



PWE16: Endometriosis & Infertility

Aubree: Welcome to the Peace With Endo Podcast. My name's Aubree Deimler. I am an author, speaker and integrative wellness coach who helps women with endometriosis naturally manage pain, increase energy and find Peace with Endo. This is episode number 16 and on the show today I'm super excited that Dana May is here from the Endo-Wife. She's a fellow endo sister, writer and host of the Endo-Wife Podcast. Thanks so much for being here Dana.

Dana: Hey Aubree. Thanks so much for having me. I truly am honored and really this is just another way to spread the message and create awareness about endometriosis and painful periods and pelvic pain and reaching out to people who are suffering and that they don't have to go at this journey alone. We are here for you.

Aubree: Absolutely. So, tell us a little bit more about yourself.

Dana: I am married. I've been married for about 13 years. I am also a foster mom, but not to children. I have a passion for the Chihuahua breed. So, we actually help to rescue and take in Chihuahuas.

Aubree: Nice

Dana: And we've been doing that for a couple of years now, and right now so other than our fur babies, my husband and I do live alone.

Aubree: Awesome. So, let's talk a little bit about your journey with endo.

Dana: So, my journey with endo early to mid-thirties. I started having some, as many of us do, I started to have some IBS symptoms, just a lot of stomach irritation, stomach pain, bloating and it wasn't necessarily around the time of my period, that's what made it so confusing for me. So really my journey started with working with gastroenterologists and trying to figure out what was causing my symptoms, you know, bouts of diarrhea and constipation, and then just pain on a constant basis, and at one time I thought that I may have had celiac or an intolerance to gluten.

So, I spoke with my GI doctor and you know she just recommended some things as far as changing my diet, trying to avoid alcohol and you know she recommended if avoiding gluten made me feel better then she didn't see that there was any problem with that and actually before meeting with her I did actually end up having my

gallbladder removed, because we thought that my pain was associated with gallstones, or a gallbladder issue. So really like I said my journey started with symptoms of IBS and just as the years went along my pain just got worse.

Then I started being affected by chronic fatigue. My energy level was not what it had, what it used to be, and I was an active person. I worked out regularly. I was one of those ones who worked out at least five days a week. I actually competed in amateur figure competitions. So, I always stayed in pretty good shape, and had been doing that for really the majority of my life. So, experiencing chronic fatigue and then constant pain, joint pain, constant pelvic pain and IBS symptoms, I just got really frustrated, and you know, I said to myself these things cannot be normal.

So, I sought medical advice from doctor after doctor. I visited my primary care physician who tested me for autoimmune diseases, Lyme disease, anything you could think of related to pain, fibromyalgia, but all of my tests always came back as normal, and everyone kept telling me you're healthy. There's nothing wrong. I even had MRI's, pelvic scans, CT scans, and the doctors just couldn't determine that there was anything serious that was wrong.

I suffered from headaches and neck pains so I went to my neurologist, who did some nerve testing, also brain MRI's and scans, and again I was told that everything was fine and I was normal.

Aubree: So, it sounds like you went through the ringer with the medical system, which I think is pretty common.

Dana: Yes. It is common, and I am definitely your typical case when it comes to mis, you know, being mis-diagnosed. So, I finally got answers back in 2014. I had several visits with my gynecologists, you know, we talked about my past history. I had decided to come off birth control pills a few years before that. So, my husband and I could, we weren't really serious about trying to conceive but I just felt like it was time for my body to kinda get back into a natural rhythm. So, my I think that's probably when my symptoms started becoming worse, and, but, you know, you don't have very many options when you do make the decision to try and conceive, a lot of the treatments now that they have for endometriosis basically prevent pregnancy, you know they're contraceptives and things that lower estrogen, that you know, you can't use if you're trying to conceive.

So, anyway, like I said, my symptoms started getting worse just year over year over year and I just got to the point where I, I couldn't tolerate anymore and I had several conversations with my gynecologist and she said, you know, you just, you might have endometriosis. So, let's just go ahead and check. So, in the summer, late summer of 2014 I had my first laparoscopic procedure, which did determine that I have endometriosis. Now, you know, often times you hear a lot about people with stages: stage one, two, three and four. My doctor, she never really explained to me, or told me what stage I was in, because she said, you know, that is really no

indication of pain. So, that really wasn't even a discussion but you know we did talk about that I did have it. She did find endometrial tissue outside of the uterus, and I also have fibroids, I have a blocked fallopian tube. So, you know, we run into some challenges with infertility, but that was when I was first diagnosed, and it was really nice to finally have the answers. Then I knew what it is that I needed to do, so it, it just kind of became my passion learning about endometriosis because at the time that I was experiencing all of these symptoms, over the course of several years I never was really able to pinpoint or find any information about painful periods and endometriosis. So, it just kind of became my passion to learn more and become educated, and you know, be able to spread the message and help other women so they don't have, you know, so they don't have really have to go through the same journey as mine, as complicated as mine was, because it really affected my mental health.

I did go through a period of depression after being diagnosed, because I really didn't have, I wasn't sure what I needed to do, how to take care of myself. The doctor really didn't give me a whole lot of information. So I just kind of had to be an advocate for my own health, and just learn and research as much as I could to figure out how I need to take care of me.

Aubree: I love that. So, it sounds like we have a similar story and I think it's similar for a lot of ladies out there that maybe don't know they have endo until, one, you get off the pill, right? Because that's masking the symptoms and then trying to conceive. Had you even heard of endometriosis? Was it something even in your vocabulary?

Dana: You know, it's funny, I had. I had had a couple people just kind of mention it, but until you have it, until you deal with it, until you're diagnosed with it, you really just don't understand of impact of the disease. So, really until I was affected, I really didn't know a lot about endometriosis or even really kind of understood what endometriosis was when someone said that they have it, which is looking back now is very said and I, I feel, my heart goes out to those women who suffered from it, especially, you know, back a few years ago when there was very little information, you know, about it, and not as much of a community or awareness that there is now. I mean, we still have a long road ahead, but, you know, we are. We're a part of change that's happening and there is a movement that's happening right now, and I'm just, I'm glad that we can be a part of that.

Aubree: Absolutely. So what, what inspired you then to start the podcast?

Dana: You know my mission with starting the podcast show the Endo-Wife Podcast show, a couple of months ago, you know, is really just another platform in reaching people and helping, you know, them learn about endometriosis and painful periods and that, that is not the norm and, you know, we shouldn't have to suffer. I hate that anyone has to go through that, because it was such a negative experience, just turn that around into something positive, and doing something productive with it, helping me, you know, kind of cope with the mental health aspects of it, and really

just being able to, to fill a purpose, because at this point in time in my life I expected to be raising a family. So, I dealt with a void, and really just being able to help other people, and help women with providing more information, just creating awareness and being able to hear other people's stories and what they have gone through, really it's, it's fulfillment to me. It helps me feel purposeful, and it's really just been, it's been life changing.

Aubree: That's awesome. So, I know, obviously there's a lot of struggles that come from living with endo, but then you add the infertility piece on, which I'm familiar with as well. Let's talk about some of those challenges that come along with infertility.

Dana: Yeah. It's been very difficult, you know, like I said at this point in my life, my husband and I expected to at least have one, you know, maybe two children to kind of carry on our names, you know and I, like I said, I decided to stop birth control several years ago and we hoped that it would just happen for us naturally but then when I found out that I was diagnosed with, you know, endometriosis, and then I had blocked fallopian tubes, and my husband has some, some issues as well, those things just kind of collide to make it a little bit harder for us to conceive. We've never been told that we would not be able to conceive or have a child, but our, you know, because of our challenges it does reduce our chances.

So, after my endometriosis surgery I talked to my gynecologist and said what are my options as far as trying to conceive? And she said, well the best time to do that is immediately after surgery. So, she referred me to a fertility clinic and we set up an appointment and my husband and I started with infertility treatments, you know, the first visit with the doctor really just kind of just lays out your family planning and what options there are for you and he said in our case, he felt like we should just go all in, and jump in and be as aggressive as possible and go ahead and go straight to IVF.

My husband and I, we weren't really comfortable with that. There is a lot of scientific engineering involved and we just at that time reading over the packet of information that they give you, we just became very overwhelmed, and we didn't want to subject our relationship to all of that stress, and that pressure. So, what we did do is we tried a round of IUI, intra uterine insemination. I went on the medications, the Clomid, the injections, and we had one round of that and my husband was kind of resistant. He was supportive but kind of resistant and just really didn't feel really, he didn't feel good about it, and I'm like that's Ok. If this is not the way that you want to go about conceiving, I'm Ok with that.

I know our window is closing, but I still feel like we have some time. So, if you want to just keep trying naturally, then I'm Ok with that, and that's what we will do. We, we never even got involved as far as planning for, for IVF. You know, we have talked about adoption. We both are Ok with adoption, but again we're still really not at that point in our lives where we have given up hope on trying to conceive naturally.

And then I will say I did have my second laparoscopic surgery actually October of last year, because my pain came back, and I was suffering again, and kind of got to a point where I couldn't tolerate it anymore. So, after that surgery, you know, I really wanted to talk to her about my concerns, our concern with the clinic that we were working with, we just really kind of felt like a number, and I always just did a little bit more research and found that they didn't have great success rates. So, I explained all of that to her and she said well what I can do is, she said, now you know, I'm not a fertility specialist, but what I can do is do six rounds of intra uterine insemination for you and we can do that here and I will help you with that, and that was supposed to start around November or December, but then some personal things happened in my life and I've, we've kind of, we've had to put that off. We may start that in the next month or so, but that's kind of where we are with our plan on trying to conceive, and still hoping that it will happen naturally.

Aubree: This whole process can be, kind of a roller coaster, right, of emotions. A lot of stuff can come up. Do you have any tips for other ladies that may be dealing with this on how to handle some of the ups and downs that come with the infertility journey?

Dana: Yeah. Absolutely. You know, because you don't want to get in a depressive state like I've heard many of us do. It's really, really important just to talk about it. Find someone who you can relate to. It doesn't even really necessarily have to be someone with endometriosis, maybe even someone who has just, you know been hurt, or been in pain before for a long period of time. Even someone with just a chronic illness or chronic pain, or someone who has migraines, who can just kind of relate, and definitely, you know talk to your family members and just kind of be vocal about it. Express your feelings. You know there's a difference in expressing your feelings and talking about it versus complaining and certainly, you know, don't feel guilty about telling people about how you feel, and telling people that you hurt and that you're in pain, because they have to have some sense of where you're coming from and how often you hurt and how often you're in pain, and just so they can in some way can relate.

And you know, then don't, don't be embarrassed or feel, just don't feel embarrassed if you, you know, need to speak with to a therapist or, you know, a counselor or someone in the mental health field because it really can be, it can be devastating to find out that you have endometriosis and then also devastating to find out that you're going to have trouble conceiving. Some women hear that they're not able to conceive at all. So, really finding a support group and a community of people who can kind of help you through your journey, you know, if you have questions, you know, they can be there to support you, and kind of explain what, what they've dealt with in the past and what they've been through, of course of all the stories that I've heard, they're all very different, and you really just have to kind of pay attention to your body and just get in tune with what's happening, and when it's happening, and you know, talk to your doctor.

The worst thing that you can do is just bottle it up inside, because then that's just going to affect your mental health in a negative way, and you know kind of speaking from my experience I don't want anyone to have to go through that. So, you know, just definitely being vocal about it and not feeling guilty if about telling people that you're hurting, and that you're in pain.

Aubree: I love that advice. For sure, find support around you, because I know it can be isolating, and especially as you get older, at least it is for me, because most people in my life have kids. But finding other people, and there's so many support groups online, which can be really helpful.

Dana: Yeah. Absolutely. So, I have found a lot of support on Instagram. I wasn't a, I was actually probably a bigger Facebook user, then I was Instagram, but I moved to Instagram several months ago and was just kind of blown away by the support there from people with endometriosis who suffer from painful periods, chronic pain sufferers. So, they've been a tremendous help and very supportive and there are also some Facebook groups that I'm a part of as well.

Aubree: And I feel, I feel like infertility, I think similarly to endo, there's still some misunderstandings from people out there that may not fully relate. Is there anything that you're, that you get tired of hearing from people when they hear that you're struggling with infertility?

Dana: Honestly, I don't. I don't get too hung up on people's opinions. I've never been bothered by, or offended by anyone's comments, I just try to keep a positive mindset. Really, that's what matters. Is not focusing on the negative or of course it is, it is kind of hard when you see all these posts about babies and pregnancies and baby showers. So, sometimes I even have to take a step away and become distant from social media because it is painful. It does hurt, but you just have to keep a positive mindset, and focus on your journey, and still having hope and faith, and you know there's other options.

You know, there's, there are children out there who need to be taken care of and who don't have parents, who don't have parents who can care for them. So, I mean, always consider adoption and do some research on that as well. You know, I think that we, a lot of us get hung up wanting, you know, to be able to go through that experience of, you know, childbearing, and... but you know, you just have to figure out how to get past that, and how to be hopeful and say, you know, there are other options. If it's, if it's not meant to happen naturally then I can still have a child.

Aubree: I do think it is grieving process and to get to that point, because I feel like there is always that jump, at least from what I hear from other people is, oh why don't you adopt? But I think there's also that period of time where you almost have to grieve the other piece of it. The idea of, you know, having your own biological child. So, that's Ok too. You know, there is a grieving process before you jump to, I

think the adoption, because that's obviously another, a whole other process, right? That comes with adoption.

Dana: Yeah. Absolutely. You know, you have to get past that and to the, you know, acceptance stage. So it's, you know, definitely allow yourself to go through those emotions and that grieving process, but you know, you'll come out to the other side, and it'll be a blessing, and you know, it will be rewarding, no doubt.

Aubree: Awesome. Well, I love that, I love that you're, you've got the positive attitude. That's amazing. So, what, Dana, what have you learned from living with endo, from struggling with this infertility, like what's your biggest take away that you could share with our listeners.

Dana: Oh, that's a good question. So, so many people are misdiagnosed. The best thing that you can do is just, like I mentioned earlier, you have to really pay attention to what's going on. Track, because I tracked my symptoms for a couple of years and had multiple appointments with my primary care physician who still couldn't pinpoint what was wrong. So, really just pay attention to what's going on, and how often, when you're affected by it.

Also how you're affected by food. Change you know a change in diet often times doesn't completely, normally doesn't completely relieve the symptoms but it kind of does subside and it does help, I've learned.

And then just learning ways to care for yourself and just researching and learning as much as you can about endometriosis and listening to other women and asking questions. What works? What doesn't work for you? Because what works for one person doesn't always work for another. It's kind of really trial and error, and it is a journey, and it does take time, but if you work on it and you work on yourself you will be able to figure out how you can manage your endometriosis be it with, you know, fitness and movement or exercise, pilates or yoga, staying active, whether it's drinking more water, whether it's taking, you know, a supplement during specific times of the month, you know, whether it's taking magnesium, whether it's seeking alternative treatments, you know, like acupuncture or chiropractic care or pelvic pain therapy or massage, you know, just hopeful and you will be able to find some relief. It's a journey and it takes some work. And you know, you are, what you have to remember is that you're worth it and you just have to stay patient. Reach out to other people who understand.

Aubree: I love that. Thank you. Thank you for sharing that. So, how can our listeners connect with you further Dana?

Dana: So, you can find me on Instagram. Like I said, that's probably one of my favorite sources of connecting with other people who have endometriosis and also suffer from chronic illness because sometimes those other diseases are linked. So, Instagram you can find me it's @EndoWifeLife, and then I'm also on Facebook

@theendowife. I also started a blog about six months ago: endowifelife.com. You can find me there, and I started the Endo-Wife Podcast Show and I am on your major podcast directories like iTunes, Google Play, Stitcher and I also was just added to TuneIn, which I think now is one of my favorite platforms. And to connect with me personally you can always send me an email at hello@endowifelife.com.

Aubree: Nice. And you telling me that you had a guide available for the ladies on your website now?

Dana: Yeah. I do. And of course, you know, I'm not a doctor. I'm not a medical profession, but I did build a self-care guide using the knowledge that I have, the personal experiences and my research about endometriosis. It's a 45 plus page guide that focuses on ten pillars of self-care and also includes, I like to make things like that you know I didn't just want to provide literature or a piece of reading material so it's kind of compiled as lessons and each lesson is about three or four pages in length and at the end of each lesson there's kind of like an interactive activity. I call them take action worksheets that can, you know, if you're looking to you know, make a behavior change or sustain the management of your endometriosis, you know, after you learn these things you've got to be consistent with it and sustain those habits so those, you know, it really makes it applicable, the take action worksheets are included with that, and you can find that on my website as well and it does help support my mission for endometriosis awareness. It helps fund the website, and the content and the projects that I work on and then as well as supporting the Endo-Wife Podcast show.

As some of us know, March is endometriosis awareness month. So, I am offering a 10% discount if you use the code Endo Aware you'll get 10% off of the, The Endo Self-Care Guide. So, I appreciate you supporting me.

Aubree: Awesome. I love that. Self-care is so important with endo and infertility. So, I appreciate you Dana for being on the show today and sharing your story with us.

Dana: Yeah. Thank you for having me.

Aubree: If you found this episode to be helpful I invite you to subscribe to continue on the journey, and if you want to connect with me further you can find me at peacewithendo.com or on Facebook, Twitter and Instagram @peacewithendo. I hope that you find some peace in your day today. Sending you so much love. Bye for now.

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