FASD Video Series Transcript: Support and Care

Narrator: Stories and Recommendations on FASD Support and Care.

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person who is exposed to alcohol before birth. FASDs can have lifelong effects, including problems with behavior and learning, as well as physical problems.

It is estimated that up to 1 in 20 U.S. school-aged children may have FASDs.

Despite the prevalence of FASDs, many individuals and families struggle to obtain diagnoses and support from the healthcare community.

This video shares the real-life experiences and recommendations of individuals with FASDs and their families. These are the things they most want healthcare providers to know.

Annette: All practitioners need to know about FASD. We need desperately need better training in the medical schools rounds. We need to get existing doctors educated on FASD. It, it really just needs to be part of their practice to, to be, to be asking the questions.

Narrator: FASD Comorbidities, Signs, and Symptoms.

Emily: 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.” I'm like, 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 or 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.

Laura: So, there are a lot of comorbidities. Over 420 comorbidities with someone with an FASD. And they could, I presume, experience those over a lifetime, right? So again, we need to look at the needs for a child, a teen, and an adult. And for Sean specifically, you know, we're looking at, you know, cardiology, right? He has a heart murmur, he has orthopedic issues. Some of these things that we did not realize with this orthopedic until again, he was in his mid-teens. We took him to a physician. They did X-rays and saw that indeed his ankles and feet were deformed from birth. It was too late to do anything at this point. So now he wears ortho, orthos. So, looking at those secondary conditions, and I think that's important. And again, you go in and you just, if he went in to a physician and said, “Hey, I think I've got a heart issue, or think, think I have a ortho.” They need to look at that bigger picture.

Annette: So, for example, my old, my younger son has already had back surgery. And when the doc, he had a bulging disc. And when the doctor, the surgeon got in there, he could see that the, the sheath that's supposed to protect was very depleted. It was very thin. And I'm convinced that was due to alcohol exposure. Check on the sleep hygiene, make sure they're getting a good night's sleep. It may seem like they're sleeping through the night, but you don't know how often they're waking up because their melatonin has been depleted. Their circadian rhythm has been disrupted. They go to bed and their mind just races. A lot of them turn to cannabis because cannabis is one thing that will kind of slow them down. So, they need sleep hygiene. They need help with anxiety. They all live with high rates of anxiety. Teeth is an issue, sensory is an issue. Gut has been depleted. So, the nutritional aspects also have to be addressed.

Emily: 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.

Rachel: High pain threshold, there's some benefits to that. But there's also, she broke her arm and didn't cry much when they called me. They said, “We don't think she broke her arm because she's not crying much.” I, I said, “Is she whimpering? Is she crying a little?” They said, “Yeah, she's whimpering.” I said, “It's broken.”

Narrator: Partnering with Individuals and Families.

Jen: Today, we have a primary care provider that we like. His med management psychiatrist is phenomenal. She has listened to me from day one. She has been on board with learning and exploring together. I think that what she does that really makes me feel supported is I feel like a part of the team. I feel like I don't have to have the medical degree that I can lean in on that interdependence from her, but that at the same time we can partner. We are working together truly to move forward in his best interest.

Rachel: He's very relational and fully respects Patima as the expert and partners with us. So, there's times when he will let me know, but he always gets her consent to have the conversation and really sees, I think, sees us as a team where it's Patima, mom, and doctor.

Patima: It's very caring, very like, we care about you. We care about how you're doing type of vibe in the office.

Julie: Our doctor, you know, she really supported me and she supported our daughter. She took the extra time, you know, to do that. She read the records, she got the school records, you know, she took the extra time to learn about how Tessa's prenatal exposures actually affected her specifically as well as her history of trauma and, you know, the abuse and all of that. She helped Tessa compose a letter that Tessa would give every fall to all of her teachers that talked about, this is how I learn best. This is the way I don't learn. But the pediatrician is the one that helped her do that. And that's where the doctors can help.

Narrator: Listening to Individuals and Families.

Jen: Don't dismiss the parents. When we come, we truly are our children's expert. We may not be the medical expert, we may not know all of the things, but we can tell you as caregivers when there is something not quite right, help us know what direction to go. Or even be okay with saying, I'm not sure, let's do some research.

Patima: Believe the parents, they're with the child almost all the time. They see things that you don't, you know, and if they have this suggestion, look into it. Don't dismiss it. Ask them what is wrong? Ask them, do you wanna talk about it? Understand that you are part of the solution for said child or teenager or adult.

Debbie: They need to learn more and, and listen to the parents that are the experts if they don't know something. And then work together, you know, to create a plan that, that will actually benefit individuals with an FASD. That's what we parents need. You know, parents like myself that have individuals with an FASD are the experts on our children. We see them every day. We parent them. We are going through all of these things with them. So, you know, doctors really need to hear us and, you know, believe us when we say this is what's going on with our child, it's not a behavioral, it's a symptom of their brain. And we need to be listened to so we can get those diagnosis and the supports we need.

Jen: I think that it would be really helpful for providers to dig a little bit deeper in their question asking. When we have information like substance exposure, you know, not being afraid to ask the hard questions, whether it be that you're talking to a biological family or an adoptive family, shouldn't matter. And then when we ask and we get a little bit of information, dig deeper, ask that next level question to get to not just was alcohol drank during the pregnancy of no, but what was drinking like before mom knew she was pregnant, half of pregnancies are unplanned. There are lots of moms with surprises.

Narrator: Accommodations in Healthcare Settings.

Debbie: An environment that's tranquil and soothing is very important to an individual with an FASD. You know, the, if it's, if it's loud and red and a lot of noise going on and bright lights, they're not gonna be calm and regulated when they go into that appointment most likely. And they're not gonna, you know, be able to communicate or really hear what, what the doctor is telling them. And, you know, make it inviting for them and, and comfortable, you know, because a lot of them do have sensory processing issues and, and it's not an environment that they feel safe in a lot of times because, you know, they're not feeling well.

Patima: Be more open on what they might need. More accommodating. Like if the lights are too bright, can you turn 'em down? Is it too loud? Can I wear these. Fidget spaces or just like fidget toys, not just for kids, but for adults who either get anxious at the, you know, doctors or, you know, whatever that need to decompress or need to have something in their hand and just normalize it their needs.

Rebecca: So, those of us with an FASD when they go into the doctor's office to have like weighted blankets or like fidget toys because it calms our nervous system. And that could make for a much more pleasant doctor experience on all accounts for the doctor and the person being seen.

Emily: I think going to the healthcare professional or just medical office in general is stressful for anyone. I think it starts when you first go into the office, not just when you're sitting down. I think can, can be a lot for a lot of people to take in, but then particularly for those who have maybe the social anxiety disorder that's associated with an FASD or the memory problems that's associated with an FASD. So, when they're first going to the desk, understanding that they might be a little bit slower to process what's being asked of them. If they take their time, that's okay. Let them take their time.

Rebecca: One thing that I struggle with is keeping appointments. I feel like the administrative assistants behind the desk at the doctor's offices, the doctors know my story. Those assistants don't. So, they, if I forget appointments, they're just thinking, oh my gosh, she's an airhead. So maybe write it on a card for them. Give them visuals to take home with them. I think like giving appointment cards, not every office does. I think those are great for visuals, but now they have the portal. So, that's a great idea, too. Not every office has a portal that you can log into and see everything that happened that day with your visit, and you can go back and revisit it and you could Google things if you don't understand them.

Rachel: Not seeing that as something extraordinary that it's just part of what a practice does that we have these accommodations for who might need them. It's like accessibility of any form. I think a lot of practitioners might find that accommodations that are beneficial to somebody with FASD might in fact benefit other patients as well.

Narrator: Communicating with Individuals with FASDs.

Emily: And then when you're sitting down with a medical professional, I want them to really take seriously when I say I have fetal alcohol syndrome, instead of giving me the blank stare and going, what does that have to do with anything?

Rebecca: I think that doctors, like even educators, doctors, providers, if they wanna learn about FASD, go to the source. Even if they are little, even if they are young, these kids have stories and they will tell you very black and white what works for them, what doesn't, what their life is like. You can ask the kids' parents too, but to get the real story about our feelings and what works and doesn't work for us, go straight to the source.

Debbie: Well, if a doctor hasn't spent a lot of time or doesn't really know a person with an FASD, they need to have patience. They need to slow down. They need to listen. What they need from doctors is to understand, you know, that they're developmentally a certain stage, not their chronological age. And I think that that's something that doctors and, and, providers in general really need to embrace and, speak to them in a respectful way, appropriate to what their developmental age is. They have to understand that, you know, their auditory processing is probably gonna be a little delayed.

Sean Patrick: My doctor, Dr. G, he was probably one of the first ones to actually listen and understand and actually learn to read a little about FASD, which actually helped a lot. He always slows down talking. He always gives me time to talk and then he thoroughly explains what I need to do.

Annette: If you're speaking to someone who has been prenatally exposed, you need to slow down 'cause they're gonna hear every 10th word. If they have poor working memory, most of the individuals have poor working memory and slow processing speed. They're not gonna catch all the instructions. So, I, it's always better to have somebody else along to hear what's been said, and maybe even be the note taker.

Sean Patrick: For some people talking like this can be like yelling and sometimes we interpret it to that as yelling. And sometimes we'll get like, why are you yelling at me? Kind of thing. Because we have sensitive ears or like we have sensitive to touch. I mean a little bump in the arm can feel like a punch.

Laura: Oftentimes I will do a lot of masking and I think Sean will as well. And that's basically covering up or making sure the, that person that we're speaking to, we're engaging with them appropriately. We may not be understanding a word that they're saying, but what we're doing is that polite socially correct. Uh-huh, I get it. Yeah, that's interesting.

Emily: So, a lot of people with FASD, we go into the office and we can present well, we can speak well. And so, so often they think, oh, there's no issues here, there's no struggles here. I don't really need to look into this, I don't need to, because they immediately think that this is just a low IQ thing. But that's so not true. There's so many individuals along the spectrum that are average, above average IQs. But that doesn't mean we don't have struggles or issues or concerns that need to be looked at. And so, I just wanted to add that piece so that they know that just because someone can communicate well doesn't mean there isn't other issues they need to look at.

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