

Stories from the brainreels podcast

February 11, 2015

Introduction

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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.

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Well, I'm here podcasting in Central Texas. I'm at my family home right now. Ironically, the weather is, I'd say probably worse than it is in Portland in February. So there's always the pleasant irony of traveling home to Texas, and it rains for 36 hours. But I'm here in my family home. I do have a 110 pound Great Dane/black Lab mix on one of my feet right now. So I feel right at home. I'm also here with two special guests. I wanna thank them very much for joining me with absolutely no warning. These guests are my twin sister, Karen, and my mom, Sue. There's a few reasons I wanted to interview a couple family members. The documentary film "Who Am I To Stop It" is pretty unusual because we are not focused on how people got injured. We're really showing people interacting with their community, interacting with their family, or in the case of Kris who doesn't have much of either, we're showing her not interacting with people. It is really important to show the family when the family is there. A lot of brain injury stories don't include the family. And you never know what's going on for them and with them and the struggles that they go through, the questions they have. And so I thought hey, I've got a few right here with me. I might ask them. The other reason is that we discovered that me living in Portland and them living in Texas, it was really hard for anyone to really understand what was going on with me in the early days when I was very weird. Weirder than before. But I made this film, a short film, "Cooking with Brain Injury." And everybody watched it. And suddenly, some of my family members said, "Wait a minute! Now I think I get what you're going through." And that was actually the inspiration and impetus for making "Who Am I To Stop It," is what is the role that art plays in helping to express and experience so that other people can get it. So that's why I'm interviewing my family. Who wants to start?

The interview

SUE: I'm your mother.

[All laugh.]

SUE: I am Sue Pelzer. I'm Cheryl's mother. And Cheryl came with a twin. So I got two lovely people.

CHERYL: For the price of one!

SUE: Yeah. I was a music teacher in my first career. I had three children and had the opportunity to go to graduate school to become a psychologist. So when Cheryl and Karen were five years old, I entered graduate school. I have a private practice. And I'm a medical expert for Social Security when a person claims a mental impairment. Then I go to court and testify about that situation.

CHERYL: Meaning when they're applying for disability benefits, and the government says, "No, you're not disabled enough," then they go to a hearing. And you would testify, based on their medical record, whether you think they qualify or not.

SUE: That's correct. Yes. And so that's what I do. And all my kids are grown, obviously. And I take care of a 100 pound Great Dane-Lab.

CHERYL: And you're also connected to a new documentary film called "Who Am I To Stop It."

SUE: Yes, I am! I am the proud Executive Producer of this film that you made, Cheryl.

KAREN: I'm Karen Green, Cheryl's twin sister. I live in Austin, Texas. And I work in the field of adult education. I work with an immigrant population, mostly, and teach literacy and English as a Second Language. And I play the drums. The work that I do is at a non-profit, community-based organization. Besides offering adult education, a low-cost dental center, food and clothing, basic needs, the last word in our tagline is "dignity." And we usually ask our students and clients and patients if they feel that when they walk through our doors. And overwhelmingly they say yes. They feel like it's a family kind of set-up that we have there. And they feel very comfortable there, and they're able to make mistakes while learning English. And as adults, it's difficult to learn something new. And so we offer them a very safe place to do that. And I believe that we are offering a kind of justice for them because we're helping them be able to speak more.

The shock of learning about a brain injury

SUE: I had a huge shock when you called me to tell me about your accident and a greater um, I can't think of a word. A greater problem, I guess, was when you didn't want me to come immediately to see you. All the other accidents that all of my children have gone through, whenever I got a call, I would immediately get in the car and drive to where you were, which was only 70 miles away, usually. And I was prepared to leave that day to get to Portland. And you told me no. So I decided that since I recognized you as an adult, I would treat you as an adult. And you said, "Don't come." So I didn't come. And those months before I got to see you were difficult for me because I didn't know, I really did not know what you were going through. And I didn't know what to expect the first time I saw you. So that first time was difficult--and that's understating it--because I wanted you to be unchanged. And I wanted you to be the person I knew. And that's not who you were.

CHERYL: Yeah. I didn't call you to tell you I had an injury. We were Skyping. And I was lying in bed. And I got up to close the blinds. And you noticed that I was limping and walking really weird. And you said, "What's wrong with you? Did you get hurt?" And I was like, "Oh yeah! I had this huge bike wreck!" And I went into it then like, oh yeah! I didn't think to tell you! And I didn't think to tell you. And then you were really upset. And I was like, "What's your problem? I'm fine! I'm not upset!" And you know, part of that is just the some post-injury confusion.

SUE: The first time I had to testify after your injury, I could hear my voice cracking. And when the hearing was over, I jumped up and ran out of the room. And when I came back, it was obvious I had been crying. That's when I said I have to tell you what's going on. So I told that judge. And then I had such relief that I didn't have to contain it. So I told all the other judges I work with. And everyone was very supportive and understanding. And then other people started telling me how many people they knew who had head injuries. And then I didn't feel alone anymore. The other thing was that I had therapeutic support from friends who are also psychologists and my colleague who was supportive. And

so I didn't have the need to go to a support group when I started seeing that I could gather support in my own community.

CHERYL: What's so great is you started to recognize I can't hold this crap in anymore. I need to talk to other people about it. And you found relief. And I think this is the thing is a lot of family members say, "Well, it's not about me. It's not about me. It's only about the survivor. I shouldn't need a break. I shouldn't need respite. I shouldn't need support." And I think that's not true. This is one of the things that I struggle with a lot of media attention on brain injury because it's all about oh the frontal lobes and the acceleration and the ahhh! Stop talking about the brain! It's a person. And then there's all the focus on the survivor and no focus on community. When you don't talk about the other people, you're putting everything on the survivor. The injury is all about you. The recovery is all your responsibility. You have to get better so you can rejoin society. My perspective is, society needs to come in and say, "I accept you as you are. I'll accept you if you improve. I'll accept you if you won't. I'll include you." But as long as we keep the focus only on the survivor, we can't open the conversation up, one, to supporting the family and the community, and two, to actually include the survivor back in society and reintegrate them. And I kinda can't take it. I kinda can't take this whole only one person is in the spotlight thing.

SUE: Yeah.

The peer with brain injury doesn't always think of family

CHERYL: When you did start to interact with me around the injury, and when you did come to visit, did I care at all what your experience was? Did I ever pay attention to anything you needed around it?

SUE: No, not that I remember. Andy would pull me aside and say something to me, which made no sense to me at that point. And I remember arguing with him that I know my daughter, and we had this relationship, and I'm treating her the way I always treated her, and I'm talking to her the way I always talk to her. So I will handle this in my way. And that was...a mistake that--I didn't know I was making a mistake at that point. Andy was very gentle. He did state his side. But he wasn't insistent, and he let me be. And I did make an attempt to talk to you to talk it out with you. And I could not understand your responses. I mean you were speaking clearly. But I couldn't understand what you were meaning. And it didn't sound like you.

CHERYL: I remember that.

SUE: But we talked enough for both of us to be soothed over.

CHERYL: You were.

SUE: OK. [chuckle] I was. I left that visit feeling terrible that I didn't know how to talk to you.

CHERYL: OK, so it sounded like Andy did some things to talk to you and help you out by just giving you more context. I was not there to help you out in any way other than try to state my case and explain myself. But I wasn't supportive to you cuz I was busy trying to support myself. And this is what happens to family members: they get dropped. All the focus often goes to the person with the brain injury, and the family gets dropped.

KAREN: The first time I went to visit you it must have been, it may have been after a year. It was a while after it'd happened. And so I also didn't realize what you had been going through. But by that time you had gone through a lot of different kinds of therapy, and you were able to tell a lot of stories about what

the care, the quality or not-quality of care that you had gotten. But you were also going, at that point, to see a counselor and doing some vision therapy, I believe. And you told me all about your glasses. And you told me all about what was happening with your eyes. And you invited me to go talk with the counselor with you. And I was very happy about that because I got to ask questions. And you were all about storytelling your own story. And also, you were very interested in helping me understand you at that point. And that was extremely educational. And I was, after that trip, was able to tell other people about what I'd learned. It was just the best thing you could've done at that point cuz you were in a place where you could understand yourself. You were going through a lot of things. But you could also stand back and analyze it and compare it to others. And you had coping mechanisms written out on your wall. And so you had gone through a lot already.

CHERYL: Yeah. I remember you going to that, and it was so helpful. And I know what I went through was, for crying out loud, people! Just get it already. Get it! Get what's going on! Without having any ability to express it to you in a way that you could follow and understand and in a non-supportive way. Just come on family! Damn it. I hate you cuz you don't get it. But it sounds like in that case, I tried a better strategy.

KAREN: One of my goals of going with you to the counseling session was I wanna know how to be with you better, how to understand you and...and understand my reactions to you [giggle] and your reactions to me.

CHERYL: I wanna go back and ask you though, mom/Sue/mother of this giant dog that is now not only on my foot but asleep on my foot. I wanna ask you-- Where you seemed to feel much freer to ask more open questions, and then we just answered them. And Kate also answered them. Kate gave you some informational brochures. But also, as a counselor, we could answer things on you know an emotional level to, not just information. But Ma, I feel like you didn't get that kinda support.

SUE: Yeah. Part of it is a professional glitch. I'm a clinical psychologist. And I also testify at disability hearings for Social Security. So my biggest coping was to fall back on technical information. And so for a long time that's how I processed this whole thing by getting more information than I already had. So I had a base of information from my training and my experience. And then I don't remember if you sent me links to articles or I just Googled it, and--

CHERYL: No, that was me sending you stuff. You didn't Google stuff back then.

SUE: Oh right. [Giggle.] I Google everything now. So I started reading. And I stayed at the technical level for a long time. And I...I didn't tell anyone about your injury until I started crying in court. [Voice shaking] And in order to get through the hearing, I had to tell the judge what was happening to me.

CHERYL: Whoa. I didn't know you went through that.

SUE: Well, I didn't...I didn't wanna tell you anything about me because I thought you had much more to deal with than I did.

CHERYL: So that's, and this is exactly why I wanted to do this conversation is because this is the mistake that I think a lot of people make is to think that no, no, no, I'm family. I'm not important in this. What I feel and what I go through doesn't matter. It's all about the person with the brain injury. And I mean, everything's on a spectrum. Everything is very nuanced. I don't mean to sound completely black and white. But I do think it's a mistake that we make where in the situations where all the focus goes to the

person with who has directly experienced a brain injury. And the family and friends get dropped. That is the classic story that happens. And I think that's a huge mistake.

KAREN: One thing Mom and I were able to do, after we'd both gone to visit you and talk to you more, was we were supportive of each other. We talked to each other about you.

CHERYL: I didn't know that!

KAREN: We had to, about the experiences. And I was reflecting a lot. And I was learning a lot just by talking about it. And I would talk to friends about what had happened to you and what you were going through. And that also helped me too. I also remember that you said a lot at the beginning, "This is all about me. I'm gonna talk all about me. I'm gonna talk about me. I'm [giggle]-"

CHERYL: I said that?

KAREN: It felt like, I mean maybe not explicitly just that. But you said you were self-centered, I believe.

CHERYL: [laughs]

KAREN: That a lot of the attention of what you talked about was gonna be about you.

CHERYL: Yikes!

KAREN: And I remember you saying that it's kind of typical, I think. I can't remember, scientifically, what happens, but--

CHERYL: Ooh, yeah, yeah. My population of people gets self-centered pretty easily, yeah. Sure. But we're also encouraged to be very self-centered.

KAREN: Mm. OK. That makes sense. So that's what I remember. But I also did try to seek out support but not necessarily always from you. Sometimes from you, like how can I be better? What can I do to help you? Or I'm going through this. And more and more you started to understand what I was going through.

CHERYL: Yeah. Well, I was like you guys can see what's wrong with me. Why can't you just adapt? So it's good to hear that you were looking--I don't know if anybody can hear the dog snoring at this point. Lemme give her the mic for just a second. This is great.

[large dog snoring]

CHERYL: But it's interesting what you say, Karen. Still some of it was you asked me, "What's the best way to talk to you, Cheryl?" Which is still supporting me. So I'm glad you were also talking to me about what you needed. But again, it's really hard.

CHERYL: I remember asking you one time, Mom, if you would go to a support group for family members. And you said no. Do you remember that?

SUE: Yes. Yeah. I didn't see. Well, lemme say this. I thought that I would have difficulty giving up my role as a therapist and go to a support group. And I didn't want to listen to other people, what they were going through. At that point, I was trying to contain my feelings. And I don't remember how long it took me to think of Karen and to put together the connection of what it must be like for a twin to have her

twin injured. And that's when I started talking to Karen and asking her how she was. But I didn't think of it initially.

CHERYL: So back to talking about the dog. No, I'm just kidding.

CHERYL and KAREN: [giggle]

"Cooking with Brain Injury," a personal film that broke down the walls

CHERYL: So I wanna talk about, not about my film called "Cooking with Brain Injury," which by the way, that's not that wasn't supposed to be the title. But I forgot to give it a title. So we're stuck with that now. What was I saying? [giggle] So I wanna talk not about the film itself, although we can if you want. But I wanna talk about your reactions and responses to the film. Cuz I made this film up in Portland. And then it was kind of a joke. And then I released it. And then people seemed to like it.

SUE: I remember you coming for a visit and bringing the film with you. And we set it up in the computer. The biggest thing I remember is I cried and laughed at the same time. And the first laugh, I laughed out loud. And then I looked over at you, and you said, "It's OK, Mom. You laughed at the right place."

CHERYL: Lemme just clarify. For anyone who hasn't seen "Cooking with Brain Injury," it is a comedy. It is intended to be funny. But it's very impairment based. Everything that can go wrong will go wrong for nine minutes and 47 seconds. So but it is intended to be funny.

SUE: I had never felt that mix of joy and sadness at the same time, where I was crying and crying and crying and laughing at the same time. It was very powerful. I took that film to court and showed it to several of the judges. And each judge would thank me. One judge said he would keep the film in mind because it helped him to understand what people were telling him when they testify about their life experiences.

CHERYL: That's what happened with you, too. You were earlier explaining in your process that, for a while, you were focused on the technical information: such and such causes a traumatic brain injury; the following impairments might be likely; blah blah blah. And you were very, very focused on technical information and not getting your feet wet with the actual lived experience of it. Cuz that was really hard and scary. One of the things that happened with the film, what you described with the judge and what you've told me in the past too, was that that film was where the technical information actually came to life, and you could experience it. But I'm curious, cuz you could see my lived experience when you were in the room with me, watching me, you know, walk into walls and cry over nothing. What is it about the film that suddenly you were more comfortable and able to engage with my experience?

SUE: It was that crying and laughing at the same time, where I could feel myself. And I could get into the lived experience. It's not just an empty word when you say "experience."

CHERYL: Yeah. I'm gonna cut you off just for a moment cuz you're stuck in the technical world.

SUE: Oh.

CHERYL: Yeah. What is it about the film that made it, watching a movie is what broke down the barriers? Lemme ask Karen real quick and give you a chance to de-technicalize yourself.

KAREN: So the "Cooking with Brain Injury" created a space to watch something that really happened to you. You were able to recreate and be really creative about how you recreated it and be funny about it,

but be really true to what happened. But it also opened up a space to talk about what the real experience was that was, that the film was based on, what really happened and how traumatic it was for you to try to cook fish! Try to follow a recipe. And it opened up conversation about other things that you had difficulty with and that you found a way to deal with, like writing the recipe out in a different way so that you could follow it. It was just a representation of some extremes that you went through that we could talk about in a time where you were calm.

CHERYL: I didn't even make the connection that it was from making the film--Well, I showed the film to Marih, who said, "You do not have to live like this. Give me a break." And Marih, with her decades of experience with this, taught me a better way to write recipes down. And it wasn't until after I made the movie that I bothered to learn a more effective way to cook, that I actually could cook. So it's not just that you guys got something out of watching this film. Because I can cook food now that is both edible and that doesn't make grease burns on my face. It's very nice. Yeah. But I was telling you guys my problems all the time. "I can't do this! I can't do that!" But when you saw it on the screen instead of my ranting about it, I guess...somehow, even though it was fictionalized, it felt more real? Or more approachable?

KAREN: Mmhmm. Approachable.

CHERYL: More approachable. I wasn't very approachable, was I?

KAREN: Not in a time where you were upset.

CHERYL: Right. And any time I recalled something, I would get upset.

KAREN: Yeah.

CHERYL: OK. Yeah. I wish people could see the look on your face when I asked, "Was I approachable?"

KAREN: [chuckle]

CHERYL: You look like you saw a ghost.

KAREN: [laugh]

CHERYL: Or you saw me four years ago.

SUE: What changed for me was your capacity to have a sense of humor about a difficult situation. And I think that's what opened the door for me to approach you other than to get technical or to start crying.

CHERYL: You didn't know I was laughing.

SUE: No.

CHERYL: You were not aware of that because typically when we interacted, it was all about information, and it was all about "help me, help me, help me. No, don't help me in that way. Stop it. You're helping too much." You and I never had the chance to crack a joke. You had no idea, at that time, that almost every single night the way I fell asleep was by lying in bed and laughing until my stomach hurt. I would laugh myself to sleep almost every night. I was tickled a lot of the time. But when we interacted, anyone in my family, it was always so tense. But we would all get our defenses up, I think. Yeah.

SUE: And the distance had a big effect.

CHERYL: The geographical distance.

SUE: Geographical, yeah. Texas and Oregon are not very accessible. No.

[All laugh.]

KAREN: The way that we interact with you--Mom and me--is very different than I see some other people interact with you because I think--I kind of feel proud now that I've taken the time to listen to you and ask you. Or you tell me, and I take it. It's hard sometimes. It's hard. [giggle] I'm doing something wrong. I'm doing something that is hurtful or, and unintentionally. And that's just a personal thing that's hard for me to deal with, for anybody who tells me I do something wrong. But we've taken the time. And I realize now that--and hope that--it's helpful for you.

CHERYL: It's is. Oh yeah.

CHERYL: Now that you two have gone through that process of your initial ways of dealing with me and dealing with yourselves, and then the learning and me becoming less selfish about it, and everybody learning better ways to communicate wants and needs, still, it's still always all about me. It's still always me saying, "I need this! And I need you to move your hands at this speed! And I need you to not talk at that time." I still never ask you guys what you want or need when you're around me.

SUE: Mm.

CHERYL: I never thought of it till just now. Still, a little bit selfish. So you should tell me what you need.

What would you tell other family members?

CHERYL: But also, since you've gone through this process, and it's been 4 1/2 years, what would you tell other people? I mean I hate to bring up this "the next family who goes through this." But people get brain injuries. It's gonna happen. What would you tell somebody else's sister? What would you tell somebody's mom?

KAREN: Well, it seems like hmm. That would be hard. I would initially just say listen.

CHERYL: Listen to whom?

KAREN: To the person who had the injury. But that person needs a lot of initial support and explanation about what's going on. And one very special thing about you is that you were able to analyze from your own educational and experiential background. You were in it and understood a lot of it. And I don't think every--not a lot of people would be able to understand so much.

CHERYL: On the technical level.

KAREN: Yeah.

CHERYL: I think a lotta people can articulate what they're going through.

KAREN: Yeah, yeah.

CHERYL: But it's in such an experiential, personalized way that it's hard for other people to accept that information. Because I'm stuck with this master's in speech therapy, I have the technical information.

KAREN: But still, the listening and being supportive with time and if someone needs some help finding other rehabilitative services. You had to advocate for yourself a lot in trying to connect the different pieces of care that you needed that I didn't know about that. And I felt helpless in that. And I felt that if you had a little bit more help with that, that would've been good.

CHERYL: Yeah. So you're still focused a little bit on me. And when you said you felt helpless, I wanna hear more about that. What would you tell somebody else's twin sister who said, "Oh my gawd. I feel helpless." That's a hard question.

KAREN: Yeah, that one is. [giggle]

CHERYL: Would you tell that twin sister what you just said: help the person connect their care, and help the person find their rehab? So it's still focused on the survivor?

KAREN: In a way, yes. But also that to not take personally [chuckle] whatever the injured, or the sister is going through or the reactions that the sister has to you. That person has changed but in essence is still the same person.

CHERYL: Thank you for saying that. I rarely come across anybody saying that second point. The person has changed....I forgot what you said. [laughs]

KAREN: Oh. The person is still essentially the same. I know who you are. I can connect to you on a lot of the same levels that I did before.

CHERYL: Yeah, yeah.

KAREN: You're still there.

CHERYL: Yeah!

KAREN: You're almost heightened you.

CHERYL: Yeah, that's been, that's one of my problems is everything is turned up to 45. On a scale of 1 to 10, I'm on 45. Yeah.

KAREN: And when I try to prepare other people who're going to meet you like my partner or a friend who I would like to meet you, I try to protect you and prepare them. [chuckle]

CHERYL: Mmhmm.

KAREN: Yet, I am so wanting them to meet you. I want them to see you and see the parts that I love about you. Yet, I'm a little bit afraid sometimes that they won't understand if you were to get upset about something. Or they won't react in a way that would be helpful if you asked them to do something that they're not used to. So I prepare them somewhat, yet sometimes I think I prepare them too much. And they're a little afraid.

CHERYL: Yeah.

KAREN: But I don't want them to be.

CHERYL: Right. And how do you find that balance of not protecting me too much, not over-preparing them to the point where they're like, "Forget it. It's not worth having dinner with this person. She sounds like a monster." Even though you don't portray me like a monster, it's so unfamiliar to some people to talk through these things that they're like, "I don't wanna bother! Disability is scary!" I mean, in total honesty and disclosure, my disabilities are so very, very mild, especially now. They've just gotten milder and milder over time. But I know earlier on, there was definitely, I was kind of a monster a lot of the time. Rawr!

KAREN: A little unexpected.

CHERYL: Yeah, all the time.

CHERYL and KAREN: [giggle]

KAREN: But then again, some people who meet you, my friends who are close to me, they do the typical, "Well, there's, there's nothing wrong with her!"

CHERYL: [laughs]

KAREN: Like OK, OK. [laughs]

CHERYL: It's so interesting because I wanna be a regular person. I don't need to be called out as Other and separated from the group. I mean, I separate myself from other people a lot because people are too hard to be around. And it's just too much. But I wanna be a regular person. But what's interesting is the way people tend to do that is to say, "You don't seem disabled at all. I don't see any disability. You're perfectly normal." And I think they feel inclusive. But that's then erasing the reality. And there's the impairments. And they're mild, but some of them are still there. But there's the political reality. When they say, "Well, I don't accept that you have a disability cuz you seem normal," they're erasing the political reality of the discrimination that I face personally, but more so, that I see in my peers and my community members. And so when you deny someone's disability just because they're hiding it because you're a stranger, and they're having dinner with you, and they're gonna hide it. I spend a lotta effort hiding it. Then, it's really sad because then that makes it harder to form a community. Cuz then you're like, "Well, will you only accept me if I continue to wear this mask and act normal in front of you?"

KAREN: I think one thing that occurs to me is there are certain times when you need to ask for a certain type of treatment, like when you get on a plane. You need certain things in place to be able to function OK and make and have an OK plane trip. Or to be able to walk down the street, you put headphones on. That is just the way that it works for you. And it makes me sad to think about the stories when you weren't accommodated to get on the plane or--

CHERYL: Oh, like when they kicked me off the plane?

KAREN: When they kicked you off the plane. I was very angry, as were you. [giggle] And so the certain times when you do need something different, that's when I think the awareness of the outside world of you and what you need just needs to be of acceptance. You know what you need. You're asking for it very directly. And there should be no hesitation to be able to give that to you.

CHERYL: I know. It's really stinking weird, isn't it?

SUE: Well, it's hard for me to not be technical from my background.

CHERYL: That's fine.

SUE: But listening to Karen and to you, I think if I were to tell someone the way to navigate this change in life would be to find someone to talk to. It doesn't matter if it's a therapist or clergy or friends or people who've been through it and are further along. That part doesn't matter. But what matters is that the person get to a place of acceptance and tolerance. Those two words are not the same thing. And Karen spoke about acceptance. And I know I had to get both of them. I had to accept the change in you and tolerate the change in you and give up my wish that this had never happened. So I finally did express that to you at one point. And it took this huge burden off of me to tell you that. But I'm also aware that a lot of people, when they're in this kind of situation, get pathologized. And the brain-injured person is told, "Well, you're depressed or you're anxious, or now you have ADHD." And people are easily guided to that form of treatment where that is a lack of tolerance of the change of the person. So not only do you have a head injury, but then you're told you're anxious or depressed and given medication for that. I don't go that way, mostly cuz of my beliefs and my understanding of people. But I still had to go through the process of learning to accept the change in you, accept the change in myself, and to tolerate myself, to tolerate my feelings when I'm around you, and to tolerate you telling me I'm doing something wrong over and over.

CHERYL and SUE: [chuckle]

SUE: And I think to myself, I can't be that dumb that I don't understand. And it has nothing to do with me being dumb. It has to do with me being willing to tolerate what you're asking me for when sometimes I don't wanna do it. And sometimes I don't wanna do it cuz I just want you back the way you used to be. So this idea of acceptance and tolerance is a process that looks like it's gonna last our lifetime. It's not something that can be fixed immediately. And it certainly can't be fixed with medication. So that's what I would tell someone who just is starting this process is to learn how to talk about your feelings and learn how to accept them and tolerate them.

CHERYL: Yeah. And like you said before, finding someone else to talk to. You often came to me for support. You often expected a lot of me, a lot of explanation from me, and I sent you a lot of articles. You asked me for a lot of support. And I think that's partly because with my professional training, before this you asked me for information. "Oh, well what do you know about this particular communication impairment. Oh, swallowing disorders." I could answer all these questions. And you continued to do that. But I got to this point where I was like, "Dude! Stop asking me to support you!" I didn't understand it. I could not understand why you were making me look these articles up for you and explain these different aspects of executive dysfunction, all this. But now I get it, why you wanted that information and why you were asking me. And then you stopped when I said, "You've got to find someone else to talk to besides me. You can't keep telling me how hard this is for you and asking me to explain things to you."

SUE: Yeah.

CHERYL: And now I understand why that was. And so that's something that I feel proud to have learned a little bit about is how much the family gets ignored and forgotten and told, "You're doing it wrong, you're doing it wrong," without anyone ever stepping in and saying, "Would you like some support and information for yourself? For you! Not how to talk to your brain-injured family member, but you." There are some places that do it. A lotta times people give out an informational brochure. Oh, your family

member's still in a coma? Here's a brochure about what you should do." Now, I was never in a coma. But for people, someone's in a coma and their mother's sitting right there, and you hand them a brochure that says, "Be sure to take time for yourself," I'm imagining a lot of mothers who would say, "Nope. I can't take time for myself. I'm busy sitting here, watching my child to see if they're gonna wake up." And then people criticize the parent. "No, really. You need to rest. You need to hire respite. Go get your nails done. Go see a movie." And people give these instructions as if they would be so easy to follow. I like the perspectives that you shared. And hopefully other twin sisters or non-twin sisters and other parents will be able to take to heart what you said. But one thing everyone should do is make movies.

KAREN: Yes, definitely!

CHERYL: [laugh]

KAREN: No.

CHERYL: I say that jokingly. But I actually mean that. If you have an iPhone or an iPod or...camera. Remember cameras, that like take pictures?

SUE: Yeah, I have one.

CHERYL: Yeah, a camera. Make a movie about anything!

The turning point was showing and talking about movies

KAREN: There was a point when I started seeing you, when you came and presented the movies. But when I saw you present, and I heard you were presenting at other places about the movies, I just felt really proud of you and that I felt good that you made, how do I say? Your time was taken up with something that you were passionate about. You're busy a lot and productive in that way that you didn't know you were gonna be doing this particular thing. But this is what you're doing. And you're doing it well.

CHERYL: Thank you.

KAREN: And you keep finding new ways of incorporating this experience and making your experience your life. I mean, the podcasts and the movies and the other projects that you're working on of sharing information, advocacy, you are very energetic about it. It is your job.

CHERYL: Yeah.

KAREN: I don't know what other kind of job you could have had that you would be so passionate about. And I'm happy for you that what you're doing keeps you going. You keep you going.

CHERYL: I deeply appreciate all the support. You two have given me huge support in terms of taking care of yourselves, in terms of learning more about what I need and providing it in any way that you can, and you both are financial backers of "Who Am I To Stop It." And what that means to me is that you two are interested not just in supporting me and my film work and my passion, but you two care about the fact that I'm publicizing other people's stories. Some of the people in the film have less privilege than I do. And you two care about the fact that that's the film that I'm making. I don't know. Maybe you're just like, "Whatever. I'll support her movie." And that you want to provide support to me to get this film out because it's going to provide snippets of other types of people's narratives and stories and experiences. So I thank you.

SUE: Thank you for suggesting this. I very much appreciate listening to Karen because you have said things I haven't heard you say before. And you were amazingly articulate with what you said. Cheryl, I appreciate you giving us this opportunity to talk to you.

CHERYL: Yeah! We wouldn't have had a conversation like this if there weren't a microphone in place.

KAREN: Thank you!

CHERYL: Yeah.

KAREN: How's that for articulate?

[All laugh]

CHERYL: Thank you.

CHERYL: Thank you for joining me on the podcast today!

SUE: You're welcome.

KAREN: [giggle] Thank you, Cheryl.

SUE: I love you!

CHERYL: I'm editing that out.

[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.

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