

Interview on Life Threatening Illness and Injury with Barbara, a survivor

0:01 **Elyse:** Hello. My name is Elyse and I'd like to welcome you back to Rising from the Ashes: Trauma Talks, a podcast series brought to you by UB School of Social Work, The Institute on Trauma and Trauma-Informed Care. This series provides an opportunity for individuals to share their witness of how strength and resiliency has allowed them to rise from the ashes. Trauma Talks follows people who have both worked within the field of trauma as well as those who have experienced trauma. Here we will reflect on how Trauma-Informed Care can assist those who have experienced traumatic events to embrace a new life of wholeness, hope, strength, courage, safety, trust, choice, collaboration, and empowerment. Today, I'm here with Barbara. Barbara is a survivor of a traumatic brain injury. On behalf of the Institute we'd like to thank you for being here today and sharing your story with us. I'm going to let Barbara begin by sharing her story that has allowed her to rise above the event to becoming a strong, more confident person.

1:02 **Barbara:** Hi everyone. My name is Barbara and I was in a series of multiple accidents in 2008 where I got concussions in each one of them. The combination of concussions led to me having something called post-concussion syndrome, however at the time of the concussions it wasn't known that I had this yet. Essentially, I was in an accident in January 2008, a car accident, and I went back to school for the rest of the semester and seemed to perform ok. In July of that year I was in a wakeboarding accident and I caught and edge off my wake board and hit my head really hard on the water. I didn't really realize at the time how severe it was, I thought that I just should get off the water for the rest of the day and take it easy, which I did, however a couple of days later, I began to experience a little bit of sensory problems and things I had never really noticed before. So for example, lights at night were really bright and sounds got really loud for me and it was kind of hard to focus on what was going on. I went back to work the following Monday, the accident happened on a Saturday, and I had a really rough day at work. I was a camp counselor at the time and I couldn't seem to keep my kids in order and everything was really frustrating and I ended up crying that day. I never really cried when I worked with the kids and it was just really out of character for me. That evening, it was actually my birthday that day, and that evening I went to a John Mayer concert at night and I remember going to the concert and feeling really engrossed in the music and it was really—I felt like I was almost high. I wasn't, but I felt like I was. This was all just really strange, but I hadn't linked any of this back yet to what had originally happened to me. I just, you know, it had been a busy weekend, I didn't have tons of sleep and so I didn't really have an explanation for this. But the days went by, I had to take the next day off of work and I was really worried about taking this day off work because I thought that everyone would judge me for not coming to work because they all knew I was out the night before. I had never been worried about what other people thought about me before, it was just that everything was out of character. So the first really odd thing that happened was my dad called me that day and asked me how I was doing because he usually calls if I'm home sick for the day and he asked me if I'd eaten anything and I said, "Yeah. Yeah, you brought me grapes upstairs earlier. Don't you remember?" and he said, "No, I'm still at work." So I had thought that he had brought me a snack and I didn't realize that I had gone and gotten the snack myself and bought it upstairs to my room. So this was the first really weird thing that happened and it just progressively got worse over the next week and a half, essentially. I got into a down spin and I had more hallucinations and delusions. It got so severe that I thought that, my boyfriend at the time, I thought that his dad was a helicopter pilot and he was coming to

ethanize me. So it got really extreme, really quickly. Obviously—my mom's a family physician—and she knew that something was extremely wrong with me. They tried to take me to emerg [the emergency department] four times and this was during the day; they tried to get me admitted. At this point my mom was kind of getting an idea that it might have been from me hitting my head on the water because I told her that I felt kind of like I had after my first concussion. But they tried to take me to the doctor, to emerg, during the day. So I remember on one of the trips and I was in emerg and the physician asked me what year it was and I told him it was 2108 and I was certain it was 2108, but I didn't understand why I hadn't aged and why my parents were still there. So it was just all of these really weird things, but he said, "You just have a concussion, so you should go home." So I did. Then it all got worse at night. I thought that my dog was a robot. I thought all of these really, really weird things and it always got way worse at night. I wouldn't sleep. I would keep my whole family up at night. My boyfriend had moved in with us to help take care of me at that point. So they took me to emerg, the last time they took me to emerg, it was in the middle of the night and they saw how bad it really was. They originally thought that I might have had encephalitis. They did all the testing for that and saw that I didn't have it and so my parents had gone home, because they really needed rest and it was the middle of the night and I was alone by myself, I think in a bed, maybe even triage. At this point I was drugged, but I also remember a lot of it. So this was the scariest time for me was when my parents were gone and I thought that the nurse, who I was alone in the room with, was trying to rape me with a tampon. I just vividly remember this and I remember how scared I was without them there. It was hard. They called my parents and they came back eventually and then I was sedated for the next two weeks, which I don't remember at all—I don't remember any events from the next two weeks—and at that point I was admitted to the psychiatric ward of the hospital. So at this point, they obviously are trying to diagnose me, they want to figure out what is going on, they wanted to medicate me, they wanted to put me on anti-psychotics. The physician, my primary physician, was convinced that I had bi-polar disorder, however my mom was adamant that I did not have bi-polar. So, it was really rough time for my family. My parents had to stop working. I couldn't be left alone, as I mentioned earlier, it was really stressful for me. So, my parents had to take 24-hour shifts, 24-hours on at the hospital with me, 24-hours off at home, so they would rotate. And so while I was in the hospital I was still suffering severe hallucinations and delusions, so for example I thought that all my loved ones were being shot in the room beside me when all the doors were slamming because I thought those were gun shots. I thought that my body was made of sand and that I was melting when I had a shower. My mattress was made of foam; I thought that when I was lying down on my mattress that the underworld was coming up and grabbing at me. And I was really obsessed with death; I was really hung up on death and dying. And it got so bad that I didn't recognize who my dad was. I thought he was someone else that I knew. So this obviously was really hard for my family. They really supported me through it. My mom had a hard time with the physicians at the hospital because she thought that I didn't have bi-polar and they thought that I did and she was really battling with them to not put me on these medications. They wanted to put me on stuff like Valium, which is used for severe bi-polar, but I was on a lot of different anti-psychotics and they helped, but they really changed me. And at this point I'm remembering more and more and my friends would start to come visit me and they would see me and they would be as supportive as they could, but I wasn't myself, obviously, and I heard stories later on after I had recovered that they would get into the elevator on the way down and would burst into tears because I just wasn't who they knew me to be and it was really hard for all of them. So eventually, after a lot of

arguing, problems with the doctors, my mom knows a geriatric psychiatrist who works in the area and he ended up coming in and he spent about a half an hour with me and after that he thought he recognized the symptoms of post-concussion syndrome. So, my mom went home and she researched it and, because she had been spending her 24-hours off researching, trying to figure out what was wrong with me. And so she did some research on it and she thought that my symptoms really looked like post-concussion syndrome, however, there's not a lot of literature on it. This was 2008 and concussions hadn't been studied that much, they were just starting to get studied and now even 7 years later it's becoming a field that people are more interested in and awareness is being raised, but even then there wasn't tons of research. It essentially just took time for my healing process. I was medicated on the anti-psychotics, like I mentioned, I was put on some drugs that they use for epilepsy to kind of control my brain waves as well. And I was hospitalized for almost two months and I was slowly, slowly, slowly coming out of it and it wasn't because of anything in particular. There was no one drug that they put me on that made me better. I think it was really just time and support from my family and friends. So I was slowly allowed to leave the hospital, sometimes for the day and then I would get my first night pass and then I was eventually discharged at the end of the summer. So, that year I still thought I was able to start university, but my mom knew better and—because I was supposed to start university that fall—and she had differed for me, she had to do the deferral. So I spent the next few months at a lot of different doctors appointments, I also had a severe whiplash injury in the wakeboarding accident, so I needed physio [physical therapy] for my neck and back. I couldn't move my head left or right, I had to move my shoulders to look any directions and I hadn't been using my muscles and you'd be amazed at how quickly you lose your muscle strength. When I got discharged from the hospital, I couldn't even lift up a bag of groceries or—I had some friends over for lunch and I couldn't even left the kettle to make them tea. That was hard in and of itself, just the physical problems. Interestingly enough, I came out of the hallucinations and delusions just as slowly as I went into them, so it started with a lot of sensory enhancements, almost and it ended with the sensory enhancements. To this day, loud noises bother me, going to the movies can be really loud for me and I don't like it sometimes or like taste is really strong still. During my recovery, I really sure to take care of myself, so I got a personal trainer and I went to the gym, I enrolled back into high school even though I had already graduated because I wanted to make sure that my brain still worked—luckily it did, I was able to still learn—and I also got a job as a tutor tutoring children. So I really made sure to exercise my brain and my body to heal properly. And now here we are in 2015 and I am in law school after having done my undergraduate degree successfully. So, I've been really, really lucky to have been able to heal to that extent. My parents weren't sure when I was hospitalized that summer if I was ever going to get better. So, yeah, that's pretty much it.

11:58 **Elyse:** That's incredible that you're now where you are. And what I heard you talk about was really support and time in your recovery was what stands out to you as the things that were pulling you through, and collaboration amongst your service providers, family and rebuilding that sense of self or safety around you in that process.

12:24 **Barbara:** Yeah, definitely.

12:25 **Elyse:** Yeah. So, those are all what makes up trauma informed care and what trauma-informed care does is ask individuals and service providers to stop asking what is wrong with a

person and move toward asking what has happened to the person. So, Fallot and Harris talk a lot about the five guiding principles of trauma-informed care where safety, trust, choice, collaboration, and empowerment are tools that service providers can use to create a more trauma-informed environment for consumers. So I want to kind of talk a little bit about your experience accessing services at the hospital, for example. I guess my first question is when you started to regain that awareness cognitively, how did you help to regain a sense of safety, both physical and emotional, what was going on?

13:21 **Barbara:** That's a really interesting question actually, because we had a few different ways to do that. So obviously the number one sense of safety for me was my parents, as I mentioned I really, really needed them, I needed someone familiar with me at the hospital, I was scared to be alone. Another way I regained my safety, sense of safety, was through a thoughts journal. And this was recommended by someone who worked at the hospital. It was definitely helpful for kind of realizing why my psychotic thoughts weren't real, so as I mentioned, I was really scared, I thought that my loved ones were being shot beside me and so it was, we called it a thought journal. On the top you would write what the thought was, so "I think that this person is getting shot in the room beside me." And then the next question is "Is this logical? Yes or no?", so then I would have to say, "no." And then you would say, "Please explain why." And so I'd have to write down why this thought was illogical and that really helped with the sense of trying to feel safe and trying to help me work through my thoughts and I feel like this is something who a lot of elderly people who are maybe getting dementia have to deal with as well. It's like you know that what you are experiencing isn't real, but it feels so real and it's this really weird struggle within yourself that you have to get over. So that really helped. One more thing that really helped was we have, my friends would come over and they would, we could do art together and we would put it up on my walls in the room, even just signs that said, "I am safe." I had a sign that said, "I am safe" and it said—I was really, really worried about my loved ones and where they were, so I had a list of all my loved ones that says "Where is this person," "Where is this person," "Where is Mom," "Where is Dad" and then right beside it I would have where they were. So if I was ever worried about where they were or anything, I could always just look at my sign and I would know. So that helped me feel safe and helped me ensure that they were safe and know that they were safe, too. So I think a combination of all those things really helped.

15:25 **Elyse:** Right. And so, when you were writing in your thoughts journal, were you sharing that or was it being shared with the doctors or nurses that were coming in so that they had an idea of what might negatively impact your sense of safety and that they could try to avoid that?

15:44 **Barbara:** I'm not sure if it was shared with them to be completely honest, I would imagine that they would have had a good idea of what was impacting my sense of safety. The problem was that most of it wasn't grounded in reality so it's hard, you can't control the doors slamming, you can't control—I needed to shower—you can't control the fact that I was scared to.

16:10 **Elyse:** Right.

16:11 **Barbara:** Obviously it is helpful when the physicians and the nurses and the PSWs [personal support worker] that you're working with are understanding of what is going on with you and where you're coming from, because everyone is different.

16:23 **Elyse:** Right. And so, often with safety, trust intersects in terms of you need to be building trust around you to start to feel comfortable. So how did that look in terms of did you trust the people that were providing services to you and how did that progression look like?

16:45 **Barbara:** I wasn't in a particular position of trust, per se. I was really just focused on people that I knew. I know that for my parents who were really my messenger, trust was hard for them because of the conflicts that occurred with my medications and with the doctor arguing what my diagnosis was. The doctor left for vacation and was convinced that two weeks later after being on this bi-polar medication that I would be better and I would have been discharged and she was absolutely shocked when she got back from her vacation and I was still in the ward. So, that was definitely difficult, however we did build good relationships with some of the caregivers that were there with me more often, so the PSWs and the nurses and some of the nursing students. I know that my parents became very close with them, they got to know them, which I think was really nice because they were at the hospital a lot. They were there for 24-hour periods for almost two months, so they got to know them and I think that building the personal relationships with the staff was actually really nice for them. They got to know one of my nurses and they got to know about what her brother was doing and they could ask her about what he was up to and just that kind of thing, it was kind of nice for them.

18:00 **Elyse:** So, I also hear you talking about collaboration and, in terms of the doctors, collaborating with your family, each other, maybe other service providers. Do you know exactly what was going on or were there any meetings that they had to talk about your care or was it very disjointed?

18:18 **Barbara:** I think that they had meetings and I wasn't present for a lot of them because I wasn't in a state to give input.

18:27 **Elyse:** Right.

18:28 **Barbara:** My mom would observe how I was doing and report that to them, I think. So, in terms of collaborating, yeah, they would have had meetings. I'm not sure how frequent they were or anything like that, though.

18:41 **Elyse:** So, would you say that collaboration among them kind of helped push you toward recovery eventually?

18:49 **Barbara:** Yeah. I think definitely the collaboration and the communication was important because it really—the physicians didn't want to give my mom the reigns, pretty much. But once they realized where she was coming from was actually grounded and there was research to back it up and they really did listen to her. However, this would be very difficult for someone who—I was lucky that I was being essentially cared for by my mom who is a doctor. She is able to—she had the resources—to go do these literature searches and stuff. I consider myself really lucky

from that point of view, so I can see how that would be frustrating for someone in the same situation who didn't have that kind of resource.

19:34 **Elyse:** Right. Here's kind of a different question. If you were the service provider, would you have done anything differently or would you suggest anything different to enhance your treatment?

19:47 **Barbara:** I think that the physician, my primary physician, could have been more open minded and could have been open to other ideas that weren't necessarily her own. Because it's hard when someone else is telling you how to do your job, obviously, but it's really important to be able to be open to those ideas that you think maybe are not right and if, maybe they won't end up being right, but if you have reasons to back it up then that's fine. So that's something that I would probably do if I were the care provider, just remain more open minded.

20:25 **Elyse:** And now are you still accessing services now or did you periodically after your stay at the hospital?

20:32 **Barbara:** Yeah. Like I mentioned, I did physio, which didn't have to do with any of the psych problems, obviously. And so I did some physio while I was still a patient and I also did outpatient physio. I also saw a neurologist a few times and I had some neuro-psych testing done as well a few months after I was discharged just to check on how my brain was in comparison to the average person.

20:58 **Elyse:** Was there any one thing or maybe it was multiple things that a service provider said or did for you that you found particularly empowering?

21:09 **Barbara:** We had an activity coordinator on the ward who organized extra-curriculars like arts and crafts that those kind of things for us for all the patients to work together on. So I remember this way was really important for me actually, it was towards the end of my stay, and I have a favorite cookie recipe that I like to make. So we brought the recipe in and the women who organized the recreational area of the floor, she made sure that she had all the ingredients, so all the patients and I worked together and we made these cookies and we distributed them to all the other patients on the floor and that was a really great and memorable experience for me while I was hospitalized. It showed that they were willing to listen to what I wanted to do. It was a really personal touch, catering the activity to me and being able to do something that I could do while I was at home. It was something I loved to do at home, I loved baking, it was able to bring it to the hospital for me and I thought that was really great of them and it was also really nice being able to share what we had made with all of the other patients on the floor. I remember them all thinking that these cookies were such big treats because a lot of them were pretty sick of hospital food by the end of their stays. Yeah, that was something that I found was empowering. It made me feel more like my old self than I had in a really long time.

22:39 **Elyse:** And so, it sounds like a community and the small things, the personal touches, made a huge impact.

22:47 **Barbara:** Definitely. It's something that I still remember and it was really nice day, so yeah the community building was important for me.

22:56 **Elyse:** Right. And do you still bake now?

22:59 **Barbara:** Yes, I do. I love baking.

23:01 **Elyse:** That's great! So that segues to my next question talking about today, how important to you is self-care and is there anything that really helps you at times when you're having a tougher day, whatever that means to you now?

23:18 **Barbara:** Yeah, so, we don't appreciate what we have, especially, you don't know what you have until it's gone. It's a big huge cliché, we don't realize how important our brains are. We don't realize how lucky we are that we can think properly. That we can watch a movie or listen to this podcast and follow what is happening in it and not be worried about any people that are coming out of the sky to come and get you, you know what I mean. So, taking care of your brain is really important and I take care of my body as well now. I have found since my head injury that I need a lot more sleep than I did before and this is still true to this day. I need to sleep at least 8 hours. I know you're supposed to anyway, but a lot of us don't. But I really need that sleep. So I need to make sure that I wind my brain down at the end of the day. I turn my screens off a half an hour before bed, I'll read a book, that kind of thing. I also have recently found that yoga and meditation are really helpful way to calm your brain down a little bit. Because sometimes we can get really caught up in our day-to-day activities and are go, go, go, bustle, bustle, bustle, but taking that hour for myself, hour and a bit for myself, everyone once in a while I find really, really helps me calm down and chill out. I know that's something that a lot of us don't take time to do, but just taking care of yourself is really important; and exercising your brain. I love learning still, I keep my brain active and I think that's really important to do and I did that during my recovery as well, so. Even simple things, like doing Sudoku or crosswords or stuff like that.

25:00 **Elyse:** Thanks for sharing that. So, just to finish and cap things off, is there anything that you would want to share to service providers or maybe a survivor of a TBI that might listening to this podcast?

25:15 **Barbara:** Sure, I'll share something for survivors of a TBI. Just take care of yourself, take the time that you need. Everyone is different. I have never heard of anyone with the exact same experience that I had. I've met other people with a similar set of facts, but a completely different outcome. So be as personalized as you can with your care and take the time that you need to fully recover before you jump back into life because nothing is more important than your health.

25:50 **Elyse:** Great. On behalf of the Institute on Trauma and Trauma-Informed Care, I just want to thank you again for being here today and sharing your story of rising from the ashes. We really appreciate it.

26:00 **Barbara:** Thank you.