00;00;09;23 - 00;00;29;13

Carrie Cobun-Stark

I was blaming myself as parents often do. The first time we saw him, he gave us hope about what Mandy might be able to do. He told me that I had a placental abruption and he said, This was not your fault. It just happens to some women. We don't know why. I remember I cried through the entire appointment. But finally, somebody has told me A. It wasn't your fault. And B, he gave me hope. He gave me a lot of hope.

00;00;50;06 - 00;01;02;00

Courtney Ringstaff

Welcome to Adjusting the Sales. A podcast for parents, caregivers and service providers for Children with Disabilities. I'm your host, Courtney Ring Staff, and this is my co-host, Melina Danko.

00;01;02;10 - 00;01;05;02

Speaker 3

Hi, everyone. We are so glad you've joined us.

00;01;05;10 - 00;01;35;17

Courtney Ringstaff

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 two Family Health Information Center. I am a licensed social worker in Morgantown, West Virginia, and I've created this podcast to be a platform for parents, caregivers and service providers. Can come together, exchange information, educate one another, and find support and connection through the relatable topic discussions.

00;01;36;10 - 00;01;45;12

Courtney Ringstaff

We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

00;01;50;18 - 00;02;17;07

Carrie Cobun-Stark

My name is Kerry Coleman Stark. I am the proud mother of one daughter, Amanda Beth Westbrook. We call her Mandy. My family has a business called West Virginia Paper here in Morgantown. It was a family run business. And when I graduated from high school, my sister and I were determined we were going to carry on the legacy and work for my father's business, which is what we both did.

00;02;17;19 - 00;02;38;12

Carrie Cobun-Stark

In fact, she still works in that business. I graduated in the top ten of my class and guidance counselor said, You really need to go to college. And I was like, Nah, I got my path. I really am going to work for my dad's business. This is what I want to do. And I didn't think about college. I had Mandy and everything changed about my life.

00;02;39;28 - 00;03;04;29

Carrie Cobun-Stark

The people that I started hanging out with were all college educated. They all encouraged me to go to school. I had no idea how I would do this. And actually, at the ripe old age of 39, I began my bachelor's degree and I did the Board of Regents program, which often gives a person college credit for life experiences.

00;03;04;29 - 00;03;29;18

Carrie Cobun-Stark

And so I got a good bit of credit through the Board of Regents, and then of course I had a lot of other classes I had to take, but I found myself taking social work classes, psychology classes. It just kind of all meshed together. I ended up graduating with my Bachelor of Arts, and then I decided I wanted to go into counseling and got my master's.

00;03;30;26 - 00;03;42;21

Carrie Cobun-Stark

I think that that getting my master's degree definitely led me to this job here at the CBD with the Traumatic Brain Injury Program. And I just absolutely love my job here.

00;03;46;29 - 00;04;12;17

Carrie Cobun-Stark

Mandy was born March 29th, 1986. I was excited to find out I was pregnant. Her father and I had planned a pregnancy. I had no really no issues with my pregnancy. I had a little bit of nausea, but that was a there was nothing to indicate that I would have any kind of problems during my pregnancy. Her birth was quite different than anything I had ever expected.

00;04;12;22 - 00;04;34;17

Carrie Cobun-Stark

So when I got to the hospital, I was dilated to three centimeters. And then when I got to the transitional part of labor, which is the hardest part, the most painful part of labor, I got stuck and I was stuck for about almost 10 hours. Her doctor immediately I remember he set by the bed. He monitor her heart rate.

00;04;34;17 - 00;04;57;17

Carrie Cobun-Stark

She appeared to be just fine. And then finally I told him I just couldn't do it anymore. So he gave me medication to make me dilate to ten. And I did. And I remember the first was was very painful. He had to use forceps to deliver her right after she was born. Another doctor in the room, also birthing babies that day.

00;04;57;17 - 00;05;21;12

Carrie Cobun-Stark

And she said really loud, wow, we've had a lot of bad babies born today. And of course, her father and I both heard that and were dumbfounded. And I bet your father and said, what does that mean? And he said, I don't know. So that was my first experience with a physician who said some really inappropriate things to me.

00;05;21;12 - 00;05;44;13

Carrie Cobun-Stark

And at the time, I didn't realize that there was a huge meconium stain, which means that the baby has had a bowel movement during birth and that's usually a sign that something is wrong. The baby wasn't getting enough oxygen, but I didn't know any of this until. Until later. They whisked Mandy away. She didn't get to lay on my chest like most babies do.

00;05;44;23 - 00;06;09;04

Carrie Cobun-Stark

I just kind of laid there and wondered what was happening. She was placed in the picture of the pediatric intensive care units, and I can remember even to this day that thinking of all the other babies that were there in the picture, you, how much bigger and healthier Mandy looks than most of them, because most of the babies were premature and very tiny.

00;06;09;22 - 00;06;30;00

Carrie Cobun-Stark

And Mandy looked completely normal. And nobody had really told me at this point that anything was wrong. They had just said she's had some lack of oxygen at birth just to be on the safe side. We're going to put her in the pit. You. I was determined that I was going to breastfeed. That had been my goal way before I got pregnant.

00;06;30;00 - 00;06;54;11

Carrie Cobun-Stark

I know how important breastfeeding is to babies, so I was pumping at home and freezing my milk so that when she did come home or I could take her to the hospital when I could nurturing there. Eventually, after 19 days, she was released and she came home. The mark and I and we didn't have a diagnosis at the time.

00;06;54;13 - 00;07;16;17

Carrie Cobun-Stark

I remember one doctor saying continue to try to breastfeed her son. Be very important for her that you do that. I'm not really sure what's going to happen with your daughter. We know she did have a birth injury, but she will tell us as she grows and develops how she's going to be. And that really didn't make sense to me at the time.

00;07;16;17 - 00;07;34;05

Carrie Cobun-Stark

But I understand what he was saying now. In other words, they don't know, didn't know the extent of her brain damage and they weren't really sure. And nobody really said the word brain damage to Mark than either one of us. So they just said, we don't really know how she's going to be. She'll tell us if she grows and develops.

00;07;34;05 - 00;07;56;03

Carrie Cobun-Stark

So we were like, okay, I wasn't referred to early intervention when she left the hospital, which really surprises me thinking back that I wasn't. So we took her home and this was our first baby. So we did the best we could. We had a small little house at the time and had everything set up for a typically developing child to come home.

00;07;56;03 - 00;08;27;00

Carrie Cobun-Stark

And so far as we knew she was, she cried all the time. The first nine months of her life were really hard because she was very irritable and cried and screamed for the majority of the day and the night. So I was exhausted because I was nursing her every 2 hours trying to comfort her. And I remember we got one of those baby swings and she practically lived in that swing because that's the only thing that would calm her down.

00;08;27;00 - 00;08;47;14

Carrie Cobun-Stark

I started noticing that Mandy was looking to the left all the time and I couldn't get her to look me near Mark right in the eye. And so when I took her back to the pediatrician, I told him, I said, I think there's something wrong with me, a decision she's not looking at. That's the way a normal baby should.

00;08;48;05 - 00;09;12;01

Carrie Cobun-Stark

And he agreed with me and he sent me to a neurologist. We went to visit her ologist. He really didn't tell us much of anything. I remember it wasn't a very. The outcome of that appointment wasn't good at all. But he did do a CT scan. So then the pediatrician called us back into his office to tell us the results of the scan that the neurologist had done.

00;09;12;23 - 00;09;35;27

Carrie Cobun-Stark

And this appointment was an appointment that it was 37 years ago. And I still remember exactly what he said, how he said it. He was eating his lunch this quarter pounder with cheese and fries, and he was in his lunch and he pulled up the scan on the viewfinder and said to Mark and I see this big black hole.

00;09;36;23 - 00;09;59;00

Carrie Cobun-Stark

This is what's left of Naomi's brain. She's had a burst injury. We're not sure what caused it. We don't know why it happened, that there's not much there's not much gray matter, white matter left in her brain that's got this big black hole. And that's how we were told initially about Mandy's brain damage. I will never forget it.

00;09;59;00 - 00;10;28;27

Carrie Cobun-Stark

I don't think, Mark, however, forget that a lot of my parents who have children with special needs that I talk to about my friends, they have very similar experiences that they're not being told in a kind, sensitive way about their child's disability. So that was our first experience. I had a friend that was working at my father's company, which my father had a family business, and that's where all of us worked.

00;10;28;27 - 00;10;49;00

Carrie Cobun-Stark

And there was a woman there that worked at the early intervention program here in Morgantown. And she I was talking with her about Mandy and she said, you really need to get her into early intervention. I have no idea what that was, what that meant. But she told me that would be really important and crucial in Mandy's development.

00;10;49;00 - 00;11;16;07

Carrie Cobun-Stark

So at five months, Mandy was referred to early intervention and that was life changing for me and her and our whole family, because with early intervention, I had physical therapy, occupational therapy, speech therapy that came to the house while I was still home with her to work with her. And they taught me what to do and taught me how to work with her.

00;11;17;17 - 00;11;49;19

Carrie Cobun-Stark

Most importantly, during that time was the social worker that was part of her team, and she came to the house pretty much weekly and spoke with me and I was very depressed. I couldn't go back to work. Once Mandy came home, we went from a two income family to a one income family. I wasn't able to work and so I was very, very depressed and really didn't know anything about services or what was out there.

00;11;49;19 - 00;12;16;14

Carrie Cobun-Stark

I mean, our whole world had just been turned completely upside down. So the social worker talked to me immediately about the services that they offered that most importantly, she gave me hope. She gave me hope that even though it appears that Mandy's injuries were very significant there, we could still have a really good life. Mandy could still have a good life.

00;12;16;14 - 00;12;52;00

Carrie Cobun-Stark

Mark and I can have a good life. She was determined to help walk us through how to do that. And she did. And I will never forget her. She was incredible. When I think about my outlook at that time, I would say that my acceptance of Mandy's condition was very gradual. I would say it took me about four years before I worked through the stages of grief, and I came to a point where I wouldn't even use the word acceptance.

00;12;52;00 - 00;13;19;03

Carrie Cobun-Stark

I adapted to what our new life was, was going to be. But it took me a long time to get to that point. Initially, I was very angry. Angry at God, angry of all my friends who had normal babies, angry people that I heard were using substances during their pregnancies. And your children came out fine. Maybe not fine, but not with the extent of the damage that Mandy got.

00;13;19;10 - 00;13;43;25

Carrie Cobun-Stark

I was really angry and it took a while to work through that, but I finally did. I don't know what I would have done without my mother and my father during this time. And my sister, my family was very, very important to me and so was Mark's. My mom was always there when I needed her. She would watch Mandy for Mark and I, so we could go out to dinner and just try to have a date night, if you will.

00;13;43;29 - 00;14;11;02

Carrie Cobun-Stark

And that was really important to us. My family's always been important to me, and during this time they were exceptionally important. When you have a child that has issues, it puts a huge strain on the marriage. People have asked me over the years, did you and Mandy's father divorce because of her disability? And the answer to that is no, at least for us anyway.

00;14;11;02 - 00;14;42;04

Carrie Cobun-Stark

We that's not why we divorced. But what happens when you put a credible strain on a marriage? Absolutely. And a lot of our friends that we had kind of went away. It's like they didn't know how to interact with Mark. And because of me, they didn't know what to say. They felt sorry for us. So we ended up developing a whole new set of friends through people we met through early intervention at the hospital.

00;14;42;04 - 00;15;01;05

Carrie Cobun-Stark

And just along the way, we met some incredible people that helped us through it. And it wasn't that our friends were being mean or disrespectful. They just they just didn't know anything about what was happening. And they felt kind of ignorance about the whole situation and they didn't know what to say when they were around Mark and us.

00;15;01;06 - 00;15;39;14

Carrie Cobun-Stark

So that was really hard. So I hung out with my family a lot during the time when Mandy was about four. My father got diagnosed with terminal brain cancer. So on top of everything else we were dealing with that we found out we have a year and a half to live. There was nothing that could be done and my father was incredibly close with me and Mandy, and it was just it was just a really, really hard time for all of us who had a stroke during the procedure to try to remove the tumor.

00;15;39;14 - 00;16;03;00

Carrie Cobun-Stark

So when he woke up from the surgery, he was never the same as he had been prior to that. I remember I wanted to spend a lot of time with him prior to the surgery because we didn't even know if he would make it through. But he did. And thanks to my mom, he lived 20 months because of her incredible care and he and Mandy were super close, very, very close.

00;16;04;20 - 00;16;35;28

Carrie Cobun-Stark

After early intervention, of course, came the school years. And she started out in elementary school and then went to middle and high school. Her school years in the beginning were were really good. She had some great teachers at elementary. She was there for several years, had tt0t and speech. But more importantly, I made sure that she was a part of that school's community.

00;16;35;28 - 00;17;03;16

Carrie Cobun-Stark

I didn't want people to look at Mandy and be afraid of her because she was in a wheelchair and she had a G tube. So I would go in as beginning of each school year and I would talk to them about Mandy and I would explain that Mandy had cerebral palsy, and I explained to them that that meant she had an injury at first, and because of that, she wasn't able to walk or talk because of the damage to her brain.

00;17;04;19 - 00;17;29;08

Carrie Cobun-Stark

But she loved when others would come up to her and speak to her, would laugh with her. So please don't be afraid to come up to Mandy and attempt to interact with her. She probably won't interact back with you, but she knows you're there and it will mean a lot to her. And so it's like with children, once you explain that to them, they were like, okay, cool.

00;17;29;08 - 00;17;58;02

Carrie Cobun-Stark

Versus some adults who tended to feel sorry for me and feel sorry for Mandy. And that's not what you need at all. But you don't need somebody to feel sorry for you so the kids were great. Once I went in and just explained the situation. Mandy had a G tube eventually and I knew that would be pretty scary for the children because I would see this kid banging out of her stomach once I explained what that was, and I remember telling them that this is how air that senses out.

00;17;58;11 - 00;18;22;15

Carrie Cobun-Stark

It's a way for her to kind of belch through the tube and pass gas. And I tried to make it kind of funny and then all the kids cracked up. And so that was pretty cool. So maybe I can pass gas too. So I always tried to make things light for the kids and it worked. And then when she was little, she had a lot of kids with her birthday parties and she went to their parties and it was great.

00;18;23;12 - 00;18;58;09

Carrie Cobun-Stark

And then when middle school hit, things started to change. When children are about 1213, they change. Everything changes. And Mandy didn't get invited to things like she was before. I still went in and talked to the class about her, but it was hard, middle school was hard, high school was a disaster because she was put in a room with I think about 20 or 25 other children who had varying disabilities.

00;18;58;09 - 00;19;29;24

Carrie Cobun-Stark

So there was children in there with Mandy who was in a wheelchair. There were children with Down's syndrome. There were children with genetic anomalies. These are all different types of developmental delays. It just wasn't good. And the teacher was great. She tried her best. So the age, but it just didn't work. So her father and I ended up pulling her out of school when she was about I think she was about 20, but she eventually did graduate with her diploma.

00;19;29;29 - 00;19;57;25

Carrie Cobun-Stark

So we were very proud of her for that. But Mandy was the bravest girl with ever known. She was beautiful inside and out. She loved music. She loved any kind of movement. So if we were going out somewhere, she'd love to get in my husband's truck and the rest of the road was the more she reacted and the more she smiled.

00;19;58;06 - 00;20;20;01

Carrie Cobun-Stark

She loved any kind of movement. She loved to be outside. She would much rather have been outside the inside. So we always tried to take her places, like take her fishing, but we took her to the park, to the skating rink. We took her as many places as we could. And so her health got to the point where she just no longer could do that.

00;20;20;01 - 00;20;44;27

Carrie Cobun-Stark

But she loved to go she loved to go shopping. I would always take her to the mall and with the shopping, she loved music. I loved bright colors. She reacted usually to the color red. I'm not sure why, but I think that was her favorite color. Mandy never spoke. She never was able to tell me with her voice, I love you, Mom.

00;20;44;27 - 00;21;21;07

Carrie Cobun-Stark

But I knew she did. And she communicated with her, her eyes, her facial expressions. That's how I and others communicated with her. She was never able to walk, so she was in a wheelchair for the majority of her life. Mandy was truly an angel. I really believe that her father and I don't something that she that Mandy never committed once and while she was on the service, Mandy had a lot of health complications that came along with her single policy.

00;21;21;26 - 00;21;48;19

Carrie Cobun-Stark

She had issues with constipation. She had issues with chronic urinary tract infections or UTI as a cycle. And when I was caring for her, I would recognize the smell of her urine was different when she had to utilize. So I almost always knew when she did have a UTI because the urine smelled a certain way and I was almost always right.

00;21;48;19 - 00;22;16;23

Carrie Cobun-Stark

And fortunately her constipation was very hard to manage. It often ended her up in the hospital, and so I could tell when I was feeding her if she was constipated because the food just didn't go in through the to like it should. She became very irritable and cranky, so he often could tell us through her her pain or her joy or what was happening.

00;22;17;08 - 00;22;43;21

Carrie Cobun-Stark

So it often was really hard to know. But when you spend 24 seven with your child, you learn, you get to know them so well that there's not much that you don't really know. And I would take her to the doctor when she was ill, when and after they started seeing her and I established a good relationship with her PCP, he would look at me and say, Well, what do you think's wrong, Terry?

00;22;44;00 - 00;23;12;19

Carrie Cobun-Stark

And I would tell him, and I would almost always be right. And I'm certainly not a doctor. They'll claim to be. But I knew my daughter really well and they listened to me and they knew I knew her well. So that that was a big part of her care. When she was about 18 months old, a doctor came here who was a renowned pediatric neurologist.

00;23;12;19 - 00;23;38;10

Carrie Cobun-Stark

And I heard that he was coming from Mandy's developmental pediatrician. And he suggested that I set up an appointment with this doctor because maybe he could shed some light on what has happened, why it happened. I was blaming myself as parents often do so I got in to see a doctor, John Bowen Steiner, who changed my life in Mandy's life.

00;23;38;10 - 00;24;02;14

Carrie Cobun-Stark

The first time we saw him, he spent about, I would say, an hour and a half with us in the room and was very honest. But he did not give us hope. He gave us hope about what Mandy might be able to do. And he told me that I have a placental abruption, and he could tell that from the CAT scan that they had done.

00;24;02;25 - 00;24;25;12

Carrie Cobun-Stark

And he said this was not your fault. He couldn't have done anything to prevent this, to stop this. It just happens to some women. We don't know why. And it happened to Mandy. I remember I cried through the entire appointment, but at the end I thought after a year and a half, finally somebody has told me it wasn't your fault.

00;24;26;12 - 00;24;45;08

Carrie Cobun-Stark

And B he gave me hope, gave me a lot of hope for Mandy. And then he said, I want you to come back in a couple of weeks and bring your husband with you. And I will go over all of her CAT scans with you in my office and we will talk again because her father wasn't able to be there that day.

00;24;45;08 - 00;25;04;00

Carrie Cobun-Stark

So we went back in two weeks and he did exactly what he said he was going to do. You went over her scans, looked at certain parts of her brain and said this is what she might be able to do because there is some white matter here. She probably won't be able to do this that I'm not sure she might.

00;25;04;00 - 00;25;31;18

Carrie Cobun-Stark

So he he didn't give us false hope, but he gave us some hope of what Mandy Mandy's life would be. When I took her back to see that first pediatrician for a checkup after he had told us of her, her brain was like a big black hole. He also added that he thought Mark and I, she put me in an institution and basically forget about her because our life would never be the same and her life would never amount to anything.

00;25;33;02 - 00;25;59;21

Carrie Cobun-Stark

And I remember looking up at him and saying, Well, that might be your opinion, but it's not mine. And I will never bring her back to see you again. And that's when I changed. From that pediatrician to seeing the developmental pediatrician, I had some really bad experiences, but thank God I was linked with early intervention and the child development doctor who got me with Dr. Ben Steiner.

00;26;00;03 - 00;26;29;26

Carrie Cobun-Stark

And from that point on, I started to feel really empowered that Mandy can have a really good quality of life. It was going to be hard, no doubt about that, but that we could make her life a really good one. And even though that initial pediatrician said what you said to me was very inappropriate in a way he gave me a gift because after he said that to me that he didn't take me and his life would be worth anything that really empowered me.

00;26;30;02 - 00;26;48;27

Carrie Cobun-Stark

I'll show you. I'll show you and everybody else in this community that people will know my daughter and they will remember her and she will serve a great purpose. And she did. And she still is, even though she's not here. When I talk about her, what I am today and then do other presentations, she's she's always with me.

00;26;49;14 - 00;26;57;05

Carrie Cobun-Stark

So in a way, he did give me ideas.

00;26;57;05 - 00;27;16;06

Speaker 3

Mary, these experiences that you had started in 1986, I know you've been working in this field now for a long time. Are there differences that you have seen in medical providers then, how they were when Mandy was born?

00;27;17;15 - 00;27;48;08

Carrie Cobun-Stark

I really think there are and I think there are positive changes. I think that physicians these days and medical students and coaches and teaching and speech therapist all really recognize the importance of family centered care, parent professional collaboration, how important it is to include the parent in all aspects of the child's care. And I don't think it was like that at all in 1986.

00;27;48;19 - 00;28;12;14

Carrie Cobun-Stark

I really don't I don't think parents were even viewed as a partner in anything. So I think it's really changed a lot for the better. I think people recognize the value of listening to the to the parents, really making them a part of the team. So I'm really glad that that's changed because it certainly needed to. So I'm really glad that it has.

00;28;13;09 - 00;28;54;23

Carrie Cobun-Stark

You know, I think there's always ways to improve. I think there's probably still families that get told in very unprofessional, uncaring ways about their children or somebody is told they have cancer. When you're delivering that kind of sensitive information to families, most medical professionals get no training on how to do that. With this blows my mind, you can be incredibly smart, brilliant person, but if you don't have the talent of being able to talk to people and relate really sensitive information to them in a way that still leaves them with some semblance of hope.

00;28;55;14 - 00;29;20;16

Carrie Cobun-Stark

In my opinion, you shouldn't be practicing. And Dr. Bowen Steiner was incredibly brilliant, man. He knew how to sit down to talk to people and he knew how important explaining the diagnosis was to Mark and I, he and I became very good friends after that and we started doing presentations together, actually, and we called the presentations delivering sensitive information to families.

00;29;20;16 - 00;29;43;15

Carrie Cobun-Stark

And he and I would role play and I would be the parent and he was the doctor, and we would do the negative way. And then the way that he did it and we did that for probably five, six years to medical students, to other other students here to university. And I think it was very well received because that's just something that they do not get in their training, unfortunately.

00;29;44;09 - 00;29;45;02

Carrie Cobun-Stark

I hope.

00;29;45;24 - 00;29;57;25

Speaker 3

That my assumption is right that it did make a difference because we are now seeing more things in medical school curriculum about how to.

00;29;57;28 - 00;29;58;08

Carrie Cobun-Stark

Talk.

00;29;58;08 - 00;30;17;08

Speaker 3

With families, have a chat with patients. And so a part of me thinks that that those bad experiences and those initial trainings could have contributed to our whole system change and the way that students here at WVU are taught to provide care.

00;30;18;02 - 00;30;44;16

Carrie Cobun-Stark

I sure hope so. That's my hope. I'm so proud of Mandy for being a part of that, and I still want to be a part of that because that always should be something that any professional is going out and working with individuals who might be presenting them with really tough, life changing information. And they need to know how to do it because believe me, the person never forgets the days or so.

00;30;45;09 - 00;31;14;01

Carrie Cobun-Stark

And I have countless friends who have children with disabilities, and they all say that we will never forget the day we were told about our child's disability. This is something that sticks with me so I hope that the people have learned how important others. One of the stories that I love to tell and I think people will always remember about Mandy is she was in and out of the hospital.

00;31;14;01 - 00;31;35;21

Carrie Cobun-Stark

As the years went by, her health issues got more and more extreme. She was in and out of the hospital all the time, and a lot of the time it was either a UTI or a chronic bowel obstruction or an illness, which is another alias, is basically just where the bowel kind of stops and slows down. It's incredibly painful.

00;31;36;03 - 00;32;03;18

Carrie Cobun-Stark

Then, of course, if you end up with develops direction, it can be can be deadly. So constipation was a huge issue for our family in Mandy and something we had to monitor and work with and try to figure out how to keep her comfortable. Every day I was lucky enough to meet a pediatric surgeon here at WVU who again was a very kind, gentle, soft spoken man.

00;32;04;07 - 00;32;27;17

Carrie Cobun-Stark

And sometimes with surgeons, they're not even approachable. But he really was. And she was in the hospital for what we thought was an illness. And he came in and was ready to discharge Mandy. And he said, Do you think she's going to go home? And I said, No, absolutely not, because the pain she's having when we came in here is still pain she's having today.

00;32;27;17 - 00;33;05;08

Carrie Cobun-Stark

On the day you want to discharge her, I said no and I wouldn't let them discharge her. And her niece had happened to have come in to visit her the day before. And she was telling my mom and I about a gallbladder attack that she had had and she started to describe the pain. I looked at mom and said, that sounds exactly like what Mandy's been going through, because what had been happening was Mandy would get about halfway or three quarters of the way through her meal and then scream and just what she was having, gut wrenching pain.

00;33;06;05 - 00;33;29;05

Carrie Cobun-Stark

And then it would subside and she would stop all of her doctors, including her developmental pediatrician, told me that they thought it was just irritability from brain damage because children with brain damage can be very irritable, he said. And I didn't buy it. I knew that it had to be something else, because otherwise why didn't she just do it at certain times?

00;33;30;03 - 00;33;53;08

Carrie Cobun-Stark

So when Dr. John came back in to discharge her, I told him about Mandy's knees and I said, Do you have do you think maybe she can have something like an ailment that sometimes and often are overlooked? Some people with disabilities have a gall bladder. Or could she have the disease? Gall bladder or appendix to the disease? Could she have gallstones?

00;33;53;29 - 00;34;19;23

Carrie Cobun-Stark

Is that a possibility? Well, it is, but it's probably not because Mandy is only one of the three. Yeah. So I said, what do you mean by that? Said, Well, usually with gallstones and gall bladder, you have to be 40 fat and female and is only one of those three. So I said, Well, what would we have to do to make sure that it's not her gallbladder or her appendix or something else?

00;34;19;23 - 00;34;46;26

Carrie Cobun-Stark

He said, Well, I can just do a simple ultrasound. And he did. I remember my mom and I went down that day and the technician, as she was doing the ultrasound said, Oh my God, look at all the gallstones. And she had 12 gallstones. 12 one is painful, but Mandy had 12 and we were all blown away. I remember my mom and I started crying.

00;34;46;26 - 00;35;10;15

Carrie Cobun-Stark

We were so happy and the technician kind of looks at us like, Why are you happy? Well, we were happy because we finally figured out what was wrong with her. And that's a big issue for parents. If you try so hard to figure out what it is that's making your child sad or sick and medicine can only do so much.

00;35;11;05 - 00;35;37;02

Carrie Cobun-Stark

There they were 12 gallstones. And what was happening was they were rolling around in the gallbladder, getting stuck in that duct between the gallbladder and the liver. And when they do that, it's incredibly painful. The surgeon, Dr. Vaughn, was completely blown away. He just couldn't believe he went in, removed her gallbladder and her appendix. And I remember you brought out the jar of gallstones and they looked like little pieces of bramble.

00;35;37;08 - 00;36;01;01

Carrie Cobun-Stark

You cannot believe that I was right and I was glad I was right. And if her niece hadn't come in, I don't think we ever discovered that. But if she had not listened to me and been willing to do a simple task like an ultrasound, if she had had an attitude problem or thought, this parent is not a doctor, she's not a nurse, I don't have to listen to her because he didn't.

00;36;01;18 - 00;36;18;18

Carrie Cobun-Stark

He knew how well my mom and I knew Mandy and he listened to us. And as a result of that, we solved the problem. That would never have been resolved if he hadn't if I hadn't had that parent professional relationship with him and also.

00;36;19;18 - 00;36;43;10

Speaker 3

Had you not specifically pushed a little bit and said, well, what tests do we have to do to rule it out? Because many parents would have just taken the. No, probably that's probably not it. But Gene said, well, what do we have to do to be sure? So taking it to that next level may have been, you know, the step that that could have gotten left off.

00;36;44;01 - 00;37;18;00

Carrie Cobun-Stark

Well, and I'm really glad you brought that up, because what I've tried to teach other parents I've worked with all these years and and I and even for anybody this in the hospital, what I stress to folks is do not be afraid to ask questions. Do not be afraid to question some of their decisions. I had to learn that the hard way with managed care, and I can usually tell the professionals who were willing to really listen to me versus the ones that just kind of blew me off and the ones that blew me off.

00;37;18;00 - 00;37;45;02

Carrie Cobun-Stark

I pretty much fired them and went to somebody else because I just didn't want to have that kind of relationship with the doctors. I didn't think I was anything about my daughter because I knew everything about my daughter. Sometimes you really have to push their buttons and not be afraid to offend them. You just have to be advocates and you have to be an advocate for your child.

00;37;45;02 - 00;38;11;04

Carrie Cobun-Stark

One of the things that I learned really early on and that sustained me throughout my journey was Mandy was getting involved with support groups, meeting other parents who had children, very similar to Mandy. I learned more from them than pretty much anybody. I remember one mom in particular, her child was in Greece in diapers and I was complaining to her about the cost of the diapers.

00;38;11;04 - 00;38;48;18

Carrie Cobun-Stark

And she said, well, why isn't your medical card paying for them? And I said, I didn't know the medical card would pay for diapers. She said, Well, didn't tell you that? No. So that's just one example of something I learned that the agency didn't bother to share with me, that I learned from her and others like her, and more importantly, having a relationship with another parent and being able to talk openly about your hopes and your dreams and your frustrations was so important.

00;38;48;18 - 00;39;14;22

Carrie Cobun-Stark

As Mandy grew and I kind of grew in the CEO of I started running support groups or starting support groups. If there wasn't one, then I just started one. And even if we only had three people that showed up, we helped three people. And I, I actually run a caregiver group today in my current role because I said what caregivers really get are the short end of the stick and they don't get lot of support.

00;39;14;22 - 00;39;50;24

Carrie Cobun-Stark

So support groups are very important for folks just to realize the importance of that relationship you have with another. I mean, I looked at them as my mentor and a lot of was because they were were Mandy was very lucky in that about the same time she got into early intervention, she got on the Title 19 waiver program, which is now called the IDR Waiver here in West Virginia.

00;39;50;24 - 00;40;15;22

Carrie Cobun-Stark

Most states have the waiver programs. They were originally designed to help keep children out of an institutional placement or nursing home placements. It's a medicaid funded program that allows you to have supports brought into your home to care for your child. He was really lucky to get on that right away. And that that program also was life changing.

00;40;16;27 - 00;40;40;01

Carrie Cobun-Stark

In fact, that program paid for a respite person to come in and help me care for Mandy. And that's how I was able to return to work. When I wanted to return to work initially. And I called around to the various daycares here in Morgantown. They said, Well, we'll take Mandy, but you'll have to pay the $60 a week fee.

00;40;40;01 - 00;41;04;16

Carrie Cobun-Stark

Plus they'll have to hire some aide for Mandy as well. And of course, there was no way I could do that. So if it wasn't for the waiver program and her being able to get respite care to a place called Visiting Homemakers, then I would never have been able to return to work, which we found a wonderful person who came in and helped us and cared for her so I could go back to work at least part time.

00;41;04;16 - 00;41;34;27

Carrie Cobun-Stark

Initially, the waiver also paid for extended services like Oat Foods. It also gave me a small income for caring for Mandy. It was initially I felt really kind of strange and weird about these and why are you going to pay me to care for my daughter? But the premise of that is, well, if she were in an institutional placement, so what?

00;41;35;01 - 00;41;59;23

Carrie Cobun-Stark

We would have to pay professionals to care for her. There is nothing compared to what we're paying you to try to keep her out of that situation. So once I kind of understood that, then it became okay, that little bit of money that we got help us to do things like put ramps on to the house, get her equipment that maybe we could have gotten to Medicaid insurance.

00;42;00;15 - 00;42;31;10

Carrie Cobun-Stark

So the Title 19 waiver program was life changing and the waivers still were life changing. And that was something that really helped our family. As Mandy got older when she was about 26, 27, she started having episodes that were, well, nobody could figure out what what was happening to her. We took her to the E.R. one night because she broke out the sweat.

00;42;31;12 - 00;42;50;21

Carrie Cobun-Stark

Her heart rate was really fast. Her spasticity was through the roof. We didn't know what was happening. And when we took her to the E.R., the doctors looked at Mark and I said, What's happening to her? And we said, Well, you tell us. That's why we brought her here. I can see why they said that. And they said, What do you think she's seizing?

00;42;50;21 - 00;43;14;26

Carrie Cobun-Stark

Is this what her seizures look like? Like, no, this is not what her seizures have ever looked like. Do you think she's having a heart attack? I don't know. Do I do? So, you know, I mean, after a while, you end up doing like you're a nurse and a doctor sometimes or just trying to learn as much as you can so they give an EMT an EKG.

00;43;14;27 - 00;43;39;19

Carrie Cobun-Stark

Everything came back normal. She was still thrashing around in the bed and calm her down. He had just gotten on hospice care. And as soon as I heard that she was going to go to hospice, my heart sank because what I knew about hospice care was when people go to hospice, that means they're gone and they only have a certain amount of time to live.

00;43;40;18 - 00;44;02;02

Carrie Cobun-Stark

It was explained to me that that's not always the case, that you can go on hospice for a while and you can go off and you can go back on the back of the hospice. Doctor that we had gotten in touch with, Dr. Dower. They call him some E.D., because I said, you better call her hospice doctor. Maybe he knows what's going on.

00;44;02;11 - 00;44;29;15

Carrie Cobun-Stark

And he walked in and took one look at Mandy and said, well, she's having she's stormy, she's having neuro storms. We were like, what's that? And that's basically when the brain becomes so overstimulated, it just can't calm your body down. It's kind of like the fight or flight that people go through. Mandy was in the the site. She just couldn't get out of that fight mode and it was just horrible.

00;44;29;29 - 00;44;52;20

Carrie Cobun-Stark

My first question was, how do we stop this? And that's what the doctors asked him. And he said, Well, the only thing that will stop this is morphine. So they brought in some working and gave it to her and within 20 minutes she stopped. And so the next four years, she went through this storming nurse storming, as they call it.

00;44;52;29 - 00;45;17;24

Carrie Cobun-Stark

And Dr. Downer later told me that this is something that he often sees in folks who are end of life. It's usually part of end of life. And the first person called after we discovered this was Dr. Baden Steiner because he was at the Mayo Clinic at the time. And I wanted to make sure that he agreed with Dr. Diagnosis, and he did right away.

00;45;17;24 - 00;45;46;04

Carrie Cobun-Stark

He said that morphine was the right thing to use. He told me how sorry was that, that this would stop the storming for the last, I would say, two years of her life. Mandy was on a low dose of morphine, 24 seven when she did start to stop. And we would have to bump up the morphine to see her go from storming to being full of morphine was really hard because she just kind of collapsed in her chair.

00;45;47;22 - 00;46;08;00

Carrie Cobun-Stark

But I would have much rather seen that and see her sleep peacefully and then go see the storm. So once again, we learned about something that we knew nothing about from a specialist, and he was willing to take some time to talk to us about it. And I'd started doing a lot of research myself on it because I had no idea what it was.

00;46;08;00 - 00;46;33;14

Carrie Cobun-Stark

And I started going on PubMed and looking at autonomic dyslexia. And over the years I've talked to a couple of mothers who describe to me some things their children were doing, and I told them to mention to their doctors that this could be a nurse storm. So I've tried to help other moms and dads learn what this is and learn how to treat it.

00;46;33;14 - 00;47;10;11

Carrie Cobun-Stark

Most importantly, because it's really hard to watch your your loved one, your child does this. The hospital stay with Mandy through the end. We have incredible care from them. Mandy was able to die very peacefully on her father's bed with him on one side, me on the other, and her step daddy, Mapp, my current husband at the foot of the bed and surrounded by all her family, my mom, all her nieces, nephews, my stepchildren was very peaceful.

00;47;11;00 - 00;47;37;09

Carrie Cobun-Stark

She didn't suffer. She eventually was on some of morphine. It just pretty much stopped for reasons I'll never forget when she we thought she had passed. And then my husband, Matt, said, no, look, she's still with us. And she opened up her eyes and looked at him and gave us some of the beautiful smile. And I swear, I think maybe she saw heaven in that moment.

00;47;38;09 - 00;48;10;00

Carrie Cobun-Stark

Then she closed her eyes and she was gone. And I miss her every single day. Her life really did matter a lot. And if I would have one thing I can say to up and coming medical providers about treating children with special needs and children with progressive illnesses, please listen to the parents. We're not doctors. We're not nurses.

00;48;10;00 - 00;48;47;08

Carrie Cobun-Stark

Well, some of us might be, but I certainly wasn't. But you will learn a lot from listening to a parent about what their child is going through, and it will help you in treating them because the parent knows the child better than anyone. And if you involve them in your plan of care, it will make all the difference for the child, the family, and for you as a physician.

00;48;47;08 - 00;49;21;02

Carrie Cobun-Stark

And here's something you guys will both be amazed with. So, Dr. Cardenas, who is the new one, the new neurologist at the Rockefeller Neuroscience Institute, guess who trained him? Dr. Bowden's staff. So it's like this kind of this circle that came together. So I was even emailing him one day about a client, and I had to tell. I said, I have to tell you that I think, you know somebody that's very special to me and he couldn't believe it.

00;49;21;02 - 00;49;44;23

Carrie Cobun-Stark

He's like, What a small world. I adore Dr. Ben Steiner. He was my mentor. He taught me about neurology, but he taught me more about how to be a good human. So in that something really gets I couldn't believe it. I'm like, Are you kidding me? Dr. Bone centers out there just changing the world. One hour. He does one hour at a time.

00;49;44;26 - 00;50;13;24

Carrie Cobun-Stark

I think he's retired. I would imagine he's retired. But the day Mandy died, he called me at the house and we had a good cry together. But he called me so much to me and he sent me a card and he is a really good. I would often go over to the hospital, over to the floor and talk to families at Dr. Ben Centers.

00;50;13;24 - 00;50;42;03

Carrie Cobun-Stark

They go talk to this mom about Eddie to go talk to this Karen about waiver. And they would say, but I can't ask them that. And I said, Oh, yes, you can. You're paying for this. This is your paying a service. And you can ask them anything you want to and make a list. Because my doctors come in there in their talk for 5 to 10 minutes when they're doing their rounds, and I learned what times they do their rounds.

00;50;42;03 - 00;51;10;07

Carrie Cobun-Stark

And so I had to make sure I was there at 7 a.m. to 8 a.m., because that's when they round it. And so I would write out my questions the night before, and I would have them when they walked in and I would let them leave the room till they answer my questions because, I mean, you're paying for a service and they need to provide you with a and it's hard sometimes to teach people that usually they won't do their best to answer.

00;51;10;07 - 00;51;31;08

Carrie Cobun-Stark

And if they didn't know the answer, I always tell folks, it's important. If you don't know the answer, just say I don't know, but let me do some research and I'll find out and I'll get back to you. And that that always meant a lot to me because a lot of doctors would do that. The hospital's not some place to be and they're understaffed or overworked.

00;51;31;14 - 00;51;35;27

Carrie Cobun-Stark

And you really need an advocate. There.

00;51;40;07 - 00;51;55;26

Speaker 3

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