Alcohol and Pregnancy: The More You Know

Season 2 Episode 3:
Supporting Individuals with Fetal Alcohol Spectrum Disorders
Transcript

Let them enjoy their childhoods not trying to punish the FASD out of them.
[Music playing]

Try to set their lives up for success rather than giving constant punishment. It's easier to change an environment rather than like change the personality of the child.

[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. Dan Alford.

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In this final episode we'll talk about what happens inside the pediatric specialist appointment with Dr. Marilyn Augustyn who is the Division Director of Developmental Pediatrics at Boston Medical Center, and Professor of Pediatrics at Boston University. We'll also hear from Finn, an adolescent living with an FASD and Kendra Gludt the Director of National Programs at Proof Alliance. She'll talk to us about building community and ways to combat the stigma and shame that can accompany the diagnosis.

First let talk to Dr. Marilyn Augustyn, a developmental pediatrician at Boston Medical Center about making the diagnosis of a fetal alcohol spectrum disorder, and addressing questions about its affects across the lifespan. Dr. Augustyn thanks so much for joining us.

Marilyn Augustyn, MD:
My pleasure.

Daniel Alford, MD:
We just finished talking about how to get a prenatal alcohol exposure history so I'd like to ask you once I've gotten a prenatal alcohol exposure history and there are some neurobehavioral concerns what's next, what should the provider do?

Marilyn Augustyn, MD:
I think it really depends how significant the behavioral concerns are, so if the concern has another explanation like it seems like this is temperament so a child is really active or really oppositional or has tough temper tantrums then it could be temperament or it could be change or trauma. So if you have an explanation that seems to explain things pretty well then I would probably just file that in the back of my head knowing that there was a history of exposure and continue to follow. That's really the beauty of primary care in the medical home is you have the chance to hold these things in your sort of picture of the child and family and bring it back as it's relevant. But if you're, instead, seeing a behavior or a neurodevelopmental issue that's bigger than the explanation that you have right now, so you're thinking about a true Diagnostic Statistical Manual, the DSM, a true DSM5 diagnosis like ADHD, a learning disability, disruptive mood disorder, major depression, post-traumatic stress.

Then that history that you've got is going to become more important and now you're talking about a differential diagnosis that may include that exposure, and so in that case you would want to go down a different road perhaps and get more specific history. So I'm assuming the history that you talked about was just a general exposure history, but if you have a behavior or a physical exam that is raising your concerns that what I'm seeing may be best explained in part by alcohol exposure then I dive deeper into the history and see where that took me.

Daniel Alford, MD:
So let's say you know the generalist who is caring for this child wants to make a referral how important is it for them to say to the parents that the evaluation will include assessing for fetal alcohol spectrum disorders. I can imagine just using that phrase could be uncomfortable for some.

Marilyn Augustyn, MD:
Most definitely, and I think any pediatric primary care clinician has some words that they have a hard time getting out of their mouth. One of them might be fetal alcohol exposure, another one might be autism, another one might be depression. Those are all words where we really want to think about how they're going to land. So that's an important conversation to reflect yourself as a clinician, you know, am I avoiding the word suicide because it makes me uncomfortable or because it makes the parent uncomfortable. Am I not talking about prenatal exposures because I'm worried about only a starting relationship that's not very solid yet, but I do think it's incredibly important that the first time that the family hears this as a potential road that you're going down that you're thinking about fetal alcohol spectrum disorder, it really needs to come from the person who first thought it.

If you think you have a history and you're thinking that this could be a potential explanation for some of what you're seeing then you need to go down the path and they who thought of it first should be they who bring it up with the family because the consultant will have no relationship with the family. They'll be a complete stranger and be starting from scratch which is a good thing, but also can be a very loaded thing, and can really almost sabotage the evaluation if a family feels like they were somehow tricked into this, that's never a great for anybody to start the relationship or a primary care clinician to continue the relationship.

Daniel Alford, MD:
If a child is referred to a specialist for an assessment of an FASD I can imagine there's an overlap between other causes of neurobehavioral issues. And I'm just wondering what happens during that assessment and maybe you can enlighten us about the actual assessment for an FASD.

Marilyn Augustyn, MD:
Sure, so I'm a development behavioral pediatrician and what we do is assess children for developmental behavioral problems, but it really depends what exactly we do on a lot of things. Like what kind of evaluation have they had before, so if it's a school age child and they've had a thorough special education evaluation, I have a psychological from the school, then I might do a much briefer assessment. I would want to do my own assessment to look at their neurodevelopmental function which is really cognition, how they're thinking about the world, and achievement, what have they been able to learn in school so far. So pretty much I'm always going to be looking at those two things, cognition and achievement. And then really if that's part of what they're presenting with but really they're presenting with more behavioral problems then I'll do more of a behavioral assessment and again depending on the age of the child, if they're a toddler I

get to do what I love to do most, which is get on the floor and play with the toddler, and see what their play is like, see if they share with me, see what their eye contact is like, see how easily they get frustrated. So that would be a behavioral assessment in a toddler.

In a school age child it's often a conversation, I have lot of dollhouses in my doctor bag so I might pull out some figures, some dolls, some action figures and see where our play takes us, see what their language is like during play, does it have to turn into a battle, do we all start hitting each other with our dolls then I know a certain way about how they play. And then in a youth, an adolescent, older school age child it really is conversational, it's having a back and forth conversation, we call it dyadic conversation can the youth engage in back and forth conversation. Can we change the topic and not have them get distressed about talking about something different? Does the conversation always go back to the same topic, is this a conversation that seems appropriate for the child's developmental age? The formal part that's looking at the cognition and what they've been able to achieve, but the sort of informal and many times more important part trying to look at their behavior really involves spending time with them and figuring out how to get to know them.

Daniel Alford, MD:
So thinking specifically about the FASD component to a child's diagnosis I can imagine that the parents want to know what to expect, what's the prognosis, what's the natural history of an FASD diagnosis in a child, and I can imagine that there's a full spectrum, but I also can imagine that the family wants to know: please tell me what I need to expect. How do you address that?

Marilyn Augustyn, MD:
So I may have some general things that I'll talk about, usually things like a lot of this may be predicted by the comorbidity, I don't use that word with families, but I can tell you about what's likely to happen due to their intellectual disability. So for example if a youth has an IQ of 65 mild learning disability I can say most likely they'll end up functioning somewhere between an eighth and a tenth grade achievement level potentially but then when I start to talk about FASD and how that is going to interact with the other potential developmental challenges it becomes a lot murkier. And then I talk a lot about earlier supports and how important getting the youth support that's consistent can really make a big difference in the trajectory. To be brutally honest there's two things I never do, I never give real estate advice, vis a vis what school a child should go to, and I never try to predict the future because there are just too many what we might call confounding variables that are a part of life.

And so I tell families I don't know for certain my guess is that he may continue to have difficulty with impulsivity, she make continue to have difficulty with attention, they may continue to have irritability. I can tell you are things that we can continue to try, and I can tell you that I will be with you through that journey as long as you want me to be a part of your life.

Daniel Alford, MD:
So I know that FASD is a permanent disorder that is going to adversely affect the child and then the adolescent and the adult. Can you talk a little bit about that in terms of the lifespan and how FASD presents itself?

Marilyn Augustyn, MD:
I mean it is permanent, I do think that youths with fetal alcohol spectrum disorder are neurodiverse, I think their brains have developed differently, I think they respond to situations differently and will continue to do that. But I really go back to and I know it's a pretty simple statement but I really believe that kids do well if they can, youth do well if they can, adults do well if they can, and if we don't have the tools or the skills at a particular developmental level to do what we need to do next, then we're not going to be able to do it unless we get the right support. So just like when a child with fetal alcohol spectrum disorder in first grade may have a very hard time sitting still and may need a lot of occupational therapy support and fidget tools and breaks and be the one who gets to take the attendance slip to the office so they can run there every morning. And then when they're in high school they may be a youth who needs to be along a more--a track where they're able to do more things hands on, so they may not be perfectly suited for college prep and spending six hours a night on homework, but they may be perfectly suited and really enjoy and thrive in something where they can use their hands [Music playing] even something where the subjects that they're doing like engineering or accounting or math if they need something that's perhaps more concrete.

And similarly when it's time to get a job, choose an apartment, choose a life partner, there may be challenges that are unique to individuals with fetal alcohol spectrum disorder. I mean that's the beauty of development is really the beauty of being human beings, is that we have these challenges and they kind of keep recurring. The strategies that we used before usually work but you kind of have to tweak them a little, and that's how I see the lifespan approach for an individual with fetal alcohol spectrum disorder.

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Daniel Alford, MD:
Next we're going to hear from Finn, an adolescent with a fetal alcohol spectrum disorder about their experience living with the diagnosis. So when was the first time you heard that you had an FASD?

Finn:
I think I was 12 and we went into this clinic thing, and I got tested and the results came back. And I had never heard of that before because it's not something that you hear about that often.

Daniel Alford, MD:
So prior to getting diagnosed with it were you given other diagnoses, or it must have been hard not knowing exactly what was going on?

Finn:
My doctors originally diagnosed me with ADD or ADHD I'm not sure which one. But my mom and I agreed that that's not quite right, so she was like maybe there's something else going on, and so they referred me to a clinic that tests for FASD.

Daniel Alford, MD:
So how does having an FASD impact your life like in school, relationships, you know just social stuff getting along with other people?

Finn:
Yes so schoolwork is definitely something I struggle with and mental health problems. I also get supervised a lot more than other people my age, and that's something that I really butt heads with my parents about. But my parents are doing their best to help me make sure that I have safe plans for doing something that I want, and even though right now I feel like I don't have enough freedom I know that they're trying their best to help me reach my dreams but also keep me safe. So definitely having a job coach and stuff like that has really been helpful.

Daniel Alford, MD:
What advice would you like to tell parents or caregivers of younger children who are diagnosed with an FASD that can offer them some hope?

Finn:
Learn as much as you can about FASD as soon as you get the diagnosis because the older the person with FASD gets the harder things become if you're less educated about the disability. Also just let them enjoy their childhoods, not trying to punish the FASD out

of them but try to set their lives up for success rather than giving constant punishment. It's easier to change an environment rather than like change the personality of the child.

Daniel Alford, MD:
What about giving advice to people like me to healthcare providers, giving them some advice about how to talk to kids and parents about FASD?

Finn:
Learning the statistics and outcome of people with FASD and understanding how bad they are currently, but they don't have to be in the future if we do better on educating and spreading the word. And understanding that there are no services for adults with FASD and how like mind blowing and wrong that is and making sure that you learn all that you can about FASD and ask for a lot of training for all of your staff, because right now it's not really taught in any college classes for medical students. Please don't tell any patient that a little alcohol is okay during pregnancy because it really isn't.

Daniel Alford, MD:
Now I've seen a video of you speaking in the past and you state that having an FASD has made you a stronger person emotionally and mentally can you elaborate on that?

Finn:
So mentally I've gone through a lot of mental health problems including depression, anxiety, self-harm tendencies, and having a support system like Proof Alliance where they have youth action teams and stuff like that where I can meet other youth with FASD has been life changing for me, and my mental health, because before that I didn't have a community, I felt very singled out. But making friends with a diagnosis that I have is something that really helped me become healthy mentally and I think being taught about my FASD has made me stronger, especially when it comes to advocating for myself and having friends who genuinely understand what you go through rather than someone who doesn't have the diagnosis, who can be helpful it's just different being friends with someone with the same diagnosis because you understand each other on a different level if that makes sense.

Daniel Alford, MD:
So just finishing up here I mean what do you look forward to most in your future?

Finn:
So much, I'm so excited for college, I'm almost there, I'm really excited for work this summer, I know that's more short term but [Music playing] you know my job is something that I really enjoy, and just being able to go out there after I graduate college

and hopefully work in an aquarium or something like that, and just seeing where life takes me and just kind of going with the flow right now. But wherever life wants to take me I'm going.

[Music playing]

Daniel Alford, MD:
Let's talk to Kendra Gludt, Director of National Programs at Proof Alliance about supporting individuals with an FASD and ways to reduce shame and stigma around the diagnosis. So I want to start off by asking you about the Proof Alliance patient card and in particular it talks about the individuals having invisible disability. I wonder if you could explain that terminology: invisible disability.

Kendra Gludt, MPH:
Sure, so this is a card that an individual can have and use as a communication tool to help them safely and quickly disclose their disability when there's an interaction maybe with law enforcement or first responder and some of the things that are listed on the card are explaining that they may not understand abstract concepts like legal rights, or they may be persuaded to admit to acts that they did not fully commit or they may be unable to knowingly waive any constitutional rights including Miranda rights can be included in the interaction that's happening.

Daniel Alford, MD:
So you talked about how important it is to create a community. Can you tell us how we can help our patients and their families build that community that is supportive of individuals with an FASD?

Kendra Gludt, MPH:
Definitely, there are many ways that we can help these individuals connect with others that are going through the same things. So now there are opportunities virtually for them to find their communities, it could be online private groups that could be found on Facebook, in apps, in Zoom meetings, in podcasts. Many ways for them to find others virtually and then also in person there are support, playdates, family fun events, retreats, camps, a lot of in person opportunities for them to connect with others. So I would encourage you to know what is happening, you can look in your state or regionally. FASD United has a collection of state affiliates so you can locate your state affiliate and they will know what is happening in your area. FASD Collaborative also lists virtual support groups that can be accessed, and Proof Alliance also lists the support activities that we have available for these families so that they can build those communities and find their villages of support.

Daniel Alford, MD:
You mentioned different aspects of the community, but I know school plays a big role in a person's life and can you talk about how schools can be both helpful and actually not helpful for individuals with an FASD and their families.

Kendra Gludt, MPH:
Yes, so schools can be unhelpful in number of ways if they are first of all discounting that there is a disability that is happening. Perhaps instead they're believing these behaviors are purposeful and that's where we see sometimes you know those just terms like oh a troublemaker, a problem child, and not really understanding that there's a disability happening here. On the flip side of that what we see as very helpful in the school system is when they are open to learning about FASD as a disability and then making those appropriate accommodations.

Daniel Alford, MD:
I want to get back to the community and when we interviewed Finn the young adult with a fetal alcohol spectrum disorder they alluded to a group that they'd talk to once a week. And I believe that's through Proof Alliance. Can you give me some details about that?

Kendra Gludt, MPH:
Yes, so when it comes to creating these communities of support we really know that there's a need not just for families, parents and caregivers to connect with each other, but also for those individuals themselves to connect with each other, everything from you know when they're children meeting other children that may have some of the same struggles. Youth, young adults, adults, they all benefit from having this community of individuals that are also diagnosed with an FASD. And they've really just it's wonderful to see the connections and friendships that have come out of this and have been sustained for many years.

Daniel Alford, MD:
I kind of want to transition now to the whole issue around stigma and shame and what I'm thinking is that as opposed to some other disabilities where people openly advocate through you know pride parades or fundraisers that are initiated by families, I don't see that so much, I don't see that all actually with FASD and I'm wondering if shame and stigma plays a role in that.

Kendra Gludt, MPH:
There are many opportunities for people to bring awareness to FASD, it's not at the level that we see compared to other disabilities for example. But using September ninth, 9/9, as international FASD awareness day you'll see every year that grows more and

more in other countries and large institutions. I know a story of someone who recently biked across the country bringing awareness of FASD. So it's probably more grassroots than other levels of bringing attention to it and that's because of this challenge of overcoming the stigma and bringing it out of the shadows and really being able to say let's talk about this and let's learn about it together.

Daniel Alford, MD:
So in closing I wonder if you could shed some light on less stigmatizing language that we should be using.

Kendra Gludt, MPH:
Sure, there are simple ways that we can just consider the words that we're using and use words that talk about FASD without including the person that was drinking during pregnancy. So instead of saying that FASD was caused by the mother drinking during pregnancy we can simply say FASD is caused by prenatal alcohol exposure, so it's caused by exposure to a substance, it's not caused by a person. Another way we can talk about FASD is that instead of it being a child of a mother who drank during pregnancy rephrase that and say it's a child exposed to alcohol prenatally, so again we're just focusing on exposure and not the fact that someone drank during pregnancy. Also think about the word admitted we tend to use admitted a lot if we're [Music playing] talking about having that conversation of drinking during pregnancy. And so instead of admitted we like to use a word like disclosed because admitted really implies that that person is confessing to wrongdoing. So instead of the patient admitted to alcohol use during pregnancy you can say that the patient disclosed prenatal alcohol exposure.

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Daniel Alford, MD:
That's it for our podcast series *Alcohol and Pregnancy, the More You Know,* Season 2. Thanks to Dr. Yasuko Yamamura, Dr. Vincent Smith, Sue, Finn, Dr. Marilyn Augustyn, and Kendra Gludt. Thanks to Jacqueline German for her contributions. Production by Rococo Punch. Music entitled Brand New World was written and performed by Kai Engel.
This podcast was created by funding from the CDC, the content does not necessarily reflect their views and opinions. For more information on FASD visit CDC.gov/FASD. If at any point you want more information on receiving continuing medical education credits click on the link in the podcast description. I'm Dan Alford and thanks for listening.

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