

Love Meets Joy Podcast
Episode 5: Bullying and the Power of Language
Transcript

Ashley Barbour: Hello. Hello. Hello and welcome back to the Love Meets Joy podcast on the Smile Train podcast network. I'm Ashley Barbour, and I was born with a bilateral cleft lip and palate. I'm the creator of Cleft Love. And by day I work as a teacher consultant with students who have hearing loss.

Iva Ballou: Hey everyone, I'm Iva Ballou. And I also was born with a bilateral cleft lip and palate, I'm the CEO of RealSophisticatedJoy and a cleft confidence coach. So today guys, we are discussing storytelling. So I loved elementary school, loved elementary school, even though there was like some dark times, it wasn't that bad, middle school was so, so, but high school, particularly ninth grade horrible. Absolutely.

Ashley: What do you think made it so hard?

Iva: Um, so for me that was, I think the longest stint I had of like true bullying <laugh> there's no other way to say it. Um, so, and it was, you know, one particular person in, like she made it her business to really let me know that I was not welcome around and just little things. And so, yeah, Ninth Grade was not fun for me at all.

Ashley: So was it all cleft related that she was, you know, saying those sorts of things, is that what you think made it the most challenging? Did she talk about other things?

Iva: So at the time it was half and half, a lot of it came from my cleft, but I can also be honest and tell the story from a different viewpoint now in adulthood, by that time, my cleft had hardened me a little bit and I was very, um, I would say, not as joyful as I am now. And so it might have also been that, but she would always lead with my difference, my facial difference. So there is that it was not fun. Yeah. It was not fun. So what about you? How was school for you? Oh,

Ashley: I am sorry. Um, I actually loved school a majority of the time. Yeah. Elementary school was great. High school was great. I think the most challenging time for me was middle school. And I think we sort of touched on in a previous episode that it was hard because we started school young. Right. And so I wonder if there was an element of immaturity as well, that sort of made that middle school time period a little bit more challenging, but in elementary school, something that I actually did that I think helped me a lot was every year sort of at the start of the school year, I would do a presentation for my class about cleft in general. And I would talk about my specific kind of cleft. And I remember one time I, I brought in a dentist mirror. Wow. And so my class could see the hole that was still in the roof of my mouth.

Ashley: And I brought in baby pictures and I let them ask questions. And I feel like that really positively impacted me, especially my elementary school experience.

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Because I found that if kids understand something they're less likely to make fun of it because then they develop some sort of empathy around it. And something that actually happened once I got to middle school, I had a friend who was in an art class and I was not in that class. And she came and she told me about this thing that happened while she was there. She said that there were some kids in there making fun of the way that I looked <laugh> and I wasn't there. So I didn't hear it. Mm-hmm <affirmative> couldn't defend myself. Right. Um, and this boy that I went to elementary school with who had been in multiple of my classes, we'd gone to school together since kindergarten.

Ashley: He went over to them and told them to stop and that, you know, it wasn't nice. And it was, she was born with a cleft and it's not her fault that she looks different and all of these things. And so I basically have loved him. Absolutely. Since he's now married with children, but I still get little butterflies when I see him. Yeah. I just think it's so beautiful to know that even though sometimes there are some challenging moments right in this and school can be challenging. Sometimes there are also a lot of really beautiful moments and beautiful people and I've found on this journey, there are many more beautiful, positive kind people in the world than

Iva: Not. It's great when you have people who can stand up for us. And as you said, I think that's really powerful that you were in elementary school giving presentations and saying, Hey, this is who I am. I wish I had that type of strength and courage to do that in elementary school. I think life would've been really different. So again, that's a great tip to do, but I, I had a similar experience because you know, it couldn't be all bad. There's always some sunshine. And for me, one of the moments that I remember the most is not middle school, you know, school dances are already a nerve wracking thing for a girl, but <laugh> to add on having a facial difference. And I already knew no one was going to ask me to dance and all my friends had either their boyfriend or their crushes,

Ashley: Or that was the story you had told yourself was that nobody was going to

Iva: Ask you to dance. The story that I had told myself was no one was going to ask me to dance, but it was true. I was the only one I wasn't on the wall cause I'm going to dance regardless. I don't care about myself or with

Ashley: Somebody. Yeah. Yeah.

Iva: Uh, one of the guy, friends, he was like the star of the basketball team for our, our middle school. He actually like asked me to dance and dance with me. And I remember some of the girls who were teasing me the way that they looked. And so it was a great moment. And like you, to this day, I still see him and I've actually been able to tell him in adulthood. And he was like, you know, I don't remember doing that, but I absolutely would dance with you again. He was like,

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you were always just good people. So why wouldn't I dance with you? And it was beautiful.

Ashley: Yeah. And what a beautiful thing that is to keep in mind for everyone that we never know the impact our actions are going to have on someone else. So for him that wasn't necessarily something he's hung onto because it wasn't necessarily a big deal, but for you, it was a shining positive moment. And so I think that's just something, a nugget of wisdom for us all to remember that our actions can absolutely powerfully impact people in ways that we don't even realize,

Iva: Like we have one little act of kindness that you're just thinking is a throw off is truly life changing. Cause it was a major bright spot for me. Yes. Um, absolutely. And it did help with changing the story that I began to tell about myself in a previous episode you had said, or coin the term medically fragile. And especially in that middle school, high school era, that's how I felt about everything. Like I couldn't do a lot of things or I, the story I told myself was that I couldn't do things like I wanted to go out for my like miss high school. Um, and some of it was added with my mom just being protective and wanting me to, you know, be shielded and as a mom, mama bear would, do

Ashley: I have a question for you? Can I interrupt you and ask,

Iva: I'll ask what's going on.

Ashley: Did you have a lot of your surgeries during the school year? And if so during recovery, were you limited medically and things that you were allowed to do? Like couldn't participate in gym class or things

Iva: Like that. So it was a mixture of both. In fact, my jaw surgery was the beginning of August. I was out of school until October. I had some in the summertime. Yeah. But being in Florida, the summertime was really when you were to be the most active. So there was a lot of things that I didn't get to participate in. Yeah. So the normal social experiences that a lot of kids had, I didn't get. So again, it was another I'm different and I'm being protected. And so it's just a cycle of stories that are told over to yourself over and over again. Um, to the point that no one else began to tell me the story I was telling it myself to me.

Ashley: Right. Then we end up limiting ourselves. Yeah. Because yeah. Oh, I just can't do that. Or I shouldn't try that because I might get hurt or, and this is a weird niche thing and I don't know if your mom did this too, but my mom had this thing with suckers where like, if I was to have like a lollipop or a sucker, I had to be sitting down <laugh> um, because she just was convinced that if I was walking around with it, I would trip and fall and it would open up my palate. And so her thing was

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if you're not going to sit and if you fall and that thing goes through the roof of your mouth, you have to call the doctor and tell him what you did because

Iva: She wasn't like that with the sucker. But I don't know if I have disclosed on here. Uh, I, I can't see out my left eye. And so I'm supposed to wear glasses, but I was just adamant, there was no way I could have these huge glasses, a cleft and be big. So it was like, mm-hmm something got to go. So I always broke my glasses.
<laugh> sorry, mom,

Ashley: Intentionally, how did you break

Iva: Them? Sometimes I would either break them like literally just crack or it was, I accidentally lost them. Sorry. And so by like the third or fourth pair, oh my goodness. Bless my mother. She said you know what? You like it, I love it. Do what you're going to do. But if you end up blind, yeah. That's the choice that you made. My mother's really been accused about making it's making a choice. And so that was

Ashley: One

Iva: Time that she was like, I cannot protect you from you. And thankfully, as I've said before, God protects babies and fools. He protected me. I, I, but it is something for a while. I would not do certain things because I have to be very careful to protect that eye. And then one last thing, when that is, I wear contact lenses. And so part of that is again about the camouflaging. But if I don't wear that, contact lens, I look different. And I remember the first time

Ashley: The contact lens gives you an iris set of pupil. Is it just white?

Iva: Otherwise it is white. And so to give me some normalcy, I wear the contact. But the story that I had always told myself was I could not go outside without that contact. So I remember the first time that I went to work and I was like 30 years old without my contact. Yeah. I was so scared but proud. And nobody noticed nobody noticed at all. Nobody knows they

Ashley: Didn't. Oh my gosh. So even

Iva: Though the story that you tell,

Ashley: Oh, this totally reminds me. I just saw a video the other day, that called attention to a study that was done in the 1980s a group of women were brought in and they were told that a makeup artist was going to come in as special effects makeup artist and was going to put a facial scar on them. And then their job was going to be to go out into the world and see how the world perceives them with this, with

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this scar on their face. So as I'm watching this, I'm like, all right, I totally know where this is going. Right. And so the women get the scar put on their face and then the makeup artists show them themselves in the mirror so they can see what the scar looks like. They know, um, then they take the mirror away, and then the participants are told that the makeup artists have to come in and put one last thing on the facial scar that they were given to make sure that it doesn't rub off or anything like that.

Ashley: So, you know, they come in, they're ready to have it sort of solidified on there. And then what actually the makeup artist did though, took the scar off the pretend scar. And then unbeknownst to the women, it was actually gone. And they went out into the world and then had to report back how the world interacted with them. Then thinking that they still had this facial scar and all of them reported that they were treated more negatively, more people were staring at them. All of these things. When in actuality, they were encountering the world physically the same way,

Iva: The story that you

Ashley: Tell when I heard that though, it kind of messed me up for a little while, because I was like, does this mean that my whole life has been a lie or like that I've totally constructed this reality that I've viewed differently. Yeah.

Iva: That's an interesting thing. Yeah. The story that you tell,

Ashley: The story that you tell and sometimes right, is probably a combination, right? Yes. Yes. There are things, real things that have happened. Real people have called attention to our difference or scars negatively, but then that information lives in us. And then we encounter the world in the way that we assume that everyone must be thinking that when in actuality, maybe they're not just like when you went to work and people didn't even notice that you're

Iva: Didn't even notice. And I, yeah, that is really strange. Cuz I get what you're saying about it, did I make this all up in my head because yeah. You know, you have this viewpoint or you're told this story that you're, you're a victim of a cleft or that you're a cleft survivor and

Ashley: Those are words. Some people use. Yeah. I've heard.

Iva: And I never like latched onto those words for myself. And so I didn't like the word of being a victim because, and maybe you could relate to this as like, I hated the feeling of perpetually feeling weak. I'm not just because I have a facial difference does not mean that I'm weak or lesser than because there's a lot of strength that goes on with this.

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- Ashley: Yes. In fact the opposite. Yes. The opposite is true. It makes you
- Iva: Stronger there are certain things that I have gone through that yes. The average person, if I were to really sit down and list them, how are you here? So I didn't like that. And then when you say, yeah, plus survivor full disclosure, I, I had my dad's side of the family, including himself, either battled cancer and survived or actually did pass away from it. So I don't really want to take that word away from that community because it's a real fight. And for me, I don't necessarily feel like I had to fight anyone with my cleft more so just my, myself in the story that I was telling myself. So
- Ashley: Yeah, that totally makes sense. And I think I agree with you, those aren't words that I would use to describe myself, but as I'm thinking about the global cleft community, I wonder if in some parts of the world where cleft treatment isn't as readily available. A lot of babies born with cleft who do not receive treatment, do end up dying. And so the people that I have seen use that on social media tend to be from other countries. So I'm wondering if there's like a cultural element
- Iva: There too, that still goes back to because it is a truly a fight to live that is different that I can understand saying yeah, yes. Oh, I'm a cleft survivor. Mm-hmm <affirmative> but you know, I would love to hear and Ashley and I would love to hear what the audience take on being called a cleft survivor or a cleft victim is, but before we can get to that, we got to go to break because I'm pretty sure Ariel's going to jump in soon and be like, we're talking too much as we always do.
- Ashley: <laugh>
- Speaker 3: 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. In 22 years, 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. Visit 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.

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Ashley: Welcome back from break. Before the break. I, I know that you and I had kind of started talking about words that are used within the cleft community or even outside the cleft community related to cleft that you know, whether they resonate with us or not. And I am going to get a big dark word out of the way, uh, yeah. For educational purposes, to talk about it. I think you probably know the one that I'm talking about, but I think it's really important that we talk about not only the words that we appreciate using and identifying with and those that we don't so people who are maybe outside the cleft community, an old, outdated medical term that used to be used for cleft was hare lip. And it basically is because when the cleft is untreated, it's split in the way that the lip of a hare or a rabbit is split. And while it was a medical term for a long time, the medical terminology has now switched over to cleft. And a lot of people in the cleft community have heard that word used as a slur, almost

Iva: It's derogatory and triggering

Ashley: <laugh>. It is it's very derogatory. So it shouldn't be used. I will say there are some people who are older who have like, are accustomed to that terminology. Yes. As the medical word. And they might still identify that way. And I think if you are cleft affected, and that's a word that you want to use, that's totally fine. Absolutely. But I also want to say, in addition to it being a slur, there's sort of a dark history behind it that I think a lot of people don't actually know. So during sort of the time period of the Salem witch trials, right. When women were being accused of being witches and then murdered, right. Uh, right. If a woman had a child that was born with a cleft, it was a rabbit or a hare is often associated as a symbol of the devil. Right. And so if a woman had a child at that time who was born with a cleft, it was said that she had had like a rendezvous with the devil and that she must be a witch. And so the baby was sometimes killed or the mother was sometimes killed. And so just identifying cleft with that dark history, using the word hare lip is just not great. So that's one that I personally don't use. And if I would say that if you are outside the cleft community, you should never use it either.

Iva: I'm going to back that sentiment. I don't like the word. I don't use the word for myself. And if you are not cleft affected, don't use it.

Ashley: And I don't know, what's crazy is like, I feel like there are so many entertainment things that haven't caught up that the terminology has changed because there are like early seasons of Greys Anatomy when cleft comes up, you know, with whoever the plastic surgeon at the time is, and they use the word hare lip in that, um, in one of the early versions, printings of Harry Potter, there's a witch with a hare lip quote unquote. Yes. Um, and so it shows up a lot in literature and on TV, but for everyone who's listening, make a note for yourself, make a note, anytime

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you hear it, <laugh> just gently correct people that, you know, the wording has definitely changed. It's not a word most of us like

Iva: It's very easy to say, oh, do you mean a cleft?

Ashley: Right? Yeah. Oh, the word has changed.

Iva: And again, as, as you said, it's one thing if the particular person who has a cleft is of a certain age.

Ashley: Yeah.

Iva: They're going to that's what, when they were born, that's what it was called. And so of course, but on the other side of that, if someone who is, says, I do not like that word. Yeah. Don't use that toward me or around me. Yeah. Just let that be right. For sure. Um, and another word that sometimes can be a yay or nay for the cleft-affected community is cleftie. And for me, I do use cleftie. Yeah. It doesn't bother me. Um, and sometimes it kind of feels a part of a special club like ah, you know, and so that's why I can use that. Yeah. Because we don't really have a lot of positive words yeah. Reflective of our community. So, and, and I don't always want to say cleft affected or facial difference because we get it. I have a cleft. Yeah. We get it. And so for me, cleftie sounds more, you know, inviting more positive to how I feel. I don't want to be seen as a victim. I'm more than a survivor,

Ashley: A cute word for you. Yeah. Yeah.

Iva: And if anything, you can call me a cleft cutie. I'll be that every day I am a cleft cutie. <laugh>

Ashley: Funny. You know, I have to be honest though. I usually don't use the word cleftie. And again, it's just one of those words that some people like, and some people don't, I don't know why it kind of gives me the ick. Like, I don't know what it is about it, it's just not my favorite. Um, I usually just use cleft affected or, um, like, I don't know why. I don't know. I can't even explain why it kind of gives me the heebie-jeebies but it just does. It doesn't bother me if like you want to use it for yourself or whatever. Like, um, that's good, but it's just not one that I use for myself. But I also know that there's something that I've noticed in the cleft community that's used that I think you and I also have sort of differing opinions on and something that I've seen other adults use, especially cleft-affected adults who were born with unilateral clefts is they refer to their good side as being their non-cleft affected side. Yeah. Which then me as someone who was born with a bilateral cleft like I have scarring and asymmetry on both sides. And so that I'm

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like, oh, like, I guess I don't have a good side at all. You know? And so I like, that's something that I've always thought was like, kind of like, eh, yeah. <laugh>

Iva: Yeah. It, that is kind of tricky because how do you say that? Because for, again, for the audience, if it's unilateral, their cleft is only on one side. So technically if they were to turn their face yes. You may not be able to see their cleft. Right. Whereas for Ashley and I, and other bilateral clefties, sorry for the word, but

Ashley: No, that's good. You use it. That's the word

Iva: You like,

Ashley: You use a girl. Yeah.

Iva: Um, no matter what side front left. Right. You're going to see some part of our cleft. And I know for myself, I do feel like I, I have one side that especially growing up that was more tolerable for myself. Yeah. So if you go back in like a lot of my pictures, you, I would only pose from one side only is one side.

Ashley: Now that you're saying that I also have a side that I'm drawn to just posing from. Um, and so maybe it's just my perception or the story I've told myself about what I think that that term means, you know, but it just seems to be that

Iva: That's talk about the story that you're telling

Ashley: Me. I know, but it just seems to be that that's the correlation a lot. And so I just want to like, remind everyone that words are powerful. Words are important. Absolutely words carry so much meaning. So I think sometimes people think that, you know, you're being too sensitive. If there are certain words that you should use or shouldn't use words, carry so much weight that I think it's a very important discussion to have. And I also feel that way about the word birth defect, because while I understand that it's not typical, I much prefer the use of birth difference just because I don't think I'm defective. You know, it kind of makes me feel like a person. Yeah.

Iva: So, for me, it depends on the context of the conversation that we're having. Yeah. If you're looking at it from a medical standpoint, yes. I have a birth defect and I will say it that way. Ah, but in conversation, I just have a difference. I have a difference from you. Cause I agree with you on the wording. I am not defective. And it's funny that you say that because I had a conversation just on Monday and it was with someone who I am very comfortable with. Yeah. I know their heart's in a good place, but they said a word directed towards me and I was triggered and it really played on those cleft insecurities. So, you do have to be very mindful of your wording. Yes. And I knew that they didn't mean it that way and they were

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just in conversation. Yeah. I, I think it's just important to make sure that being intentional about the words that you say. Yeah. Because you don't know the story that somebody's going to tell themselves when you say it.

Ashley: Yeah. Or what someone has experienced throughout their life mm-hmm <affirmative> and how it might affect them. Right. Like using the H word. Right. If someone has been targeted using that word than it's going to carry more weight. Exactly. And at the beginning of the episode, we touched a little bit on school experience and I'm wondering,

Iva: Right.

Ashley: What your experience was like with bullying. Did you experience bullying, uh, at what point in your life was it the most challenging?

Iva: So I, for me, I had a rollercoaster of as far as bullying. So when I say rollercoaster, there were times when I was bullied. Yeah, absolutely. And then there would be periods where I wasn't. So I would say up until pre-K up until the Fifth grade. Yeah. No bullying stands out to me that I can really, really remember. Yeah. I had teasing obviously, because kids don't know, they didn't know about it. I wish I would've done as you did and had done the presentation that would've been helpful, but fifth grade was a major bullying moment for me. Um, so one thing my mom is part of her, wanting to make sure that I had a sense of normalcy. Yeah. Um, all of her children played an instrument. Ugh. I loosely played the flute. Okay. Oh.

Ashley: Was it hard to play the flute with, um, the hole in your mouth? Why did you pick the flute?

Iva: <laugh> because it was, I couldn't do the clarinet and they tried to give me the triangle, but I was like, oh, that's for babies. So, the only thing that I could find was the flute.

Ashley: I'm trying to think what there is, that doesn't require. There's nothing. Mouth like nothing. Yeah. Guitar. I mean, I guess you could have done percussion.

Iva: No. Okay. So no that wouldn't have worked either.

Ashley: So anyway, no, no.

Iva: I was coming back from a band recital and I'm so I'm walking down the hall. One of my classmates is walking in front of me. And as we're walking down, there is on both sides of the hallway. There is a second grade class.

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Ashley: Yeah.

Iva: And as I begin to walk down the hallway, they begin to laugh and say, look at her face, just in the, and oh my goodness. There are times when I'm like, did I really did that really happen? Because it was straight out of a scene of a movie or television show. So in fifth grade I was like 10. Yeah. Even at that age, my only thought was, I know you want to cry right now Iva and you can cry later. Yeah. But right now you cannot let them see you cry. Yeah.

Ashley: Gotta

Iva: Hold it together. You will hold your head up high. Yeah. And you will walk down this hall. And so ironically, my classmate ahead of me, me, he looks back and the look on his face. I will never forget because he looked so sad, both because of what was happening to me. But also I feel like, because he, he knew he wasn't going to do anything. Yeah.

Ashley: But he wanted to, he

Iva: Wanted to, but he didn't know what to do. Ugh. And I remember looking at him like it's okay. It's okay. Yeah. So I had to be strong for me and strong for him. And it wasn't until, yeah. Like maybe a month later that my mom found out. And the only reason why she found out is because I think he told his mom, oh, who told my teacher. Oh, who told my mom.

Ashley: Oh, and did your mom do something? I know you've said that your mom's like a big mama bear.

Iva: Oh, I will just say it like this they were not prepared for Carolyn Ballou that day. <laugh> she? They were not prepared for her that day.

Ashley: <laugh> oh, no.

Iva: Like my, I it's one thing that I will never take away from my mother. She definitely was mama bear. Yeah. And so she did go down to the school. She wanted everyone to be in trouble and it's like, okay, it's not that serious, but it was something like, and it's one of those things that as much as I am now doing what I'm doing. Yeah. Part of me does carry that along with me. Yeah.

Ashley: Yeah.

Iva: Other than obviously ninth grade is that I mentioned at the beginning of the show, those are like my two biggest moments of bullying. Yeah. That I have that's and anything for you.

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Ashley: Um, first of all, I'm sorry that you experienced that, that sounds like a really terrible experience. And I think it shows how it's hard to be a kid in a lot of ways. It was hard for you. It was hard for that child in front of you who knew that they should be doing something, but it's hard. I mean, as an adult, sometimes when, you know, you should say something and it's, and you don't, I mean, we've all had that experience, I think. And then it's also hard likely that the entire class, it was like a mob mentality. Right. That took over. So it was, I bet that there are kids there who to this day are like, oh my goodness. I can't believe that I did that to that girl or to Iva, you know, like anyway, um, my experience in school, I said earlier that I loved school overall, I honestly had a really great school experience.

Ashley: I feel like, okay, there were moments of teasing or kids saying mean things. Yeah. Related to my cleft or how I spoke. There was someone in middle school who, you know, made fun of the way that I talked, because I talked really nasally when I was in actually in elementary school, a girl that was grade above me. She mm-hmm <affirmative> um, called me booger nose. And I think it's because it was soon after my lip revision and I'm sure it was all numb. And so when my nose would run, I couldn't feel it. And so I probably did have a booger nose. I'm just saying,

Iva: Yeah, I still can't feel mine sometimes.

Ashley: Yes. And my nose after my rhinoplasty, uh, still is a little numb and that was five years ago. Uh, so I am very cognizant of checking my nose now as an adult because I can do that. But as a kindergartener, I wasn't thinking that. But overall my experience, I, I didn't have a ton of bullying. There were more kids who said, mean things. I think when I was in middle school again, because I had sort of come away from doing those presentations. There were just so many more classes and it just wasn't practical anymore. But I think that I got lucky, not only because I was sort of in the business of educating people about it, but I grew up in a college town where there were a lot of different kinds of people. There were just people from, you know, all over the world,

Iva: All walks of life. Yeah.

Ashley: Yes. And so I really think that that contributed to me having a positive growing up and school experience because kids were used to seeing other kids and adults who were different from themselves. So I think that was, um, definitely something that was, you know, a positive thing in my life. Yeah. And I'm interested to know for you, how did you respond to bullies? Because for me, when someone made fun of me, I would just ignore it. I would pretend like it didn't happen. I wouldn't call them out on it. I wouldn't do anything honestly. Like I would just ignore it and go about my life. Like keep on keeping on. And I think that that actually was a powerful response. Like in doing nothing, it was a great

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response because the people looking for a reaction out of me didn't get it. And so I think that was something that I did that helped me as well because people were like, oh, well it's no fun to pick on her because she doesn't do anything about it. It's no fun.

Iva: Yeah. So as I said, in elementary school I did as you did, I ignored it. Yeah. I kept my focus and I lost sight of that. So yeah. In middle school and high school, yeah. I was tired of turning the other cheek

Ashley: Yeah. They can be tiring, you know,

Iva: Michelle

Ashley: Go high

Iva: And when they go low. Yeah. I was tired of going high. I went low <laugh>. Yeah. And I'm not proud of it now, but back then I went low because I just was like, okay, if you're going to come for me, I'm going to come for you. And I'm realizing, you know, as I grew up.

Ashley: Yeah.

Iva: And I started to find my own sense of love for my cleft. I had to be honest, maybe that was a story that I was telling. Yeah. And no one was coming for me all the time. So I do wish that I would've kept the strength that I had in fifth grade and just held my head up high yeah. About certain situations. Um, but then we also expressed that part of that was because of the hurt of like my father passing away too. Yeah. It was just too much together. Yes. And I was just, I was, I was angry for a little bit. Yeah.

Ashley: And yeah.

Iva: You know, as they say hurt people hurt

Ashley: People. They do. And I think it's worth noting again here that this whole thing is a journey. And just because you respond one way, mm-hmm <affirmative> at one time in your life doesn't mean that absolutely. That's going to be how you want to respond later. And mm-hmm, <affirmative>, you know, you might try something that works and then you try something that doesn't work and something that works in one school building or with one bully or someone who's being mean might not work with someone else.

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Iva: Absolutely. That's actually how RealSophisticatedJoy came about. I was like, being mean and nasty is no longer serving me. Yes. I, I want a change I wanted, I just wanted to change and that's where it came along.

Ashley: But I'm curious. Is there anything that you appreciated that your mom did? Or is there something that you wish that your mom didn't do or that you wish she would have done or did instead that would've made your life easier? Cuz, I feel like that's a question a lot of parents have for cleft-affected adults. Like what can I do to make my child's life easier?

Iva: One thing that I will forever tell my mother, thank you for. Yeah. And that I'm forever grateful for. Yeah. Is she taught me the importance of advocacy and that is something that she always taught me. She like, if you don't speak up for yourself, no one's going to speak for you.

Ashley: I like definitely know that that's a lot of what my parents did. And I think that they just were always there and willing to talk to me. I remember laying in bed with my dad at night because we would always read, you know, every night before bed mm-hmm <affirmative> and then my dad, I remember we would go through scenarios. Like what if someone says this negative thing to you? What would you do? You know, that's what you get when you have social work parents <laugh> you're like before bed, like let's prep you for like what you can say. So,

Iva: But it's needed. It is it's needed

Ashley: So needed. It's so important. Yeah. So I'm just really grateful that I had the amazing parents that I did. It sounds like you had really incredible parents who were always mm-hmm <affirmative> super supportive and your biggest advocate as

Iva: Well. Yeah. And yeah, my dad, his, his thing was you're bigger than your cleft. You're bigger than your cleft. It's okay. You don't have to let that be your only thing. And then always brought such a huge smile to my face.

Ashley: Yeah.

Iva: And you know what, I think speaking of smiles it's time to get into our favorite segment. And that is the Smile and Slay segment. We talk about a question that we have heard from either friends, family, or even you the audience. So for this episode's Smile and Slay question. Ooh, Ashley, it's a good one. Have you ever been discriminated against at work because of your cleft? Let's hear about it.

Ashley: I personally do not think that I have been discriminated against at work. I know I have heard people talk in some adult cleft groups that they feel like they've been

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passed over for certain things because of their cleft. I have never experienced that. I will say when I started a new job once I was a few months in and I had to have an adult cleft-related surgery. And so I had to go to my supervisor and tell him like, Hey, I'm going to need some time off. Here's why here's what's going on. And he, bless his heart. Right. Was trying to relate to me I think. But he ended up spending the next, like 15 minutes talking about how there was a boy he went to school with who was born with a cleft. And did I know that cleft isn't just a cosmetic procedure and all of these things. And I was like,

Iva: Yeah, you don't say

Ashley: Ha, this is my supervisor. I can't go off on you. But this is like the biggest mansplain I've ever experienced.

Iva: <laugh> it's mansplaining. And also just, I'm sorry, just stupidity. Like you don't say that it's more than fast. Like I'm telling that was your cousin. I have it. I know, I know.

Ashley: I know.

Iva: Bless him. Bless

Ashley: Him. Bless his heart. So

Iva: Yes, majorly bless his heart. So it wasn't a full-out no for the job, but he, so I had a supervisor who made the comment of, he didn't know how I would fit as far as being, in the front of the office.

Ashley: So was it for like a, like a front desk position kind of thing.

Iva: It was a front. Yeah. It was a front desk position. And he, he was really questioning. Could I handle, he was like, because you know, you're going to be the first person that they see. Can you handle that? And I'm thinking, well, I wouldn't have applied for this job.

Ashley: Yeah. If, if I

Iva: Didn't think I could handle it. And are you saying that you can't handle me as the front person for this particular office? Right. And this is your way of skirting around that.

Ashley: Yeah.

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Iva: Um, but I actually, I did end up getting the job because I was good at it. And I was, by that time I was putting myself in places that made me feel uncomfortable so I could get over it. Yes. Yeah. Yeah. So that was how I dealt with it. Yeah. But it was just that I knew what he was saying without saying, and I too have heard other, you know, cleft affected people say that they have, they purposely don't get jobs like that

Ashley: And

Iva: Or that they have been turned down.

Ashley: Yeah. And I definitely think that that's a real possibility, right. Like, because for some of us speech is much more difficult. And so I imagine that that plays into like what you do at like an interview, how you are able to present yourself. But I also have to wonder if part of it is again, the story that we're telling ourselves and maybe we don't know the full story, right? Like that's good, maybe, maybe it was related to the cleft or maybe, you know, there was someone else internally who applied. And so we just automatically assumed that. But all right, this has been fun and interesting as always Iva. I love talking to you, but that's our show for today, but all of you listening, don't forget that we would absolutely love to hear from you. What was your school experience like? Did you experience bullying, please, please, please let us know. As always you can find me on Instagram at CleftLoveIG and on Tik Tok at CleftLove.

Iva: And you guys can find me on Instagram and Tik Tok at RealSophisticatedJoy. Don't forget to go to smiletrain.org, to learn more about all of the wonderful things Smile Train is doing for the cleft community around the world. And you can find us at your favorite podcast streaming site while you're there. Don't forget to leave us a five-star review. Those reviews help us bring awareness to this wonderful community that Ashley and I love. And thank you so much for listening guys. We'll see you next time. Bye

Speaker 4: Bye.

Speaker 3: If you like this show, be sure to subscribe, leave a review, follow us on social and tell all of your friends to listen. Please reach out with any questions or episode ideas by emailing 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. 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 is that Smile Train developed a sustainable model that empowers local healthcare workers around the world to

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provide lifesaving cleft treatment, to all who need it everywhere on earth 100% free. Learn more at [smile train.org](http://smiletrain.org). The information provided in these recordings is meant to be helpful to you and is provided as is for informational purposes. Smile Train cannot guarantee it is accurate up to date or error-free. We are not responsible for the content and disclaim all liability concerning actions taken or not taken based on these recordings.