Kailey: Living with Endometriosis

Kailey: I started my period when I was 11. They were always painful. And I remember I would talk to my mother and my grandmother and they would say that ‘That's normal. Periods are supposed to be painful, and it's just part of being a woman.’

I noticed something was wrong when I was in school and I wouldn't be able to get out of bed in the morning.

I would be extremely fatigued. I would be bloated. I would be nauseous. I wouldn' t be able to eat.

It was a real struggle. When I was 27, I was put into medical menopause and the thought there was that it would stop my periods for one, and then it would decrease my symptoms and it would decrease the growth of the disease.

But in reality, it was only a band-aid.

I've seen about 12 different doctors before I even heard the word ‘endometriosis. ‘

So, I remember sitting in the hospital bed and her looking at me saying,”You have endometriosis.”; And at that point I was excited.

I figured once I heard the word endometriosis, it would be an easy answer.

You take a medication and you're better. But that wasn't the case. I tried many medical therapies. I had three surgeries over the course of seven years.

The last surgery I had was excision, which is where they cut out the endometriosis.

I ended up having a partial hysterectomy, so I can no longer have children.

Endometriosis has taken a lot away from me. I struggled really hard throughout college. I never graduated because I had to drop out because of the pain.

I've lost jobs over it. It's affected every part of my life.

One of my passions, something I love to do, is exercising. I' ve had to change that up quite a bit.

I used to be super into CrossFit. And I was a runner, that lasted about four years and then pain just got too intense, too much. I had to stop.

So I started seeking alternative ways to work out like yoga, stretching.

I jumped to hula-hooping, which is something I' m very passionate about.

Through going through that journey, I was very frustrated and I blame my disease.

This disease is preventing me from doing even the things I love to do.

Throughout the years, I' ve switched my mindset and now I' m more lean to, I am able to walk, I can hula-hoop, I can stretch. Even if it's only for five to 10 minutes a day, I can do something.

And I think it's important to hold on to that positivity when you can.

So I started going to therapy two years ago. And I could have used it throughout the whole time in my endometriosis journey but I didn' t think I needed it – and what I found out was that I definitely did.

For a good part of my journey, I felt alone and it was very detrimental to my mental health and I don't want anyone else to feel that way.

That led me to start ‘Hello Endo Chick’ - which, when it initially started, it was a creative outlet for me.

I started writing and blogging about my journey, and it was a way for me to process my trauma and my emotions.

It escalated into a support group community. Hey, guys, thanks for joining in today.

We can go around and we can just say our name and how our day' s going.

[support group participant on other end of Zoom meeting]: Okay. Sounds great. Hey, girl, it' s good to see you.

Kailey: It grew organically. Now it's a hub for information and for people who want to connect with others in the community.

[support group participant on other end of Zoom meeting]: Yeah, I was trying to make lemonade out of these dang lemons.

Kailey: I'd like other women to know that you don' t have to go through this alone. Even though this disease can feel very isolating, there' s people who are here to support you.

You have to keep fighting, you have to keep pushing, but you also have to allow yourself grace and compassion and acceptance.

Today, I feel like I'm managing my symptoms the best I can. It' s taken me about 10 years to figure it out.

I had a year of relief since my last surgery, and now I feel like my pain is just starting to come back.

But just from connecting this group of individuals together, it kind of brings about a sense of empowerment.

Even though there is not too much known about endometriosis, if we all can band together and learn from one another, I think that's how we can bring about change.