

Stories from the brainreels Transcript

February 28, 2017

Introduction

[music]

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

Today I've got two stories for you, and they might be a little different from the stories you come to expect in gearing up for National Brain Injury Awareness Month in March. But you are listening to my show after all. First up, me. Second up, Joan Miller. Enjoy.

Music by Blue.sessions and David Szesztay.

Concussions are not a weapon

[slow, pensive music]

I'm gonna ask you to picture something. Picture something in your mind. You can start big like a place you went one time or some people you know. Or go small like the raised crack in the sidewalk you avoid because you don't wanna trip. Or the color of your own eyes in the mirror. Doesn't matter. Just pick anything and see it.

Now unsee it. Can you do that? Can you imagine a specific person or place you've been before with all the memories you have and remember it but not see it?

I don't usually talk about my disabilities in detail, just that I have some. And I rarely ever tell anyone how I got hurt. I'm more interested in talking about the ways that people erase me by telling me I don't have disabilities. Or the ways people armchair diagnose politicians as having too many concussions as a way to discredit them.

Hillary got it on the campaign trail so much, people saying she couldn't possibly be a reliable president because she's so brain-damaged. Now Trump and his supporters are getting armchair diagnosed by famous people and some of my own friends that clearly, obviously, duh, too many concussions explains it all. What is this desire to take worldviews and perspectives and practices and policies, and if you don't like them, just say the person who thought of them must be brain-damaged?

I wish that people would stop describing disagreements as, "I'm correct, and that person had too many concussions." Concussion is not the opposite of correct. Brain-damaged is not the opposite of thoughtful. If you disagree, then you disagree. Concussions are not a weapon to argue that people are incapable when what you mean is that you don't support their ideas or their practices.

You want to know what it's like to have too many concussions? I can tell you. Picture that place or that someone I mentioned a minute ago. Now try again to unsee it. Completely. Go into the depths of your memories and have nothing come up in your mind's eye.

When you hit the back of your head so hard that your brand new helmet splits all the way through and the circle of EMTs and firemen hovering over you pass it around to admire it. The ER doctor asks you to mount it on your wall as a reminder of how you escaped death. You mail it to the manufacturer with a story of what happened, and they send you a \$20 gift card toward the purchase of a new one. The new one arrives, and it's the exact same pattern. You chose the same pattern so that if you ever rode your bike again, you would have pleasant associations with that helmet. Gold-accented pink flowers on a white background. Or something like that. Can't remember. I replaced it again last year for good measure.

When you hit the back of your head like that, your mind's eye can go blank.

[distorted, awkward waltz]

I could walk out my front door and have no idea where I was because there were no recognizable landmarks. I had only lived in that house for four years at the time.

[bus roars past] I could get on the #6 bus, because that was my bus, and then get off somewhere that looked familiar but was nowhere near my destination. Because I could no longer picture in my mind what my stop looked like even though I could tell you the names of the cross streets. I would panic because I had no clue where any bus would take me. Because I could not picture the route in my mind. #9 Powell goes down Powell. #9 Powell goes down Powell. Then what? What about in the other direction? Does it even go in another direction? And so I would cry and wander downtown until I found a #6 stop or maybe a #4 or #44. I knew that when the automated bus voice said "Cook Street," I could get off the #4 and walk straight until I saw the name of my cross street. I knew to turn right. I read the street signs but did not recognize the houses. Because you know, I'd only been there four years at the time.

And by the time I'd been living in that house for five years, I could write down my bus route in a day planner. I could look out a window, then walk outside and find the window and look back in. And even recognize that that's where I just was.

After hitting the back of my head again a year later and having a period of the most vivid hallucinations and then a few years of sparkling lights and imaginary car headlights flashing at me, things mostly work OK now. And that, my friends, is the reality of too many concussions.

March is National Brain Injury Awareness Month. Events are often centered around stories of wrecks and rehabilitation. Lots of anatomy and physiology lessons. Raising money for causes. Bringing hope and inspiration to survivors through their storytelling. Hooking new survivors and families in to resources and information and each other.

[slow, pensive music]

If I could ask you for anything this month, dear podcast listeners and readers, it would be to take a pause and a breath before you use concussion as a tool to discredit people. If you have a working mind's eye, imagine me or someone you know who really does have too many concussions. Imagine us sitting there with you as you type into a Facebook comment or rattle off a joke in person. Picture us there as you are about to use our lived experience as a joke. You are using my pain as your joke when you do that, and you don't have to do that if you speak your truth. Instead of giving in to the temptation of assigning someone a disability they don't have as your way of discrediting them, speak your own truth. That will give us people who do have too many concussions more room to speak ours. And then you will know for sure what it looks like to have too many concussions.

For more stories about having too many concussions, please check out teenageconcussion.wordpress.com and Julie Norris's site, which is no longer active but still has lots of posts about concussion in women and girls: herconcussion.com. Also, there's theconcussionblog.com and theinvisibleinjury.net. Most places that collect personal narrative on brain injury—and there are many—include concussion stories for you to read and contribute your own.

Part 2

Now we turn to my dear friend and mentor, Joan Miller, and her story for National Brain Injury Awareness Month. Joan mentions starting a support group in her story, and it was at that group that I first met her and started following her around like a lost puppy dog. I met her, Marih Alyn-Claire, and

so many people with self-advocacy and determination coursing through their veins, ready to take on the world. Mariah is the one who taught me that relearning how to cook requires breaking down the task into manageable steps, and she wrote out those steps for me. And this Spring, Joan will be coming to my house to teach me crock pot cooking. It's the ultimate for saving time, saving energy, and making sure there's something amazing to eat. Meaning it won't taste like I made it if she shows me right. I dedicate this whole episode to the women in brain injury community who are more than friends, more than mentors, more than anything in the world.

I live with my injury; I am not my injury

[peaceful music]

Hello! My name is Joan Miller, and I have been living the past 17 years with a traumatic brain injury that was the result of a hit-and-run drunk driver, and I was almost killed. I really do believe that the day I almost died, my life was restarted again. I chose to forgive the driver as soon as I was coherent enough that I even knew my name. From then, I just kept moving on. I started a support group, which was fabulous to bring everybody together that had injuries: brain injuries or a disability of some sort, that we could all learn from one another instead of being sad and being alone. We were all together as a group, and cohesively, we just mended.

I live with my injury; I'm not my injury. I will not let brain injury define who I am.

I speak throughout the city in different Victims Impact Panels that are through Clackamas County and Multnomah County, and here we address people that have been arrested for impaired driving, and it's part of their diversion to attend this panel. That's been a really healing thing for me and a healing thing for other people too because it's a mistake. Most times people have made the mistake, and they're drinking and driving. It's a choice, and it's a bad choice. But they honestly don't set out in the morning saying, "I'm gonna see what I can do wrong and screw up somebody's life." So if I can help change that thought processing for them, by all means, that's what I wanna do. I love going into the schools and talking to the kids about choice. The choices that you make are paramount for the way that you live your life. The choices of the color of socks you put on in the morning don't matter, but the choices that you make throughout your day might matter, and especially when it comes to something that you're gonna put in your body or do behind the wheel.

I've joined Toastmasters, and I love speaking to people on all different venues about whatever I feel like. And again, the community of people that are supportive in moving people forward in any direction they choose to go, it's that support and the, "Keep it up! Keep it up," push people along. And everybody goes through a slump. That's natural; that's life, you know? But if we can have someone that we can put our arm around or that can put their arm around us and say, "Keep going. Keep going," I like to be that person that someone can grab. And I also like to be able to find the person that will help me out of my whole. 'Cause we all fall into those holes, and I'm not gonna keep digging the whole deeper. I want someone to put their arm down, as I will put my arm down, and pull me out and me pull them out.

[upbeat ukulele]

I've said many times when people are going through rehab of any kind, whether it be physical, mental, anything in any way, shape, or form, there's a light at the end of your tunnel, and it's not a train. It's me holding a flashlight showing, you, "This is the end. And then we start living."

I don't wanna go to anybody's pity party, man. I do not have a gift for a pity party. But I'll tell you what: I have all kinds of gifts for anybody that wants to move forward, and that's just two ears to listen, one mouth to talk. I try to use them in that order. It doesn't work all the time, but you know, what the heck? But I'll always have ears to listen, and I'll always use my mouth for support. It's far too easy to be condescending, to devalue people. People get hung up on that, and I find that with that same amount of energy, you can change someone's life. And it's so easy to do you. You can start by smiling at a person. You have no idea the power behind a smile. It can change someone's day and maybe move into the week, the month, who knows? Who knows? But if you're genuine, say something nice to a person. Don't do anything fake. Be genuine. Be who you are, and respect the person that you're talking with. And the world will be a much better place. It's gotta be from your heart.

My biography, [Learning to Make Toast](#), is soon to be published. It's by Kelly Sharp. She's in the final editing process, and it should be published in March of 2017. It will be available on Amazon. She came to me. I never asked, went out looking for someone to write my biography, my story. It's not just about me having a brain injury and then making my way through. It brings my list of bad choices that...you'll have to read the book, and you'll find that kind of stuff out. She was gonna be writing a 500-word story for a magazine, and after she interviewed me, she said, "Oh my goodness. This is my first book." So that's very cool. I'm her first book. Kelly's been writing for

years, and she's a published writer, but she's not a published author. Oh, well, she will be in March. If the words from the book can change or help someone's life, then by all means.

I know my parameters and still learn my parameters, and those are the only things that will stop me when it comes to my health or safety. But the injury? Nah. It's just there. It just hangs around. [chuckles] In fact, it's kinda fun sometimes! I surprise myself at some of the silly stuff I do. And it's like, "All right! I've got some great material. I can crack some good jokes and tell some funny stories. It's life!" For example, maybe a few of you know this, but yet a lot more don't: The lever you use to flush the toilet is located on the toilet. It's not on the wall. That's the light switch.

Oooooooh! I get it! Turn the TV on first, then look for the channel. I'm bound and determined to figure this technology out. But right now, I'm thinking it's nap time.

Here's something very sweet. Out of the mouths of babes: Blessed little girl in Joanne's Fabrics who was so excited she got to pick out the fabric and was gonna be making pillows with her mom. As they were leaving, I said, "Have fun with your mom!" She looked at me and said, "You have fun with your mom too." Well, I lost my mom two years ago. My heart melted. But I remembered as a little girl, all the hours my mom and I would spend in the fabric store, picking out fabric then sewing in the basement. Beautiful day. That was a beautiful day.

You know, I wish they'd make this stuff easier. Your phone goes in the charger; your glasses go on your face. Not the other way around.

[peaceful music]

These fun things that've happened to me are really all true, and I put them on my blog on my website at JoanWins.com. J-o-a-n as in Nancy, w-i-n as in Nancy again, s as in Sam. Nancy and Sam. They're buddies. JoanWins.com. Click on "blog," and you'll head right to them. My speaking engagements are listed there too. There's a calendar of everything I've got going on, and just life in general, how life is so good. It is so blessed. I've been blessed with great friends and a wonderful, supportive family, and a husband that is my absolute rock.

What I've gone through is nothing compared to what so many other people have gone through or will go through. This is part of who I am now. My brain injury is what I live with, but again, it won't define me, and it won't stop me. It absolutely will not stop me.

Wrap-up

[music]

Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture and transcripts of all podcast episodes at WhoAmIToStopIt.com.