

# Stories from the brainreels podcast transcript

August 5, 2015

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## Introduction

CHERYL: Welcome to Stories from the brainreels monthly podcast about brain injury and disability with a focus on art, culture, and disability pride.

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CHERYL: Earlier this summer I spent several days living up in University Place, Washington. The goal of my time there was filming a promo video for the non-profit Brain Energy Support Team. And while yeah, sure, I did film that promo video, something else exciting happened. I got a first-hand look into this really intimately connected brain injury community in the University Place-Tacoma area.

If you know me at all, you know I'm so not someone who likes to focus on the positive and ignore anything that might be seen as negative. But I have to tell you, there is something pretty amazing about having your organization name have "Brain Energy" instead of "Brain Injury." I don't mean to say that everyone is completely happy all the time, focusing only on their brain energy and avoiding discussion of disability. (Side note: a lot of the people there seemed completely happy the whole time I was there!) What I mean to say is that this organization and the people in it are dedicated to focusing their energy on what can build community, directing their energy toward improving their individual lives, and energizing each other with something that is unmistakably a deeply-rooted sense of compassion and love for each other.

Today's episode is a series of conversations I collected as I filmed for the video. You'll meet Ellen Krawiecki, Board member Jeff Hartson, and Diane Rasch, all BEST members. The episode wraps up with a longer discussion I had with Founder and Chief Visionary Penny Condoll. All four are peers with brain injury who bring their first-hand experiences with brain injury and disability to their work at BEST, seeking support when needed and always lending even more support to others.

Check out today's blog post at [www.WhoAmItoStopIt.com](http://www.WhoAmItoStopIt.com) for links and more of the technical information about Brain Energy Support Team's programs and services and who else they're connected with in the Washington State brain injury community. And thank you to Adam Selzer on [FreeMusicArchive.org](http://FreeMusicArchive.org) for today's music.

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## The Interviews

### Ellen Krawiecki

ELLEN: My name is Ellen Krawiecki, and I am from Tacoma, Washington.

CHERYL: Would you tell me how you found out about BEST?

ELLEN: So I found out about BEST through a series of events. So about a year and a half to two years after my brain injury, I was driving to college. And I saw on the back of a bus like a little advertisement for TBI Washington or brain injury, one of those website; I don't remember the quite name. So I went home and Googled "Washington TBI" and found a website. And then I saw support groups. And then I saw Tacoma, Washington. And then I saw that there was one that took place at Tacoma Coalition for Individuals with Disabilities, which is on the same campus as my college. They actually had a group called Stitching It Up, which started about half hour after one of my classes got out. So I started going after class and meeting all these great people. So it was definitely a sign [laughs].

CHERYL: Yeah, yeah. Did you go to support groups before you found Stitching It Up?

ELLEN: No, I didn't know anyone that had a brain injury the first few years. Every symptom I had, I dealt with on my own. Having an invisible illness is kinda hard because people don't understand why you're having troubles or like why you can't do your homework. But finding a group of people that have similar experience as me has really lightened up my life because I can go to them and hear their stories and be like oh, me too. So having something you can relate to when you felt so alone for so long has really been a great thing.

CHERYL: Yeah. One thing that I noticed right away when I came here is there is a really big age range of people who are all peers here.

ELLEN: Yeah, I think I'm definitely one of the youngest. I'm 22. There are a few teenagers that come in. But I would say most people are over 30 and 40. But I don't really see it as a difference. I already come from a community with wide age ranges, "Rocky Horror Picture Show," where people are 15 to 70. So I love people in all groups. And you know, some people might think it's weird having a friend who's 60. And I'm like, "She's a good friend, you know?"

CHERYL: Yeah.

ELLEN: Age doesn't really matter.

CHERYL: It doesn't because you have important things in common. So why should it matter that you're different ages?

ELLEN: Yeah [giggles].

CHERYL: Yeah. Tell me what you do with "Rocky."

ELLEN: Oh, I do shadow-casting. So what you do is you play the characters in front of the screen while the movie's on the back. So I play Columbia and Rocky. Oh, and I love making costuming. And I have opportunity to make costuming here with all the Stitching It Up supplies [laughs].

CHERYL: Perfect!

ELLEN: But "Rocky" came at a good time in my life because it was about six months after my injury. And I was really missing doing sports and stuff cuz that was a big part of my high school. And "Rocky" gave that team environment, plus something that I could easily do and that made me happy. So it gave me some good things in my life, including friends and experiences. A lot of things happened in my life that are good that wouldn't have happened had I not had a brain injury.

CHERYL: Oh, do tell.

ELLEN: So for example, I didn't drive the first month or two; I didn't feel like it. So I took the bus to school. And I met one of my best friends. And so that was great. And then, on my class trip to Florida, I couldn't ride the roller coasters cuz I'd get dizzy. So I hung out with another friend. And she invited me to "Rocky." That's where I met my boyfriend. So had I not had a brain injury, I wouldn't have met a lot of these great people, had these opportunities. So try to focus on the positives, too. Oh, and I wouldn't have come here [laughs].

CHERYL: Right.

ELLEN: This is pretty awesome.

CHERYL: Right.

### **What do you want people to know about you or brain injury?**

CHERYL: What do you want people outside of BEST to know about you or to know about brain injury?

ELLEN: I'd like people to be more aware and also more aware of the risks. One thing I'm really passionate about is--or one thing that really bugs me, rather--is when people don't wear helmets when they're on a bicycle! I just wanna scream, you know! Cuz you can really get hurt really bad [laughs].

CHERYL: Living proof. Yeah, you really can.

ELLEN: Yeah. I've met people with plates in their skull cuz they weren't wearing a helmet. And that's just really unfortunate. So one thing I'd like people to be more aware of is that you can prevent some worse outcomes by protecting yourself.

CHERYL: Yeah, and I'm really interested in talking to people about safety and prevention as well, for sure. Do you participate on any speakers panels or do any lectures around that?

ELLEN: Nope [laughs].

CHERYL: I don't know if they have them in Tacoma. They have them where I am in Portland.

ELLEN: Mm. Do you guys have a helmet law down there?

CHERYL: I don't remember. I see a bunch of hipsters, and I can see their hair and how they styled it.

ELLEN: [laughs]

CHERYL: I look at them, and I just cry. Stop.

ELLEN: Cuz how is your hair gonna look if there's a scar [laughs]?

CHERYL: This is what I tell people. When I give presentations, I say, "I don't care what your hair looks like. Having beautiful hair is not worth a skull fracture."

ELLEN: The friend I met on the bus, he didn't always wear his helmet when long boarding. So after seeing what I went through, I convinced him to wear a helmet while long boarding. And a few weeks ago, I see him riding his bike without a helmet. I texted him, and I was like, "Where's your helmet?" And he

was like, "Under my bed. Why?" I was like, "I saw you riding a bike without it." And he was like, "Oh, I only wear that when I'm boarding."

CHERYL: No!

ELLEN: So I got halfway there.

CHERYL: Halfway is better than none-way.

CHERYL: What do people misunderstand about our community of people with head injuries?

ELLEN: Some people might think that brain injuries are maybe more serious in general. And they may not understand that you can go on and do things with your life and that there is a lot of ability with disability. One thing is that people maybe don't understand that I'm brain-injured cuz they don't see it. So maybe they're like, "Oh, you're doing fine," you know [chuckles]. So I guess just the invisibleness of it. Well, I did have a brain injury when I was young too.

CHERYL: Oh, you did?

ELLEN: I obviously don't remember this one. But this is what I've been told. So 18 months old, I was in a car accident. And back in the early '90s, you could still have kids in the front seat. They didn't even think I was gonna grow teeth or be able to go to normal school. But I did. I kinda had headaches a little bit as a toddler, I remember. But I wouldn't really say I remember being affected by that because you don't really start forming memories till you're two. So my normal has always been normal [laughs].

CHERYL: That's right.

ELLEN: Yeah, and I wouldn't say that's affected me too much, just maybe the experience of it, accumulating head injuries, maybe. And then in 2010, I got two sports concussions, I think maybe it was at least a six-month span. But still, too close for comfort. The one in 2010 was a little, little rougher to continue on with schoolwork and stuff.

### **Lack of educational support in grade school**

CHERYL: Did you get support in school?

ELLEN: Mmm, OK. So my doctors were like, "OK, she doesn't have to do homework for two months." And then I'd go back to school. And then I'd get a little bit of leeway. And then after two weeks to three weeks, the teachers would start giving me assignments again. And I'm like, "The doctors told me I wasn't supposed to." My mom had to do a lot of my English and History homework cuz the school just wasn't accommodating. I even remember a situation where--I don't remember the class. Let's just say English. I got called into the advisor's office a few months before graduation. And the teacher's like, "Ellen, you have a C in English, and aren't you worried about that?" And I'm like, "Um, I had a brain injury a few months ago." And they're like, "Oh yeah, I forgot about that" [laughs]. If I could go back again, I wish would just let me attend school and just get the cap and gown. But there's state regulations. They can't do that. There's supposed to be work done. So I'd say I did the work that I could. My mom would read aloud to me. And then maybe I'd speak to her. And we'd write our essays together. It wasn't all her. I did as much as I could. But one thing that was really affected was reading, which still for several years after that, reading was really hard. I wouldn't say the school was as accommodating as it could've been. But it wasn't necessarily anyone's fault. It's just the system that we're in. They can't not put stuff in the grade book, you know.

CHERYL: Yeah, that's really hard. Did you get a 504 Plan or anything like that? Does that sound familiar?

ELLEN: I don't know what that is.

CHERYL: Oh! Bummer! That would've made them federally required to give you the accommodation.

ELLEN: Yeah, that would've been good.

CHERYL: Yeah, this is one of the problems with the acquired disabilities is that students and families don't find out that there are structures in place. So you've heard of Special Education, right?

ELLEN: Yeah.

CHERYL: OK. So there's Special Education. And then there's General Education. Kinda in the middle is 504. It's sorta this thing where you don't get a label and you don't get fully into Special Ed. But they try out some services. I wonder if she'll do better if we give her math tutoring or if we change the homework assignments this way. And then they check back: is it helping?

ELLEN: I think less homework would've been better [laughs].

CHERYL: Exactly, yeah. So that's the kind of accommodation somebody can ask for on a 504 Plan.

ELLEN: I did have a thing where I could just, if I started getting a headache, go to a teacher and be like, "I'm gonna go to the nurse," stay there for a period and a half, and then go back. So that's one thing I did have. But I didn't wanna miss school. I wanted to continue going, seeing my friends, do as much as I could cuz I'm kind of a perseverance person.

### **What do you like best about BEST?**

CHERYL: So what do you like the best about BEST?

ELLEN: [giggles] Some of my favorite things about BEST are the people, being together, discussing, doing crafts together, volunteering together, and just hanging out [giggles]. I like to think of my life I have different families. And this is one of my families. We had a Christmas party last December. Everyone got presents, and we took pictures with Santa, and we all got food. It's definitely a good environment. I won't say I use it too much, but I know the word that goes around to talk about this community is the BESTies. So I'm hanging out with my BESTies today [giggles].

CHERYL: I love it! Anything else you would like to say about yourself or about BEST or about brain injury?

ELLEN: I'm really glad that BEST came into my life cuz it's definitely made my life a lot brighter and given me a lot more hope and a lot more satisfaction in life.

[music]

### **Jeff Hartson**

CHERYL: Jeff Hartson, welcome to the podcast.

JEFF: Hi there. My name is Jeff Hartson, and I live in Tacoma, Washington. I got my brain injury back in 2003. I was assaulted by an inmate. I worked in a correctional facility. I worked in corrections for 20 years. I had a medical retirement due to my head injury back in 2003. I had a very good career in corrections. I just really enjoyed the people I worked with, as well as the job. I learned a lot.

Unfortunately, when I was assaulted by the inmate, then that ended my career because my skills at being able to make life or death situation decisions was impaired. So I decided it's best to not pursue that anymore.

CHERYL: Yeah, it was a career that you enjoyed?

JEFF: I did. I did immensely. It was very rewarding and made a lot of really good friends and had a really neat time. Yeah, we had our tough times. It was challenging. You know, we had some serious criminals in there, people you just don't want to be having as your next door neighbor. But these are people that were there for a reason. And our job was to make sure they stayed there, and they didn't go out and hurt other inmates or hurt us. It was a neat experience, a very neat, hands on experience.

CHERYL: Are you connected to the Department of Corrections community or your old work community anymore?

JEFF: My brother still works in a prison down in California. A lot of the friends and coworkers that I had have retired by now. 20 years, once you get that time, it's time to go looking for the fishing pole and the camping gear and all that stuff. So yeah, it's a few of them are hard to come across. So most of the people that I've been able to make contact with are in Corrections right here in Washington.

### **Training law enforcement to recognize and support people with brain injury**

One of my other little ventures that I'm doing is my business where I'm trying to promote brain injury awareness with law enforcement so there's a better understanding with law enforcement on how to deal with people with brain injuries. Because you can't tell a person's got a brain injury simply by looking at them. A lot of times, they're over-diagnosed for something that they don't really have. I've known of several people that have had situations either in the prison system or out in the community here, where they've had interactions with law enforcement. And no fault of the law enforcement people, because it's all about education and training and familiarization, recognizing people with brain injuries. It's not something they teach in the academy. But this is something I've taken upon myself to try to present to our law enforcement community of an awareness for people that do have brain injuries, especially like folks coming back from Iraq, Afghanistan. And they're at home. A lot of them have PTSD. There might be a family dispute or something. And for some manner, shape, or form, the police are called, law enforcement's called to intervene. And sometimes the person that's having the PTSD or the brain injury just needing some other routes to be taken rather than the criminal route, because what he's got going is not something he can easily control. He's wanting help to have this problem controlled, whether the PTSD and the brain injury. These all trigger each other.

So by training law enforcement and corrections, giving them some tools to try to familiarize them on the person having symptoms of a brain injury, I'm trying to inform people now: if you have to call law enforcement for whatever, if a person's acting out, and they have a brain injury, please tell the dispatcher that the person has a brain injury, OK? So they have some idea that the person is not on drugs, he's not going crazy, psycho, that sort of thing. Brain injuries can change in a fair amount of time, simply by taking, so to speak, the fuel out of the fire. This is what the message is I want to try to convey to people and make them aware of.

CHERYL: That's great because who better to do that? You had so many years working in corrections, so much experience on that side. And then the life experience of your own brain injury and being at BEST. You just sound like the perfect person to be doing those kinds of trainings.

JEFF: Thank you, thank you. My business name is JPH Consulting. My email address: [jffhrtsn53@gmail.com](mailto:jffhrtsn53@gmail.com). That way we can set up, if anybody's interested in doing a class. I've already been through the training at the Washington Criminal Training Academy up at Burien. So I was cleared with the classes up there.

I'm involved with [[Heroes to Hometowns](#)], which is a program for Veterans, and just trying to learn what their needs are and so forth, in regards to brain injury and just offering them any type of support that we can offer. Whatever the community has in regards to brain injury, just being able to offer ourselves to them and say we're here to help out and just provide that for them. That is fantastic.

### **First joining BEST and becoming a mentor**

CHERYL: So your brain injury was in 2003.

JEFF: Yes.

CHERYL: When did you first find out about BEST and start coming here?

JEFF: Well, I was living in Lacey, which isn't too far from here, at the time. I was involved, already, with the brain injury support group for Tacoma. Coming up here to BEST just kind of, actually at TACID is where we started off at. And then, when we finally got funding and everything fell into place, we were able to get our own building here for BEST. So I've been hanging around since then. I just kind of really enjoyed it. You know, it's been a great recovery--how would I put it?--recovery process learning to be around other people with brain injuries and learning what they're going through and how it affects me or how I can help try to get people back in a normal life cycle, OK? Get their lives back together again. And this was really being portrayed here at BEST. Penny has really put a lot of effort into putting a lot of heart and soul into people with brain injuries. And I just really felt an attraction to that type of environment. So that's why I've really enjoyed it. I had a situation in Lacey that came up. So I decided well, you know, it's time to move over here to Tacoma so I can be a little bit closer to the office here. So I did. It's the best move I've made. So I'm real happy to be here. And it's a good environment and just it's here for people with brain injuries, just a lot of the potential, a lot of the programs that we have going.

Being a mentor for a few of the people that come here and being involved with the programs that we have as well, has just been very instrumental in my recovery. And what I've been able to get out of it, I've hopefully been able to share with other people and help them with their journey and make life a little easier for them. It's a catalyst of what we need in this community, I think, in all of the brain injury communities is to have this type of an operation going, this type of a community resource available. We have people with the actual injury to facilitate programs and be able to help people with brain injuries. Who else can walk the walk and talk the talk, as we used to say? You know, those are the ones that do this sort of thing. I just give it all I can to help out and make things happen.

CHERYL: Can you describe some of the areas where you do mentorship?

JEFF: I've been taking a program called Moving On. Penny's been doing that. I'm just about done with it. I'm also being a peer mentor to another fellow that comes up here and just helping him with his journey, giving him encouragement, and just empowerment, basically. Because as a male, you know he's needing some reinforcement in those areas. With a brain injury and life hassles that he has to go through, we talk, and we share what he's going through. We just have a good communication between each other. And we're able to help figure out different problems and strategies and just try to make his life that much easier for him, make things a little noteworthy for him so he has some goals to achieve.

He has little projects that he's doing. So when he brings them here, I'm helping him with them so he's able to get the projects done and be able to take them out into the community and display them at businesses so that he can be sold at businesses. He's energetic in that area and a little entrepreneurship there, so to speak, you know. Just to try to motivate him to keep going with it because it's a new strategy for him. But you know, he's putting forth the effort. And it's seeing it come out of him and all that. It's really changing him quite a bit.

We have a lot of support groups across the state that are trying to help other people with brain injuries. BEST is there to support them. We have trainings that we're trying to stay caught up with to better equip ourselves with skills that we can do for facilitator training, for Moving On.

CHERYL: That is great.

JEFF: Yeah.

CHERYL: Anything else that you want to share about yourself or about BEST or about life with brain injury?

JEFF: As far as BEST is concerned, I think this is probably one of the better programs I think I've seen. There's so much potential here with people that are working behind the scenes that want to make the best out of it.

[music]

### **Diane Rasch**

DIANE: Hi, my name is Diane Rasch. And I'm from Tacoma, Washington.

CHERYL: Have you been here your whole life?

DIANE: No, actually, it will be three years in September. Moved from the Midwest.

CHERYL: Oh, OK. What brought you to Tacoma?

DIANE: Our children. Our oldest has been out here since '04 and our two younger ones since '06.

CHERYL: Oh, nice. I have seen your handmade cards. I would love for you to describe and talk about the cards that you make.

DIANE: So I had my last brain injury, well, actually I've had some since then, but a real devastating one in '06. But I also had some prior to that with medicine ball and accidents and stuff like that. And so being as that, I'd never been in a support group in the Midwest. So when I was told that out here there would be more help, I was very excited. So February 14th--it's very important to me--of 2013, I went to my first support group. And I met Penny. It was just delightful. That was before the space happened. They were talking about well, how could people help doing things with BEST? And I'm like hmm, I know what I could do! And actually, as of April, 2013, I did the first birthday card for someone in a support group. So what I do is I do birthday cards for two support groups here in Tacoma and then also people in Puyallup or around. And again, I've been doing that now since April, 2013. Every year I have a new design. This last January, I started a new thing called the You Are Special Campaign. And so I wanted to make it be more personal. So what I did was I asked people, "So what is your favorite color? What is your hobby, or



what do you like to do?" And so now when they get a card, they get their favorite color and then something that pertains to them so it's more personal.

The thing that really gets me with this is that one of the first cards that I sent out, on the envelope, I put my return address but not my name. Cuz I figured that's enough. I don't even remember how long later in the mail came this envelope with my return address! And I'm like, "What? What is going on here?!" And I opened it up. Somebody that I'd sent a card to wrote me a card thanking me for the card. I started crying because it was like this card meant so much to me as one of the, like the only card I got. And I have this sitting out so I can look at it all the time. And when that happened back then, I knew that this was something that--again, 2013--I knew that this was something that I was gonna keep doing. And so like I said, I've been doing it. And I just love it. Because of that, I now have a new goal. My new goal is to, well, I wanna do it this year. But I guess it's gonna be a process since everyone's brain-injured. And you know how we are!

CHERYL: [giggles]

DIANE: To get a birthday card--it's called the Birthday Card Project--to get a birthday card into everybody's hands in the state of Washington with a brain injury that's involved in support groups.

CHERYL: Oh!

DIANE: Now, it's a process. Let me tell you. Because I'm [laughing] talking to a lot of brain-injured people! But I myself want to do it. I mean, I just wanna get names and just do it myself cuz that is how passionate I am. Because even now, people just say, like when I go to a support group, and I'll say something maybe about Birthday Card Project and how things are so exciting for me. They'll go, "Yeah, I got one! And thank you! It's just so wonderful." And it really is special to get a birthday card. And we don't realize how important things like this are.

CHERYL: Cuz it's that connection. And it's that "I'm thinking about you."

DIANE: Yes, yes! And as I'm doing it, I actually do think of that person. And not only do I say happy birthday, but I say something special inside that will really speak to them. And it's really rewarding and really special.

CHERYL: That's beautiful.

DIANE: Yeah. So I've been doing that. I started a class called Moving On with Penny. And I'm telling you, it's really changed my life. I've really moved on in a big way and been figuring things out, what I should be doing. I previously had worked with children for years and years and years. And can't do it anymore. Sorry. I love them, but I have a hard time being around them: all their excitement and stimulation and all that stuff. Because of Moving On, last August when we were out at Dash Point, we were doing a campout, it was very exciting because we had a little Moving On there. And we got done, and Penny said, "I know what we're gonna name you! You're going to be called our Gratitude Specialist."

CHERYL: Aw!

### **BEST's official Gratitude Specialist**

DIANE: So I am BEST's official Gratitude Specialist. Not only do I do birthday cards, but I listen at the meetings or different people tell me. And all the sudden in the mail could come congratulations, get well, thinking of you, things like that. So I'm becoming very more in tune about people. And my big

thing, and I told Penny, was I really believe how important it is to honor people. And so whatever anyone does, I wanna honor them. So with that, I woke up this morning, and I wanted to make this for you to honor you--

CHERYL: Oh me?!

DIANE: and to thank you for coming and doing this. I am so excited when I first found out about you a while ago. And I know [starting to cry] that what you're doing is so important. And it's going to touch so many people's lives. And you have no idea, but I know it is. You're gonna change people's lives. And things are gonna happen. And it's all gonna be so beautiful. So thank you, Cheryl. So that's something special. I even wrote a little thank you inside for you too, just to let you know how special you are and [sighs] things like that [laughs].

CHERYL: Nobody has ever made me cry in an interview. I'm so touched!

DIANE: You're welcome.

CHERYL: Thank you!

DIANE: You're welcome.

CHERYL: And I love this.

DIANE: And I have something else for you too. A month or so ago, we had this appreciation dinner or dessert thingy. Being the Gratitude Specialist, so what it is was I wanted to make something for everybody to honor them for being part of BEST. This is for you, called BEST Brings Hope.

CHERYL: Oh!!! It's beautiful. Oh, I love butterflies. Thank you!

DIANE: You're welcome.

CHERYL: And I love the textured paper. I am so touched. I mean...I think I haven't met you before, right?

DIANE: No!

CHERYL: No, but it feels like we have. This is--

DIANE: That's what Penny said, we would connect.

CHERYL: Oh. It's, I mean...I know this is your job. But it does, it feels really special. And it's very sweet. I'm incredibly touched. I mean, everybody has been very generous. And I just feel like OK, I'm on the clock. Let's go. Let's work, let's work. But thank you for reminding me why I'm actually here.

DIANE: Right.

CHERYL: I am very caught off guard and [laughs].

DIANE: Yay [claps]! I love to do stuff like that.

CHERYL: Yeah, yeah, it, it, I mean this means, it means a ton to me. Thank you so much.

DIANE: Yeah, you're welcome.

CHERYL: So, in a nutshell, this is what you do at BEST!

DIANE: [laughs]

CHERYL: You make people cry [laughs]!

DIANE: Yeah. And how it came about was Penny had seen how I touched different people's lives. So when she asked me and said about how about you being the Gratitude Specialist, I was just overwhelmed and honored because she saw that. And that meant so much. Yes, I had my card business called Heartfelt Tidbits of Creativity, actually. But it's more than that. Really, it was when I became involved with BEST and being able to honor these different people that don't ever get honored, to share their tears. You know, I've even sent sympathy cards, things like that, that sometimes in our community that doesn't happen. People don't get us. And so this whole card business, I'm so excited now because I can just surprise people at any time, like you--

CHERYL: Yes [laughs]!

DIANE: and do things for them. I really wanna honor the people that are out there and say, "Hey, someone cares about you." I am so passionate about this Birthday Card Project. Anybody who hears this, why don't you do that?

CHERYL: Yeah!

DIANE: Seriously. If you want information, I can help you do this. But just think about it: if everybody got a birthday card! I mean, there's a lot of people that don't get a birthday card.

CHERYL: And not only a birthday card but with a personalized message. And it's a handmade card.

DIANE: Yes.

CHERYL: You know, I used to hand make cards too.

DIANE: Oh!

CHERYL: What I love is that moment of which one would be perfect for that person? You slow down, and you spend time: what do I know about that person? What would make them really happy?

DIANE: Yes.

CHERYL: This is just precious. Now, did you do this kind of paper crafting before your brain injuries?

DIANE: I did do paper crafting to thank people and just birthday cards. But I never thought it would be a business. I thought it would be fun to be in business. People said it would be neat if you did a business. But it wasn't till I moved out here that it became a business.

CHERYL: Oh, great!

### **Missed brain injury diagnosis**

CHERYL: You said you did not go to support groups in the Midwest.

DIANE: Mm-mm.

CHERYL: Were there none near you?

DIANE: No, I'm sure there were. But I was not recognized as having a brain injury. I was recognized of everything was in my head, and there's nothing wrong with you.

CHERYL: Yeah, I've been down that road too. You can even fail the tests they give you. And they still are like, "Well..." I had somebody write in their notes--the neuropsychologist said--you know, "She failed this test, but she was just distracted." But he didn't make a note of what possibly happened that could've distracted me during that test. And it's the same test I had failed in the past. So it made sense that I--So I've been down that road too.

DIANE: Well, to me, it was where "Hurry up. We need to get through these tests." I spent a lot of time crying during that time. And now that we know--cuz I actually had one out here, and now to realize that--it was, you know? Totally different. It was kinda sad how I was treated back there.

CHERYL: Yeah, I'm so sorry to hear that.

DIANE: So I'm really thankful. I mean, it was perfect timing that we moved out here and become involved out here. And my life's out here. BEST, it really is my family. This is my family. And everyone is very, very precious to me. When we were at the brain injury conference, a good friend of ours, Nancy, said, "I just can't believe. I remember meeting you in January, 2013. And you were just a shy little, and you were just like in this little shell. You were just like that." She goes, "And now you're way out there!" [laughs]

CHERYL: Wow! And that's because of your connections here, right?

DIANE: Yes! It is! It is because of here.

CHERYL: Man, oh man.

DIANE: I know it is.

CHERYL: This is like a fairy garden, unicorn, angel rainbows.

DIANE: It is. It is! This is phenomenal.

CHERYL: Yeah.

DIANE: It is a phenomenal place.

CHERYL: Oh my gosh, wow.

### **Message to caregivers**

CHERYL: Are there any other stories that you wanna tell or any message that you want people with or without brain injury to know?

DIANE: I think the main thing is especially for caregivers, first of all, I wanna thank you, caregivers, for all you do. I know what my husband goes through when I have my little temper tantrums or shut downs or whatever. I just want to thank you, caregivers for all you do. And those of you who are just out there

and are hearing this, yes, we're broken. But like we say, OK, we're either like a survivor, but we wanna say we're thrivers and that we are thriving. I think even getting connected with a group, you will change. I just wanna say, have hope. It's gonna come. It may be a while, but it's gonna come. Just have hope. Just like our thing says: BEST brings hope [giggles].

CHERYL: Well, thank you.

### **Penny Condoll**

CHERYL: Penny, thank you so much for being on the podcast.

PENNY: I'm excited to be here.

CHERYL: There are other people on today's episode, as you know. I've been at BEST for three days now. And so we're wrapping up my three days of filming and podcasting, by talking to you.

PENNY: I think probably the way I'd like to introduce myself is maybe I could share why I came into TBI advocacy. I experienced a brain injury 11 years ago. During that time, I was a medical Social Worker. I did discharge planning and worked in hospitals, in several different hospital. And I really believed that I understood what people needed when they left the hospital. I was a good social worker. My brain injury changed my perception about that and made me understand that there's a lot more to conversations like, "You're not gonna be able to drive anymore" that deal with identity. And so as I was starting my recovery after my brain injury, recognized huge gaps in services, which included me being able to access the essential services that I needed, primarily because of my executive function and my initiation. So when we think about statistics for homelessness that include somewhere in the 80-90% of people have experienced a moderate to severe brain injury, when you look at people that are incarcerated and the numbers, I was absolutely hmmm--can't find the right word. But I was devastated to learn that that was what happened often after a brain injury. And so, out of that, I found a support group locally here in Tacoma. And I found other people who were having the same experience. And we recognized what we really needed was a network. We really needed a way for us to join together to help people from falling through these cracks. So that was what the initial drive was for me to be involved in advocating.

### **Experiences around brain injury rehab**

CHERYL: Did you do rehab after your brain injury?

PENNY: I did. Right after my brain injury, I would've sworn to you I needed no rehab. But at three months, I went to my first speech therapy visit. One of the very first evaluations that she did with me, I was forced to recognize that I had huge challenge finding words. Those were things I didn't even recognize was happening. I knew people were talking to me different. But I didn't recognize it was on me. So rehab was helpful in helping me to understand where some of those things that I didn't have the awareness for at that point. So that was very valuable to me.

CHERYL: What was your overall experience in rehab?

PENNY: If I was gonna be honest, I'd say I don't remember most of it. I truly started understanding how to live happily with this brain injury through my support groups. Through peer support I learned about things like cranial sacral therapy. I learned about things that were not being talked about: vestibular rehab. I had huge dizziness; couldn't even turn my head for the first four or five months without getting nauseously dizzy. And wasn't really until I found an online support group where I learned about vestibular rehab. That gave me the power to go back to my doctor and say, "Can we try this?" And he

said, "That's a great idea!" So what I started to understand was that when we take control and power of our recovery of our whatever--recovery is kind of a strange word in brain injury--but in our moving forward and making our lives as good as possible, that we become very empowered for all of our lives. And that should be around our medical care and should be around our relationships. It should be around our job that we're empowered that way.

CHERYL: Yeah. You mentioned that being part of the support group gave you some new ideas for different kinds of rehab to address some problems that your doctor wasn't already addressing. But then you said something about relationships and jobs. So did support groups stuff address things beyond rehab and medicine?

PENNY: Absolutely. You know, one of the reasons I feel so strongly about support groups is because you have the opportunity to understand what other people who have similar things. Every brain injury's different. We all approach this journey in a different way. And that's beautiful, and we should. But we do hear common themes. And I often, still, 11 years later, I hear conversations in our support groups and in our small groups up at BEST that I can imagine how I can institute that in my life and make it real and make it a difference for me right then. Because sometimes a challenge with brain injury is connecting all of those dots. And sometimes there's simple solutions that I haven't quite connected yet. I think peers give us this great opportunity to think about it in a different way.

CHERYL: Definitely. Yeah.

### **Peer feedback and support at BEST**

CHERYL: So we've hit on BEST just a tiny little bit. And you've talked about support groups. But BEST is actually not just a support group.

PENNY: We were really fortunate about a year and a half ago to find a space in University Place, Washington. We actually offer services around the state. But the BEST Space has been a wonderful place for us to be able to pull people together physically to work on projects, to work on outreach, to work on our educational things that we do, our classes. But also, to participate in social activities, which provides the perfect platform for a what a lot of us needed after our brain injury, and that's a safe environment to be able to push the limits and get feedback from peers. And so that is kind of what the BEST Space has become for us, is really this kinda staging ground for a movement.

CHERYL: Is the feedback peers give each other unique in some way or different from feedback you might get from a loved one or from a doctor or clinician?

PENNY: Absolutely. So I started going to support groups about seven or eight years ago. And I watch, almost on a daily basis, how profound it is when someone hasn't had the experience of being around someone with a brain injury, and they start to talk about things. And the person that you're talking to doesn't roll their eyes, doesn't look at you like you have an extra horn in your head. That in itself gives you this comfort to be honest. You know, talking about things about your brain, about mind, about your behaviors, that's scary for people. And so a lot of times, we carry those things around in our heads, which is also scary, right? So having that opportunity and understanding that other people may have had some similar experiences is really important. I think the other huge piece is 11 years ago, when I got out of the hospital, I spent probably three weeks searching the internet like crazy. I was desperate to understand what that thing they kept, I didn't remember my accident or the next month afterwards. But they told me that I'd had a brain injury. And I was really curious what this meant for me. It was really hard to find role models, to find people who were succeeding, to find a message that said this event

happened, and you still can have a beautiful life. In fact, my experience is I know several people who will say to you very clearly their life is better after their brain injury. I'm convinced that it can be. That's kind of what motivates me.

CHERYL: Yeah! You were still BEST before you had the space. Now you have the BEST Space. What was it like the first day you opened? Who was there?

PENNY: Oh, first day was so exciting! Let's see. I may not be able to give you exactly. So I apologize if I forget anyone. But in my memory, I'm profoundly remembering Tawnya Padilla and Gloria Kraegel and Karen Shepherd, who's our Stitching It Up coordinator, and Paul Bishop as we were moving furniture into the space. There was a moment where we all caught ourselves in the hallway, and we all had tears in our eyes because we knew that this was the next move on something really big. And we knew that it was created by us, not given. It was created by us. It felt so beautiful to understand that this was going to be our new staging ground.

CHERYL: The work and the services and the programs offered at BEST, do you call that rehabilitation? Or is that called something else?

PENNY: We don't call it rehabilitation. Rehabilitation has a different kind of context than what we're trying to create. Rehabilitation is a wonderful part of what we're trying to create. You and I kinda hit on a funny one yesterday.

CHERYL: I don't remember!

PENNY: Life after brain injury is often a dance. I use that because the rest of my life I'm gonna do a brain injury dance. And I'll move three steps forward, one back, two steps forward, three back. I think this is true for all humans. It's just that sometimes these additional challenges with the brain make those things even more difficult. So if I get really good strategies for those, I can do my dance better. So perhaps rehab is a different part. Maybe we are the dance specialist, and we're learning how to dance with this new brain injury. And that involves how we move, how we look, how we talk, yeah.

CHERYL: As soon as you started to say it, I remember it. And one thing that you said yesterday was--I don't remember how we got on the topic, but we were talking about rehab. And I think there is a lot of people with or without brain injury believe that kind of your job after a brain injury is to get better, better, better. Improve, improve, improve. Some people say you need to become who you were before and get back everything. Some people are into, OK, let's get good at who you are now. But rehab has so much effort put into fixing as many problems as it can.

PENNY: Absolutely.

CHERYL: And you talked about well, we don't offer rehab classes; we offer dance classes! And that image. The thing is, I do think that there are ways that some rehab can be done as more of a dance class where, instead of the clinician saying, "Well, Penny, this is what we're gonna work on today, and here's how we're gonna do it. I'm the instructor; you're the student." That instead of it being that dynamic, that if it's more of a dance where you say, "Wait. I'm gonna take the lead. You follow. We're still gonna dance together. We're even maybe even gonna do the same dance steps. But let me lead for a minute." And I can picture that partnership better when I think of a dance class than when I think of rehab, and I'm in the room with the speech therapist. And they've designed the plan for me. And I have to just follow the plan. Rarely do I hear people talk about such a beautiful thing as dancing.

PENNY: [giggles] Right.

### Learning about a focus on strengths

PENNY: I was thinking about Dr. Tim Feeney, who we've studied under [HeadStrong](#), which is another organization in Seattle uses his work. And we do too. He talks about that as we participate with people who've had a brain injury, that we really have to remain ever vigilant that it's in context of their lives. And so when we walk into a situation with our own expectations about what the context of their lives are, we've completely missed the fact that they don't have food in their house because they couldn't initiate going to get it. We may completely miss the big things because we're focused on this behavior. I found the Moving On Personal Futures Planning out of Mt. Sinai about seven or eight years ago and absolutely fell in love with the complete opposite way of thinking about how we move on. And that is that we create a support team around us, we really take a look at relationships and how we do better in those, and that we put focus on where our interests and strengths are: what we do great. Because if those are the things that we're doing on an everyday basis, then through neuroplasticity, those are the areas that are gonna be stronger. So not only will we be a better employee, but we'll have strategies to be able to perhaps be better than other employees that you have. And I think I'd shared with you the funny one about Kathy Moseller in Oregon, who's the creator of the [My Bionic Brain](#) gave me this beautiful image of: if I can get good at my strategies, I can present to an employer that I have a habit now of writing down every time you tell me a task. And I can probably assume that not every one of your employees do that. But you can be guaranteed I'm gonna do that. Now, isn't that powerful?

CHERYL: That's an asset. That is a huge asset in an employee, mmhmm.

PENNY: That's right. So if we can look at our strengths and say, "These are where my strengths are," then we can sell those either through creating our own businesses, doing out of the box kind of projects and things, or simply going maybe back to what we wanted to do, just in a different way.

CHERYL: Yeah. Now, you don't only serve--Serve isn't even the word because you guys, seriously, you call yourself a family. And after three or four days in this town, it is so clear you're a family. The BESTies are, you guys are BESTies. So it's hard for me to say, "Oh, well when you serve these people." In terms of the programs and the activities and the space that you have. We were just talking about work. But you don't only have people in your community who are headed back to work.

PENNY: Absolutely.

CHERYL: You have a lot of people in the BEST family who have more significant impairments. And they're not going to hold a paid job ever again.

PENNY: Absolutely. We really have to rethink about that language. Doing valuable things is really the most important. And sometimes that involves that people pay you for doing valuable things. Sometimes it involves that you're paid through that feeling that you get when you do something that's valuable. But rarely do you get that valuable feeling if you're doing something that doesn't mean anything to you. So we love that our BESTies are focusing on the things that move them. You met Jeff. Whether it's someone like Jeff who wants to--

CHERYL: Is that the one who made this bracelet?

PENNY: No, Jeff is the--

CHERYL: Oh, Jeff! Sorry.



PENNY: No, no, no worries. Greg made the bracelet. But Greg's a great example. So Greg has had Cerebral Palsy his whole life. And he is absolutely one of the most charming bracelet sellers and bracelet creators. I think you may have taken some pictures. But you can see on his body and his spirit that when he's doing things that feels valuable, he's not folding washcloths or being asked to do something that doesn't mean anything to him, doesn't have any value to him. But he made you a bracelet. The look on his face when he pointed to you and said, "Can I?" was priceless, you know? It's priceless to feel like we're doing something valuable. At BEST, we don't anticipate that we know what that is. And so, in Moving On, our coaches are highly encouraged to never start that you think where that journey is going to end. Just go along for the journey, offer the resources that you know, talk about the strategies that you've learned.

### Listening more than talking

CHERYL: Over the past three days, as I was filming some footage for the new BEST promo video, I did overhear meetings you were having. You were working on a Living Well program with a couple people and doing some Moving On stuff. And you know, I tried to not listen. I wasn't recording audio; just recording images. But I'm in the room. So I could hear. Something that became very clear immediately, the difference between the different kinds of rehab that I go and the way that you were interacting with people, it's in some ways indescribable. But in some ways it is describable. And one of the things is that you listen so much more than you talk. Now, you talk. And at certain parts in the program, you have a lot of things you have to say. But when you're listening, you are listening. And you don't come back at people with unsolicited advice, because there's judgment behind that. So when somebody said, "You know, I'm doing this thing kind of in this way that's not working," you didn't jump in. You gave that person the space and encouragement: "Well, do you wanna solve that? Do you wanna work on it? How about we brainstorm--with no judgment--brainstorm all the possible ideas?" And I think a lot of people, especially when you only have 50 minutes a week together, a lot of clinicians are kind of forced to jump in and just tell you, "Well, just do it this way. It'll be better."

PENNY: Mmhmm.

CHERYL: There's no ownership. You kinda feel stupid. Why didn't I think of that?

PENNY: Absolutely.

CHERYL: But you have the time and the space. And because you're a peer and an advocate and an activist and Chief Visionary, you make all the space and time that is needed for people to own it, free from any humiliation or embarrassment.

PENNY: Thank you. I'd love to share. One of the things--and this is funny, since you're doing a podcast--Barbara George, who is a support group facilitator in Hoquiam--we train support group facilitators. So every year, we do an all-day workshop. And at the last workshop we were doing it about boundaries. A majority of our facilitators have had a brain injury or care for someone who has a brain injury in the state. And in Barb's group, they use a term, "This is a should-free zone." They make sure not to should on each other. She gave the explanation of why this group wanted to be a should-free zone because we get should on a lot. Right? And that's kinda what you were talking about is the should on me. So we've kind of turned it into this funny about, I don't wanna get should on. I think one of the reasons this is so significant for us, as I do my daily life, I know the challenges that I have. And having them called out, even through a, "You should do that" gives me that extra red marker flag I've done another bad thing. I am a mess. I'm a big pile of I should haves. Cuz I've got those for myself. And so when those are added. Another way, instead of shoulding on someone is to share what worked for you. So in our support

groups, we say we're a should-free zone, but we'd love to hear what worked for you. So it kinda changes the conversation, right?

CHERYL: Yeah.

PENNY: And it doesn't make us feel like we've done something bad.

CHERYL: Mmhmm. One of the other things I observed happening was somebody said, "Oh, I'm having trouble doing such and such." And you waited for that person to then say why. And that made all the difference. When that person explained why they're having trouble doing that thing, it's a whole new world. That person brought up something that I bring up a lot, and I've done trainings with speech therapists. And I do a little aside on here's why you might consider erasing the word "non-compliant" from your vocabulary. Sometimes, even though your treatment plan is really even perfect, it's great, it's perfect, it's well thought-out, it's research-based, maybe we don't like it. Maybe we don't like the activities. Or in the case of the person who I heard the other day, doing that activity just reminds them that oh, I'm not in the place where I wanna be. And so I don't wanna do it because it just reminds me I'm not. And so that can't be solved by, "Well, write it down and just do it. Just do it."

PENNY: Put it in your calendar!

CHERYL: Yeah. This person is saying, "It is kinda in my calendar. But I just don't like that I have to." So there's the one side of I got this rehab exercise, and I don't like it. And it doesn't relate to my identity. And so I don't wanna do it. And so we get called "non-compliant." But what this person brought up was this other, much deeper level of it hurts my soul to have to stop what I'm doing and be reminded that my life changed. And I don't like this aspect. This person seems to like their life just fine,

PENNY: Absolutely, sure.

CHERYL: and has a very happy family. If you only focus on the behavior and making people more compliant, you're leaving out this very precious, deep issue that they need to get out on the table. As a group of peers with a structure in mind, you're able to let people bring that stuff up, and it's OK to hate being reminded that this is hard.

PENNY: Mmhmm. I don't think that it's me. I really, that communication happens all the way around. I truly do believe that we are doing something very special and that we are creating a different way, as humans, to interact with each other and to understand each other.

### **Disability as an experience and approaching people more compassionately**

PENNY: And perhaps this brain injury was an opening for us to think about the way we approach people differently. After my brain injury--and I'm sad to even have this recorded--I can remember times in my life when I have looked down on people or made fun of them. And I am currently in same situation, perhaps worse. And I see it very differently.

CHERYL: You hit on something. I can say that having disabilities put me, also, in that well, allowed me to be in that position too, of examining ableism, which is what you're talking about.

PENNY: Yeah.

CHERYL: Our society has to label people with disabilities as having disabilities. We just have to have that label. And we have chosen, collectively as a society, to equate that with inferior and I don't care if that

activity's valuable to you; you can't make any money. Therefore, it's not valuable to society. Not all cultures are like that. It's not a universal given that if you have an impairment--temporary or permanent--that you lose your humanity and your value in your community. But that is a broader U.S. value.

PENNY: Right.

CHERYL: I first came into the disability community, actually, as a non-disabled person participating in mixed abilities art. That was really fortunate for me to be able to come into this disability culture space that had no service provision. Nope. We're making art. So I was very fortunate to get into that world so that later, when I have acquired actually other disabilities besides the brain injury--but as I acquired disabilities, I didn't have to question my humanity. I didn't have to feel inferior. And I see the disability arts and disability justice scenes providing that space. But I don't see that very often in the brain injury community.

PENNY: Right.

CHERYL: Brain injury's very medical: injury...fix it. But BEST is doing that. You have a culture, and you have a way of speaking to one another and interacting with one another.

PENNY: In our lives, that's what's gotta be created. We have to be able to create that. We recognize the consequences of not having the support. We know that there are huge numbers of people who don't have these networks and don't have the ability to reach that. And it almost makes me sad knowing that this is gonna go out on the airwaves for people to listen to. And if you're in some small town in Arkansas, you may not have this type of. And I just remember being desperate for it. I remember really needing to know someone else who's experienced this.

CHERYL: Yeah.

PENNY: So we offer things online. So I encourage you to check out the [BrainEnergySupportTeam.org](https://www.brainenergysupportteam.org). We're working on online classes, and we do webinars. If you don't have local resources that provide you that kind of support, people like Craig Sicilia and [TBISN](#) and the [Brain Injury Radio](#), amazing ways to start to hear these messages. I was standing with Desiree Douglas, who is the founder of HeadStrong, at the TBI conference. We were standing together and thinking about how far we've come in the last eight years and what a different world brain injury is in Washington State. The family that has been created all the way across the state is incredible. And that really has been built on peers connecting with peers and helping people not fall through the cracks.

### Wrap-up

CHERYL: I just wanna wrap up by saying Penny, that it is my huge privilege and honor to not only get to--I met so many people in the BEST family--I got to stay at your house and be fed and treated like family. And the film screening that you let me have last night where some community members, the--It's not Upper Peninsula. Where are you? University Place! The University Place Mayor came to the screening. I can't even express how important that is for an elected leader at a high level to come to a community event around disability and care.

PENNY: Right.

CHERYL: There were a bunch of people there I hadn't seen before at the BEST space. And that felt really good. And I just feel so flattered and so honored. I wish that University Place and Portland were

connected. I look forward to connecting with BEST much more and to a partnership that we're gonna form around the documentary film. Thank you so much for all your generosity and for letting me see what this beautiful family is and this culture that you're creating.

PENNY: It was wonderful to have you. It's wonderful to have you as part of our family. And that was what was beautiful for me is watching you there as a professional, as you're recording, as you're putting your stuff together, and you just owning it. Those are the messages that we want to see. And so, welcome to our family. I'm glad you're here [laughs].

CHERYL: Thank you so much!

[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](http://WhoAmItoStopIt.com).

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