Alcohol and Pregnancy: The More You Know

Season 2 Episode 2:
Identifying Prenatal Alcohol Exposure
Transcript

Like I would have to retie his shoes several times to get the bow just right. It was, you know, one kind of clear example early on, that you had to do things his way.
[Music playing]

Daniel Alford, MD: Welcome back to Boston Medical Center's podcast *Alcohol and Pregnancy, the More You Know*, Season 2. I'm your host Dr. Daniel Alford.

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In this second episode we'll discuss prenatal alcohol exposure screening in pediatric clinics. We'll welcome Dr. Vincent Smith, who is Division Chief of Newborn Medicine at Boston Medical Center and Professor of Pediatrics at Boston University. He also serves as the Medical Director for the American Academy of Pediatrics FASD Program. We'll hear more from Sue who is the mother of a child with an FASD. And we'll also hear a demonstration of a pediatrician screening for prenatal alcohol exposure and making a referral to a specialist to be assessed.

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Dr. Smith thanks so much for being here today.

Vincent C. Smith, MD:
Thank you for having me, it's my pleasure.

Daniel Alford, MD:
Can we just start with a broad question? Can you talk about the importance of screening for prenatal alcohol exposure?

Vincent C. Smith, MD:
So first let's back up to like who it is that we're screening because it kind of varies maybe slightly depending on who you're talking about. So if we're talking in a primary care practice as part of routine care doing universal screening, which is what we actually recommend, then it's all comers and it's people who may not necessarily be having any issues either they're pregnant and they're meeting pediatricians, or their first well child check visit, or they're new to your practice and you're just kind of getting to know what their history is.

And then you're going to ask them the standard three questions 1) How far along were you when you found out you were pregnant. 2) Before you knew you were pregnant how much alcohol did you drink? And a lot of people will specify like beer, wine, hard seltzers and those types of things just to be really clear about what it is that they're talking about. 3) And then after you found out you were pregnant how much alcohol did you drink.

In doing that it kind of gives you an idea of whether or not there was prenatal exposure because you could assume that the pre-pregnancy pattern of drinking continued until the person found out they were pregnant. Then hopefully they made a change after discovering that they were pregnant, and that's also really a great teachable moment to say you know great job in understanding that you were pregnant or learning that you were pregnant and making a change to make the healthiest option for your baby.

But there's a second part to that that comes in if you have a pediatrician who is having a child who is having some behavioral challenges, because that's another time in which case then you're probably going want to do the screening if you don't already have it. And the reason why you want to do that is because a lot of times the behavior challenges that you're seeing could be related to prenatal alcohol exposure. And if you don't ask those questions from that history they'll never even pop up into your differential.

Daniel Alford, MD:
How do you communicate this information from obstetrics or family medicine to the childcare provider so that this information gets transmitted in a way that can help the child?

Vincent C. Smith, MD:
So I will tell you in a lot of instances that's not done very well. Unfortunately, a lot of times the obstetrician or the family medicine individuals have worked with the birthing individual and had this information and they have it available, but it doesn't get passed onto the team that's providing care for the child in the hospital, or the team that's providing ongoing care for the child after discharge.

What I always encourage people to do is to have a consistent way that they document this information so then people get accustomed to this is where I look for this information and this is how I write down this information. And it makes it much more reliably to be present where people are looking for it.

Daniel Alford, MD:
If you do universal screening as a pediatrician and you identify a child who did have prenatal alcohol exposure but there are no concerning behaviors, development seems completely on track, how do you have that conversation with the parent?

Vincent C. Smith, MD:
There's some definite benefits even if the child isn't having a problem. You explain to the family what some potential challenges that could happen based on prenatal exposure and explain that they change kind of over time. So a lot of times the behavioral issues they're talking about you may not see in the very beginning and they may develop over time. Sometimes there's subtle learning disabilities like the child may not be great at doing math, but until you get the point where you're actually doing math it may not come up.

So sometimes it's just saying okay once we know about this exposure then we know that there are things that we need to watch for as the child grows and develops. The other piece of this is understanding that you've had one alcohol exposed pregnancy can maybe prevent you from having another alcohol exposed pregnancy. And so there's that kind of teachable moment that kind of comes in with this as well.

Daniel Alford, MD:
Okay, now we're going to hear from Sue who has a child with an FASD. You may remember her from episode one. Here are some of the subtle behaviors that she noticed when her child was young long before he was diagnosed.

Sue:
Like I would have to retie his shoes several times to get the bow just right. It was, you know, one kind of clear example early on, but you had to do things his way. So it seemed maybe it was more like oppositionality, he was very--things had to be just so.

Daniel Alford, MD:
And there were behaviors that were not so subtle and frankly worrisome as he got older.

Sue:
People tended to love him because he's very, very social and fun, and outgoing. He basically quit school in ninth grade due to his use, but he had a very strong peer group. One example he has such high risk behaviors which have been kind of terrifying to myself and his father. An example is you know he's at a Friday night party in the neighborhood and he decides to jump through the fire to liven up the party, and he had a horrible burn on the back of his leg. That's kind of an example of his high risk behavior that was constantly--like he's been chased by cops and bit by dogs, but no his friends loved him because he was always, there was always action when he was around. I would say it was more the rowdy boy crowd that he hung out with.

Daniel Alford, MD:
Okay Dr. Smith so now you have a child who is having behavioral problems and who had a prenatal alcohol exposure, and you want to assess them for an FASD, what kind of specialist would you send them to?

Vincent C. Smith, MD:
First and foremost it's important to remember some of the behavioral challenges that you can see associated with prenatal alcohol exposure are not necessarily unique to alcohol. And so you have to figure out is this an FASD, is this prenatal alcohol exposure the reason why we're seeing this, or is this something else?

And so a couple of things like if you're seeing their physical features that are present there are a set of characteristic facial features that can be associated with fetal alcohol syndrome specifically which is one category of FASDs, then that's kind of pathognomonic. So if you have all of those features then you have it, but sometimes you can have more kind of subtle findings that could be associated with prenatal alcohol exposure but aren't pathognomonic for prenatal alcohol exposure meaning that if you see this equals this. In which case then it's important to bring in maybe a geneticist or a dysmorphologist to make sure that it's not some other type of syndrome that's masquerading as a fetal alcohol spectrum disorder, and so you look for that.

Then because the behavioral challenges can be a little bit more subtle in distinguishing the different types of attention deficit or the subtle differences in the way that the behavior challenges are manifesting it's helpful to have either a neuropsychologist or a developmental behavioral pediatrician to be able to do formal testing because then they can look at these different domains of adaptive living, and neurocognition. So there are different categories of behavioral challenges that they can be looking for and testing for specifically. But if they don't know that there's a concern about prenatal alcohol exposure, they may not do those testing things, so when you're making the referral it's important that you say that you're worried about prenatal alcohol exposure and considering an FASD in your differential and they would look for those things.

So I said a geneticist/dysmorphologist, a developmental pediatrician, a neuropsychologist and I mean the thing I should have led with, which I didn't because they're not that common, is an FASD center of excellence or FASD expert because in those places they can do one stop shopping, they can do most of the testing themselves [Music playing] and they can also help with the treatment and the management. The problem is there are not very many of those and they're very regionally specific so they may not be available.

[Music playing]

Daniel Alford, MD:
After years without a definitive diagnosis and multiple assessments Sue's son was diagnosed with an FASD and it was a long and winding road to get that diagnosis.

Sue:
Well, you know, there was a long path from the time he was three and kind of started having issues that were concerning to me mostly around his being very stubborn and very--he kind of had sensory issues were kind of the first things that showed up. But when my son kept having school challenges, behavioral challenges, his characteristics that were most concerning were the oppositionality and the social anxiety.

He didn't get diagnosed until he was 16 and my son got involved with juvenile court. He had a county social worker who is supposed to be helping us, and I told her that because I was aware that I had used some alcohol during pregnancy that I thought he should maybe be assessed for an FASD. I was the one who brought it up to this mental health worker who was supposed to be supportive, and she said oh that can't be, she said I want you to take him in for an autism assessment, I think he has autism. So then I did and of course he came out as not having autism.

Anyway when he was 16, he got an assessment and one of the--his barriers was his IQ was very high and that is, I think, one of the barriers is when kids are intelligent and very articulate, professionals don't want to believe it can possibly be an FASD, for some reason. By the time he was 14 he had started his long history of substance use disorder.

Daniel Alford, MD:
The people in Sue's life, including her healthcare providers, had lots of different reactions to this diagnosis.

Sue:
I didn't tell a lot of people and people I did tell would pooh-pooh it, that was very odd including my two sisters. They didn't want me to blame myself, it seemed like that was people's concern, oh no, no, no, you know. And it was like I wasn't having issues with blaming myself, I can deal with the truth, I became involved with the National Birth Mothers Network and that was empowering.

So for me it made a difference for my son I don't know that it made any difference. He didn't blame me, you know we talked about it, you know I said I wish this had never happened maybe your life would be a lot different if it hadn't. It's like overall there isn't a lot of kid blaming mom, kind of, in the field it's like people are just that's what I got from the birth mother network that birth moms are strong, and their kids don't hate them. So I wasn't worried about that and that didn't happen. Two things that happened to me at one point my son was taken to detox and being admitted to a local hospital adolescent, in my city, program.

I was doing the parent interview and he had already been diagnosed and so the assessor talked to me, and I was giving history and she said is there anything else you want to tell me. I said yes, my son has an FASD and she said "oh", end of conversation, like she didn't probe anymore, she didn't say are you his birth mother, she didn't say anything, like it was just this cold response. When women are willing to disclose this history when they're trying to get help for their kids and providers are really uncomfortable.

Then at the same hospital probably five years later he was in a psychiatric emergency room in the midst of a drug episode and again she said, this was a different assessor, "Is there anything else I should know or anything else you would like to tell me?" And I said my son has an FASD and she said, "Oh, was he adopted?" That just like smacked me in the face because I wasn't ashamed, you know, I was just like that's how you respond to a woman who discloses that she used, that her son has this disorder. It

doesn't matter whether she's the adoptive mom or the bio mom or whatever, but the fact that she presumed then that no birth mother would ever mention that showed me where she was at.

Daniel Alford, MD:
So Dr. Smith, it sounds like providers are uncomfortable talking about fetal alcohol spectrum disorders. So I can imagine that when a provider wants to have a child assessed they feel uncomfortable talking to parents about the reason why.

Vincent C. Smith, MD:
What's preferable is for the person who know the family the best who is usually the referring provider, to sit down with them and say look these are the things that I'm concerned about, I don't know yet if this is what it is, but this is what I'm worried about. And I want you to go to a place that could help us to understand what kinds of services, what kinds of treatments are we going to need to do to make the best outcome that we can for both your child and your family.

Daniel Alford, MD:
Let's say the child is diagnosed with an FASD, at what point do you tell them, and is it helpful to tell the child?

Vincent C. Smith, MD:
I'm of the opinion that it's actually pretty helpful for the child to understand what they have or potentially what they have. So once you know that that's what it is usually, we encourage you to tell the child and you're going to have to tell them using language that's developmentally appropriate for their level wherever that is, and you're going to have to tell them again and again and again as they get older and their understanding kind of grows.

Because you know when you're 5 like those words aren't going to mean the same thing to you as when you're 15 and if you're trying to struggle to understand why some tasks and why some things are much harder for you than they are for some other people it's helpful for them to understand that they have a brain based disorder that causes them to have challenges. And it's not because they're dumb, or it's not because they have no ability, those are not the reasons, it's like their brain has been changed in a way that sometimes will make things harder and believe it or not it sometimes makes the kids feel kind of better because they understand that it's not their fault. And people recognize that they're doing the best they can and so it's helpful.

Daniel Alford, MD:
So I want to ask you one more question because I know you've talked to me and others about how individuals with an FASD can run into legal problems. Can you explain how common it is and why it happens?

Vincent C. Smith, MD:
Hopefully, the education system is more common than the legal system, just saying. So I think one of the challenges, and this is going to be true for both the legal system and the education system, is that they don't necessarily understand fetal alcohol spectrum disorders, what that means for the individual and what that's going to mean for how that individual reacts and interacts with them. And so let's talk about the affected individual, the person who has a fetal alcohol spectrum disorder.

A lot of times because it's a brain based disorder a lot of times that individual can be much more gullible, can be much more suggestive, or open to suggestions. And so that makes them a lot of times a victim, because people will sense, oh I can get this person to do whatever I want or they can convince this person, so people may interact more with the legal system because you know they get preyed upon.

So the other piece of that is sometimes they have a hard time understanding abstract concepts and believe it or not ownership is an abstract concept. If there happens to be a cellphone laying on a table and no-one's at the table a person with FASD may think oh that phone is just available because it's just laying there.

The other thing is sometimes these individuals have a challenge with their memory and so sometimes they can confabulate things to kind of fill in the gaps. You ask them well did you just confabulate that they're not going to be like no, they're like I'm telling you what happened. But it's just like that's actually not what happened at all so those things all combined can mean that there's an increase in involvement with the legal system.

So now we have to talk about the education system because as I said that's way more important. Oftentimes in the education system people may not be aware of what fetal alcohol spectrum disorders are and the way that's going to affect how you have to teach the individual and the memory challenges, and how written things may not work as well as having visual graphics at the point of interface.

And so it sometimes is really helpful to meet with the teachers or the classroom where the individual is going to be and to explain the nature of the disorder and the brain based nature of the disorder, and the ways that education kind of works and functions for that individual [Music playing] and then like to you know have an education plan in

place to be able to maximize the outcomes for that particular individual in that particular classroom kind of setting.

Daniel Alford, MD:
You'll now hear an example of a conversation that a pediatric clinician has with a patient whose three-year-old child Noah is being seen after being asked to leave childcare due to behavioral issues. You will hear how the clinician screens for prenatal alcohol exposure and brings up the potential for the diagnosis of FASD.

DOCTOR: Hi Jen, I asked our medical assistant to weigh Noah and do a vision and hearing screen so we could talk privately for a minute. Is that okay?

JEN: Yeah, sure.

DOCTOR: I see from the triage note that Noah has been having a rough time at childcare. Can you tell me more about that?

JEN: Yeah, he got thrown out again and this time after only two weeks, it's hard enough he still isn't potty trained but now I have to figure out who is going to watch him while I work until I find another place.

DOCTOR: I'm sorry to hear that, I'm sure the stress only makes it all harder. Did they tell you the reason behind his removal?

JEN: Well they said they just didn't have enough staff to control him. He's fine when I drop him off, he runs right in and doesn't even look back. But I guess he doesn't like to share, and he can't sit still at circle time, and he takes all the other kids' snacks, he even hit the teacher on the last day when she wouldn't let him jump on the trampoline. Pretty much the same story as the last childcare, but that time at least he lasted three months.

DOCTOR: Have you had similar problems at home?

JEN: Yes, you know, sleep is a big issue too, if he doesn't nap at childcare which he usually won't that's part of the problem, I let him watch TV and he usually falls asleep by 9 or 10 at night.

DOCTOR: So what is his typical day like?

JEN: Well like I said he goes to bed around 10, I have to wake him up at 5:30 and he's usually pretty grumpy. Then I pick him up from school after work, we go to the park for a

while, but he makes me nervous because he's always running around from section to section and climbing on everything. Last week he even pushed another kid off a swing, we usually eat dinner all together while watching TV and once he's asleep I carry him to his bed.

DOCTOR: So when he wants something like a turn on the swing or time on the trampoline how does he usually let you know?

JEN: Well usually he'll point and sometimes name it like "swing" or "my turn" so he does put, you know, two words together.

DOCTOR: Does he run pretty well at the park?

JEN: Yes, too well, that's part of the problem.

DOCTOR: It sounds like his language may be delayed and that he's also struggling to interact with other kids. Have you been worried about his development in general?

JEN: Maybe a little, I know he should be talking more, but my mom said I didn't talk until was five and then I wouldn't shut up.

DOCTOR: Yes, sometimes problems like language delays or self-regulation difficulties can run in families. I'd like you to see a specialist doctor who can take a closer look at his development, behavior usually has meaning and so he may be trying to tell us that there are things he just can't do right now without extra help from us. Sometimes these kind of development challenges can be associated with things that happened while his brain was developing. You might remember when we first met, I asked about your pregnancy, to make sure that I have the details right I'd like to ask again, is that okay?

JEN: Sure.

DOCTOR: Before you knew you were pregnant how much alcohol, beer, wine, liquor did you drink?

JEN: We'll I've always had a glass or two of wine with dinner at night to unwind.

DOCTOR: After you found out you were pregnant how much alcohol did you drink?

JEN: As the pregnancy went on and stress got worse at work, I may have increased a little.

DOCTOR: How many times did you have four or more drinks in a day?

JEN: I think maybe just once at my sister's wedding.

DOCTOR: Were there any prescription or non-prescription drugs that you took while pregnant? Can you tell me the names of the drugs and how often you took them?

JEN: No, I didn't take any drugs or prescriptions.

DOCTOR: Has there been a time when you smoked cigarettes?

JEN: No, never.

DOCTOR: Is there anything else that you might want to tell me about your pregnancy with Noah?

JEN: Nothing that I can think of.

DOCTOR: Well thank you for sharing about your alcohol use. The reason I ask is to better understand and support you and Noah. Now you might not know this but there is no known safe amount of alcohol exposure during pregnancy. As I said I'd like to have you see a developmental doctor so we can better understand the challenges Noah's having. Most of the time we don't know what causes a delay in a child, sometimes it does run in families and sometimes it has to do with substances the child was exposed to in utero while their brain was developing, it's called fetal alcohol spectrum disorder and that's something my colleague can talk with you more about okay?

JEN: Wait, so are you saying that my drinking is why he's behaving like this?

DOCTOR: Look it's possible but I don't want you to worry or blame yourself. That's why we want to send him to a specialist to better understand what's going on and depending on what that specialist thinks there will be specific ways we can help Noah. And I want you to know that I'll be supporting you every step of the way.

JEN: Okay, thank you, I appreciate that. His behavior has been really stressful and I'm ready to get some help.

Daniel Alford, MD:
Thank you for listening to this episode of Boston Medical Center's podcast *Alcohol in Pregnancy, the More You Know*, Season 2. I want to thank Dr. Smith for sharing his expertise and once again Sue for her willingness to share her and her son's very personal experiences.

In the next episode we'll hear from Dr. Marilyn Augustyn, the Division Director of Developmental Pediatrics at Boston Medical Center, and Professor of Pediatrics at Boston University. From Kendra Gludt the Director of National Programs at Proof Alliance, and from Finn an adolescent living with an FASD. This podcast was created with funding from the CDC, the content does not necessarily reflect their views and opinions. For more information on FASD visit CDC.gov/FASD.

I'm Dan Alford, thanks for listening.

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