

FASD Video Series Transcript: Emily

Narrator: Lived Experiences with Fetal Alcohol Spectrum Disorders.
Emily.

Emily: My name is Emily Hargrove, and I was diagnosed with fetal alcohol syndrome at one year of age, but it's just a small part of who I am. It's not my entire essence. It does affect every area of my life. But like any diagnosis, we are so much more than just that.

Before I was adopted, I had to stay a week in the hospital just to detox from all the drugs and the alcohol. And my life-giving mother wasn't allowed to keep any of her children. So, in that sense, we were fortunate to have that history, that known history of prenatal exposure, exposure to alcohol. And so, they finally took me to a specialist and she said, "Oh, it's fetal alcohol syndrome, but there's nothing you can do about it." And, that's all they were told. And then she said, "She has growth hormone deficiency. We can give her some shots." You know, all of these things, and that's really all that we can do for you. And then it's kind of sent me along the way.

There's no plan, no plan of action, no resources, nothing. And that was in rural southern Illinois at the time. And unfortunately, 30 some odd years later, it's still the same. There are no resources in rural Southern Illinois for FASD. When I was in high school, I had a lot of heart conditions. And so, we went to go see a couple of cardiologists wondering what's going on here? And I told them, every one of them, I said, "I have fetal alcohol syndrome." Every one of them looked at me and said, "That has nothing to do with your heart", but it does. We know that it does. We know that of course, it doesn't just affect the brain systems. It can affect other organs, organ systems as well.

Because my life-giving mother drank every day, I pretty much have something going on with every organ system and with the central nervous system, with the prefrontal cortex, concentration is a big one. I can forget entire days. I can forget people I've known my entire life. It can affect, are you remembering to take your medications? Are you remembering to go to the doctor? Are you remembering to brush your teeth? Are you remembering to eat? I have chronic migraines. I have two heart conditions. I have scoliosis. I have cysts on my kidneys. My joints pop in and out of place. I had a cancer diagnosis. I have a hearing deficiency. So, what is going on? Is there an epigenetic component? Are we aging much faster? We don't exactly know. We're asking researchers to further dig into this and further look into this. But again, if we understand that all of the organ systems might be being affected, that we are aging at a different rate, we can again look at that person in a more holistic approach. This isn't just a brain-based childhood diagnosis. This is a lifelong whole-body diagnosis. And just because I'm an adult doesn't mean the FASD just went away or doesn't affect me anymore. In fact, it could be compounding because of the physical problems. And that's what we need to look at.

I don't feel pain in the same way. I have extremely high pain tolerance. And so, if I were to go in and say "I'm having some sort of issue", which I was, and I was having

pain, they would chalk it up to some something that wasn't that big of a deal because I wasn't displaying the pain in the same way someone else would. And so again, if they were to understand that I don't feel pain in the same way they could have helped me look into this and I could have got diagnoses much earlier than what I did.

FASD is not a one size fits all healthcare approach. This affects everyone differently. This is why it's a spectrum, right? With any other spectrum diagnosis, with any diagnosis, there's so many people that need to understand they're not just an FASD, they're not just that negative prognosis that so often comes with it. They're not just the health struggles.

Yeah, okay, we might be running the race with a few extra weights in our backpack, but that makes us strong, right? So, as I share my story, as I research FASD, I am hoping that others are also finding their strength in this, that others are understanding they are not alone. You have challenges. Your voice needs to be heard, but you also have strengths, and we can all build upon those.

Narrator: For more information, visit www.cdc.gov/fasd.