MHPN Podcast

Transcript

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A Conversation About… Alcohol, Pregnancy and FASD

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Host (00:01):

Hi there. Welcome to Mental Health Professionals Network podcast series MHPN's aim is to promote and celebrate interdisciplinary collaborative mental health care.

Hester Wilson (00:18):

Welcome to MHPM Presents A conversation About. Today we are talking about FASD, fetal alcohol spectrum disorder. My name is Hester Wilson. I'm a GP and addiction specialist, and I'm the host of this MHPN Presents podcast. First of all, I'd like to acknowledge country, to acknowledge the traditional owners of the lands on which we live and work and pay my respects to elders past, present, and emerging, and any Aboriginal people who may be here with us today or listening in. I'm on Gadigal Country of the Eora Nation here in Sydney. I'd also like to recognise people with lived and living experience of drug and alcohol use and harms, and acknowledge their strength and resilience. And welcome any of you here today. In this conversation about FASD. I'm going to be joined by the wonderful Angelene Bruce and the extraordinary Vanessa Spiller. Hi Angelene. Hi

Angelene Bruce (01:18):

Hester. It's wonderful to be here. I'm on Wurundjeri land.

Hester Wilson (01:20):

Great. And Vanessa -

Vanessa Spiller (01:21):

Good morning Hester and Angelene, I'm coming to you from Southeast Queensland, which is the lands of the Turrbal and the Yuggera peoples.

Hester Wilson (01:30):

Welcome both. Angelene, I wanted to just get a little bit of a sense of you as to why FASD is important for you and why you're here today.

Angelene Bruce (01:39):

I'm here today and fetal alcohol spectrum disorders is dear to my heart because I have an almost 16-year-old biological son with fetal alcohol spectrum disorders. He's diagnosed and it's super important and close to my heart because fetal alcohol spectrum disorders, as we know, is caused by prenatal alcohol exposure. Being a biological mother pretty much means that the buck stops with me, and it can be a very challenging as a biological mother and because you feel what you feel as a biological mother, but there's also societal stigma as well. So my son is diagnosed with FASD. It's very important to me that we discuss it with courageous conversations all throughout the community in order to drop the stigma surrounding FASD in Australia.

Hester Wilson (02:30):

Thank you so much, Angelene. And look, just from the bottom of my heart, thank you so much for standing up and speaking about this. It's so important and hard as someone that says, I'm a biological mom, and the buck stops with me. So we are so privileged to have you with us today. Vanessa, tell us why are you here today? How is this important to you?

Vanessa Spiller (02:51):

Well, FASD like Angelene is something that's very important to me, and I guess I came into it in a slightly different way. I kind of live at the intersection of a number of different ways of working and supporting people with FASD. The first is I'm a clinical psychologist. So I first sort of came across FASD within my professional role, and it's something that I still do, supporting families who are impacted by FASD and individuals. I also am a carer, well, I'm a mum to a now nearly 25-year-old. So I had a little person who came into our care when he was two and a half, and he was very unusual because he was diagnosed with FAS, which was the diagnosis that came before FASD. So that was fetal alcohol syndrome, and he turns 25 in a week's time. So I've had a lifetime of raising this beautiful young man.

(03:44):

So I get to live it 24 hours a day, which has given me a great passion for the last bit of what brings me into FASD, which is knowing how challenging it is to raise a young person. There's lots of strengths and pros and cons of this, but there is some real challenges and there was an absolute lack of information out there about how to support these young people. So that takes me to my third role, which is a trainer and educator. So I do a lot of training of professionals, but also of parents and carers of people who have young people with FASD. And I've written a couple of books about this topic. So for me, my third passion is how do I support other people to support people with FASD so they can have the most successful lives possible.

Hester Wilson (04:30):

That's great, Vanessa. So Angelene and Vanessa, you're just perfect people to be talking about FASD. I should say for myself, I don't have anybody in my life that has FASD, but as a GP, I see lots of people in my community and I'm in a unique place to be able to have conversations with the people that I see, women of childbearing years around alcohol and around the risk of alcohol during pregnancy. And really for me, how can we change this? This is a serious disability that is preventable. And so really thinking about how we as health professionals or in our lives can have those conversations about alcohol and pregnancy and the risks so that we can really shift this trajectory. But the other thing for both of you, you've got two beautiful young people in your lives who have this issue and are beautiful human beings as well. So it's a lovely part of the narrative is around the beautiful people that you have in your lives who have this diagnosis and are now adults and getting on with their lives. So welcome, welcome, welcome. It's so brilliant. I wanted to come to you, Vanessa. First, just what is FASD? Tell us a little bit about what it actually is.

Vanessa Spiller (05:40):

So that should probably take me about three and a half hours Hester, but no, the very short answer. What is FASD in Australia? It's a diagnostic code. It's a diagnostic term that's used to describe people who have a couple of things. So under our Australian diagnostic guidelines, it's considered a neurodevelopmental condition, neuro meaning brain, developmental meaning this goes across the entire lifespan. It falls in that same class as, things like autism or ADHD. The thing that's a bit different about FASD though is that we have an understanding of why people have this neurodevelopmental difference. So essentially what they have is some brain and body injury that occurs due to prenatal alcohol exposure. So in order to get the diagnosis in Australia, you need two things, and then there's a little thing at the end. So the first thing is that we need confirmation of prenatal alcohol exposure, and that could be at any point in the 280 days of pregnancy.

(06:45):

The second thing is after a really comprehensive assessment, people are identified as having severe impairment in three out of 10 brain related domains. So these are things like attention, emotional regulation, the everyday skills of life memory. So it can be any three of these 10 domains. And then finally in Australia, you can get the diagnosis with or without what they call sentinel facial features. So originally when people were thinking about FASD or fetal alcohol syndrome, they were thinking about these three features that are very unique to people who have alcohol exposure. But what we know is that because those facial features only occur in a really small number of people, somewhere around 15%, you can have that diagnosis with the facial features or without. And you can still have a really high level of impairment even if you don't have the facial features. Because here's my first fun fact for today. The facial features actually appear only within a very specific window. So if you have 280 days of pregnancy and your facial features are developing between day, I think it's around somewhere around day 17 to 21, if there's not alcoholic exposure during that window, you don't get the facial features. So that's sort of the first of the myth. That's a very long-winded answer to what is FASD.

Hester Wilson (08:12):

And Vanessa, how common is it in Australia?

Vanessa Spiller (08:15):

Now we don't have an Australia-wide population study, so we have to go and look at the prevalence rates in countries like Canada and the US that have very similar rates of drinking because the rates of FASD are linked to rates of drinking in the general population. So we think it sits somewhere around between three and 5% because Australia does have a pretty high drinking culture. But we also know that there's subpopulations of people unfortunately, who are disproportionately impacted by FASD, and that includes kids in out-of-home care, which we think is up to around 25%. And unfortunately, people in corrections populations, they're very overrepresented as well for different reasons. So when you compare it to something like autism, it's about two and a half times more prevalent than autism. So most people know at least one person with autism. So that means that we know many more people with FASD. But the other statistic that's really important in this space is unfortunately how rarely it's diagnosed. So they believe about 98% of people with FASD actually are undiagnosed. And if you're an adult in Australia, I actually think it's probably much higher than that because we don't have any diagnostic clinics for FASD in Australia.

Hester Wilson (09:34):

That's such a high figure. I'm going to come back to that diagnosis in a minute, but I've been working as a doctor for quite a few years, and when I started it was like, well, you don't want to drink too much. That's changed though, hasn't it? Let's be really clear around what our thinking is around the risk of alcohol and fetal exposure, Vanessa.

Vanessa Spiller (09:52):

Well, the Australian guidelines around drinking actually changed around 2009, and that was what, seven years before our FASD diagnostic guidelines ever came out. So around that time, we started to recognise that alcohol absolutely is a really potent chemical, particularly it's a teratogen, so it's a substance that causes birth defects and it's a neurotoxin. So around 2009, those guidelines came out that said no level of alcohol during pregnancy is safe, and that's because of those teratogenic and neurotoxic effects. Unfortunately, not everyone has kept up with the guidelines. So we still unfortunately have some medical professionals who have forgotten those guidelines or they've got a billion other things they're trying to remember. So that's probably one of the most important things. There is no safe level of drinking during pregnancy. That's not to say that everyone will be impacted who has even one drink, but we have to look at the risk factors. And certainly Vanessa, the more you drink, the higher the risk. Certainly risk goes up and look, it's a very complex thing. But yes, the more alcohol you consume, the more frequently you consume it, obviously your risk is going to go up on every one of those occasions.

Hester Wilson (11:04):

So bottom line, do not drink during pregnancy. Do not drink. When you're planning a pregnancy, really think about your risk as a young woman of childbearing years who's having sex. Think about your risk and about what alcohol looks like in your life. I've wanted to come to Ange, who's been very quietly sitting there and nodding and agreeing. Just to understand your experience with your young man. How did he present in his early life?

Angelene Bruce (11:31):

My son is a little bit of a different story, so I'll just say a little bit about my story in short, because I could spend another three and a half hours just telling my story, but we'll keep it a little bit shorter than that for the audience. So in short, my mum got a diagnosis of glioblastoma, which is a brain cancer that nobody survives, unfortunately still to this day. So she passed in 2007. When I was a little kid, I had some big complex trauma, but my home was my safe place. So I was always at risk of falling into trouble with alcohol and other drugs from what occurred in my childhood. I was always in a sort of a higher risk factor. I was always felt quite different, and I managed to hold that together with, I dunno how mum did it, but with so many extracurricular sports and activities I'm thinking about now that I dunno how mum kept up, but it was because I couldn't be in my head for too long.

(12:28):

It was a scary place. So mom was diagnosed in 2006. She passed in 2007, and that was my catalyst actually. It was almost my catalyst. I then found out my son's father and myself, we couldn't fall pregnant without IVF. I had zero chance of falling pregnant, I'd got sober, I'd got into a long-term rehab, and I came out of that long-term rehab still with mum's passing and still with the knowledge that I couldn't fall pregnant. So I relapsed pretty quickly, and then six months later I found out I was pregnant with my miracle boy. So by that stage I had relapsed big, which is what happens in alcohol and other drug sectors. As you would know, Hester, it's a solution to pain. And I wasn't expecting to fall pregnant, of course. So when I found out that I was, I was elated, my miracle, how could this be?

(13:20):

And then I was horrified because I realised exactly how much he'd been exposed to already. So I went to my doctor an OB/GYN. As soon as I found out I made an appointment and I went there and the response I got was really not complimentary. I said that I had relapsed. I said that I had come out of a long-term rehab. I was pregnant, I wasn't supposed to be. I wanted to be of course. And the advice I got was actually pretty good advice for someone who's maybe having one or two social wines a week or whatever, which was that's bad for the baby, you need to stop that and you need to stop that before you see me again. And of course for someone who's a 24/7 almost top up drinker, that is woeful advice for both myself and for my baby. I knew that at the time having come out of a couple of detoxes and I knew how bad they were.

(14:10):

So his pregnancy was very lonely for me. So this is why I do what I do as well. It was in 2009, so the guidelines were a bit wishy-washy, and ironically, I hung onto the bit that said it's safest not to at that point. And we need to be really clear that no amount of alcohol is safe during pregnancy, and I'm really, really proud to have been part of the process of getting the mandatory red, white and black mandatory pregnancy warning labels on all products now. So mine was a story of reduction. It was very lonely. I did not disclose to anybody else after that. I mean, I've got A-negative blood, so I needed to have anti-D shots and all of the usual ultrasounds and things like that, but I didn't even tell the midwives at the end of the bed when he was in trouble when he was born.

(14:58):

So that's how much the first interaction with someone who's willing to disclose that kind of thing. I left feeling like a failed empty vessel, and my miracle baby was only eight weeks, but I didn't have a referral to go anywhere. So I spent most of my pregnancy on the computer because his dad worked night shift at the airport. And all I could really find was FAS at the time, foetal alcohol syndrome. Sorry. I did try four times within pregnancy to just stop. I was really just, I don't want this. I don't want to walk this line between detox and not having too much in my baby. I love my baby. And so yeah, the four times that I just said, look, that's enough. I ended up in hospital and he would be miscarrying. He couldn't handle the withdrawal part of it. So in a sense, I had to consume alcohol to keep my bubba alive, but my pregnancy is one of the most complex wraparound services, a pregnancy that you would need.

(15:59):

So he was born early. I couldn't tell them why, and then I just sat and waited for a couple of years. I just loved him. That's all you can do between age zero and three anyway, before diagnosis. So I did all the things you meant to do. I looked him in the eye and oh, I must backtrack for a sec to say that during pregnancy I did everything that I possibly could to mitigate. So I drank a lot of water, I walked every day. I had a Staffordshire that helped me with that. Soon as the shoes goes on, you're walking, you have no choice, you're walking. So I walked every day. I ate as well as I could. I ate really well, actually. I didn't eat any of the soft cheeses and stuff you're not supposed to eat. I slept as well as I could, although he thought it was party time in the middle of the night.

(16:43):

I think that's common. And I took a prenatal vitamin every single day. So I did all of the things that you're supposed to do, except I could only reduce my drinking. So I'll never know just how much that mitigated. So I just loved him, did all the things we're supposed to do, super important for stable placement, bonding, holding him, responding to his needs, looking him in the eye, laughing with him, and just basically loving him. And then when his language skills started to develop, that's where I noticed it first. He was quite a bit behind his peers when language came out. So I took him off for a diagnosis and I disclosed the prenatal alcohol exposure. Unfortunately, the psychologist who was assessing him was looking for FAS. And of course, even my son doesn't carry all three sentinel facial features, and he was high risk exposed.

(17:36):

He doesn't even have all three of those. So the next possible thing that it looked like that it presented like was autism. Autism mimics FASD incredibly well. And so that was his very first diagnosis. And at that point I had done kindergarten teaching at Melbourne Uni. We'd done a little bit about autism. It was still pretty fresh back then, but it just wasn't presenting in classic autism style. I don't have any of it in my family lineage. And he'd been prenatally exposed to alcohol. So I went to a second pediatrician, and fortunately he was FASD informed. So of the second diagnosis and the correct one was fetal alcohol spectrum disorders with sentinel facial features because he does have one of them. So that is how his diagnosis came about. But that is how he presented very, very much like autism to the point where that's what he was diagnosed with because FASD is so unknown through lack of education in the country, even though it's so prevalent that she just didn't have anywhere to go with it.

(18:45):

It was either FAS, but it couldn't be because it didn't have all these facial features or it was autism, which it isn't because it is FASD. So this is where we get with courageous conversations through allied health and all that sort of stuff, just education. So yeah, his second and correct diagnosis was FASD. He was four years old. And that's incredibly early or considered incredibly early for a diagnosis, and that's always best too. So yeah, I had to be courageous twice. I had to be courageous a lot actually where we get to interventions. But yeah, it was worth it. The correct diagnosis is always the best diagnosis and it just didn't sit right with me. So yeah, I went and told my story again to another person, and on the second time we got really lucky and his diagnosis was made.

Hester Wilson (19:31):

That's great. We'll come to treatment in a moment. I just wanted to flag for you, Angelene, you had an alcohol dependence that's really hard to change on your own. We as health professionals need to diagnosis that need to understand that absolutely women who are pregnant want the best for their babies and they need a lot of support to change that. So get in contact with your specialist services, make sure that the support is there to help women do that. It's not enough just to say don't do it. When you have a dependence, you need lots of support in order to safely change that and successfully change that behaviour. Vanessa, I wanted to come to you from a sort of a general point of view. What are the ways that people present? What might they notice or what might their family notice?

Vanessa Spiller (20:15):

Well, this is the $60,000 question because it's so varied. So again, we can have severe impairment in a minimum of three, but up to 10 brain related domains. So if you think about something like autism, what happens is we get this very steady pattern of the ways in which people with autism present, they'll often have some difficulties with social functioning. They often have some difficulties with what we call executive functioning. They have some really stereotypical and repetitious behaviours, which means that over time, while everyone with autism is a little bit different, they actually look quite similar. People with FASD, you can have those severe impairments in any combination of those 10 domains. So that's actually up to about 120 different combinations of behavioural symptoms. So it looks different in everyone. But the common things that we find, probably some of the things that Angelene already mentioned, we do get kids that look quite similar to autism.

(21:18):

So they are different in the sense that they'll often be very socially interested, but they have enormous difficulties making friends and keeping friends. They're often incredibly impulsive and they can't link cause and effect. So they're often doing things and making mistakes that other people go, how can they keep making those same mistakes over and over again? They often have the very first diagnosis for that. Probably most people with FASD get is actually ADHD. So I think there's a lot of people who've been mistakenly given an ADHD diagnosis when in fact they may have FASD. So they often have significant attentional difficulties. They can also have some difficulties with their learning and academics. They can have difficulties with a cognition. But again, this is a common misconception is that everyone with FASD will have an intellectual disability, for example. But again, we know that's not the case.

(22:14):

These can be young people and adults. Most of them will have average to low average IQs, but you can have superior IQs, but they will quite often have difficulties with processing information. They'll often have difficulties with problem solving. So we can get this incredible variety of ways in which it presents depending on which of the underlying domains have been impacted. My young fella, our experience was probably that the ADHD features really stood out and no, that's because they're externalising, they're really obvious. He was like a human tornado. He would wake up in the morning and he would hit the ground and he was running and literally climbing walls. While he had this charming, delightful personality, he could also switch on a dime and he would go from very happy to really outrageously destroying a room and attacking us. So it is just so different, and that's one of the things that we're often looking for is these kids who actually probably meet criteria for a whole range of diagnosis. They may be kids who have the laundry list of diagnoses, but something seems not quite right and it doesn't seem to fully explain it.

Hester Wilson (23:35):

And you're looking for exposure to alcohol.

Vanessa Spiller (23:37):

Absolutely, yes, you need to always ask about that. And that's probably the number one thing for professionals that I have, which is always ask about prenatal alcohol exposure. Whenever you're doing a developmental screen, whenever you're asking about someone's developmental history, we need to include those questions. And as professionals, we are really good at asking sensitive questions. We know how to do that thoughtfully and carefully, and we need to make sure that that's there and we need to record the answer so that even if we are not giving a diagnosis of FASD, there is a record somewhere that someone has asked about prenatal alcohol exposure and it has been confirmed in some way.

Hester Wilson (24:20):

And so for a mental health professional listening to us today, they think, okay, so I'm seeing someone, I've got that history of alcohol, I'm thinking that it's FASD. How can they help that child or person and their family get that diagnosis? Are there some trickiness around actually getting the diagnosis?

Vanessa Spiller (24:38):

Yes, there is some trickiness unfortunately, and I wish it was straightforward, but I guess the main thing is being aware of referral pathways. So we want to make sure that people are getting in front of either a team of professionals who know about FASD or that they're being directed to a group of professionals who know about FASD. So if we are lucky, if we live in a major city, we have FASD diagnostic clinics always for children unfortunately at this stage Sort of a one-stop shop, we can send them to some of the FASD diagnostic clinics in Sydney and in Melbourne and in Brisbane. We've got a couple, they often work. So it can be a little bit tricky to get in and there can be waiting lists. The other option, I guess, is to do what I call is sort of the do it yourself pathway, which often requires a medical professional to be coordinating this.

(25:35):

So we need people like psychologists, we assess about seven of the 10 domains. Speech therapists, they assess one of the domains or maybe two of the domains, occupational therapists, they also assess one to two of the domains. So if we can find professionals from those backgrounds as well, it's useful to have a medic as well, a pediatrician or a child psychiatrist or even just a GP who is interested and knows a bit about FASD, hint, hint, anyone who wants to go and get some more training, this could be really good.

We can actually take those reports, we can take that collected information and someone can confer the diagnosis. So this is really important when we are living in rural and remote communities where we may not be lucky enough to have a one-stop shop, but again, this requires some assistance. We need to help families do this because if you've got a young person with FASD, as Angelene was saying, it's a full-time job on top of your full-time job. So it's a big ask to ask families to coordinate this. So we will need to step in and really help them pull together and get the diagnosis made.

Hester Wilson (26:46):

So now that we've got the diagnosis, let's say we've got it. And Angelene, what helped once you had that diagnosis for your son, what did he need and what actually helped him to get on and live his life?

Angelene Bruce (26:57):

Once we got the FASD diagnosis, that allowed for referrals to a speech therapy clinic, a referral for an occupational therapist. And I also started looking into the NDIS and whether he qualified for the NDIS, and he does qualify for the NDIS. So that in itself was challenging. There isn't a box on the carer's form or on the NDIS that actually says FASD. There's boxes for everything. There's a lot of them, but there isn't one for FASD on the government forms either. So I was a little bit puzzled by the NDIS, but I did actually reach out and the wonderful Meg Perkins reached out to me. And yeah, she helped me to get on to the NDIS because it is a DSM five diagnostic standard. And yes, he was eligible for the NDIS. It took quite a bit of paperwork, but in the meantime, I got really creative. I used the Medicare plans to get three sessions of speech, I think, and two sessions of OT.

(28:00):

And I got those tests that Vanessa was talking about started, it was called a self test in speech therapy and an ABAS with his occupational therapist. Then he had a psychologist on board to do a neuropsych test, which is a full scale IQ test. And although the numbers of that test at the end, as Vanessa said, will often come out at low average, the overall number is really not a testament to true ability of a FASD child, but it is a blueprint to see not only where the deficits are, but to also see where his strengths were. I'm all about strength-based myself. I love strengths. I think they're awesome. We talk a lot about deficits because we have to, but there's also a heap of strengths there. So I got to find out what kiddo's strengths were, but the problem was that the speech therapists and the occupational therapists, the whole clinics, they hadn't learned about FASD in their training.

(28:56):

So they'd learned a lot about interventions for ASD or autism spectrum disorders. And when they tried to apply everything they knew to my child with FASD, it didn't work and they despaired. An example of this is that interventions for FASD need people to understand that the kiddos and the grownups, they've given you everything they have. They're not being aversive to this kind of stuff. And I think with what I saw from the ASD interventions is it requires a little bit of pushing. And long story short, within a couple of weeks, my son was so overwhelmed, he was just this little ball of rage that was flipping over tables and running out the door. And I'm thinking, what now? I've got him into speech therapy, he's into OT and it's got worse. So his speech therapist was lovely. She went to see her lecturer who did say to her, no, this needs to be very different, very different in its approach.

(29:53):

And I'll probably leave Vanessa to explain a little bit more about that. But in short, what it meant was that the therapies she was trying to engage for his chronological age were too grown up for him because he suffers from dysmaturity. So the lecturer actually said to her, pull him back to what you would do with a five-year-old due to this dysmaturity. And ever since then, like magic, it was just clear sailing from there. I was very guilty of thinking an occupational therapist would be there for handwriting skills and gross motor skills, kicking a ball, whatever. I could not have been more wrong people. The OTs a really important person in the team for emotional regulation, but my son, Shay, he does not mind me saying his name, that's where the majority of his emotional regulation has come from. But of course, we were all despairing at the start, allied Health included, because my son's no exception.

(30:47):

Most kiddos with FASD have these glorious personalities and you just want to love them and help them and hold them and hug them, and they're just fabulous. But yes, they can flip on a dime, and it's simply because their little central nervous systems and brains and bodies are just overwhelmed and they don't have the words for it. So they will act it out. But I can see that being a really big problem in Allied Health with Allied Health people that really want to help. OT's speech, psych’s, all that kind of stuff. But due to the lack of education, everybody despairs because the little one's getting all wound up and it seems to be making things worse. And if that's the case, it just needs to be a little bit different with FASD. So I would like to see a lot more education around that given its prevalence.

(31:30):

And given its very close presentation of autism, it's not a far leap to say, right, well, this works with this child, so I'm going to apply it to this child who presents the same, and now why is he flipping the table? And yeah, I'm making it worse. So his speech therapist was despairing. She went to the lecturer, we fixed it up. But yes, a little bit more education through studying for Allied Health would be fabulous. So that was just another barrier. And then of course, I had to explain to them what FASD was, which meant that I had to say that he was exposed to alcohol by me again, another two or three or four, five times, and we're not even at school yet. So education's really important, but knowing that the interventions are different is also really important. And Vanessa can probably speak a little bit more about that.

Hester Wilson (32:15):

Yeah, Vanessa, over to you.

Vanessa Spiller (32:17):

This is absolutely my ballpark because that's exactly right. This is what I found in my professional life, and it's certainly what I found in my personal life. I was teaching parenting courses, I was teaching interventions. I was providing these to many, many families. And certainly when my son came into our life as a clinical psychologist, I'm a doctor of psychology, and my partner was an ex-school teacher. So we thought we had a lot of skills, we had a lot of experience in supporting young people with really complex stuff going on. Exactly like Angelene and her professionals discovered. None of it worked, and it would often make things worse. And the hard thing is we would go to other professionals, of course, I absolutely go to speech therapist and OTs and I'd say, look, how do we help him with this? How do we help him manage particularly his rage and his frustration and his anger, but also his speech and his fine motor control?

(33:15):

And they would give us things and we'd go, well, we've literally tried all of those things and they are not working. In fact, it's making him worse. So we found time and time again that we were the most educated people in the room. We'd gone and done the research. And I guess that that's really why I've landed in intervention is I think diagnosis is absolutely important, but there was nowhere for people to go after that. So how do you raise a young person with FASD? How do you raise them as an infant? How do you raise them in middle childhood? How do you support them as adults? And so I went to the scientific literature and read everything I possibly could, and most of it wasn't about interventions. Again, it was all about brains. So that is where I guess I wrote my first book, which is Explained by Brain.

(34:04):

And this was specifically written so that we could educate, starting with parents and carers because they're the ones who are living with these little people every single day. They needed some strategies that would work, and they needed to understand why the strategies they were using weren't working. And I guess what I've learned over now 20 years of experience is that there's lots of strategies out there that are designed for neurotypical kids with the presumption that they have neurotypical brains and this belief that everyone has a brain that's the same, and so it's going to respond to things like consequences and punishment and talking therapy. All people will respond the same when what we know is these kids have different brains, and so we have to adapt everything in their life, including their therapies and interventions to the brain they actually have. It's an enormous amount of work.

(34:55):

So I've written two books around that, and they are for parents and carers, but also for professionals. So we want professionals to have an understanding, what are these 10 brain domains? How having impairment in these three domains, what does that look like in real life? What does that look like in school? What does that look like at home? Therefore, what kind of supports can this kid benefit from what's going to be most useful? Where is the demand going to outstrip what's demanded of them? And that's where we end up with these behavioural symptoms. That is pretty much what I devote my life to these days. I don't do so much diagnosis. We have a wonderful array of people doing diagnosis. Mine is how do we help these young people succeed and thrive in the world because they really can, like Angelene has said, and like my son, life isn't perfect, but he, he's doing amazing.

(35:49):

He's working, he's contributing to the community. But he couldn't do that without the interventions, without people understanding FASD and without us understanding FASD and working out what he needed around him to be successful, including things like the NDIS and before the NDIS schools and other services. So that's a very short answer, but intervention is absolutely my jam. And unfortunately, it's the area that has been neglected very much in research. So there's been lots of focus on diagnosis, there's been lots of focus on some of these things. We're only really just starting to get into interventions, and we really need to be pouring some resources into that because the evidence base is still extremely thin on the ground and we just need to do more on it.

Hester Wilson (36:39):

That's great. Vanessa, look, I think thinking about it, I'm thinking prevention in the first place by no alcohol in the prenatal period, but also that early intervention, being aware there may be issues, getting it diagnosed early and then getting the right treatment for your little one is really important, but at the same time, it's an evolving area. We're going to have to finish up today, but I wanted to come back to you both. What's your one takeaway that you want people listening to this podcast to take away with them?

Vanessa Spiller (37:09):

Can I cheat? I'm going to give you a couple. I want to finish on Angelene. I think we need to finish with her story and contribution. There's actually two. So one is if you need more information education, it is available in Australia. So we have two organisations, NO FASD in the FASD Hub, which are fantastic sources of information. No FASD is our number one peak advocacy group for parents and carers. So if you've got a parent and carer and they need to know something about FASD, go and look up the No FASD website. If you're a professional and you need to know something about FASD and you need some resources and information, FASD Hub. So they're the peak body for professionals around FASD. We also know that FARE has some great resources as well. We have some great resources out there. I have a truckload of resources for a bit of self-promotion, but in terms of the number one thing I guess I would say is always consider the possibility that FASD might be going on. I think we just need people to get it on their radar and to think about it when you're thinking about giving a kid a diagnosis of ADHD or autism, and you're going down that track of trying to look at what's going on, always consider the possibility of FASD and ask about prenatal alcohol exposure.

Hester Wilson (38:28):

Angelene?

Angelene Bruce (38:29):

I couldn't agree more with that, especially with the courageous conversations. Alcohol, it's a culture here in Australia, it's in sports, it's everywhere. So I do work one day a week now for the Foundation for Alcohol Research and Education, FARE. And so I do stand up speaking on stages at conferences and stuff, and one of the questions I get asked the most is, how do we ask without stigmatising you? And my response to that is always, it's not stigmatising me. Prevention is always best, but preparation is next best. So the earlier mums can know that it may even be a possibility the earlier they can head to know FASD and be prepared for FASD to come along. It is lifelong. So courageous conversations, I would like to see it much like tobacco. I would like to see it just put down as a birth marker because it really does make it a lot easier at diagnosis time than to try and have mum remember how much she may have had to drink on that cruise when she fell pregnant that time three years ago.

(39:34):

It's really challenging, particularly for women who are not 24/7 top-up drinkers like me. It's difficult and challenging to remember sometimes. FASD is not just for children of women like myself, it's for everybody. And if I could put a little tip in as a patient, I do often see at conferences as well, I can see people in their heads going, oh, did I drink in my pregnancy? Oh, and it's really important to remember that it's about the person that's sitting in front of you that needs to get really vulnerable to say, yes, I did consume alcohol during my pregnancy and my baby was exposed. But the very last and strength-based of course thing to leave everyone with is that prenatal alcohol exposure is never malicious, and it can occur at any time and with any amount, any type of alcohol throughout the entirety of pregnancy, even before pregnancy is confirmed.

(40:32):

So women live in Australia, we're blanketed with alcohol advertising. We are encouraged to drink every day. So it's important to support us when we do just that and then fall pregnant. It's not malicious. We really love our bubbas. We need professionals to be courageous and strength-based. And a tip that I would say, instead of saying, do you drink alcohol? Maybe say, how much alcohol do you drink? We do live in Australia. So you're either going to get, oh, I don't drink at all, or closer to what the truth is because it's really, really challenging for us. And we may even lie and halve it or whatever, but at least it's there. And FASD awareness month is in September. We got 64 things lit up red last year, so look forward to that because we're planning already. We need to start in February for September. And individuals with FASD, they need a lot of scaffolding with their strengths around their deficits, but they really can live quite full and productive lives.

(41:30):

It's just important that we have education and we have correct interventions and scaffolding around them to allow their strengths to shine because they all have them. Big ones, big strengths, and that's the best way to accommodate anything. And that includes when you're talking to pregnant women who are quite frightened. The best thing I would suggest is honesty. So top tip, prenatal alcohol is never ever malicious. It's super challenging to talk about for all parties involved, but we really do need to have the courageous conversations in order for other kiddos to have the outcomes that my kiddo has. Sometimes I feel like a bit of survivor's guilt because he's doing really well, and I just want it for all of them. If there's any biological mums out there or someone who thinks they may have a misdiagnosis, if there was prenatal alcohol exposure, it's okay to say it feels like you should have hashtag on it. But yeah, it's okay to say to your GP that there was prenatal alcohol exposure because it's actually 50% of the diagnosis and required. So I think if we could all work together and be really, really courageous about this, yeah, we could start making some ripples.

Hester Wilson (42:38):

Great. So hashtag it's okay to say, have courageous conversations and look for strength. Look for the things that you can build and create. I just want to say thank you for joining us for this episode of MHPN Presents A Conversation About, you've been listening to me, Hester, and Angelene, and Vanessa. If you want to learn more about me and my guests, or if you want to access the resources we've mentioned, go to this episode's landing page and follow the hyperlinks. We'd love to hear what you thought of this episode. If you want to learn more about FASD or the resources FARE offer as part of the Every Moment Matters campaign, once again, it's on this episode's landing page. The Every Moment Matters website has heaps of information, and there's also training for healthcare professionals. And on the landing page, there's a link to MHPN's feedback survey. Please follow the link and let us know how this episode was received by you. Was it interesting? Was it helpful? Provide any comments and also suggestions to help shape the future of MHPN podcasts. Thank you for your commitment to and engagement with multidisciplinary mental health care. Stay tuned for the next MHPN Presents podcast, which will be released Wednesday fortnight. In the meantime, take care and to you, Vanessa and Angelene, take care, strength and love to you and those beautiful kiddos in your lives. Thank

Angelene Bruce (44:06):

Thank you Hester.

Hester Wilson (44:07):

Thank you.

Host (44:09):

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