

Stories from the brainreels podcast transcript

October 16, 2013

[music]

Introduction

CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at info@storyminders.com with questions or topics and guests you want to hear on an upcoming show.

[music]

Well, this is one of my special 3rd Friday shows. And today's guest is artist Cavin Balaster. He's doing a big, exciting Kickstarter campaign through November 2nd. And today, I'm gonna play you a pre-recorded interview I did with Cavin recently as well as a few clips of the music that he's made after he sustained a severe traumatic brain injury a couple years ago. So for regular listeners of this show, you'll notice this is kind of a different interview. Because usually, we don't talk about how people actually got their injuries or talk about their impairments. Cavin is such a marvelous storyteller. This time around, I've included stories of his brain injury, time in the hospital, and his recovery. Here's a warning, though: if you're sensitive to these kinds of details about brain injury and impairments, please know that we come back to these ideas over and over throughout the conversation. And an apology to you, Cavin: I did go ahead and delete some of the more graphic descriptions related to your injuries and surgeries cuz some of these details are not for the faint of heart or weak of stomach. So I took those out. But if you want them, you can find them on Cavin's blog.

So to follow his story and get all the juicy details, you can go to www.CavinBounce.com. His name is spelled C-a-v-i-n. And you can find links to his music, both before and after his brain injury. You can read blog posts about his experiences, about his research into neurology, nutrition, and healing, and then see videos and photos of him in the hospital as well as through parts of his recovery. So his Kickstarter campaign: he's raising \$15,000 to publish his book, which is called "Lights, Coma, Action!" This campaign will get him enough money to print the book as well as release it in ebook and audio book format. And on the Kickstarter campaign, he talks about this name, "Lights, Coma, Action!" Lights is the story of who he was. Coma, the story of how he sustained a serious brain injury. And action is his strong recovery.

So please go to Kickstarter.com and search for "Lights, Coma, Action!" Or you can search for his name, Cavin Balaster. And as of today, he's got 14 days left, and he's at 64% funded. That's amazing. He's in really good shape with Kickstarter. So let's keep going and get him all the way up to his minimum or even higher. His music you can find on Soundcloud.com/CavinBalaster. And then his blog again is at CavinBounce.com. So I'll start out today with just a short clip from his song, "Take Me To A Doctor," which is very impressively recorded on an iPad. And then we'll just jump right in to the interview and have a couple of music clips in there.

[music]

The Interview

CAVIN: The video's sort of gone viral, and I'm being contacted by a lot of brain injury survivors and giving them advice and helping them out. And it's really, it's very cool; exactly what I wanted to do.

CHERYL: People are contacting you, and they're asking for advice just about living with brain injury?

CAVIN: Yeah, somebody just contacted me whose best friend/boyfriend/something just recently fell from a water tower, actually, which is what happened to me. And he just recently came out of a coma, and he's still not talking. And just talking to him about different methods of recovery. With her, I'm talking about how for me, it was like somebody hit the reset button on my mind, and it was like I had to go through every developmental stage from infancy where I was completely dependent on other people to my terrible twos [chuckles], and onto my teenage awkward rebellion, and finally to the point where I was coming to terms with what happened and with where I was and deciding to push forward and to help others.

CHERYL: So is that the reason that you're writing the book, is to help other people?

CAVIN: You know originally, it was much more selfish. It was basically that nobody else could understand what I'd been through if I didn't even understand it. And so it began with that. Uncovering it and understanding what had happened was quite possibly the most therapeutic thing for me. I wrote something about how I have damage to my corpus callosum. Actually, let's back up. What happened is I fell 20 feet from a water tower on a rooftop in Brooklyn, NY. I hit the front of my head on the steel scaffolding on the way down and the back of my head on the concrete rooftop. I was instantly unconscious. So I was rushed to the hospital, and the EMTs put a bag on my mouth and were pushing air in and out of my lungs. And as soon as they got to the hospital, they intubated me, which is where they shoved a tube down my throat and connected me to a respirator that breathed for me. And I was in a coma for 12 days. On the 2nd day, they tried to extubate me, and it didn't work out. Well, they tried weaning me off of oxygen to encourage me to breathe on my own. Now, they had a soft tube down my throat, and my involuntary reaction was to bite down as hard as I could when they started turning down the oxygen.

CHERYL: Oh!

CAVIN: Which of course, stopped all oxygen from getting to my lungs. Before that, the medical reports said that I was moving all four extremities, and after that, I was no longer moving the left side of my body. So I most likely had a hypoxic stroke.

CHERYL: Because you involuntarily bit down on the breathing tube?

CAVIN: Yeah.

CHERYL: It just, you know, we hear it all the time: people with brain injuries, we make such bad decisions. We have such bad judgment. [laughs] You shouldn't have bitten down on that damn tube!

CAVIN: I know, I know.

CHERYL: [laughs] But you were unconscious. You were not--

CAVIN: I'm learning, I'm learning. You know, next time I have a brain injury, I'm not gonna bite down on that tube.

CHERYL: Nope. Even in the middle of a coma, you will make a better choice next time.

CAVIN: Yeah, I will make a better choice. That's right.

CHERYL: But you weren't aware of any of that, right? You had to find out that story later, right?

CAVIN: Absolutely, yeah. So you know, months go by, a year goes by, pretty much, and I decide to go back and start writing. And I'm going through medical reports and digging up all sorts of things and asking my mom for as much information as she can provide. And she didn't wanna go through it again. She was like, "Fine. Here you go. Leave me alone." It must have been extremely traumatic for her.

CHERYL: Yeah.

CAVIN: In fact, it was. And she's incredible. She was by my side hours after. She flew from Austin, Texas to New York City and was there and has been by my side ever since.

CHERYL: There's so many nice pictures on your blog of you with your mom, smiling.

CAVIN: Yeah, yeah, she's Mother of the Century in my opinion.

CHERYL: So you said a year after the injury, you started writing.

CAVIN: That was interesting. So I'm going through medical reports about what happened and trying to find out why my left side isn't working and just really dissecting every piece of it. That's when I realized I must've had a hypoxic stroke. And so I started writing. And this was after I regained some clarity basically through nutrition. I was in a fog for a year, complete brain fog. Can you relate to that?

CHERYL: Yes, I can relate to that.

CAVIN: Yeah, yeah. That's one thing that every brain injury survivor can relate to.

CHERYL: Yeah, the brain fog.

CAVIN: Yeah, and it's funny because every memory I had of while I was in the hospital was how do I describe this? Was a clear memory of an unclear moment in time. So it's like a foggy memory, but it's how I experienced it. It's how I remember experiencing it is completely foggy.

CHERYL: Yeah, and you were--

CAVIN: No, go ahead.

CHERYL: I don't remember what I was gonna say. So you go ahead!

BOTH: [laugh]

CAVIN: Yeah, it's just how it goes.

Kickstarter Campaign for "Lights, Coma, Action!"

CHERYL: So OK, you started writing. And now I wanna talk about your Kickstarter campaign. So tell me, this thing that you started writing, is that what is becoming the book that's on your Kickstarter campaign?

CAVIN: Originally, I thought that that was gonna be my book. And it took me a bit to realize this is not gonna be my book. I'm going to use this blog to write my book. It's kinda like a first draft but not even that. It's like a pre-draft. But I wanna leave it up because it kinda tells a dual narrative. It tells the story of when I'm talking about, which is basically on the year anniversary of my brain injury, I started writing about where I was the year before on the anniversary of each important event as they happened. So on the day I fell, I wrote about that. On the day there was the extubation attempt and I bit down on the tube and probably suffered a hypoxic stroke, I wrote about that. And then the day I came out of the coma, I write about that. And on and on and on.

CHERYL: So your campaign and this book is called "Lights, Coma, Action!" And I'm a filmmaker so I adore this title, "Lights, Coma, Action!" You're looking for \$15,000, and that is to put together the book but also an ebook version and an audio book version.

CAVIN: Yes, yes.

CHERYL: So tell me why you're interested in doing an audio book here at the outset.

CAVIN: Well, after my brain injury--and to a lesser degree before--I always had trouble reading text. I'd sit and read, and after just a few paragraphs, it felt like every part of my being was pulling me from the page and wanting to interact with the environment rather than stare at words on a page. I don't know, but I just found I learn so much better when I hear things rather than when I read them. So I began listening to podcasts a whole lot and audio books, and I love it because I can move while I'm taking in information. And humans were made to move, you know? Humans learn better when they move.

CHERYL: Some do. For folks who are physically disabled and can't move, they just adapt and come up with all sorts of wonderful workarounds and are able to learn just as well.

CAVIN: Right.

CHERYL: But I'm a lot like you too in that I do better if I'm wiggling around and moving and walking.

CAVIN: Yeah!

CHERYL: And I'm twisting in my chair right now.

CAVIN: [laughs]

CHERYL: I wasn't like that before, but I pay attention much better now if I'm walking around in circles.

CAVIN: You fidget. There's a brain injury counselor at the program that I go to every day, and he says, "I think fidgeting is a good thing. It seems to help."

CHERYL: I had never experienced it before. But yeah, when I leave the house, I always have my audio books or podcasts. I never listened to either of those before my injury. But I couldn't read very well for quite a while after my injury in 2010. And so I switched to audio books and podcasts. And now I still

listen to them all the time. I love it, and when I go walk somewhere--cuz I don't ride my bike anymore, cuz that's not safe. I ride a little but not like I did before.

CAVIN: Right.

CHERYL: So I walk everywhere. And I just put on my book and learn something new.

CAVIN: Absolutely. Yeah, it's great. It's great. Technology is incredible. You know, learning how to adapt technology to make things work for you. I say it all the time: technology is your friend. To every brain injury survivor, I'm like, "Look at what technology has made available to you and take advantage of it."

CHERYL: Mm. My email program tells me when it's time to take out the garbage.

CAVIN: Yep, there you go.

CHERYL: We only get garbage pickup once a month, and we have two cats. We do not wanna miss garbage day. And I can't remember garbage day, but my email program tells me when garbage day is. And I am not embarrassed that I need that kind of technology and that kind of reminder. It's fine. I love that it's there, and I love that it does that for me. Yeah. And I don't really interact with humans face to face that often. So I love my email [chuckles].

CAVIN: I guess it's all about finding something that works for you and using what's available to you. And that's why I love technology, because it makes a whole lot of things available to you.

CHERYL: Absolutely.

Getting back to playing music, vision therapy, and tracheostomies

CHERYL: Now, I wanna ask you something about what you just said about finding what works for you and using it. On your Kickstarter video, there's a whole thing about as soon as you could wrap your fingers around that guitar, that's what you were doing.

CAVIN: Mmhmm.

CHERYL: And as soon as you got your voice box put back together, you were singing.

CAVIN: Yes.

CHERYL: Can you talk about that a little?

CAVIN: Yeah. So imagine this, and actually try it to get a really good picture of it. My left hand was in a position where it was like my left fingers were trying to touch my left forearm, the inside of my left forearm.

CHERYL: Oh, yeah. Mmhmm.

CAVIN: So it was stuck like that for months. I mean, I went to Occupational Therapy, and they'd tell me, "All right. Here's a ball. Now, with the back of your hand, push it to me." [chuckles] I just couldn't do it. And so I'd take my right hand and do it. They'd be like, "No, no, no, no, no!" What they did was brilliant. They made a splint that would push my wrist a little further up, and so it would go just a little bit more. And then a week or two later, we'd adjust it and put another brace on. So I wore a brace all the time,

just to encourage my wrist to be free again. And my toe, my left toe was the same way. I call, my friends called my left wrist the claw.

CHERYL: [laughs]

CAVIN: And I called my toe, my left foot, my ballerina foot.

CHERYL: Oh, outstanding! That's what I wanna be for Halloween. I wanna be a clawed ballerina. That is awesome. Oh, but with a pirate patch.

CAVIN: Yeah, you need the pirate patch.

CHERYL: [laughs] Did they call you a pirate when you had to wear the eye patch?

CAVIN: Oh yeah. Yeah, but nobody messed with me. I looked tough.

CHERYL: Yeah.

CAVIN: Speaking of the patch: the reason I wore that patch is because after my brain injury, I had double vision. And I didn't even know I had double vision because I was in such a fog. I just knew that I closed my eye a lot to see things clearly. And I still have double vision. Both my eyes see clearly, but the image I see with my left eye and the image I see with my right eye don't match up. They don't converge. The one in my right eye is lower and a little bit to the right of the image I see in my left eye. So I wear a prism in my right eye that shifts the image that I see higher. And in doing that, my eyes can bring the image together.

CHERYL: Right.

CAVIN: But before I had a prism, I wore an eye patch. And I'd switch that eye patch from eye to eye every 20 minute.

CHERYL: Oh, that's good.

CAVIN: So that both eyes would stay strong. Plus, I got to wear an eye patch and look like a super villain.

CHERYL: You know what I'm talking about? I'm talking about the fact that you got to wear an eye patch, yeah. It's pretty [laughing] pretty awesome!

CAVIN: [chuckles]

CHERYL: I never had the eye patch, but I did wear the prism glasses.

CAVIN: You missed out, Cheryl. You missed out.

CHERYL: You know what? And I didn't get the helmet either. I didn't get the big post, when they--

CAVIN: I didn't get that one either.

CHERYL: Yeah, and you know I've had people tell me, "You got short-changed. Why have a brain injury if you're not gonna go to the hospital, get a piece of your skull removed, and get to wear the helmet?"

CAVIN: [laughs]

CHERYL: Now, I think a lot of the people who wear the helmet may not say that it was the coolest thing that they ever wore and ever did. But I did wear the prism glasses. For a while, my eyes were converging too much and crossing, and then they were pointing outward too much.

CAVIN: Did you do any vision therapy?

CHERYL: I did a ton of vision therapy. Yes, I did.

CAVIN: Nice.

CHERYL: Well, I'm thinking I might have to go back to vision therapy cuz I'm having a lot of problems. If something moves fast in front of me, no matter what direction it's moving, it feels like it's coming right at me. And so I flinch and tense up a lot. And that's just really, it's not a good form of exercise, basically.

CAVIN: What's incredible about vision therapy is that it's not fixing your eyes; it's fixing your brain. It's so cool. The reason I see double is because I have what's called 4th nerve palsy. In your brain, you have what are called cranial nerves, and you have 12 of them. The 4th nerve, which is what is partially paralyzed for me is the trigeminal nerve, which--Or no, no, no. I'm sorry. It's the trochlear.

CHERYL: Yeah, that's the 5th.

CAVIN: Yeah.

CHERYL: Trochlear, there you go.

CAVIN: That's it: the trochlear nerve. I caught myself, at least.

CHERYL: Yes, you did. You caught that fast. I was like, trigeminal? No way! No way!

CAVIN: You got it all wrong. You don't know what you're talking about.

CHERYL: Where did you get your brain injury [laughs]?

CAVIN: I love it. I love it.

CHERYL: OK, so your 4th cranial nerve is partially paralyzed.

CAVIN: So the trochlear nerve, which controls the muscle that orients your eye--you know, there's several muscles, but there's one called the trige--Nah. Gawd. There I go again. I can't even remember what it's called. It'll come to me.

CHERYL: Is it the trochlear?

CAVIN: No, no, no. The trochlear nerve innervates the superior oblique, which moves your eye outward and down.

CHERYL: Wait, the superior oblique? That's in your abdomen, isn't it? No, I'm just kidding [chuckles]. Sorry. Please continue with what you were saying.

CAVIN: [laughs] You made me second guess. So that nerve is partially paralyzed. They didn't start me on vision therapy. They just gave me a corrective lens, and I didn't do any exercise. And two or three months later, when I had moved to Austin, I went to vision therapy, which was not covered by anything. I told my mom, "It's not a big deal if I have to wear glasses for the rest of my life. It's not like nobody else has to do that." So I was like, let's prioritize here. That's not that important. And she was like, "No, it is important. We're doing it." And so I started going to vision therapy, and first I was assessed. And Dr. Denise Smith did the test on me. She said, "You're doing what we call eating up the prism." Basically, if she gave me more and gave me more of an opportunity for my brain and eye to be lazy, it'd like that, you know?

CHERYL: Oh!

CAVIN: So I was deteriorating. I was like, man, I'm not happy. I'm kinda seeing double a little bit. It's not quite right. And I was like, mm! But we started therapy. Miraculously, I began converging and seeing single.

CHERYL: Wow, yeah.

CAVIN: And right now, it's kinda plateau-ed, but who knows. Maybe it'll get better. Only one way to find out.

CHERYL: Right, keep doing those nasty fusion exercises. Excuse me. Those fun fusion exercises.

CAVIN: That's right. They're fun.

CHERYL: Some of them I never could figure out and get good at and hated them. But yeah, I'm glad you had such a good experience with vision therapy. It was one of the most valuable parts of rehab that I did.

CAVIN: Yeah.

CHERYL: It was wonderful because it's retraining the brain.

CAVIN: Yeah, absolutely, and possibly, probably, helps with other functions of the brain.

CHERYL: Oh, you know, in my personal experience--I can only speak for myself--through doing the vision therapy, there were other thinking skills that improved. And I just loved it, and my vision therapist had been through vision therapy herself, which is how she became a vision therapist. The vision therapy was so profound in getting her life back that she became a vision therapist!

CAVIN: There is so much to be said for medical practitioners that have been there and learned out of necessity, not out of passing a test. But there was a lot more on the line cuz their entire life was on the line. So learning the aspects surrounding their condition wasn't just like to pass the test; it was to survive.

CHERYL: Not that we want all doctors and therapists to have some kind of a life-threatening condition.

CAVIN: Right.

CHERYL: But it gives them a kind of insight that other people just can't have. And that's OK. There's nothing wrong with not having that insight.

CAVIN: Yeah.

CHERYL: But it's such a relief, I think, for us when we're patients, such a relief to have somebody go, "Yeah, I know. Me too. I take my glasses off, and my eyeball goes over to the side too. Don't worry about it."

CAVIN: [chuckles]

CHERYL: It's a huge relief.

CAVIN: And there's a passion that goes with that too.

CHERYL: Yes.

CAVIN: There certainly is passionate doctors that have not experienced this, but a lot of the time, they have some sort of personal story, like a family member or a loved one of some sort has experienced something that gives them that passion. Anyways, we're off on a tangent.

CHERYL: Oh, um, that's basically yeah, that's par for the course. I don't even think in terms of tangents anymore because we weren't going in a straight line to start out with, right?

BOTH: [chuckle]

CAVIN: I like that.

CHERYL: One thing that happened was that I think I distracted you from finishing a story that I asked you about: how you started, as soon as you could, you started playing music and singing again.

CAVIN: So I was talking about how my wrist was down, splints were used to lift my wrist. And as soon as--I feel like I haven't really explained the story too well of where I was and how I got to different places. But I had a tracheostomy done. After I woke up from the first coma--cuz I had two comas--after I woke up from the first one, I was talking [gasping noise], I would enter that sound in between every word. And I had a lot of trouble breathing. And I don't remember this, but I was not happy. And I kept on trying to get the nurse's attention. My mom was like, "What's wrong? What's wrong?" I'm like, "Something's not right." And I was freaking out. And so they keep on sending these residents up. And these residents are like, patting me on the shoulder and telling me that I just need to calm down, and here's some anti-anxiety drugs.

CHERYL: [gasp] No!!

CAVIN: And then, at one point the chief resident comes up, and he happens to go by my room. And he calls all the other residents over, and he uses a little moment to teach them something. He's like, "What do you see here?" And I'm using every muscle to breathe, every single muscle in my muscle, everything just to breathe. And he's like, "Can't you see that this patient needs to be intubated immediately?"

CHERYL: Oh my gawd.

CAVIN: "He can't breathe." And I looked back on the medical records and talked to my mom about it, and I can't believe that they're treating the anxiety that I'm experiencing because I can't breathe as the main issue, right? Why are you treating the anxiety? That's obviously a symptom.

CHERYL: I'm not at all surprised to hear that that happened.

CAVIN: Yeah. So I went back in a coma, and then I came out of that coma just long enough to be transferred to Mt. Sinai in Manhattan. By the way, they only take you if you're ready for rehab. They don't take people with tracheostomies. They said they're in the business of taking tubes out, not putting tubes in. And two days later, I developed breathing problems again, and they didn't mess around. They were like, "Give him a tracheostomy right now." And so I had that. So for four months, I couldn't eat, walk, or talk. And my hand was stuck in the class position, and my toe was stuck in the ballerina position. All right. So back to the guitar. I got my wrist up to the point where I could wrap it around a guitar, and that's what I did. I immediately started playing music, and it was so frustrating. And if you've ever played an instrument, especially if you just start off trying to learn an instrument--

CHERYL: Oh, yeah [chuckles].

CAVIN: You suck, right?

CHERYL: Yes, you do. It sounds terrible!

CAVIN: It sounds terrible, and it's frustrating. And it's like, I wanna play like that guy, but I can't! And so it was like learning how to play guitar all over again. My hand just didn't act the way it used to at all. But I'd been through it before, learning how to play an instrument, and if I'd done it before, I could do it again.

CHERYL: Yeah, yeah.

How music saved Cavin's life

CAVIN: It's what I thought. So I started to play, and I really think that music did save my life. Being a musician, having that mentality, because every musician intuitively understands how the brain works, how they can learn a new lick, a new technique, you know? If you could only practice four hours, you wouldn't do it all at once. If you suck at guitar, and you just try to play for four hours straight, it's not gonna be nearly as good as if you do 15 minutes, 15 minutes the next, 15 minutes the next, and on and on or even less; you do 5 minutes a day. It'll come eventually. Your brain learns by having time to rest and then time to implement that new skill. So understanding that as a musician, understanding that learning a new thing isn't gonna all happen at once, and you need to just keep at it every day, you don't need to do it for hours. But you need to do it for at least a minute. That's what I started doing. I started doing a chromatic scale on the guitar every day, just a chromatic scale up and down the strings cuz it uses all my fingers, and I could do that in a minute and then do all the other therapy I'm doing. But I really feel like that right there was incredible therapy for me. And I started producing music before I could play music at all satisfactory for me cuz I used to produce music before. And I just wanted to see if I could still do it, and I could. I understood the language of music, and I knew where to put things. I actually kind of think my music after my brain injury, my productions are kinda, I mean they're pretty cool. I feel like it's better than a lot of my stuff.

[Cavin's electronic music]

CAVIN: I was diagnosed with dysarthria when I finally had a tracheal resection. Your trachea is about the size of your forearm in diameter. Imagine that down to a drinking straw [gasping]; you're breathing like that. When they did the surgery, which is amazing, they almost couldn't do it. If the area that was occluded was one centimeter more, maybe even a half centimeter--I don't remember--then they couldn't do it. But it was just in the margin. I say they slit my throat to save my life.

CHERYL: And they did.

CAVIN: And they did.

CHERYL: And you could speak again.

CAVIN: I could speak, but it took a lot of effort.

CHERYL: I bet!

CAVIN: So yeah, I was diagnosed with dysarthria, and it was very difficult to speak. It was like pushing toothpaste through a pinhole. It took a whole lotta effort to get nothing out. Recently, I was talking to another brain injury survivor. He has trouble speaking. I can't talk really fast; I can't rap, and I sing songs slower. But this brain injury survivor, he just put it so beautifully. He was like, "I know exactly what you mean" when I was talking about. He's like, "It's like every word is a tongue twister."

CHERYL: Oh.

CAVIN: And I'm like, "That's exactly right." What happens with a tongue twister? You think about what you wanna say, right? Now, you could say that in your mind hundreds of times without a hitch and say it fast in your mind. Then, when you try to translate that thought and vocalize it, you get tripped up because the communication between your brain and your mouth isn't quite as fast. And he said it perfectly. It was like every word was a tongue twister. So yes, as soon as I could speak, I tried to sing immediately. And again, it was very difficult. I started recording after a couple months, and there's one recording on my SoundCloud that's after the brain injury: [SoundCloud.com/CavinBalaster](https://soundcloud.com/CavinBalaster), all one word. And it's painful to listen to.

CHERYL: Is it the one where you have in parentheses "Bad"?

CAVIN: Yeah, that's the one. That's the one. Bad.

CHERYL: Yeah, yeah.

CAVIN: Painful. Yep.

CHERYL: You were singing and playing guitar just a few months after coming out of a coma. I mean, you know, I was listening to it yesterday, and I was thinking I was able to appreciate your left hand, your right hand, and your voice are doing three separate things all at the same time. That's pretty impressive no matter what, no matter who's doing it and in what condition and how well they're doing it. That's three separate things at once all keeping the tempo and remembering the words and remembering the words. And so I listened to it, and I thought, my gawd, I mean he just came back to life a few months before recording this. It doesn't sound like your other music that's on there. It's a lot slower, right? But when you think about the steps that you're taking toward getting back, it was very humbling to listen to and to think about those tongue twisters and your claw. I mean, it's a lot to struggle through to play.

CAVIN: Mm, the claw.

CHERYL: Yeah.

CAVIN: Yeah, yeah. Apparently it was.

CHERYL: Yeah.

CAVIN: Yeah, it was just a couple months after.

CHERYL: Yeah.

CAVIN: Yeah, music is amazing. And that line, "music saved my life," well, you know, all the doctors nurses and people that had spent countless hours and years researching what they do, they saved my life. And especially my mother saved my life.

CHERYL: Mmhmm.

CAVIN: But I like to say that music saved my soul.

CHERYL: I mean, there's different ways to define a life. Of course, your heart is beating, and you're alive. But there's that other part of life that goes beyond just sitting there being alive. And that's yeah, oh that's beautiful.

CAVIN: Well said, well said.

CHERYL: Well, I just repeated you. I don't even remember what I said.

CAVIN: No, you said there's more to life than your heart beating and your brain functioning.

CHERYL: Oh, did I say that?

CAVIN: Yeah.

CHERYL: You know, when you're rushed to the hospital, and you're in a coma and you have to be saved, that whole idea of is he gonna play music again, that can't be on anybody's mind. They're trying to save your body and your life and make sure that you're gonna wake up.

CAVIN: Mmhmm.

CHERYL: But once you do wake up, then it's that time to start addressing all those other parts of life.

CAVIN: And that's where my mom saved my life. She was determined to keep me sane through everything. And I joke with my mom, "Mom, I was never sane to begin with. What are you talking about?"

CHERYL: [laughs]

CAVIN: But seriously, she did everything to just make me feel loved, feel like I had a reason to recover, and then not fall into complete depression about what had happened. And she's Mother of the Century, you know? Millennium. Mother of the Millennium.

CHERYL: Yeah, and the universe.

CAVIN: The universe.

CHERYL: She sounds like she crosses all four dimensions in terms of mom.

CAVIN: You're right. She also flies.

CHERYL: She flies?

CAVIN: She flies, and she does telepathy. And she can break locks with her vision. It's incredible.

CHERYL: [laughs] She's obviously had more vision therapy.

CAVIN: Yeah, that's what it is.

CHERYL: I didn't get to the breaking through locks in vision therapy.

CAVIN: That's the next level.

CHERYL: Damn it. I knew there was gonna be a consequence for me dropping out. Damn it. And actually, I joke; I did drop out of rehab.

CAVIN: I like that: a rehab dropout.

CHERYL: I'm a rehab dropout, and my dark secret is that I was actually trained as a speech pathologist. And so I have a degree, and all the 400 hours of training or whatever it was to be a rehab therapist, but when I became a patient, I dropped out.

CAVIN: Wow.

Functional medicine and finding your own healing with nutrition

CAVIN: You know what I'd love to talk about?

CHERYL: What's that?

CAVIN: Well, I was diagnosed with a diffuse axonal injury while I was in a coma, and basically the nurses told my mom that the neurology department can do nothing more.

CHERYL: Yeah.

CAVIN: And researching, it's like the neurology department can cut out a piece of your skull to give your brain a place to swell, and they can do surgery on a tumor. And that's most of what conventional neurology does. Or they give you drugs to cope with your impairments, but nothing to actually heal from your impairments. I just tried to get better and began researching a lot on nutrition. But I really began researching nutrition when I began to see a functional neurologist who was absolutely incredible. And I began seeing Dr. Thomas Culleton, a functional neurologist and chiropractor. Now admittedly, I was like what does a chiropractor have to do with my brain? What chiropractors work with is the central nervous system. Your spine is part of your central nervous system. Your spine becomes your brain; it becomes your brain stem and then your brain. And so a chiropractor understands the central nervous system, and a good chiropractor--or really a functional neurologist chiropractor or chiropractic neurologist--

understands methods. And I love chiropractic medicine because it's not as reliant on the scientific method, which is great. Don't get me wrong. The scientific method has done all sorts of amazing things, and it is, in some ways, a far superior form of proving things to be effective, right? But when you're looking at the brain, first of all, no two brains are the same. Small variances in the brain result in major behavioral changes. If the brain is inconsistent from one person to another, how are you gonna get 500 of the same, of consistent variables? You can't, right?

CHERYL: Right.

CAVIN: So, the scientific method relies on consistent variables. So if no two brains are the same, no two brain injuries are the same either. And say you were to test a certain type of brain injury. First of all, you'd have to inflict the same brain injury on like 500 subjects, which is impossible. But even if it wasn't, really [laughs]?

CHERYL: Yeah, yeah! You'd have a hard time getting funding for that. It's a little bit cruel.

CAVIN: Yeah. Sign me up. 20 bucks? Definitely. I'll do that.

CHERYL: [laughs] Oh. Snacks? Great! Sign me up.

BOTH: [laugh]

CAVIN: Right. So I say I really hope this isn't something anybody's trying to perfect, giving the same brain injury.

CHERYL: Yeah.

CAVIN: If inflicting the same brain injury is impossible, and having consistent variables is impossible, using a form of medicine that is reliant upon consistent variables when you're looking at an inconsistent organ, it makes it impossible. It just doesn't work. Now, with functional medicine and to some degree with chiropractic medicine, it more relies on anecdotal evidence. So basically, where they've seen a method to be effective several times, hundreds, or thousands of times, it has worked, there's no guarantee that it will work, but it has several times in the past. And so what you look at is, is it dangerous, right? This is how I steered my recovery and still do. I look at the risks versus possible benefits surrounding any therapy that I'm going to try. I changed my diet to eat what humans have consumed for the vast majority of their existence.

CHERYL: Fritos?

CAVIN: [laugh] Totally. Pringles too.

CHERYL: [laughs] Pringles, yes.

CAVIN: And Frosted Flakes. Don't forget Frosted Flakes.

CHERYL: I don't know if I've ever tasted a Frosted Flake, but yes. So you were talking about real food.

CAVIN: Real food, yeah. Real food. Food that humans have been consuming for hundreds of thousands of years.

CHERYL: Mhmm.

CAVIN: I hate fad diets and stuff and paleo's been accused of being another fad diet. But it's not. It's based on biology and evolution, the same thing that medicine is based off of. Actually, can I read you what I wrote in this post? So it's basically saying, "Humans have existed for about 200,000 years. About 97% of our existence was before the agricultural revolution. So let's eat like we used to? Do that. It's kind of impossible to eat exactly the way we used to. Everything's changed: our soil's depleted; things like that. But we can try to get close. This just made sense to me. If we evolved, then our digestive system evolved too. So we've evolved to eat these foods. We did not do over 50 year tests on highly processed food, trans fats, artificial sweeteners, GMOs, and high fructose corn syrup before pushing them onto the American people and other countries. We are the guinea pigs. I think that new foods could possibly be beneficial, but I for one will be conscious about being a guinea pig to study the long-term effects. This epidemiological experiment that we've all been a part of has shown a pretty strong correlation that the combination of these foods leads to heart disease, obesity, and other chronic conditions compared to when we ate butter rather than margarine, were not afraid of saturated fat, used lard in just about everything, and made our own damn dinners."

CHERYL: Damn it [chuckles].

CAVIN: Damn it.

CHERYL: Processing and over-processing and over-refining and then adding in all sorts of crap that does not need to be there and getting you addicted to these certain flavors that have no nutrition and fill you up with garbage.

CAVIN: Yeah.

CHERYL: And then we go put high octane gas in our car. What?

CAVIN: Right.

CHERYL: You care about your car more than yourself?

CAVIN: High octane fuel for our body, yeah.

CHERYL: Yeah, exactly!

CAVIN: We eat the hell out of the nutrients in our food. We are running on very low octane fuel. Essentially, go around a grocery store. Don't go in the middle aisles. Just go around the perimeter, and most of that stuff is--I'm gonna say most of it is--real food. But then, usually there's a freezer section there sometimes, and the bakery. I've learned about brain-building nutrition. I call it Food For Thought.

Wrap-up

CHERYL: Mmhmm. The recording is gonna run out fairly soon.

CAVIN: OK. I'm enjoying this, though.

CHERYL: Oh, I am too. But once the recording ends, the phone connection will die. And then I will fall asleep.

CAVIN: I know. That's it.

CHERYL: Thank you so much! It was great to talk to you.

CAVIN: Absolutely, absolutely. It was really fun.

[Cavin's music]

[music]

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, WhoAmItoStopIt.com.

[music]