend them filling out the form on their website, they will help you. They will not turn you away.

They will talk to you. So that's very important.

Also, if anyone ever wants to reach out to me personally, I do that.

I just talk to people to help them try to figure out what may be the next best step for them.

[44:24] I'll never forget, I was downtown and at my favorite jazz club with one of my best friends during the the summer.

And it was a little after I got my first surgery.

And she was just telling me like, I haven't been feeling well lately and all this kind of stuff.

And I just remember crying because I was like, I'm so sorry.

But I think you have endometriosis. And I really think you need to get checked out. And she did.

And within a week, she had her appendix taken out, she had the endo excised and she had it done in um georgia where her family was so she could have family around she lived in new york though at the time i did too and um so just hearing the symptoms and stuff i can tell you like this is probably what you need to do um unfortunately just going to a gynecologist and telling them your symptoms unless they actually know unless the word excision is somewhere on their websites, they will not know what you're talking about, unfortunately.

[45:34] And I think that type of tip is so helpful because...

I don't think until you've gone through it, the amount of gaslighting and bullshit you get from doctors trying to get a diagnosis.

For me, that sent me to a very dark place for a while.

And I'm still, every time I drive past UC Davis out here, which was the main culprit, I just want them to burn down because it's so harmful what so many doctors do because they don't know what what they're talking about, but they like to pretend they have all the answers.

What are you currently grateful for?

I mean, I'm so grateful that I met Dr. Sechkin. I will say that.

After my surgery, I had to work so hard just to get the down payment and everything for it, but, I would pay a million dollars over and over again for that surgery because I was a brand new woman after I recovered. I was a completely different person.

[46:40] He gave me my life back and I could walk my dogs again. I could go to restaurants again.

I could go to concerts with my mom again.

And it was getting my life back. I was just so grateful.

I just cried happy tears because I just felt so good.

And I was like, oh my God, this is what I was supposed to be feeling like the whole time. And I'm like, this is what it feels like to not be ridden with disease.

So I just, I'm so grateful that I met him and that he could help me in the way that he did.

And Dr. Chu as well. They're both amazing people. And they often give me quotes for pieces that I'm writing.

I only trust them because clearly no one else knows what they're doing.

So the fact that I could get that surgery just means the world to me.

And I will be forever grateful for that.

[47:34] I am so glad you were able to do that, too, and that you've created this way for other folks who are living through this to connect, to rant, to feel community.

If folks want to find you, if they want to find you, all of that, plug all of your sites and socials. Oh, yeah.

It's literally spelled the way it sounds, like D-O-Y-O-U-E-N-D-O.

And we are on Facebook, Instagram, Pinterest. Pinterest, so you can directly get articles from there, but it is just doindo.com.

Also, just one small thing that I'd like to say.

If you see a doctor who recommends you go on Lupron or Orlissa, do not do it. Those are chemotherapy drugs.

[48:21] They're just a band-aid. They don't help the endometriosis, and while very few people may experience relief, the long-term damage that it does to your body and your bones is not worth it it's also extremely expensive and doctors are preying on people with that right now it's so expensive so they're trying to just fill the little pharmacy cases so you'll get it do not do that i mean obviously anybody can do anything they want it's their body but i am telling you right now it is dangerous it is and and the company is so rich that they've hidden all the lawsuits luckily do you window still has one up that you you can read about, but those drugs are dangerous and not good for you.

So just please, if your doctor says those words, run the other way, get a different doctor, stand up and leave.

[49:15] That's exactly why folks who think they might have this or who know they haven't and haven't gotten a diagnosis or who have a diagnosis and want to connect with others need to go and connect because otherwise you're not going to find this out.

It's great. Thank you so much for being on the show.

And I am so glad you're feeling better. And folks, we're going to have all of those links and more in the show notes.

Check out Do You Endo? Check out Tabitha.

She writes some really great and some really fun stuff. It's not all health care and serious. curious, and thank you for being on the show.

Thank you so much for having me. I always love to spread awareness whenever I get the chance.

[49:51] Music.

[50:21] Thank you for listening to this episode of Fat Chicks on Top.

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