I wasn't just crying, I was screaming. It is grief that brings you literally to your knees, that you cannot believe that you are still moving around.

Welcome to adjusting the sales a podcast for parents, caregivers and service providers for children with disabilities. I'm your host, Courtney Ringstaff, and this is my co host, Melina Danko.

Hi everyone. We are so glad you've joined us. Melina is the Assistant Director of Communications and Marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family to Family Health Information Center. I'm a social worker in Morgantown, West Virginia, and I've created this podcast to be a platform where parents, caregivers and service providers can come together, exchange information, educate one another and find support and connection through the relatable topic discussions. We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

My name is Samantha Coyne. I'm currently a law student at WVU law. I'm in my second year. I am also a lend trainee, which brought me in connection with adjusting the sales. And I listened to a couple podcasts, and I could so resonate with so much of the mothers, what they were saying, even though their children had very different needs than mine, there was a commonality to what we all experience as a special needs parent. My daughter died about five years ago. She was 20 years old. My only child, absolutely the love of my life, my dearest friend. And her death was very unexpected. She had chronic issues that we maintained. But, you know, it was the surgery that went well, and we were talking and everything else, and she, gosh, I fell asleep for an hour, and she died. We think it was a blood clot, but I didn't order an autopsy, because she'd had already probably 13 surgeries in her life, and I just didn't want anybody else to touch her do anything to her already ravaged little body. This is what brings me to why I'm on the podcast, because I reached out to Courtney and said, Have you ever dealt with this topic of a parent losing a child with a disability because my entire my life's purpose was my daughter, and every single decision I made from the day she was born was based on what is going to be best for her. And I don't think that that is probably true when you're parenting a typical child, and I hate the words typical, normal, special needs, you know, all that stuff, but my kid definitely she she needed a lot more help to get where she was going. When that reason for living is is taken away from you very unexpectedly or even Expectedly, it's, it's disorienting in a way, in ways you can't even imagine. I mean, losing your child is terrifying enough, and then waking up every day and thinking, well, now what am I going to do? Is is

equally terrifying.

I got pregnant at

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had her when I was 32 it was a largely unremarkable pregnancy, and it was just an offhand remark. I went to see my OB when I was about seven months pregnant, and I'm like, don't you think I'm like, a little large for only being seven months pregnant? He was looked at me and he was like, Yeah, you know you kind of are. Let's just check it out. Well, then they found out that Hadley had bilateral pleural effusion, so she had water on both of her lungs. She had a single chamber, umbilical cord. I'm trying to think, what else but nothing that pointed to an exact diagnosis, but enough that I was monitored much more closely. We had an amniocentesis done, and it came back that her chromosomes weren't normal. Everything was where it should be. They decided to induce me. I had to go through a series of injections. I can't even remember what they are now, but that were designed to help strengthen your baby's lungs. And they finally induced me about six weeks early, mm. My husband and I were terrified. I mean, thinking about how doctors approach people and patients, DOB really didn't have a lot to offer in this area, so I started seeing a needle neonatal specialist. And while he was probably, I mean, definitely a genius doctor, his bedside manner was complete crap. I was just so scared the whole time. And I went on most of these appointments myself. And, you know, there was very little like, okay, you know, this is, this is how you might want to prepare yourself. Or, you know, maybe there's nothing, but we don't know. Like explaining it all to me, what it what it would be like to be induced. None of that happened. Everybody lived to tell the tale, but it certainly wasn't pleasant. So now the genetic specialists were really, really nice, and that was another thing too, that my and my husband had to go through genetic testing to see if we had anything that would be passing on to her.

No, we did not. I was in labor with her. I

went in on a Wednesday evening, and they induced me, and I did not have her until Friday evening.

I was

having contractions, but nothing was happening, and my original OB Finally, his shift ended, and then my other OB came on. And I said, if you do not take this baby for me today, you may as well wheel me up to the psych ward, because that is where I'm not doing this anymore. He was like, if you don't go by 5c section. So we had a C section. I had a C section, and I'll never forget the feeling of relief when they pulled her out and he said, Oh, she's beautiful. We thought everything was fine. The doctor in the NICU was like, she's blue. She was blue when she came out, but she's stable. So she's, you know, she's a little sick, but she's stable. And I just wanted and then they took her away. I didn't even get to hold her or anything

like a day later, my

husband and I are sitting in the hospital room, and two women come in sit down, and this was a Friday I probably get my days up, but this was a Friday evening, and they sat down and said, So we believe your daughter has a syndrome called Noonan syndrome, And we based it on this, this and this. And then basically said, All right, well, we'll see you later. And they left. I'm frantically calling my family, like, can you google this for me? We didn't. Not everybody had a laptop. Then there were

no smartphones.

The syndrome was called Noonan syndrome, and there was no blood test for it. It was based solely on observation. There was a wide range of how it could affect a person, okay, that obviously didn't help, that you're left with, well, we have no idea what to expect here. Doctor come visit, just again, the same kind of like, Yeah, well, I don't know how she's going to do. And you know, a lot, I know a lot of patients who with Newton's who really didn't do very well, and you know they're talking in that tone, and you're like, really, like you do you find this helpful at all? We were in the hospital for about two weeks until because she was having some bradycardia, I think it's called, where her heart would was not beating regular. She had to go so many nights, and we put her in a car seat. I was there with her, and I had just gotten her to sleep, and it was a teaching hospital, so they brought in she was different. They brought in an entire class of nurses, and were like, Oh, do you mind? We've never seen a baby with Newton syndrome, and they're all crowding around her, and they wake her up. And, you know, I'm exhausted. So I was so pissed at that point, I went out to the nurse's desk and I'm like, I'm going home. And she was like, Well, of course, you're gonna go home, Samantha. And I'm like, No, I'm going home today. We need out of here. We left the next day. She wasn't medically fragile. There was no reason that we couldn't go home. You know, they did the tests and stuff. This is none of this is helpful, none of none of the supports that you would think in a large hospital and in a major metropolitan area that would be able to come to you and say, like, okay, these are the kind of things you might be thinking about. Now, I did have a nice social worker come there, and she recommended the Allegheny intermediate unit. So I was in Allegheny County, so that's, I guess, Birth to Three, where you can have somebody come into your home. And she was good about it, because she said, You know, I wish we could do this for all new parents. You don't know what you're doing anyhow. So it's helpful to have somebody who knows about babies come to your house. So we did that. We went home and I had a good a really good pediatrician and a pediatric group when it was really apparent that Hadley was a healthy child, you know, gaining weight, they said, well, we'll just treat things as they come, because she's a healthy kid. Samantha. Like there's, you know, you don't need to come here. Every time she sneezes, she's not that. You don't need that. Okay, we tried to get further information about her diagnosis. I was trying to digest all this information. There just wasn't a lot. And again, it was, you could find some things on the internet, but certainly it wasn't as robust as it is now medical needs. I mean, Hadley, she wasn't on any medication, you know. I mean, we just did the usual baby stuff at home. She ate a lot because she was so tiny at but and all. But then, because she was early, she would fall asleep. And I was breastfeeding, and I hated it. So to any mother out there who is breastfeeding and you hate it, and your doctor and all these men are telling you why it's so good for your baby, I'm not listen breastfeed till they're three. I don't care if that's what you want to do, but for me, I breastfed until she was like, whatever the like was like, eight weeks, and my life changed for the better the second I did that, because then she could drink a full bottle, and she was sleeping better at night, and I was sleeping better. Hadley was just a joy. I mean, she was didn't walk till she was like 21 months old, but, and you know, we found later that she had an undiagnosed, chronological neurological condition. Everything else she did she was really advanced, like, as far as, like, understanding me, following directions, playing things like that, and she didn't she said some words, and for a long time, she just said, was that? Was that I want to point at things? As soon as she started walking, it was like someone turned on a faucet. She went from, you know, was that, to, oh, your silver bracelet is so pretty. Like, I'm not even kidding you. That's how when we would take her to the doctors, they would be like, How old is she? And by the time she was three, it was like, I felt like I had a 34 year old next to me, who just happened to be two feet tall, you know, and, and I was very fortunate that I could stay home with her. I do, because she needed all kinds of we did the home therapy. There were doctors appointments because there were concerns. So some of the things that come with Noonan syndrome, you know, she had to get her heart checked out. A heart defect is, is a big part of having noon syndrome. So we had to get that checked out and then rechecked and, you know, her vision, she one of her eyes had ptosis, so one of her eyelids was kind of closed. So taking her we, you know, she started going to the eye doctor when she was eight months old or something. To what do we do with that? So there were tons and tons of doctors appointments and and her physical therapy, and then when she turned three, I didn't want her. I wanted to be there when the therapies were taking place, and I was working part time, but we decided to go with private physical therapy. We had good insurance, and I went and got Medicaid qualified, because our insurance would only cover up to so many PT visits a year. So I got that insurance for her, and so that way I could go to all the, you know, go to all the PT things, and she didn't really get OT. I mean, she was okay. She didn't start getting ot till she was, like in kindergarten, when it really became apparent that she needed help with her handwriting and stuff. But yeah, I mean, we had a ball. I mean, I just love doing stuff with her, and I love being her mom, and I love making Christmas decorations and Valentines, and I loved going to her school. And I used to be, anyhow, crafty. I don't have time anymore, but I just loved being around her and

people stared at her.

It's hard. It's hard when this

human being, who you love more than anything in the world, to have someone look at them like there's something wrong with them. Oh my god, I probably worried a decade off my life wondering what it was going to be like when she went to school. Were people going to be mean to her? I'll never forget, we were sitting in the pediatrician's office, and I mean, Hadley looked a little different, but certainly not frightening looking. And there was another little girl there, probably around her age, and she looked at Hadley, and she, like, cringed and ran away and went to her parents and that mom did not say one single thing. Maybe you're more attuned to it when you're a special needs mom, but I just feel like that's one human being. That's the grace you show another being, a human being, and you teach your kids to do the same. So there were definitely, there were incidences like that that would knock me

flat on my back.

I was lucky. I had,

like one of my dearest friends from college, her daughter born not that long after mine, but she had spina bifida. So Rachel and I had a lot of things. Things in common, and it that was really important, too, to be able to call a friend and say, like this, this just sucks, like I am exhausted, or this is what happened to me at the doctor's office today. But I remember I went into the pediatrician, and she was one of my favorite pediatricians, and I started to cry, and she's standing there with her arms crossed, and the pediatrician says, I hope she bit that little girl. And then she says, I'm not supposed to say things like that. I'm like, I understand that, but I said and I meant this, and it was true, from the day she was born till the day she died, if I could have hand picked a kid, that kid would have been Hadley. And I used to tell Hadley that too when she got older, a lot because I think, well, I mean, just because I wanted her to know. But I also when we start to talk about school advocacy and things like that, and kids are getting awarded or praised for things that maybe my kid can't do. Okay, so if it's physical things, if it's they play soccer, if they it's they do this, you know, and I would oftentimes say to Hadley, like, Listen, you are better than those kids. You are smarter than those kids, you are funnier than those kids. You handle so much more than those kids handle on a daily basis, but it's not the kind of thing you're going to get a prize for, and that that's a little heartbreaking too. Hadley's life in school was was pretty good. The wheels didn't really fall off the bus until high school, up until then, up till the end of middle school. You know, kids were still pretty friendly. Her teachers really made an effort to know her. And you know, I learned what to do, like reach out to the teachers in the beginning of the year and say, Hey, listen, this is Hadley, and this is what our some of her strengths are, and some of this. And you know, this is our philosophy on raising her, which I basically said, I don't want her treated like She's precious, as long as she's physically safe. I want her and when you know she has the accommodations that you need, that she needs, I want her to be treated like the rest of the kids. I remember her fourth grade teacher, or no, I'm sorry, second and nicest, nicest man. And I said, Well, what's how's she doing in school? And he was like, Well, you know, she plays around with her desk a lot. She plays her desk. I'm like, Well, do you put her name on the board when she does that? Because that's what happened when you got in trouble. And he was like, Well, no, I'm like, put her name on the board. I'm like, What do you think's gonna happen to her? And then she lied to me about it, you know? I'm like, she needs to know how to get around things and and then, as she you know, we'd have funny times too, because, well, when Hallie was about five, is when she started having more serious health problems. We discovered that she needed a she had a tethered spinal cord, which sounds really awful, and believe me, getting to the point of that diagnosis and how to treat it was pretty bad, but she hadn't had you can have some like a child. It all starts around when they're four or five, they have a growth spurt. All of a sudden, the spine starts to stretch a little bit, and if it's connected to the base of their spine, then you may start to see things for us, it was Hadley's one foot just one day, turned in, and I was like, What are you doing? As soon as I Googled it, I knew what it was, but you can see children regress in toilet training, things like that, and it's it's because of a tethered spinal cord. Well, then, in addition to her tethered spinal cord, we also found out that she had hip dysplasia, just a whole host of orthopedic issues. So we went through a period of, I don't know she was, probably till she was eight or so. I mean, she had bilateral femoral st osteotomy, so both of her femurs cut, and then she was non weight bearing, and, you know, couldn't go to school, and these very significant casts, she had to have a bilateral pelvic osteotomy. And she was in, again, obviously non weight bearing. And she was in a Spica cast, which is the one that goes from your armpits to, like, the whole way down. It's, it's so challenging. And she, you know, sometimes you'll see infants in Spica cast because the dysplasia is found pretty early, and at least you can carry them, you know. I mean, Hadley was, I couldn't carry her anything the

second round, well, she was still,

she was in her she was

not early grade school, but, and now, then she had to have tendon lengthening. I mean, the list just goes on, and it was horrible. But when she got a little older, I sent her to school because I'm like, there's no reason for you to just sit here all day. I went to the school. They hired a nurse to, you know, be there to take her to the restroom or help. She was wearing diapers. I guess, if that were, I can't remember, needed a bed pan or something. But, you know, in the district did that. I should backtrack a little bit. My school district, which is an excellent Blue Ribbon School District, had never educated a child with no cognitive delays but physical disability. So it was, I mean, her first year, her kindergarten teacher was wonderful, her first grade teacher was one of the most despicable human beings you will ever meet in your life. And she would make Hadley walk long distances after her surgeries, like she knew she would constantly say to her things like, Well, I don't know how you think you're ever gonna walk normal. And this, she was just too much. So we had some issues with that where, you know we were there at the school, like screaming, okay, like one time she said, for the Halloween parade, can you tell Hadley that it's going to be too hard for her to walk in the Halloween parade, so she's going to wait in the office. I was like, I absolutely cannot. She's like, well, it's going to slow the other kids down. I'm like, I don't care. Find somebody to push her wheelchair. I called that woman more names than you can even imagine. Like I had names for her that and then later, like, we Hadley knew. I mean, she knew, you know what I thought of her and her husband? This woman's husband left her, like, 10 years after Hadley had her, and I would make it a point to tell every single person that had this teacher with and Hadley's like, Mom, why do you why does it make you so happy to say that Mrs. So and so's husband left her and I'm like, because she deserves it. I'm like, she was a horrible person, you know? I'm happy. I'm happy we use humor a lot in my house, because there is bullying, you know? I mean, it's a little I think, when they're younger. I mean, really, in her younger years, it didn't seem like as many of the kids noticed, or they just didn't care. But she had times where people would sit and be like, I don't want to be in a group with her because she's a cripple. I'm like, Who says a person is a cripple? Nowadays, in middle school, a girl brought a Bible in to read to Hadley because she felt like maybe Hadley needed help, and that part of the reason was the way she was was because she hadn't had the proper religious instruction. And, I mean, like the Bible one, she just came home and said, Hey, Mom, you know, Susie brought her Bible in and was reading to me. And I'm like, I'll call the school, you know. And the school knew me by then, and they knew I worked at law schools, and, you know, they knew that I was not going to stop talking until they they did what was, what was a legal right for my child, our children, as far as supports and one, like, just a funny thing I Hadley must have been in second grade, and somebody was really mean to her. And I went and I said to her, did I want you to go to school tomorrow and you tell her that your mother said she's a bitch, and I hope that she gets pregnant and 16 and ends up living in a trailer and Hadley's, like, I can't say that. I'm like, you can. I will totally back you. And I could talk to her on that level when she was, like, eight years old. Do you know what I mean? So we would just laugh. Or I'm like, you know, and I am gonna, you guys will bleep this out, but you know, everything, I'd be like, Well, did you tell them to go fuck themselves? And she's like, No, Mom, I did not. She's like, why is that your answer for everything? I'm like, it is the all purpose answer, you know. Or did you tell her that your mother said she thinks she's a whore? No, Mom, no, I did not, you know. So, you know, we would laugh hysterically. But sometimes that's, you know what I mean, it helps Hallie get through the day, and I wanted her to develop some perspective, like there is some humor in all this. You know, it's not apparent on many days, but I mean, that's why I liked her so much, too. She was like my biggest fan. She laughed at all my jokes. You know,

what was not to love.

Did she go to school and tell that girl that in second grade? No, she did not. She knew that would have been a fun conversation with the teacher. I would have loved, loved loved it No. And one of my my friends, has has a son who is high functioning autistic, and she said, you're lucky she's not autistic, because she would have gone in the next day and repeated exactly that. And I'm like, you know, I can't, but even if she would have, I would have been like, well, she is a bitch, you know? I mean, why is she talk calling my kid a cripple? So, you know? So there were, there were definite ups and downs there, but where it was in high school that I felt like things really just

went awry. Hadley was

so there are kids. And I mean this, I mean this in the most generous kind way that the kids are nice to because the other children are nice to because it makes them feel better. So a kid who is perhaps intellectually disabled, and it's like a

Oh, he's so cute, we're friends,

but a lot of times that's not a meaningful friendship. Yeah, offending it is. It is. And you know, when I would talk to her educators about this, I'm like, because they're like, Well, you know, we have the period. I'm like, Hadley doesn't need that. You know, she does not need someone holding her hand and patting her on the head. Sometimes, finding those friendships, and she had her dearest friend dumped her in high school, different priorities, right? So Hadley started hanging around with a group of kids, like they were like theater kids and and Hadley was gay. I found out through a parent of the the girl who had dumped Hadley said, you know, she wants Hadley to unfriend her on Instagram. She doesn't want to be friends with her because she doesn't want other people to think she's gay. And I'm thinking, Okay, well, I guess it's better to be mean than gay. But I just went home and said to Hadley, did you do this? Is this, you know, is this on your Instagram? Yeah. And I said, Okay, well, first of all, let's just dial up the privacy settings on your Instagram, because that's just makes good sense. And you know, I said, Why don't you tell me? And she said, you know, well, I know how much you love me, but you never know how a mom or dad is going to react to something like this. And I was like, Really, I don't care who you love if you as long as you love someone. That's great with me. So she became friends like and then she joined the Gay Straight Alliance at her high school. And I often wondered for her, and I let her dye her hair blue, and, you know, all kinds of stuff, but I often wondered for her, and by that time, she was using a mobility scooter too. I often wondered for her if it was better to be the gay girl with blue hair who also happened to be in a scooter like that was a way to create an identity for herself that was outside

of her handicap.

And, I mean, maybe it was, maybe it wasn't. And in any case, it was a wonderful experience for her. You know, she she got her little core group, and they had meaningful friendships with like there was a little girl in particular. Her name was Susie, and Susie is autistic, and Susie could tell sometimes in high school when other kids were she knew it wasn't right how they were talking to her, but she didn't exactly know what was going on. Well, Hadley and her friends would step in, and they also made sure she ate lunch with them every day. Like and they like. They liked her as a person. You know, I had all Hadley's friends come to our house before homecoming one year, and I did everybody's makeup. And, you know, and I'm talking to these kids, and I'm like, these kids aren't weird. These kids are like, I would hang out with them in a heartbeat, like they're fun and funny and they really like each other and and also, Hadley discovered Dungeons and Dragons, which is, you know, the graveyard of the nerdy, of the nerdiest. And I was always like, I'm sorry. I just, is just one journey I cannot go on with you because I don't understand anything that you are talking about. But she found that group too, and so she kind of found her place. And I've always been in the minds, if you just have one or two people who you can really talk to, that makes a difference. Her senior year was rough, and she didn't go very much because all of her friends had graduated, and I wasn't going to make her go to school when she didn't have anybody to talk to. So she did largely online learning. She had an incident in the high school, which is what led me to that decision. And I know anybody listening to this podcast who has a child with a disability does not need to be told this, but so much of what children do is influenced by how their parents treat other people, or how their parents talk to them about children with who are different and everybody is different. Hadley spilled her coffee one day in the cafeteria, and you know, a number of her friends were there. So imagine you're by yourself. You're in high school. You spill your coffee. She cleaned it all up herself. No one helped her.

It wasn't until a teacher came

and helped her, and we sat an IEP meeting, and I said to them, don't ever pat yourselves on the back about what a great school this is, or how you're so concerned about other students. And I said, if this would have happened to any of you at work as an adult, you would have quit. But here I have to send my kid to this place. Is every day. It just, it really saddens me to think that people who are in the business of saying that they want to take care of children and encourage inclusivity cannot take steps to combat things like that, like I just have to imagine it wouldn't be that hard, right? There are schools where they have a No one sits alone policy. You get a group of high achieving kids or really friendly kids. It's like, nobody sits alone. Nobody should sit alone at lunch. There's a dad who does a podcast. I think his son is autistic and he does a podcast, or he does has done like TED Talks and things about this, about how important it is, and how it makes the children who are doing this sitting with them, it's good for them too, especially nowadays. And I would preach to the school district about, you know, when she would be called a name, or somebody, a young in high school, somebody said something to her about being gay and being weird. You know, I'm like, these kids are all gonna go work somewhere, someday, or go to college. I'm like, this stuff is not tolerated, not this language, not this behavior. There has to be a zero tolerance for it. But so much of it starts at home. And Hadley never really mind, like, if people stared at her something, because if it was little kids, they were usually like, Hey, what's going on with you, you know, or why do you use that? And she was like, she was happy to answer. She was in Giant Eagle once in the grocery store on her scooter, and an older lady was coming towards her in another Scooter, and she said to Hadley, Hey, what's wrong with you? And Hadley just laughed her head off, because, you know, this woman was just curious. She wasn't being cruel or anything. There's definitely a piece missing when we send our disabled children to school, and I don't know how to fix that, other than to raise awareness with podcasts like you have, hoping you I wasn't just crying, I was screaming. It is grief that brings you literally to your knees, that you cannot believe that you are still moving around.

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is the Assistant Director of Communications and Marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family to Family Health Information Center. I'm a social worker in Morgantown, West Virginia, and I've created this podcast to be a platform where parents, caregivers and service providers can come together, exchange information, educate one another and find support and connection through the relatable topic discussions. We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

My name is Samantha Coyne. I'm currently a law student at WVU law. I'm in my second year. I am also a lend trainee, which brought me in connection with adjusting the sales. And I listened to a couple podcasts, and I could so resonate with so much of the mothers, what they were saying, even though their children had very different needs than mine, there was a commonality to what we all experience as a special needs parent. My daughter died about five years ago. She was 20 years old. My only child, absolutely the love of my life, my dearest friend. And her death was very unexpected. She had chronic issues that we maintained. But, you know, it was the surgery that went well, and we were talking and everything else, and she, gosh, I fell asleep for an hour, and she died. We think it was a blood clot, but I didn't order an autopsy, because she'd had already probably 13 surgeries in her life, and I just didn't want anybody else to touch her do anything to her already ravaged little body. This is what brings me to why I'm on the podcast, because I reached out to Courtney and said, Have you ever dealt with this topic of a parent losing a child with a disability because my entire my life's purpose was my daughter, and every single decision I made from the day she was born was based on what is going to be best for her. And I don't think that that is probably true when you're parenting a typical child, and I hate the words typical, normal, special needs, you know, all that stuff, but my kid definitely she she needed a lot more help to get where she was going. When that reason for living is is taken away from you very unexpectedly or even Expectedly, it's, it's disorienting in a way, in ways you can't even imagine. I mean, losing your child is terrifying enough, and then waking up every day and thinking, well, now what am I going to do? Is is

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I got pregnant at

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had her when I was 32 it was a largely unremarkable pregnancy, and it was just an offhand remark. I went to see my OB when I was about seven months pregnant, and I'm like, don't you think I'm like, a little large for only being seven months pregnant? He was looked at me and he was like, Yeah, you know you kind of are. Let's just check it out. Well, then they found out that Hadley had bilateral pleural effusion, so she had water on both of her lungs. She had a single chamber, umbilical cord. I'm trying to think, what else but nothing that pointed to an exact diagnosis, but enough that I was monitored much more closely. We had an amniocentesis done, and it came back that her chromosomes weren't normal. Everything was where it should be. They decided to induce me. I had to go through a series of injections. I can't even remember what they are now, but that were designed to help strengthen your baby's lungs. And they finally induced me about six weeks early, mm. My husband and I were terrified. I mean, thinking about how doctors approach people and patients, DOB really didn't have a lot to offer in this area, so I started seeing a needle neonatal specialist. And while he was probably, I mean, definitely a genius doctor, his bedside manner was complete crap. I was just so scared the whole time. And I went on most of these appointments myself. And, you know, there was very little like, okay, you know, this is, this is how you might want to prepare yourself. Or, you know, maybe there's nothing, but we don't know. Like explaining it all to me, what it what it would be like to be induced. None of that happened. Everybody lived to tell the tale, but it certainly wasn't pleasant. So now the genetic specialists were really, really nice, and that was another thing too, that my and my husband had to go through genetic testing to see if we had anything that would be passing on to her.

No, we did not. I was in labor with her. I

went in on a Wednesday evening, and they induced me, and I did not have her until Friday evening.

I was

having contractions, but nothing was happening, and my original OB Finally, his shift ended, and then my other OB came on. And I said, if you do not take this baby for me today, you may as well wheel me up to the psych ward, because that is where I'm not doing this anymore. He was like, if you don't go by 5c section. So we had a C section. I had a C section, and I'll never forget the feeling of relief when they pulled her out and he said, Oh, she's beautiful. We thought everything was fine. The doctor in the NICU was like, she's blue. She was blue when she came out, but she's stable. So she's, you know, she's a little sick, but she's stable. And I just wanted and then they took her away. I didn't even get to hold her or anything

like a day later, my

husband and I are sitting in the hospital room, and two women come in sit down, and this was a Friday I probably get my days up, but this was a Friday evening, and they sat down and said, So we believe your daughter has a syndrome called Noonan syndrome, And we based it on this, this and this. And then basically said, All right, well, we'll see you later. And they left. I'm frantically calling my family, like, can you google this for me? We didn't. Not everybody had a laptop. Then there were

no smartphones.

The syndrome was called Noonan syndrome, and there was no blood test for it. It was based solely on observation. There was a wide range of how it could affect a person, okay, that obviously didn't help, that you're left with, well, we have no idea what to expect here. Doctor come visit, just again, the same kind of like, Yeah, well, I don't know how she's going to do. And you know, a lot, I know a lot of patients who with Newton's who really didn't do very well, and you know they're talking in that tone, and you're like, really, like you do you find this helpful at all? We were in the hospital for about two weeks until because she was having some bradycardia, I think it's called, where her heart would was not beating regular. She had to go so many nights, and we put her in a car seat. I was there with her, and I had just gotten her to sleep, and it was a teaching hospital, so they brought in she was different. They brought in an entire class of nurses, and were like, Oh, do you mind? We've never seen a baby with Newton syndrome, and they're all crowding around her, and they wake her up. And, you know, I'm exhausted. So I was so pissed at that point, I went out to the nurse's desk and I'm like, I'm going home. And she was like, Well, of course, you're gonna go home, Samantha. And I'm like, No, I'm going home today. We need out of here. We left the next day. She wasn't medically fragile. There was no reason that we couldn't go home. You know, they did the tests and stuff. This is none of this is helpful, none of none of the supports that you would think in a large hospital and in a major metropolitan area that would be able to come to you and say, like, okay, these are the kind of things you might be thinking about. Now, I did have a nice social worker come there, and she recommended the Allegheny intermediate unit. So I was in Allegheny County, so that's, I guess, Birth to Three, where you can have somebody come into your home. And she was good about it, because she said, You know, I wish we could do this for all new parents. You don't know what you're doing anyhow. So it's helpful to have somebody who knows about babies come to your house. So we did that. We went home and I had a good a really good pediatrician and a pediatric group when it was really apparent that Hadley was a healthy child, you know, gaining weight, they said, well, we'll just treat things as they come, because she's a healthy kid. Samantha. Like there's, you know, you don't need to come here. Every time she sneezes, she's not that. You don't need that. Okay, we tried to get further information about her diagnosis. I was trying to digest all this information. There just wasn't a lot. And again, it was, you could find some things on the internet, but certainly it wasn't as robust as it is now medical needs. I mean, Hadley, she wasn't on any medication, you know. I mean, we just did the usual baby stuff at home. She ate a lot because she was so tiny at but and all. But then, because she was early, she would fall asleep. And I was breastfeeding, and I hated it. So to any mother out there who is breastfeeding and you hate it, and your doctor and all these men are telling you why it's so good for your baby, I'm not listen breastfeed till they're three. I don't care if that's what you want to do, but for me, I breastfed until she was like, whatever the like was like, eight weeks, and my life changed for the better the second I did that, because then she could drink a full bottle, and she was sleeping better at night, and I was sleeping better. Hadley was just a joy. I mean, she was didn't walk till she was like 21 months old, but, and you know, we found later that she had an undiagnosed, chronological neurological condition. Everything else she did she was really advanced, like, as far as, like, understanding me, following directions, playing things like that, and she didn't she said some words, and for a long time, she just said, was that? Was that I want to point at things? As soon as she started walking, it was like someone turned on a faucet. She went from, you know, was that, to, oh, your silver bracelet is so pretty. Like, I'm not even kidding you. That's how when we would take her to the doctors, they would be like, How old is she? And by the time she was three, it was like, I felt like I had a 34 year old next to me, who just happened to be two feet tall, you know, and, and I was very fortunate that I could stay home with her. I do, because she needed all kinds of we did the home therapy. There were doctors appointments because there were concerns. So some of the things that come with Noonan syndrome, you know, she had to get her heart checked out. A heart defect is, is a big part of having noon syndrome. So we had to get that checked out and then rechecked and, you know, her vision, she one of her eyes had ptosis, so one of her eyelids was kind of closed. So taking her we, you know, she started going to the eye doctor when she was eight months old or something. To what do we do with that? So there were tons and tons of doctors appointments and and her physical therapy, and then when she turned three, I didn't want her. I wanted to be there when the therapies were taking place, and I was working part time, but we decided to go with private physical therapy. We had good insurance, and I went and got Medicaid qualified, because our insurance would only cover up to so many PT visits a year. So I got that insurance for her, and so that way I could go to all the, you know, go to all the PT things, and she didn't really get OT. I mean, she was okay. She didn't start getting ot till she was, like in kindergarten, when it really became apparent that she needed help with her handwriting and stuff. But yeah, I mean, we had a ball. I mean, I just love doing stuff with her, and I love being her mom, and I love making Christmas decorations and Valentines, and I loved going to her school. And I used to be, anyhow, crafty. I don't have time anymore, but I just loved being around her and

people stared at her.

It's hard. It's hard when this

human being, who you love more than anything in the world, to have someone look at them like there's something wrong with them. Oh my god, I probably worried a decade off my life wondering what it was going to be like when she went to school. Were people going to be mean to her? I'll never forget, we were sitting in the pediatrician's office, and I mean, Hadley looked a little different, but certainly not frightening looking. And there was another little girl there, probably around her age, and she looked at Hadley, and she, like, cringed and ran away and went to her parents and that mom did not say one single thing. Maybe you're more attuned to it when you're a special needs mom, but I just feel like that's one human being. That's the grace you show another being, a human being, and you teach your kids to do the same. So there were definitely, there were incidences like that that would knock me

flat on my back.

I was lucky. I had,

like one of my dearest friends from college, her daughter born not that long after mine, but she had spina bifida. So Rachel and I had a lot of things. Things in common, and it that was really important, too, to be able to call a friend and say, like this, this just sucks, like I am exhausted, or this is what happened to me at the doctor's office today. But I remember I went into the pediatrician, and she was one of my favorite pediatricians, and I started to cry, and she's standing there with her arms crossed, and the pediatrician says, I hope she bit that little girl. And then she says, I'm not supposed to say things like that. I'm like, I understand that, but I said and I meant this, and it was true, from the day she was born till the day she died, if I could have hand picked a kid, that kid would have been Hadley. And I used to tell Hadley that too when she got older, a lot because I think, well, I mean, just because I wanted her to know. But I also when we start to talk about school advocacy and things like that, and kids are getting awarded or praised for things that maybe my kid can't do. Okay, so if it's physical things, if it's they play soccer, if they it's they do this, you know, and I would oftentimes say to Hadley, like, Listen, you are better than those kids. You are smarter than those kids, you are funnier than those kids. You handle so much more than those kids handle on a daily basis, but it's not the kind of thing you're going to get a prize for, and that that's a little heartbreaking too. Hadley's life in school was was pretty good. The wheels didn't really fall off the bus until high school, up until then, up till the end of middle school. You know, kids were still pretty friendly. Her teachers really made an effort to know her. And you know, I learned what to do, like reach out to the teachers in the beginning of the year and say, Hey, listen, this is Hadley, and this is what our some of her strengths are, and some of this. And you know, this is our philosophy on raising her, which I basically said, I don't want her treated like She's precious, as long as she's physically safe. I want her and when you know she has the accommodations that you need, that she needs, I want her to be treated like the rest of the kids. I remember her fourth grade teacher, or no, I'm sorry, second and nicest, nicest man. And I said, Well, what's how's she doing in school? And he was like, Well, you know, she plays around with her desk a lot. She plays her desk. I'm like, Well, do you put her name on the board when she does that? Because that's what happened when you got in trouble. And he was like, Well, no, I'm like, put her name on the board. I'm like, What do you think's gonna happen to her? And then she lied to me about it, you know? I'm like, she needs to know how to get around things and and then, as she you know, we'd have funny times too, because, well, when Hallie was about five, is when she started having more serious health problems. We discovered that she needed a she had a tethered spinal cord, which sounds really awful, and believe me, getting to the point of that diagnosis and how to treat it was pretty bad, but she hadn't had you can have some like a child. It all starts around when they're four or five, they have a growth spurt. All of a sudden, the spine starts to stretch a little bit, and if it's connected to the base of their spine, then you may start to see things for us, it was Hadley's one foot just one day, turned in, and I was like, What are you doing? As soon as I Googled it, I knew what it was, but you can see children regress in toilet training, things like that, and it's it's because of a tethered spinal cord. Well, then, in addition to her tethered spinal cord, we also found out that she had hip dysplasia, just a whole host of orthopedic issues. So we went through a period of, I don't know she was, probably till she was eight or so. I mean, she had bilateral femoral st osteotomy, so both of her femurs cut, and then she was non weight bearing, and, you know, couldn't go to school, and these very significant casts, she had to have a bilateral pelvic osteotomy. And she was in, again, obviously non weight bearing. And she was in a Spica cast, which is the one that goes from your armpits to, like, the whole way down. It's, it's so challenging. And she, you know, sometimes you'll see infants in Spica cast because the dysplasia is found pretty early, and at least you can carry them, you know. I mean, Hadley was, I couldn't carry her anything the

second round, well, she was still,

she was in her she was

not early grade school, but, and now, then she had to have tendon lengthening. I mean, the list just goes on, and it was horrible. But when she got a little older, I sent her to school because I'm like, there's no reason for you to just sit here all day. I went to the school. They hired a nurse to, you know, be there to take her to the restroom or help. She was wearing diapers. I guess, if that were, I can't remember, needed a bed pan or something. But, you know, in the district did that. I should backtrack a little bit. My school district, which is an excellent Blue Ribbon School District, had never educated a child with no cognitive delays but physical disability. So it was, I mean, her first year, her kindergarten teacher was wonderful, her first grade teacher was one of the most despicable human beings you will ever meet in your life. And she would make Hadley walk long distances after her surgeries, like she knew she would constantly say to her things like, Well, I don't know how you think you're ever gonna walk normal. And this, she was just too much. So we had some issues with that where, you know we were there at the school, like screaming, okay, like one time she said, for the Halloween parade, can you tell Hadley that it's going to be too hard for her to walk in the Halloween parade, so she's going to wait in the office. I was like, I absolutely cannot. She's like, well, it's going to slow the other kids down. I'm like, I don't care. Find somebody to push her wheelchair. I called that woman more names than you can even imagine. Like I had names for her that and then later, like, we Hadley knew. I mean, she knew, you know what I thought of her and her husband? This woman's husband left her, like, 10 years after Hadley had her, and I would make it a point to tell every single person that had this teacher with and Hadley's like, Mom, why do you why does it make you so happy to say that Mrs. So and so's husband left her and I'm like, because she deserves it. I'm like, she was a horrible person, you know? I'm happy. I'm happy we use humor a lot in my house, because there is bullying, you know? I mean, it's a little I think, when they're younger. I mean, really, in her younger years, it didn't seem like as many of the kids noticed, or they just didn't care. But she had times where people would sit and be like, I don't want to be in a group with her because she's a cripple. I'm like, Who says a person is a cripple? Nowadays, in middle school, a girl brought a Bible in to read to Hadley because she felt like maybe Hadley needed help, and that part of the reason was the way she was was because she hadn't had the proper religious instruction. And, I mean, like the Bible one, she just came home and said, Hey, Mom, you know, Susie brought her Bible in and was reading to me. And I'm like, I'll call the school, you know. And the school knew me by then, and they knew I worked at law schools, and, you know, they knew that I was not going to stop talking until they they did what was, what was a legal right for my child, our children, as far as supports and one, like, just a funny thing I Hadley must have been in second grade, and somebody was really mean to her. And I went and I said to her, did I want you to go to school tomorrow and you tell her that your mother said she's a bitch, and I hope that she gets pregnant and 16 and ends up living in a trailer and Hadley's, like, I can't say that. I'm like, you can. I will totally back you. And I could talk to her on that level when she was, like, eight years old. Do you know what I mean? So we would just laugh. Or I'm like, you know, and I am gonna, you guys will bleep this out, but you know, everything, I'd be like, Well, did you tell them to go fuck themselves? And she's like, No, Mom, I did not. She's like, why is that your answer for everything? I'm like, it is the all purpose answer, you know. Or did you tell her that your mother said she thinks she's a whore? No, Mom, no, I did not, you know. So, you know, we would laugh hysterically. But sometimes that's, you know what I mean, it helps Hallie get through the day, and I wanted her to develop some perspective, like there is some humor in all this. You know, it's not apparent on many days, but I mean, that's why I liked her so much, too. She was like my biggest fan. She laughed at all my jokes. You know,

what was not to love.

Did she go to school and tell that girl that in second grade? No, she did not. She knew that would have been a fun conversation with the teacher. I would have loved, loved loved it No. And one of my my friends, has has a son who is high functioning autistic, and she said, you're lucky she's not autistic, because she would have gone in the next day and repeated exactly that. And I'm like, you know, I can't, but even if she would have, I would have been like, well, she is a bitch, you know? I mean, why is she talk calling my kid a cripple? So, you know? So there were, there were definite ups and downs there, but where it was in high school that I felt like things really just

went awry. Hadley was

so there are kids. And I mean this, I mean this in the most generous kind way that the kids are nice to because the other children are nice to because it makes them feel better. So a kid who is perhaps intellectually disabled, and it's like a

Oh, he's so cute, we're friends,

but a lot of times that's not a meaningful friendship. Yeah, offending it is. It is. And you know, when I would talk to her educators about this, I'm like, because they're like, Well, you know, we have the period. I'm like, Hadley doesn't need that. You know, she does not need someone holding her hand and patting her on the head. Sometimes, finding those friendships, and she had her dearest friend dumped her in high school, different priorities, right? So Hadley started hanging around with a group of kids, like they were like theater kids and and Hadley was gay. I found out through a parent of the the girl who had dumped Hadley said, you know, she wants Hadley to unfriend her on Instagram. She doesn't want to be friends with her because she doesn't want other people to think she's gay. And I'm thinking, Okay, well, I guess it's better to be mean than gay. But I just went home and said to Hadley, did you do this? Is this, you know, is this on your Instagram? Yeah. And I said, Okay, well, first of all, let's just dial up the privacy settings on your Instagram, because that's just makes good sense. And you know, I said, Why don't you tell me? And she said, you know, well, I know how much you love me, but you never know how a mom or dad is going to react to something like this. And I was like, Really, I don't care who you love if you as long as you love someone. That's great with me. So she became friends like and then she joined the Gay Straight Alliance at her high school. And I often wondered for her, and I let her dye her hair blue, and, you know, all kinds of stuff, but I often wondered for her, and by that time, she was using a mobility scooter too. I often wondered for her if it was better to be the gay girl with blue hair who also happened to be in a scooter like that was a way to create an identity for herself that was outside

of her handicap.

And, I mean, maybe it was, maybe it wasn't. And in any case, it was a wonderful experience for her. You know, she she got her little core group, and they had meaningful friendships with like there was a little girl in particular. Her name was Susie, and Susie is autistic, and Susie could tell sometimes in high school when other kids were she knew it wasn't right how they were talking to her, but she didn't exactly know what was going on. Well, Hadley and her friends would step in, and they also made sure she ate lunch with them every day. Like and they like. They liked her as a person. You know, I had all Hadley's friends come to our house before homecoming one year, and I did everybody's makeup. And, you know, and I'm talking to these kids, and I'm like, these kids aren't weird. These kids are like, I would hang out with them in a heartbeat, like they're fun and funny and they really like each other and and also, Hadley discovered Dungeons and Dragons, which is, you know, the graveyard of the nerdy, of the nerdiest. And I was always like, I'm sorry. I just, is just one journey I cannot go on with you because I don't understand anything that you are talking about. But she found that group too, and so she kind of found her place. And I've always been in the minds, if you just have one or two people who you can really talk to, that makes a difference. Her senior year was rough, and she didn't go very much because all of her friends had graduated, and I wasn't going to make her go to school when she didn't have anybody to talk to. So she did largely online learning. She had an incident in the high school, which is what led me to that decision. And I know anybody listening to this podcast who has a child with a disability does not need to be told this, but so much of what children do is influenced by how their parents treat other people, or how their parents talk to them about children with who are different and everybody is different. Hadley spilled her coffee one day in the cafeteria, and you know, a number of her friends were there. So imagine you're by yourself. You're in high school. You spill your coffee. She cleaned it all up herself. No one helped her.

It wasn't until a teacher came

and helped her, and we sat an IEP meeting, and I said to them, don't ever pat yourselves on the back about what a great school this is, or how you're so concerned about other students. And I said, if this would have happened to any of you at work as an adult, you would have quit. But here I have to send my kid to this place. Is every day. It just, it really saddens me to think that people who are in the business of saying that they want to take care of children and encourage inclusivity cannot take steps to combat things like that, like I just have to imagine it wouldn't be that hard, right? There are schools where they have a No one sits alone policy. You get a group of high achieving kids or really friendly kids. It's like, nobody sits alone. Nobody should sit alone at lunch. There's a dad who does a podcast. I think his son is autistic and he does a podcast, or he does has done like TED Talks and things about this, about how important it is, and how it makes the children who are doing this sitting with them, it's good for them too, especially nowadays. And I would preach to the school district about, you know, when she would be called a name, or somebody, a young in high school, somebody said something to her about being gay and being weird. You know, I'm like, these kids are all gonna go work somewhere, someday, or go to college. I'm like, this stuff is not tolerated, not this language, not this behavior. There has to be a zero tolerance for it. But so much of it starts at home. And Hadley never really mind, like, if people stared at her something, because if it was little kids, they were usually like, Hey, what's going on with you, you know, or why do you use that? And she was like, she was happy to answer. She was in Giant Eagle once in the grocery store on her scooter, and an older lady was coming towards her in another Scooter, and she said to Hadley, Hey, what's wrong with you? And Hadley just laughed her head off, because, you know, this woman was just curious. She wasn't being cruel or anything. There's definitely a piece missing when we send our disabled children to school, and I don't know how to fix that, other than to raise awareness with podcasts like you have, hoping you