When Things Like This Happen – TC

TC: When things like this happen, it’s okay to grieve. It’s okay to not know what the future is going to look like, and it’s okay to be scared about that; that’s normal. But it’s not okay to give up hope and think that you’re just stuck, because you’re not.

CR: Welcome to Adjusting the Sails, a podcast for parents, caregivers, and service providers for children with disabilities. I’m your host, Courtney Ringstaff, Paths for Parents program manager, and this is my co-host, Melina Danko.

MD: Hello everyone.

CR: Melina is the Assistant Director of Communications and Marketing at the Center for Excellence in Disabilities and the Project Director for the West Virginia Family to Family Health Information Center.

MD: We are so glad you can join us.

CR: I am a licensed 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.

MD: Joining us today is Tina Crook. Tina is a parent whose journey with her son has led her to her work at the WVU Center for Excellence in Disabilities as a Parent Network Specialist. In that role, Tina helps families on their own journeys of parenting a child with disabilities or special health care needs, find the resources, and services, and place that can help them. We’re happy to welcome her today as she shares her experiences with us.

TC: I’m a mother. I’ve got 4 children. All of my children were born healthy, typically developing children. I’ve got 3 sons and a daughter. She’s the youngest. My middle son, when he was 13 years old, he got sick one summer and it was kind of like, you know, flu symptoms and stuff like that. We bounced around from doctors and emergency rooms trying to figure out what was going on with him, and it was when his speech started really slurring that they realized that okay, this is serious. This isn’t the typical flu or something like that. He ended up getting admitted into the hospital in Morgantown where they did a spinal tap on him that confirmed that he had HSV Type 1 Encephalitis. So for anybody that doesn’t know what HSV Type 1 Encephalitis is: HSV is the Herpes Simplex Virus, also known as the common cold sore. So instead of him just getting a common cold sore like most people do that have that virus in them, his somehow travelled into the brain and caused mass infection and swelling. Daylin was in the hospital a total of 30 days. After about 1 week in the hospital, the swelling just became too much and his brain started rupturing and ultimately left him with left frontal lobe brain damage. He lost his ability to read and write, tell time, his speech was really impaired, just words – your every day words that we use – for him, he couldn’t get them out. The wrong word would come out. Aphasia is what they called it; and they described it to me as, “Our brain is a massive filing cabinet of words, and in Daylin’s brain that filing cabinet got dumped out.” So he was, you know, scrambling in his brain trying to pick and choose and find those right words; and he might be asking, you know, wanting a drink of water, but he looks over and he sees a fork laying on the table and he’s going to say, “Give me a drink of a fork.” We had to do a lot of the guessing game as far as what’s he trying to say? what is it he’s wanting?

After he left the hospital we went to Health South, and we stayed inpatient there for a couple weeks for some pretty intense therapies. We were discharged and the journey began as far as not having everybody right there to tell me what I needed to do. I mean it [4:40] that’s when it got really scary. We continued to do rehabilitation and therapy as outpatient 3 days a week for several years after that.

CR: And what was his medical team telling you was going on?

TC: They were thinking like West Nile Virus, they were thinking mosquito bite, they were thinking it could have been meningitis. They weren’t sure, so they were treating for a wide variety of things. They were treating for viral and bacterial both, and then just trying to manage his symptoms. His fever was really high, he was in and out of consciousness… Once they finally got the diagnosis – once the results of the spinal tap came back – they said it didn’t look good. They just basically told me to pray and that they would do everything they could, but it was probably going to get a lot worse before it got better. They said that he would have some lifelong deficits. We didn’t know the extent of what those deficits would be, because he was in and out of consciousness so much those first few weeks in the hospital. He wasn’t talking to us, he wasn’t telling us how he felt, we weren’t really see…we wasn’t seeing the impact yet of what it had caused until later on. After the brain had ruptured, they had told me that he would probably never regain everything that he lost. He’s come a long way and a lot further, I think, than anyone expected him to.

MD: When you… You mentioned when you were leaving Health South to go home that that’s really when your journey began and life got scary, and I think that that really resonates with a lot of parents because all of the sudden you’re child isn’t the same as the last time you were in your home, and now everything has to change; so what… can you tell us what were some of those things that had changed from your day-to-day life when you did get back home?

TC: The biggest impact and the biggest change was I had to quit working. So we took a…a really big financial loss there, and we had to make a lot of uh cuts to make the ends meet. When you’re in the hospital or you’re in the rehabilitation center, you’ve got people there to help you. When you get sent home and it’s kind of like okay you’re on your own and you can’t just push a call bell when things get scary or you’re not sure what to do or what’s going on, so it had a pretty big impact on the siblings as well. Daylin acted different; he was very short-fused, his behavior was really erratic. Everybody – it was almost like walking on eggshells all the time – nobody really knew what would set him off. And they didn’t understand – especially his sister who was the youngest – didn’t really understand what happened to her brother and why is he acting different? Why is he saying funny things? Because to her, when that wrong word would come out, she would giggle and she thought it was funny because he wasn’t like that before. So she kind of thought you know that he was just being silly sometimes. But then he would get mad at her because she was laughing at him, so you had all that kind of chaos there, and then the…his older brother who – I don’t want to say “shunned” him – but he just didn’t know how to deal with it. His way of dealing with it was to try to stay away; he didn’t want to be near Daylin, and he just didn’t want to be faced with that, I don’t think. We all deal with things in different ways, and his way of dealing with it was just trying not to deal with it, if that makes any sense. And family – like my father and my sister – I don’t think they realized how bad it was. They’d come around and they’d come up and visit and stuff, and they didn’t know what to expect until they showed up that first time and when they left they were just like, “Oh, my…” It impacted Daylin’s friends – the friendships that he had – his friends would come visit after he got to come home from the hospital and they’d show up one time and then never come back. Where he couldn’t read or write…and teenagers – their method of communication is text messages, so he would have me send them a text and ask them if they wanted to come out and spend some time or hang out for a little bit, and it just got to where slowly, little by little, they just stopped responding. And he was 13 at that time, you know 13-year-olds – and I don’t blame, I don’t feel bitter toward any of them kids. At 13 years old, you’re still figuring out who you are, and it’s a hard thing for a young teenager to understand when something like that happens, you know, to one of their friends. We went through a lot of changes as far as friends, family, work, and just the home life – the siblings and everything. His interests didn’t really change. He was still interested in a lot of the same things. His mindset kind of went back a little bit, for instance it was October – August is when he was admitted in the hospital – and it was October when we finally got to come home after Health South, and all…he got it stuck in his brain that he had to have a Halloween costume and he hadn’t dressed up for, you know, several years, but you know he wanted a Halloween costume; and he got really upset because I didn’t have one right there for him, so it was one of those things like, that’s fine…if you want to dress up you can and we will get you a costume. Start thinking about what you want to be. He used to be – before the brain injury – he was the most calm and mellow kid ever, and he was my easiest out of all 4 of my kids, he was probably the easiest, the most laid back and that changed. He was… he couldn’t control his emotions and he didn’t have a filter. He had to basically relearn proper behavior too. We all… we see things, we think things in our head, we’re a little judgey at times, but we don’t say them out loud; we know that that’s inappropriate to say certain things out loud. Well, where he… his filter wasn’t intact, if he thought it he said it; and a 13-year-old boy saying what he’s thinking is not a good thing. We had to kind of go back and relearn what was okay and what was not okay to say. He wanted to hug everybody all the time when he seen somebody new or he wanted to hug, so we had to relearn that, that we don’t just go hugging everybody. Not everybody’s comfortable hugging. But he also…where he knew that he used to know certain things and he didn’t know them no more [*anymore* 12:10] like being able to read and write and remember people’s names; he knew that he should know that. He knew he used to know that. And he was so upset that he didn’t know that, he actually became suicidal. All knives, I mean steak knives, everything had to be put away and hid where he couldn’t find them. He used to collect pocket knives, and so all his pocket knife collection had to be taken out of his room and put up. We’re a family of hunters, so guns and stuff like that had to be moved out of the house; anything that we thought he could hurt himself with we had to hide from him and put away. We were driving down the interstate – my sister and I – coming back from his physical therapy and speech therapy that day, and we were coming down I-79, and he got upset because he didn’t get to sit up front; he just threw the door open on I-79 going to try to jump out. One thing I didn’t do was give in to him and say, “Okay, because you’re acting like this you get your way” because I didn’t want to create that monster either. It got to where somebody had to sit in the back with him if there was somebody up front. If it was just him and I, and he was sitting in the passenger seat up front he was fine. But if we went somewhere and he had to sit in the back, somebody else had to be back there with him. And, you know, that went on for several months before it got better, and they tried different mood stabilizers with him. And they eventually found something that did help. Some medications seemed to make it get worse, but once we found something that did work, it was a God-send and he was able to kind of control his emotions a little bit better. And then the recovery started getting better once he could control that. Seemed like it was just trial and error of figuring out what would work for him, what didn’t, what made it worse, and learning how to parent again; because I couldn’t parent him the same way that I did before. He was one – after the brain injury, if I raised my voice or sounded too stern he would get all upset. So I had to always talk to him in a really calm voice. I know someone had once said to me, “He’s not a baby; quit talking to him like a baby.” And while I wasn’t doing baby talk, I was talking just very gentle with him, but that’s what… that’s how I had to, to keep things from ever escalating.

We had moved and we had to get you know new doctors, and we were about a year out post the brain injury, and we had went to this neurologist for the first time and he was looking through Daylin’s records. He started asking me some questions about Daylin. He said, “Is he back in school yet?” and I said, “No, he’s still on medical homebound” and I said, you know, “He still can’t read or write to grade level.” And he said, “How often is the homebound teacher coming to the house?” And I said, “Well, once a week if we’re lucky.” And he said, “Now if he was in school how many days a week would he be getting to see a teacher?” And I was like, “Eh, 5 days a week.” But he then started asking me just you know questions about what Daylin does around the house you know “Is he getting up…setting his own alarm and getting up at a certain time every morning, does he make his bed, wash his own clothes…” things like that, and by this time Daylin’s 14. Of course, I’m answering “No” to all those. He finally said, “If you want him to get better, you need to get him back to doing what he used to do. And that’s when you’re going to see the recovery really take off.” He released him to go back to school and back to sports. A lot of people – when you think of brain injury, you think, “Oh gosh, sports…that’s… sports and brain injury, you can’t do that.” So the way it was explained to me is: there’s kind of 2 types of brain injuries as far as the kind that, “Okay, you’re never going to be able to do contact sports again” and then the kind that you still can. So with Daylin, when his brain started swelling and the skull lifted up a little bit – when that swelling all came down, everything came down together, and the skull came down with it; so everything was still tight and intact, the only difference was Daylin was missing pieces of his. The neurologist told me, he says, “You can’t hurt what’s not there.” But some people, the skull doesn’t come down, and then there’s some clay left in there between the brain and the skull and they may never be able to do sports again. So for Daylin, they released him to do sports. Before his brain injury, he was into wrestling, baseball, football; they released him to go back to all of it. The first year, all he cared about doing was wrestling. He never did go back to playing baseball. He did go back to wrestling; he unfortunately couldn’t remember the moves, and he had to relearn how to wrestle. My husband had never wrestled a day in his life, but he started going to all the practices and he started watching all these different Youtube videos on wrestling and the moves and…and stuff… and he started working with Daylin at the school and at home; and he actually became the assistant coach for the high school wrestling team because he wanted to be there to help Daylin out. Once we got him back in school, he did have to have an IEP. He did special ed Math and English, and then he had pull-out classes for the rest of his subjects. I remember that, his 9th grade year when they brought report cards home the first time, and he was on the honor roll again; I just remember being so happy about that, like, the joy it gives us even though, you know, he may have needed some assistance to get there, he still did it and that was still all him. We were living in Lewis County and they did an IEP for him, um but it was like medical homebound at the time, so he wasn’t in the school. And then we moved to Raleigh County while he was still on the medical homebound. The initial evaluation was never done when we were in Lewis County, which I was okay with that because so much was changing with him from one month to the next as far as just little things that were starting to come back to him. I was very fortunate with the school, because they were really good about the accommodations that they gave him in his IEP. The only trouble that…the only struggle I really had with the school was he would change classes each semester, he’d get new teachers, where in the mainstream classes they wasn’t aware that he had an IEP. He would come home from school or I’d get on *Schoology* and I’d check his grades, and it’d be like really low – 20s, 30s, stuff like that – and then I would have to email or call the teacher and be like, “Hey, what’s going on? Was [*were* 20:11] you aware that he has an IEP? He’s not able to fluently read the material. He’s supposed to have somebody reading it to him, or if it’s on the Ipad he’s to be able to use the speech-to-text and text-to-speech on it with his earphones.” And it wasn’t always so much that it was…that the teachers didn’t know as Daylin was old enough that he needed to advocate for himself and sometimes, I think, he was a little bit embarrassed to speak up and to do that and to say, “Hey, this is supposed to be multiple choice for me” you know or “I need someone to read me this” or “Can I go out to the…the library or somewhere to sit to get this done. Just different little things, so the whole four years of high school it was constant, when you’d have those changes in the semester or the year, where I’d have to reach out to the teachers. Once they were aware – even though they should have been aware – once I made them aware, they were very accommodating, and they…they did really good with him. But it was also Daylin’s part and my part to teach him to advocate for himself. Let people know when you need help; let them know what your accommodations are supposed to be. Don’t be afraid to ask for this, it’s okay to ask for that. He did learn to do that. He wrestled all four years of high school and he played football 3 of those years as well. It got to where everybody knew Daylin’s story; they were all really good about helping him out when he ever needed something, or the coaches would hand out papers that they had to fill out or something like that and the other players, his teammates, would be like, “You need help with that? Do you understand what that says?” And nobody really looked down on him for that; they were so accepting of it, and they all loved him. In the beginning for probably the first 6 months that we were home, I didn’t take care of myself. I lived on caffeine; that was like what got me through my day. I didn’t take time for myself; I didn’t get a break. I was to the point of exhaustion to where I started having really bad anxiety attacks at night. I held it all together, you know, through the day, and then once I got all the kids put in bed at night, it would hit me like a ton of bricks laying on my chest. I finally had to go to the doctor. I’m like, you know, something, I feel like I’m having a heart attack every night. It was anxiety. Of course, you know, giving me some medication to help me with that anxiety through the night and talked to me about the importance of taking care of…of myself, taking care of me. I didn’t trust just anyone to leave Daylin with, so I just…I learned to cope and…and deal with it. My sister was really good, as far as just somebody I could call and…and unload on, and she understood. My dad got to where he started coming out to the house once a week, and he was good about, “Go take a shower…go, do whatever”, and he would sit and play Uno with Daylin, which was awesome because that was teaching Daylin – Uno was a big thing in our house at that time, because Daylin was learning colors again plus numbers by playing Uno. That was my respite was when Dad would come to the house; and if that just meant that I could go and take a hot bath and shave my legs or whatever, then I could do that. But I…I was too scared at that time because we hadn’t got the medications regulated enough to control Daylin’s emotions, so I was too afraid to just go to town and go grocery shopping and leave Daylin there with Dad. I know now looking back my dad could have handled it, but I was just too overprotective, I think, too scared. I parent a lot more calm now. I was a yeller. Me and the kids, we talk and we take joy in the little things, you know, and I ask more often now – and it wasn’t that I didn’t do it before, but I think I didn’t do it enough, you know – “How was your day? How are you feeling? What would you like to do?” Things like that. Daylin is 21. He is living on his own; he is working in the oil field, well drilling rigs; he has 2 welding certifications; he’s engaged to be married; he’s doing really, really good. Daylin will probably always have a little bit of deficits. He still gets his words scrambled up a little bit when he tries to talk or he can’t think of the right word. But he has learned ways to navigate that, for instance, if he can’t figure out what that word is he’s thinking of he will talk around it, he will describe it to where you know you know what he’s meaning. And he’s gotten very, very good at that. Sometimes his auditory processing is a little bit slow too, and so when somebody says something to him, he hears them…it might take him a few seconds longer to comprehend what they actually said, so what he does is: when somebody says something and it didn’t really register with him right away, he’ll say, “Huh? What was that?” And so then they repeat it back to him, and most of the time before they even get it all the way out the second time it already registered with him and he’s responding. Daylin does like lots of reminders; if it’s something he needs to remember, he’ll put a reminder on his phone. Paying his bills, he does auto-pay; that way he don’t forget them. So he’s found ways to cope with all that, but those are things that he’ll probably always have issues with. Short term memory, too; if I’d ask him what he ate for breakfast, he may or may not remember; he might be like, “Gosh, I can’t remember or know what I ate.” But that’s I don’t know that that’s something that will be lifelong there, because that is something that I’ve noticed is getting better and better and better even still today. And I’m sure that some of it is just that you live a busy life, and we’ve all got so much to remember that sometimes it can be hard to remember it all. Now Daylin would forget things like brushing his teeth, putting on deodorant, stuff like that if he didn’t have a reminder. Some people might say, “Oh, that’s a typical teenager too.” For Daylin, that wasn’t him; he was very clean, he cared about his hygiene, and stuff like that, so when it was things like that that he’s forgetting you knew that that was part of the brain injury.

MD: That just reiterates the feeling that you know your child. You know what is normal for them, and you know what is not normal for them. And so for somebody to brush it off and say, “That’s a typical teenage boy”, and you could say, “No, it’s not typical for him and so we need to address it” I think is really important for parents to know, is that we know our child. We know it when something is normal and it when something is not. So I think that that resonates.

TC: Right.

CR: I have a two-part question and it’s What services did you find were helpful? and Looking back, what did you wish you knew that you know now about services that were available?

TC: At the time, nobody pointed me in the direction of where there were any services. Support group was something that I desperately needed at that time, and I searched high and low and the only support groups I could find for brain injury were where the person with the brain injury and the parent or caregiver came together to it. That wasn’t something I was comfortable with. I needed a support group where I could go and I could vent, and I could talk about my son without him hearing me. Now we do have support groups like that; we have the one that I do and we’re getting ready to start up some more. But at the time when we came home from the hospital, there were no supports. There was no one pointing me in the direction of resources. The social worker at Health South, she helped me get an application for SSI filled out for Daylin. Other than that, I didn’t have no resources. Now seeing all the resources I’ve learned about over the years being a parent network specialist, how much I didn’t know that there actually is. And that’s one of the things that led me to this job was: I know how desperate I felt; I know how scary it was; and I was able to learn about all these resource over these past 8 years that I didn’t know about back then, and I want to be able to help other families. I don’t want them to have to feel scared like I did. I don’t want them to feel alone. I want to be able to connect them to everything that I was never connected to. Don’t give up hope. It’s scary, and you may feel all alone, but there are people out there that want to help you, that want to pray for you, and it will get better. It will get better. It’s going to take time and lots of patience, but it will get better; so don’t give up hope. When things like this happen, you picture your child’s future in your head and it’s scary because you don’t know, will they ever be able to live on their own? Are they ever going to be able to get married and have children? All this stuff that you had thought would just happen, now you don’t know if it’s going to happen. So don’t dwell on that and don’t give up hope. It will get better. I would like to share a letter that Daylin wrote me. Something I do – I started after Daylin’s brain injury – was for Mother’s Day, I tell my kids, “I don’t want a gift. All I want is for you to write me a letter about a memory you have.” And I tell them this I tell them because when I get old, if I start, you know, if I would ever get Alzheimer’s or Demensia, somebody could read me these. And they’re just nice to reflect on. So here’s a letter that Daylin wrote me Mother’s Day of 2019. It says:

“Dear Mom,

Some of the best memories I have of you started in August of 2014. I know that’s a bad time to look back on because of my brain injury, but you, Mom, didn’t stop believing in me to make it through it all. You prayed for me, you stood beside me every second through it, you never gave up on me, and I just want to thank you with everything in me. When I started recovering, you helped me relearn so much, and you wouldn’t let me give up on myself even when I wanted to. When I look back at how bad I was after I came home from the hospital and how I am now – how much better I am – I wouldn’t have gotten to where I am without you. Thank you for all of it.

Love,

Your Sugarplum,

Daylin”

To think that right after this happened, he couldn’t even write, couldn’t even recognize the alphabet, and then four years after – four years into his recovery – I’m getting a letter, with commas and…and there’s punctuation. That made me cry and I still…it chokes me up still, reading that.

MD: [Overlap of words 33:28] Thank you so much for sharing that with us, Tina. That really is very heartfelt, and I think…you don’t think about the fact that the day-to-day stuff…it didn’t go unnoticed. I mean, maybe it did in the moment, but when he looks back he knows that you were the one that was by his side all the time. And… and he has a hard time remembering things.

TC: Yeah.

MD: So you know it means even more that he remembers that.

TC: Yeah.

MD: I think just one last question is: As a parent network specialist, what are some of the things that you can help parents with or that they should call you for?

TC: Oh, goodness they could call me for anything. [background laughter 34:14] and if I don’t have what they need, I’ll find it. That’s my motto. Support group, connect to other parents. If you’re having concerns about your IEP or different services that you think your child may qualify for but they’re not receiving, uh different things like that. I do a lot of connecting families to different financial resources, whether it be sending them an application for Waiver or the you know CSHCN (Children with Special Health Care Needs) Program, there’s so many things out there to help these families in so many different areas. No matter what your need is, there is probably something out there that I can find and get you connected to.

CR: We are so honored that Tina was able to join us and share her story. Her journey is one of true relatability – a story of a mother’s worst fears and greatest challenges, but of hope and inspiration. If Tina’s story resonates with you, or if you would like to get in touch with more questions or comments or resources, please see the show notes for her contact information. There is a community of support available to you. You do not have to feel alone. Please connect with us on Facebook where you can read more about Tina and her son and post on the discussion board where listeners tell us what topics they would like to hear in the future. Thanks for all you do every day, and thanks for being there. We will see you next time.

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