

Love Meets Joy Podcast
Season 2 Episode 4
Navigating the Intersection of Mental Health and Cleft Care with Dr. Leanne Magee
Transcript

Ashley Barbour: Hey everyone. Welcome back to the Love Meets Joy podcast on the Smile Train podcast network. I'm Ashley Barbour. I was born with a bilateral cleft lip and palate. I'm the creator of Cleft Love where I share my journey of self-acceptance and spread awareness of cleft.

Iva Ballou: Hey everyone, I'm Iva Ballou Smile Train's Cleft Community Development manager, CEO of Real Sophisticated Joy and a cleft confidence coach and advocate. I also was born with a bilateral cleft lip and palate.

Ashley: And Iva, our guest today is a little bit different than our usual. So typically our listeners know that we usually interview people who are directly impacted by cleft, but I know that something you and I have talked a lot about is the psychological impact of cleft on our lives. And so today's topic and guests are incredibly important.

Iva: Yes, they are.

Ashley: So, I would love to introduce Dr. Leanne Magee. She's a pediatric psychologist at The Children's Hospital of Philadelphia, and she's an assistant professor of clinical psychiatry at the Perelman School of Medicine at the University of Pennsylvania. She specializes in working with children with appearance differences. She's been a member of the CHOP cleft palate and craniofacial team since 2009. Dr. Magee's clinical and research interests include psychosocial adjustment in children and families affected by acquired and congenital appearance differences, psychological aspects of plastic and reconstructive surgery, body image and anxiety.

Iva: Woo! Yes.

Ashley: So with all of that, we just want to say welcome and thank you Dr. Magee for being here.

Dr. Leanne Magee: Hi. Thank you so much for having me.

Iva: So I have to admit Dr. Magee, I am fangirling. Everybody knows that I'm so excited to have you on today. For those who are listening who may not know, Dr. Leanne Magee is very unique in her role and what she does and the care that she gives to our community. Typically, on a cleft care team, you would have a plastic surgeon or a craniofacial surgeon, a pediatrician

orthodontist, a pediatric dentist, maybe a speech and language specialist, ear, nose and throat, and possibly a social worker. But to have someone that can really speak to that psychosocial aspect of the cleft journey, and that is why Ashley and I were like, we have to have Leanne on. And if you ever get a chance to hear or read anything that Dr. Magee puts out, you can tell that she has such a level of care and respect for our community that again, I just have to say thank you. Thank you for being here, and thank you for all that you do. We really just wanted to celebrate a psychologist that's working for the wellbeing of our little community of appearance differences. So, I just have to know because if Ashley and I did our research well enough, you don't have—you weren't cleft affected, you don't have anyone who's cleft affected in your family. So how did you become interested in working with the cleft and facial difference community?

Dr. Magee:

Well, it's an awesome patient population to work with. So much variety. But yeah, I kind of came into it in a serendipitous way. I was interested initially in anxiety and clinical anxiety and social anxiety, and that's what I studied in my graduate program. It was through my clinical internship year. I was at a VA hospital and I got to work with patients who had acquired injuries. And so they were adapting to differences in their bodily appearance and function as a result of injuries. And I thought, oh my goodness, this is so fascinating. So many of us are anxious about public speaking or dating or job interviews, and that's without a visible difference. And so I had the great opportunity to be invited by a colleague of mine who I'd gotten to work with when I was an undergrad and she was a graduate student, and so she was looking for someone to help her with some of her research work at a time that I was looking to get my first job as a psychologist. And I just fell in love with the field. It was something I had never had any experience with, but I did a two year pediatric psychology fellowship where I got to work with and observe the care that we provided in our cleft team. It's been thrilling me ever since. I think it's been such a gift to get to work with families, to get to watch kids grow up and to get to support them during really critical aspects of growth and identity formation through medical and surgical stuff. So it just feels always exciting. Every family's different and it keeps things fresh. So I really loved it. And we have a obviously great patient community working with folks like you. There's a lot of, I think, sense of belonging when people share a difference in common, but also professionally it's been great because I've gotten to collaborate with other psychologists and social workers who are at centers across the country. There aren't many of us, but we work really well together to try to advance our mission of improving the quality of life of patients with cleft and craniofacial conditions.

Ashley:

I love that. That's so great. You said initially you started working with people who had acquired facial differences and then you kind of switched

over to working with kids who were born with cleft. Did you notice a difference in how the facial difference impacts someone if it's something that they're born with versus something that they acquired?

Iva: That's a great question.

Dr. Magee: Yeah, I mean, I think certainly the social consequences can feel the same, that people can be treated differently no matter whence they have a difference. But what I thought was really cool is that for kids who are born looking different, it's who they are. It's what they know. It's a part of their life and their identity from the beginning. And so I think in some ways there is a greater acceptance of that into your sense of self because it's just a part of who you are. And I think when I worked with young adults and adults with acquired differences, there was often more of a traumatic impact that was a sudden change in appearance as opposed to something that was always a part of who they are.

Ashley: And I bet there's just a difference in, because you know what it's like to operate in a world where you're not facing it with a difference and then to have developed it.

Dr. Magee: I imagine that that would be a big shift for sure.

Ashley: So we know that you have done so much great collaboration with Smile Train, and so I'm curious if your association with Smile Train has changed any of the work that you've done or impacted anything that you're doing right now.

Dr. Magee: Totally. I think one of the things when you work in academic medicine is that there's always opportunities to do research and collaboration with the other physicians and specialists that are on our care teams. And I think working with patient and family community organization like Smile Train has really helped me to keep the family experience at the center of the work that I do. And so a lot of the work, my interests and actually hearing from cleft affected individuals themselves about what they value and prioritize has helped me advocate for things that we should be looking to understand better, things we should be looking to shift in how we deliver care, how we coordinate and collaborate with our patients and decision-making. So that's been a big part of my focus of late is just kind of going directly to patients and qualitatively tell me what this is like for you, what would make it better and how can we do that? Not you, but we want to do that job for you. So I've started to do a lot more work on the patient experience and understanding what's it like to go through a jaw surgery and what do you wish you knew and what surprised you and how can we help other kids in the future? And I think there's nothing like that person to person experience and it's different. Even the best doctor who's explaining

it in the most perfect way just doesn't hit the same as talking to someone who's been through it. Right.

Iva: Again, I'm still over here just like, yes, yes, yes. Because you are speaking the language that we have talked about before about how the doctors, they mean well, they do mean well, but there's something about that lived experience. I know that you have a love for research, so listeners, if you're ever bored and you just want to go dig into all of her journals that she has done, but one of the journals that you co-authored, I want to bring up, because it's so fitting about what you just said, the parental reports of intervention services and prevalence of teasing and multi facial craniofacials, microsomia pediatric study. In there, you actually made a good, there was a quote that I wanted to pull out that approximately 35% of youth in the US general population experienced bullying, but children with craniofacial diagnoses are up to five times likelier than peers to experience teasing. And we've talked about that before about how your face is your calling card, but people make judgments off of your face. And so how have you seen that play out as far as with your patient that you're treating?

Dr. Magee: So first of all, the research I do, I want to make sure— I don't do that research alone. I'm often the helper, but I'm so grateful to the other psychologists and social workers and physicians who we get to collaborate with because some of these conditions that we study are relatively rare. We get to get more patient and family experiences by combining forces. And so we work a lot on research together across health systems, but we're all psychologists, and so we get to bring our psychology lens to that and help focus some of the questions we ask. So yeah, our kids certainly do experience more teasing, more social awareness of their difference. They're sort of like, you can't be invisible when you look different. And so I think that from an early age, our patients and our families are really aware of that. My goal is that we actually take a preventive approach to that. And so starting from birth, I like to make sure that the parents are informed about what are we going to do when someone asks a question or stares too long or makes a comment. So rather than it being something we have to fear or hide from or avoid that we arm the parents and the kids with the tools to say, yeah, it's going to happen. People are curious about you, so what are we going to do? How are we going to handle it? How can we distinguish between curiosity and something that's a little more mean-spirited, like teasing or name calling because they require different levels of response. If someone asks a question like, “Hey, what's up with that?” Right? Even if it's not a great question, we want to assume positive intent. And so if a child can say, oh, that's a scar from an operation I had, I had a cleft lip and palate when I was born. I had a surgery when I was younger. That goes a long way in teaching that peer about like, “Oh, cool, I didn't know that about you. Let's go play.” Whereas if people think that it's

something that can't or shouldn't be spoken about, yes, then that child feels like, "Oh, I've got to hide this. People saw me." And so I really focus on building those social skills and building that self-confidence and self-advocacy from before they can talk. I want the parents to learn it first and then to really help shape that in their kids.

Ashley: And I love that you're arming the parents with things that they can say too, because I think sometimes parents don't even know how to respond to, "What happened to your baby or why does your baby look like that?" or any of those sorts of mean-spirited things. I remember when I was little, so my parents read to me at night until probably far later than most people. (11:48) I was probably well into middle school. And I remember my dad in particular, both my parents are social workers. My dad in particular would be like, what would you say if someone said this to you? How would you respond if someone said this? Something else Iva and I have talked a lot about that's really helpful is to have our elevator speech or your ten-second response to the, "What happened to your face?" Because I know for me, even now I am well into adulthood, when somebody asks me that, I feel very dysregulated. And so it's really important for me to have a quick speech. So I love that you are doing that. I'm curious about in your bullying research, if you found that many kids don't report their bullying experience to parents because I know that that was for sure my experience. I didn't tell my parents, but also I was sort of surprised to learn within this community that has been kind of a shared thing. Many of us didn't talk about it.

Dr. Magee: Yeah, I think what we find a lot in psychosocial research is that parent and kid perspectives don't match.

Ashley: So interesting!

Dr. Magee: And so parents have one view of the situation and they might think, "Hey, things are going great," or sometimes, "things must be terrible." And then when we go directly to those kids and we ask and we can get a child's perspective, we find that it's a totally different lens. And so, I think a lot of kids who experience teasing and bullying, whether it's because of a facial difference or something else, there's a lot of shame that can come with that.

Iva: Yes, yes.

Dr. Magee: And a lot of sense of not wanting to own up to it or to admit that they're having a hard time. And so I think it's very natural that some kids just internalize that and they try to make it go away by ignoring it. But at a certain point, I think kids sort of get to a point where it's like it gets to be too much right? And you just can't hold it in anymore. And so what I try to

advocate for are those check-ins, right? With kids. Like Ashley, your dad's doing, what would you say if, or has this ever happened? I talk a lot with kids, what would you do if a friend who's being bullied who might you tell about it later so that they're not thinking about it for themselves, but they're practicing the skill anyway. And again, just acknowledging that it's going to happen I think goes such a long way.

Ashley: I think a lot of people don't realize how impactful education can be in reducing bullying. That was something else I feel like really was beneficial to me is I did class presentations when I was in elementary school and it really, I feel like had a positive impact because kids knew what was happening at the time, but then it trickled on even into middle school when somebody said something negative. There were kids I watched school with in elementary school that were able to explain why that wasn't okay for them to say.

Dr. Magee: Exactly. Education is key. And so that's why I like kids to be able to educate their peers or parents to be able to educate teachers because a lot of teasing and bullying comes from just not knowing and not understanding another person. And I think with confidence, like that elevator pitch, you get to change the tone of that interaction. So if someone comes at you and says, why do you look like that? You can say, "Whoa, whoa, because I got my hair blown out last week, so it looks great." So you can kind of take some ownership and take the power out of that negative initiation and kind of reclaim that. And I think that can be just so important that we can arm kids with that. So information can go a long, long way.

Iva: You talked a lot about the external bullying, but do you talk to the kids about that internalized negative self-talk? Because it's really hard when you are dealing with that day to day, and I've always been self-proclaimed bully to my own self, and so I know that I'm not the only one who did that. How do you talk to the kids about that?

Dr. Magee: Yeah, it won't surprise anyone. I'm very pro therapy for everybody all the time, and I really like to create an environment and I see some of my patients, my kids only once a year for 30 minutes, but in that time I like to really normalize that we can talk about the hard stuff. And so I ask very specific questions about, do you ever find yourself having negative or critical thoughts about yourself, your behavior or your appearance? And sometimes they're like, "Oh wait, you knew that?" And so once I put it out there, it's like, well, yeah, we normalize it because it does happen so often. And so I think as psychologists, we have this great lens to understand the power of thinking on how we feel and how we behave. And we've got tools to help kids check that out. So I help the kids I work with in therapy for instance, start to catch those repeated thoughts or messages we're

sending to ourselves, often the negative ones are the trickiest ones, and we check it out and say, well, how true is that? Who told me that? Where did I learn that? And do I believe that anymore? Does that match with what I want to think and feel about myself? And if not, how can we shift that? How can we shift the focus and drop maybe an old habit of thinking and try to see if we can adapt a new one? So, using cognitive behavioral therapy techniques is one of the strategies that can be helpful for kids even starting at a pretty young age. And so just identifying that we have those thinking patterns and being willing to get a little more flexible with them can go a long way.

Ashley: I think that's so important because, as I'm sure you know, when you grow up in a plastic surgeon's chair, I feel like things have maybe gotten a lot better compared to when we were growing up. But, once I was an adult and I started exploring what the impact all of this had on me, it's pretty crazy to think that you spend hours, a whole day once a year, where there's a team of people who just come in hour after hour and they touch and they look and they talk about all of the things that aren't right. And I remember there was a plastic surgeon appointment that I had when I went to maybe talk about a rhinoplasty when I was a teenager, and they ended up talking about like, "Oh, I could get a chin implant and cheek implants," and, "You could do something with your ears and you could- we want all of this to be symmetrical." And so there were things that I was like, I never noticed that my chin was flat. Yeah.

Dr. Magee: I never even thought about that!

Ashley: I didn't even know. And so, I think making sure that we understand how we're speaking to ourselves as kind is really important. And I also think that the way that cleft is talked about within families is super important as well. And so I know that when I was growing up, we had my baby pictures and it was just a very open thing. It wasn't something we talked about all the time. It wasn't like my mom talked about being a cleft mom all the time, but it was something that we could talk about and it was available. Do you have any suggestions for families? Because I feel like a question I get a lot is, "When do I start telling them about their cleft?" or "When do we start talking about it? How do we talk about it?" Because I think sometimes people, like you said earlier, don't want to talk about it because they're like, "My kid's normal. You just need to be normal," and all of that. So I'm curious what your thoughts are in how families talk about that with their kids.

Dr. Magee: Yeah. I'm very pro early conversations at birth, that experience of being in the doctor's office and feeling like you're being examined, right?

Ashley: Yes!

Dr. Magee: Everyone's all up in your face and your nose and your mouth. And kids have an awareness of that from a very early age. And so I tell my families as soon as kids, and this could be one or two years old.

Iva: Wow, that's young.

Dr. Magee: They know they're going to the doctor. Let's talk about why we're going to the doctor. What are we checking out? We're checking out your mouth and your nose and your ears because your body's growing from when you were a baby, and we want to make sure everything still is working as good as it can for you. And so I try to use lots of language about growth and development so that kids can just feel like this is just a part of how I take care of my body. So yeah, I really encourage that conversation from the start. And I know that for my kids that I see, I also direct questions to them instead of the parents as soon as they're old enough to talk. And so I can really make sure that that child understands who we are, what we're helping out with, who they're going to meet, and that we can help give some information about what to expect.

Ashley: I love that so much. And something that I always want to share with families is it's so important to follow your child's lead because I think it can be easy to just sweep it under the rug and say, "We're not going to talk about this because you've had surgery and now you're just like everyone else." But the other thing is I feel like sometimes parents are like, "We need to talk about this. Why aren't we talking about this? We need to tell your school. We need to talk to your class and we need to talk to the principal." And it's overwhelming. And I always like to remind parents that it's not a linear journey, and just because your kid doesn't want to talk about it this year doesn't mean they're not going to be open next year. It totally ebbs and flows. And so I always just want to tell parents that it's just so important to respect where they are.

Dr. Magee: I think taking a kid's lead is really the heart of it because some kids don't want to talk about it because they feel great about it and they feel fine about it and they've learned what they want to know, and they're like, "No, it's cool. It's actually not that interesting to me." But yeah, I think some natural times is certainly preschool age kids, developmentally, are aware of differences. They start to be interested, they're very curious. They ask those funny, embarrassing questions about people in public. And so that's often developmentally the first time that kids start to say like, "Well, I have this, where's yours? Where's your scar?" And then I think when kids start to do school entry, that's a natural time when their peers are a little bit more interested in their differences and wanting to learn. And so I think those are sort of natural developmental times when these conversations might be a little more likely to come up.

Ashley: I love that. Oh, this has been such good information so far. We have so much more to talk about. But first we have to go to break, but please come back and we can't wait to hear more from you.

Announcer: We are happy to tell you more about our sponsor, Smile Train. Smile Train pioneered a sustainable model of partnering with local medical professionals in more than 70 countries. Since 1999, it has supported more than 1.5 million safe cleft surgeries, more than all other cleft charities combined. And as many people in our audience know, children born with clefts often need more essential cleft treatments than just surgery. Because their partners provide local year-round care, Smile Train is also able to fund nutritional support, dental care, orthodontic treatment, speech therapy, and psychosocial support for those who need it. Smile Train invests in their partners, providing them with the state-of-the-art equipment and training they need to make safe and quality care possible for those who need it most. But this isn't possible without your support. Go to smiletrain.org/donate/lovemeetsjoy today and donate \$21 a month to make sure that every child with a cleft can receive the care they need whenever they need it. That's smiletrain.org/donate/lovemeetsjoy.

Ashley: So I'm curious if you have any good tips on building confidence in kids as well?

Dr. Magee: Yeah, I hope so, because I think that's one of the core things that we do, right? As a psychosocial provider, I'm a huge fan of just figuring out who kids are beyond the cleft and making sure that that gets to be a focus of their care too. And so anytime I meet with families, the first things I ask about is, "Tell me about your family. Tell me about what you're doing for fun these days. What's school been like and what are your hobbies or activities?" And really making sure that kids and families are feeling connected to their broader community. And I think we build confidence through the connections that we keep. And so when we have positive relationships in our lives, whether it's through family members, community members, friends, they are, I think, one of the best supports in helping us realize we have value, we have connection, we have strength through that. And so I always like to make sure that kids are feeling as engaged in activities as they'd like to be, right? If they're not, because they're anxious, then that might become a focus of some therapy work we can do together. But it can go such a long way to just kind of find your interest. What is it? Is it music? Is it sports? Is it drawing? Is it playing with your pets, teaching your dog a trick? That there is this sort of sense of ability and confidence and competence in something beyond appearance. And I think that really helps give a bigger sense of self.

Ashley: And then how does that translate into the medical environment? How do you build capacity in kids in that space?

Dr. Magee: So as a psychologist, I'm really focused on resilience and building resilience factors. And I think that comes with knowing our risk and protective factors. So, we might know the risk is, we got a lot of doctor's appointments and surgeries coming up this year and that makes us really anxious, but we also have these great protective factors: these best friends, this family, this school who's going to be supportive and accommodating. And so when we're going into the medical care, we're thinking not just about getting through surgery, but what's happening around surgery? What's happening before? What's happening after? Who are we telling about it? Who's coming over to watch movies with you when you're healing? What are we going to do when we have to take a break from your sports? Maybe it's art class instead, so that we're finding ways to stay connected to that greater sense of a bigger life beyond surgery. So I think finding that strength in connection and confidence can go such a long way in coping with just the stress of cleft care. It's hard. It's hard to go through all of that care for so many years, and so you can't do it alone.

Ashley: So true.

Iva: It is hard and it is so many years, but then you know around 16, 17, you kind of had that push out of that cleft care team. What do you say to those pre-teens or teenagers or that cusp of 18 to 19 who they're trying to get their last little bit of cleft care or they're embarking on finally getting cleft care without mom and dad's help? How do they find help and where do they go?

Dr. Magee: To you guys? That's where I send them.

Iva: Well, thank you. Thank you.

Dr. Magee: It's making sure they get connected to the cleft community because that's where you're going to learn what it's like to navigate these next stages. I think there is this sense of flying the nest from cleft team. Our team, we tend to follow kids a little bit later sometimes into their early twenties. That transition to adult care can be tricky. And sometimes there's not a lot of medical care anymore. And then it's just like, oh wait, I got to get a job and make friends and go to college. And so it's about finding your people, and I think finding people who have shared some of that journey is really valuable. So I've been so excited at all the resources and information that's been available through Smile Train. I refer a lot of my teens and young adults to your podcast as a cool way to connect and know that people are thinking and talking about this stuff. And that really decreases the sense of isolation that sometimes people feel that they feel alone. And there are so

many people who have a similar, never the same but similar path. And I think there's just so much comfort in knowing that other people are going through it and have come ahead of you, and there are people who are going to follow in the path behind you as well.

Iva: And so do you have a little tip that you could maybe give to a mom who has a preteen who's going off just one little tip that you might want to share with them?

Dr. Magee: Yeah, I mean I like to, I'm a big informer, so making sure that that teen knows, even if they feel like, "I don't need that, I'm not interested in that." Did you know there are these resources available if you ever wanted to connect with another teenager or just know that there are other teenagers going through that? Go to the website: There's these videos, there's these webinars, there's these conferences. Just so they can sort of know it exists. I think that's really important. And then social media is a huge influence on teens. And so being judicious about the types of things that we follow and getting positive, powerful role models in place in there. And I think that's a way that parents can also help teens feel like they are seeing the great stuff about cleft that's out there and not just the hard stuff. Yeah.

Ashley: I love that. That's a really good idea. So when you were talking about that transition to adult cleft care, I know something that happened for me is when I was 16, 17, I went in for that appointment to get the rhinoplasty consultation and I said, "you know what? I am done. I am over this. I have no interest in this. I don't want to do it." See you never, was my plan at the time. But then when I hit 30, that kind of rolled around, I was more curious about it, and I remember not knowing where to go to get that. So I went to two plastic surgeons that just were random plastic surgeons who were rated well, and I got consultations with them. And it wasn't until after I had those two that I thought, I really feel like I want to see someone who specializes in cleft, but the only thing that I know about is the pediatric team and they're not going to want to see me. But it was sort of serendipity or something because maybe a couple months before I had run into my childhood surgeon and I had talked to him about some of my desires for cultivating the cleft community online, and he had given me his email address, and I remember emailing him and saying, "How important is it that I see a cleft surgeon versus a regular plastic surgeon for this?" And he was like, "Come see me." And I had no idea that the pediatric surgeons often still have maybe one or two days a month that they operate on adults. And so I think that that point is really, really good.

Dr. Magee: Yeah. Even when we graduate families from our clinic, we tell them, we're not going anywhere and so come back at any time. So I think it is great that you were able to have that reconnection with your provider. Even if our surgeons can't operate on adults, they are really well connected with

their colleagues and throughout the country, throughout the world. And so very often that warm connection with someone can be helpful. I also like to direct— So I think that transition to adulthood is something we actually could stand to understand a little bit better and to improve, I'm really active in the American Cleft Palate Craniofacial Association, so that's a professional organization, but there's also a patient and family arm to that. And I know that one of the things they're looking to expand are the resources and the professional listings and things like that for folks as they're transitioning through adulthood. So checking out resources like that can sometimes help you find a provider or you can call directly and connect with someone whose only job is cleft craniofacial care, and they'll help find those connections. So that's an important resource I think that families should be aware of. They can go to acpacares.org to view a lot of the support and resources that are available.

Ashley: That's really great.

Iva: So again, I told you so, I told you so. We knew that Leanne was going to have so many great tips and resources for us, and I want to let the audience know they will all be in the show notes so that way you can find them and that way you can get any and all the help that you need.

Ashley: That is going to be so great because you've given so many. So I feel like it'll be good to have them all in one spot. Something that I have been interested in in my own journey, but then also I've seen pop up in other people's journeys, is eating disorders. And I'm curious in any of the research that you've done, Leanne, have you done any specific research about eating disorders and cleft or have you seen trends with that?

Dr. Magee: I haven't done any research or academic work in that domain. I know that some of our young patients who have feeding difficulties might be a little bit more likely to struggle with eating and feeding. And I think once that becomes a source of distress in a family, we can return to it. I know it can be really tricky for our kids in the post-op period when they're on soft diets and liquid diets that there can be a lot of fear about returning to regular food, either afraid that it's going to hurt, afraid they're going to choke, just things feeling different. And so I think in young kids, I have seen a little bit of an increase of avoidant and restrictive food intake disorders: ARFID. So it's not quite like anorexia or bulimia where there's a weight component, but there's like a fear associated with food intake. But in my teens, I have seen, and it could be coincidence, I don't know, but a couple of patients really struggle with, maybe they already had a burgeoning weight or body image concern and then they go through jaw surgery, for instance.

Iva: Yes, yes.

Dr. Magee: And that sort of kicks off this process of weight loss, of preoccupation with food, fear about eating, and it almost normalizes that it's okay to stop eating. And so we have navigated with some of our teens having a really rough recovery where they cruise into disordered eating that requires much more focused care that's separate from their surgical recovery, but becomes a real psychological and behavioral concern. And so the treatment is really very similar for anybody else with an eating disorder, but there is this component of there being a medical event that precipitated it, or was the stress or the straw that broke the camel's back that kicked it into a full blown restrictive eating disorder. I think it's an area that probably deserves some more research and understanding because there is— when it's our mouths, it's our faces, it's our appearance. It's really ticking all the boxes that eating disorders tend to overlap with.

Iva: Yeah, it's funny that you say that. It was the onset of that jaw surgery, because that's what it was for me, because I had gotten down to a size that I had never been. I went to the fall formal, I got to wear this beautiful dress and I was determined to stay that weight. So up 12 o'clock at night trying to jog in place and do jump ropes and just trying to stay small and it just wasn't going to be the thing. But as you said, it was onset by something that I medically needed.

Dr. Magee: Yeah, and the timing of it overlaps with when there are risks for eating disorders. So you're a teenager, you're really focused on appearance and social relationships and what other people think of you. And so we're changing someone's appearance, often for the better with a jaw surgery but maybe also contributing to reduction in food intake or body size, and it's just like the coincidence and timing can be really tricky for kids. And so I think some preoperative counseling is always important. Making sure nutrition stays on point throughout the recovery process and that families and doctors are really mindful of what's too much weight loss, what's too long to be on that restricted diet, what's too much exercise so that we can really focus on holistic health and wellness, that it's not just, “Well, jaw looks great, see you in a year!” but thinking about that whole patient and what their life is like in those post-op months and years.

Ashley: Yeah, I remember when I had my jaw surgery, I had started restricting probably the year prior, so I had lost a lot of weight leading up to jaw surgery. And I actually remember being worried that I was only going to be able to have milkshakes because it sounded like it was going to be too many calories. At the time it didn't feel like that's why I was restricting but I'm sure looking back on it now and things that I have to be mindful of now is, I can't control what my face looks like but I can control what my body looks like and I can literally, “If I work out more, if I eat less, if I do

have more protein or whatever,” then I can modify that. So I would love to see more research on that for sure.

Dr. Magee: Yeah. Well, I think that's why it's so important to have psychosocial services as a part of cleft team because if you could identify those patterns or habits you're slipping into, folks who are struggling with that now, I think it's important that they could talk with their doctors about that to say, “I've kind of been a little focused on my weight and I'm worried that that might be tricky.” It really resonates with me that idea of, “What's the part of my appearance that I can control?” And so thinking about healthy ways to be appearance focused, like it's okay to want to like how you look and to want to look good, but how can we do it in a way that builds us up and helps us feel stronger as opposed to that kind of diminishing of ourselves, which can often happen with weight-based eating disorders.

Ashley: So, thinking about jaw surgery, I know something sort of a jump from that is, I remember my jaw surgery was one of the first ones that my parents said, it's up to you if you want to have this or not. But I also remember both that and the rhinoplasty when I was a teenager, my parents were under the impression that once I turned a certain age, I would no longer be on their insurance. And so it would be a whole different ball game. I remember that, and the jaw surgery in particular. It's interesting because my parents gave me the choice, but at the time, because nothing medical up until that point had been a choice, it felt like a fake choice, if that even makes sense. Like, it felt like they were offering it, but like it actually wasn't a choice.

Iva: It wasn't really...

Ashley: Yeah.

Dr. Magee: I think one thing that my team does really, really well is that conversations about surgery happen over years. And so there is this sense that it's not like suddenly the ball is in your court to make the decision. But we're monitoring growth and we're monitoring development, and we're kind of setting the stage for, as you get older, there are things that we're going to be discussing: These are the pros and cons, these are the costs and benefits, and this is kind of an ongoing process. So for a lot of our patients, that conversation happens four or five years before they even could be ready for those surgeries. And so what I think that does is really put kids in the position of being like, “Well, let me think about it. Let me learn about it. Let me see how I feel about it.” And it doesn't feel like a pressured decision where it's like, “Well, actually, if I'm going to lose insurance, I got to go. I guess I have to, right?” So there is this sense of maybe being able to take some more time to make peace with whatever your decision is.

Iva: Yes, they can.

Dr. Magee: Insurance issues can be really tricky and I think are certainly a real life barrier to care. And again, having those conversations with your team sooner rather than later helps you figure out, are there alternatives? Are there secondary insurances that you can get on that will cover you for longer? Are there letters of medical necessity? What can your team do to help give you that time to get to the place where you're feeling not just physically ready in terms of your growth, but emotionally ready to make the commitment to a major surgical change?

Iva: What's been your experience like when it comes to coverage for mental health services? Because we all, as you said, insurance can be tricky and especially in that age pocket of that 25 and you're transitioning off your parents' insurance. I think for a lot of us in the community, that's actually where we need it the most for that psychosocial, having that identity crisis of like, "Okay, I have to make peace with my cleft or my craniofacial," and you need someone to talk to.

Dr. Magee: I think this is a huge challenge for the field of psychology in general is this idea of mental health parity, that there can and should be equal care and coverage for mental health concerns as there is for medical concerns. But even orthodontics was considered non-essential sometimes and we think for clefts, how essential that is. A lot of things that we do is really try to work to figure out what the resources are. I think one of the wonderful things, COVID was not great, but it advanced technology in some really important ways. And the availability of telehealth services means that it can be much easier for patients to find someone who knows cleft, even if they live in a different state. Many of us as psychologists can apply for a telehealth license that allows us to practice across states virtually. And I think during the major parts of the pandemic, insurance companies were pretty open to covering more mental health services because there was a real significant increase in mental health needs, but there's a huge shortage of providers and services that are available. We have unfortunately started to see some of that disappear again. And so stuff that had been covered is kind of expiring. Those agreements with insurance are starting to expire. So we're getting back to a place where there are, the need for mental health services is outstripping the availability of providers and families' ability to access and pay for that care. So being an advocate, if you ever see stuff coming up on the state or local level related to supporting mental health parity, that can be really important. Contacting your insurance companies directly or asking your therapist to do that on your behalf to find ways to get that coverage, I think is important. But it takes such hard work and persistent work, and that can be really tricky to do, especially if you're not feeling too great, right? When we're depressed, we don't do our

best making phone calls. So finding your people to help with that legwork can go a long way.

Ashley: I feel like insurance companies intentionally make it hard because they're like, if I deny you 10 times, then you won't come back an 11th time.

Iva: Yeah.

Dr. Magee: You need those tireless advocates. I know Iva, I've seen your mom speak, she did it. She went for it.

Ashley: Yeah, you got to do it!

Dr. Magee: She kept those receipts and she persisted. And having someone who's willing to do that work with you is so important.

Ashley: Yes, having someone in your corner. I will say having mental health services covered has been something that I've struggled with. I adore my therapist that I have now. I really kind of stumbled upon him, but he doesn't accept insurance. So it's like, I have go through the insurance company and get reimbursement up to a certain amount, but they don't start covering it until probably after I've paid a really exorbitant amount of money. And I also love that you mentioned how important it's to find a therapist who specializes in cleft. And I also think even if it isn't someone who specializes in cleft, I think having a therapist who specializes in trauma, particularly recognizes medical trauma, because I sometimes hate talking about it because it's such a buzzword right now. But I feel like once I discovered trauma and the breakdown of how trauma can impact you and all of the different parts of you, I feel like my life changed. It made sense. I no longer felt crazy if something weird happened. So anyway, I love the idea of finding someone who specializes in those things because I think sometimes when you look for a therapist, you don't even know what to look for, you know? So hard.

Dr. Magee: Yeah, I always tell people to have a list of questions going in. So if you get a list of 50 people from your insurance company, how do you sift through that? So, part of it is figuring out what are you looking for? What areas of your life are you hoping to explore or change? And asking that therapist, when you have that first call, are you available? Are you accepting patients? What do you charge? Where are you located? Helps you know if that's even going to be possible for you to see them. And then finding out, well, what's your approach to working with people with medical stress and trauma, with visible difference, with health concerns, with appearance concerns? And then I tell people, it's like finding a pair of jeans. It's all about the fit. They could be great on paper, but just not the right fit for you. And so, give it a couple of sessions, two or three sessions,

but be willing to move on to the next one. Or communicate with your therapist, which can be really vulnerable to do, but to say, “I’m just wondering if this is going to work for us because I’ve felt like maybe you don’t understand something.” And having that convo, there are lots of therapists who will be like, “Oh, great, let’s talk about it. Let’s dive in. How can I be better as a provider for you?” And some people will say, “Yeah, I don’t think I have the skills that’ll be a good fit for you, but I know someone who I think could.” And so I think a great therapist is about supporting the patient even if it means helping connect them with a different provider.

Iva: Well, Leanne, this has been amazing. Thank you so much again for coming on the show. We have one last question for you, and it’s just, what’s something you wish more people understood about the psychosocial care in the cleft community or what is most understood about the psychosocial care within the cleft community?

Dr. Magee: I am a strength focused person. And so I think when we think about psychosocial, people assume that it’s because kids with cleft have a hard time and isn’t it terrible, right? And so I like people to know that actually pediatric psychology is all about building strength and resilience and coping and making meaning of the hard things that we’re going through. And it’s for everybody. It’s not just for someone who’s depressed or anxious or having a hard time, that psychosocial services are really about quality of life and improving your own lived experience as you’re going through care. And so, I think some people are resistant to seeing the psychologist on our team because they’re like, “We’re fine. We don’t need that.” And again, my bias is showing, I think we all need it. I think we all, regardless of what we’re going through, could stand to have a check-in with someone once in a while about like, “No, well how’s it really going? And how can we help?” So, I really want to decrease the stigma associated with mental health care. I think more and more teams are including psychologists and social workers as a part of their team. And I think that really just normalizes that we are part of the whole package of caring for that entire patient, that entire family. We’re not just anatomy, that there’s a whole person. That’s actually the most important thing. I want to knock down those walls to accessing psychology services.

Iva: Okay, guys, that’s our show for today. So Leanne, please tell everyone where they can find you if they just want to learn more about you or the work that you’re doing.

Dr. Magee: They can check me out on chop.edu. That’s the Children’s Hospital of Philadelphia. And I’m always happy to receive an email. I can be emailed at MageeL@chop.edu.

Iva: Guys, please reach out to her and tell her how much you appreciate all that she's doing and how much you loved listening to her today. And don't forget, we love to hear from you. You can find me on Instagram and TikTok @realsophisticatedjoy.

Ashley: And you can find me on Instagram @cleftloveig and on TikTok @CleftLove. And don't forget to go to smiletrain.org to learn all about the wonderful things Smile Train is doing for the cleft community around the world. You can find us on your favorite podcast streaming site and while you're there, please don't forget to leave us a five-star review. Thank you so much for listening. Bye!

Iva: Bye guys!

Announcer: If you like the show, be sure to subscribe, leave a review, follow us on social, and tell all of your friends to listen. Questions or episode ideas? Email us at lovemeetsjoy@smiletrain.org. We can't wait to hear from you. Love Meets Joy is a product of Smile Train. Our hosts are Iva Ballou and Ashley Barber. Our senior producer and editor is Ariel Nachman. Our Smile Train producer is Adina Lescher. Love Meets Joy is presented by Smile Train, the world's largest cleft focused organization. One in 700 babies is born with a cleft, a potentially life-threatening birth difference that can cause difficulties eating, breathing, hearing, and speaking. The Good News? Smile Train has developed a sustainable model that empowers local healthcare workers around the world to provide life-saving cleft treatment to all who need it in more than 70 countries. 100 percent free. Learn more at SmileTrain.org.