

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

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- ANNOUNCER: 00:00 Look Closer. My Brain Injury is Invisible. Presented by Stacia Bissell on Tuesday, August 20th, 2024. This presentation is sponsored by the Northern New Jersey Traumatic Brain Injury System and Kessler Foundation.
- JEAN LENGENFELDER: 00:17 Good afternoon, everyone. Welcome to our quarterly virtual speaker series, Summer Brainstorm. This series is sponsored by Kessler Foundation as part of our TBI Model System grant, which is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. It's now my pleasure to introduce Stacia Bissell, who will be presenting today, Look Closer. My Brain Injury is Invisible. Stacia is a brain injury coach, educator, author, public speaker, and survivor. Passionate about education, Stacia spent much of her career as a secondary math teacher until taking on roles in administration and academic coaching. In 2011, she became a licensed middle school and high school principal with aspirations of running her own school in the near future. However, a bicycle accident left her with a TBI and her career as a public school educator came to an end. With support from her speech-language pathologist, the Brain Injury Association of Massachusetts, family and friends, Stacia began focusing her attention on helping the brain injury community. She has co-authored the best-selling book, *Deserts to Mountaintops: Choosing Our Healing Through Radical Self-Acceptance*, and has also written about her post-TBI journey featured in *Brain Injury HOPE Magazine*. She has been a keynote speaker for several conferences and events. She has appeared as a guest on various podcasts. She serves on the Advisory Council for the Brain Injury Association of America.
- LENGENFELDER: 02:08 She's a program leader for LoveYourBrain, and she was co-founder of the Northampton, Massachusetts Brain Injury Support Group. She is an established coach and mentor to other survivors and caregivers offering the services designated to help promote healing and forward movement. Stacia is a native of Berkshire County in Western Massachusetts. She has three grown children, two grandchildren, and a cute camping trailer named Starla. Thank you, Stacia, for being here with us today.
- STACIA BISSELL: 02:42 Thank you, Jean. That's really nice. I actually, as of last month, have a third grandchild. So that's the exciting news since I wrote that bio to you. Hi, everyone. I'm Stacia. And I know you can hear me because-- I think you can all hear me and see me okay. Wow. Hi, new friends, and I see some old friends. So I can't mention all the names, but my goodness, Mona and council members and Candace and so forth. Lovely to see you. Wow. I am feeling your energy today and I'm glad you're all here. Thank you for being here. And I just want to-- I understand that there are a lot of survivors here and maybe some caregivers. So welcome to all. And I have to admit that I always worry when I do a virtual presentation that the technology is not going to work and you're just going to be out there and I'll be here in my office and we're not going to be connecting. And when I do talks in person and the microphone or the slides don't work, it's okay. You always manage. After all, we're all in the same room. This virtual is a whole other ball game. And for a while, that's all I was doing. And then I'm back on stage now and now back to virtual. But I love that I'm able to reach so many of you in so many different locations. So I'm happy to be here today. I am talking to you from

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

the East Coast Western Massachusetts. I want to thank the Kessler Foundation for having me here today, in particular, Jean, who has been very patient in her attempts to get me here. I have to tell you a cute little story that in April of this year, I discovered a pile of emails that came in from my website that were never forwarded. And in that pile was a very nice invitation by Jean to speak to you all last year. So better late than never, here I am.

BISSELL: 04:40

So I usually love to move around on a stage, but today I'm going to do my best to hang tight with you from my chair. I can't guarantee that life's not going to happen along the way. My neighbor's dog might bark. My doorbell might ring. I'm obviously not going to get it. And like Jean said, we're going to leave time at the end for Q&A. So I invite you to jot down any questions or comments you have along the way. Save them up for then. And I say this almost every time I speak, but my goal for you is the same as it is for myself whenever I'm in an audience. And that is to walk away with one thing, one thing to think about, one thing to talk about, one thing to do, one thing to change. And even if only one of you does that today, I'll be happy and know that progress was made in the world and work of brain injury. So sit back, relax. This is a story. This is my story. I've been invited here today to tell you the tale of my brain injury. I'm hoping it makes you feel less alone and more understood. In exactly 13 days, it will be 13 years since I sustained my brain injury, at which time the first version of me was boxed up. And this new version of me began existing. And I'm guessing many of you can relate to that. I'll talk about how it happened and what the journey back from it has been like so far. And I say so far because no one is putting an expiration date on my healing. And speaking of healing, I had to learn not to confuse healing from a brain injury with a cure for brain injury, since there is none that I know of, unless you call acceptance a cure, that might just be the one miraculous cure out there. Rather, I look at it as a healing process with no end. And it's not always linear, is it? We all know it kind of goes like this.

BISSELL: 06:40

I personally haven't always liked the journey. I didn't do well for it for a long time. I lost a lot personally and professionally. I conquer it most of the time now, with a lot of management, I'll add. So welcome to those who have joined us since we started. Again, my name is Stacia Bissell. I used to be TBI free. I was a multitasker. I was a high-energy person. I was a person who mostly looks like me today. Primary labels 13 years ago of mom, wife, teacher, and school administrator. Now I live with a TBI, which equals confusion with more than one task at hand, some low energy days and some killer headaches, constant ringing in my ears, noise and light sensitivities to the point where I can barely function in a place like New York City. I'm no longer a wife or teacher of mathematics anyway. And now I have a label of brain injury survivor. And overnight, it was pretty tough to trade labels. Actually, it wasn't overnight. It was in a split second that it happened. My teacher label was swapped for unemployed brain injury survivor. And my type A personality gave into this confused, slow, and inefficient way of being. And my high-energy social self was gone. And it was replaced with an often fatigued, anxious, and isolated outsider. I went from feeling healthy to someone who still lives in and lived with physical pain on the right side of my body and has some unaccounted for other pains and medical issues.

BISSELL: 08:26

Thankfully, I'm still a mom. I'm also a friend and daughter and niece and aunt and sister and now grandmother. I'm a brain injury coach and mentor. I'm an advocate,

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

public speaker. I'm an author. I bike, I hike, I kayak, I camp, I play the piano, I garden, and I volunteer. These are also the things I am in addition to being a survivor, which I like reminding myself of. The fact that I live with a brain injury, like many of you, means there are two versions of me, like I said earlier, the one before you, and the other, I have this picture of her now in this tightly sealed glass box. And it's glass because I can definitely see her. She goes wherever I go. Only I can't access her the way I used to. She doesn't cooperate. I can see her sitting there in this box the way she used to be with a very confident manner on a mission to prove herself. She was a workaholic at times. She enjoyed family time, social time, alone time. I always had a long to-do list, and I was in complete control of getting it all done. And I could look out and really clearly see where I was going personally and professionally. And then in a split second, a TBI hits. And then comes this blurry, confused, emotional, tired stranger, stranger, who tries accessing the old me, only I can. No matter how hard I'm banging on this glass box. Honestly, I'd go and do something as simple as making pancakes. And I was a gourmet cook. And I found I couldn't even make pancakes, but I could remember doing it. So I felt like I should be able to do it the same way.

BISSELL: 10:23

Suddenly, acquiring a brain injury is a pretty odd feeling. You don't have a choice of the changes to your personality or your functioning power. You don't have a choice of what happens to your former strengths or weaknesses. Your strengths may be gone. Your worst traits may become even worse. And what you do and say, it might be completely new and unrecognizable to yourself and others. Maybe you don't move the same way. You're probably pretty angry, disappointed, worried, frustrated, all making the process of recovery that much harder. Brain injury can be grim. I don't like to dwell on these aspects, but do feel it's necessary to portray what can often happen. It is well known that brain injury survivors often suffer from simultaneous anxiety, depression, often from the losses we encounter, or responses to cognitive difficulty, fatigue or chronic pain, which can lead to additional deterioration physically and a greater number of post-concussion symptoms overall. And these symptoms can sometimes be more severe than. It can be a vicious cycle. I've come to realize that brain injury is like being handed a ticket to a forced megaflop. You will try to do things the same way and you won't be able to. It's like someone has moved the keys around on your keyboard with the expectation that you can immediately type at the same rate. It's difficult learning to eloquently be this new person when cognitive and sometimes physical and emotional parts of you are suddenly unrecognizable. But then you look in the mirror and you get confused by the recognizable. The person looking back at you often looks exactly the same. Thus the title of my presentation, Look Closer. My Brain Injury is Invisible.

BISSELL: 12:21

But when all of this floundering occurs, it can be a pretty powerful tool for the beginning of the reestablishment of yourself. And it can be the fuel you need to motivate you to find new methods for living life. Because forcing yourself to live like you were, well, that's just punishing yourself. Others have to invest a lot of time to get it too. And for parents or loved ones of the survivor, the journey is also very tough. So this is what happened. It was Friday, September 2nd, 2011, and I was biking with a friend on a beautiful bike path called the Ashuwillticook Trail in the Berkshires of Western Massachusetts. I was riding my maroon colored 12-speed bike, and I was sporting a coordinating maroon helmet. It was the first week back at school where I

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

was the newly appointed assistant to the principal in the middle school where I had been teaching math for quite a few years. My friend and I were riding together and we got our signals crossed. I flipped, I fell, I flattened. I don't know. I don't remember it. In addition to a broken arm and some ugly cuts and severe bruising on my face and body, I suffered what was classified as a mild to moderate TBI. I did not lose consciousness. I was wearing a helmet, as I said, otherwise the doctor told me I wouldn't be here. And if I were here, I probably wouldn't know it. The moment of contact between my helmet and pavement was when that old me, version one, was boxed up in that tightly sealed glass box. And this new me, version two, began existing. I don't remember the 10 miles or so on the bike trail before I fell or the accident or my day at work or the hours in the ER while they treated my bones and bloody skin.

BISSELL: 14:19

I had amnesia roughly 20 full hours. My first memory was actually waking up in my own bed and I was really confused by having a cast on my arm. I sat up and I woke my husband up not so calmly demanded to know why there was a cast on my arm. And he told me that I'd been bike riding. I fell. I broke my arm. I went to the ER where they put a cast on my arm and now I was home. And I'd look at my cast in surprise, I'd say, "Hey, why is there a cast on my arm?" So he would repeat that I had been bike riding. I fell, I broke my arm. I went to the ER where they put a cast on my arm and now I was home. And I would look down at my arm and again ask why there was a cast on it. I simply could not remember his answers as soon as they were out of his mouth. And I was released from the hospital without much mention of a concussion, only that my husband should watch me for a few days. And that's surprising because in the hospital, I'm told I did the same thing as I did in my bed that night. I asked a battery of the same 12 or so questions, 30 or 40 times, pretty rapid fire. Things like, "Where were the three children? Did school start yet?" And then I'd look at my husband whose birthday is always in early September and I'd say, "Is it your birthday soon? Do I have a present for you?" And he'd shrug and chuckle and say, "I don't know." And then I'd catch sight of my ring-- my hand, sorry, and see that I was wearing my dear friend, Pat's ring. And so the next question would be, why? Why am I wearing Pat's ring? Well, I hadn't remembered that she had died six months earlier and had given me this ring before she had died. And so there in the ER, I'd gently be told the pretty traumatic news that she had died.

BISSELL: 16:08

And I'd cry and I'd finish my questions and then I'd start all over with my questions. Where are the three kids? Did school start yet? Is it your birthday soon? Do I have a present for you? Why am I wearing Pat's ring? 30 or 40 times I'd hear the news that she had died, like it was the first time I'd heard it each time. So talk about a little repeat trauma there. So I know I'm skipping ahead a bit, but when I was six years out, one doctor assessed me at being 65% of my old self. That was actually really difficult to hear after six years of healing, adjustments, losses, more adjustments, more losses, doctor's appointments, etc. But in retrospect, I think he may have been onto something. Now at 13 years, I would say maybe I'm close to 80% of who I remember me being before my brain injury. But I can finally accept that I'm 100% of this person. And I ask you to consider asking yourself that same question later today. What percentage of your old self are you? And can you accept 100% of that person? There's no right or wrong answer. Just consider. So my neurologist at the beginning, her name

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

was Dr. Debert. She classified my brain injury as mild to moderate, moderate because of the amnesia and because of some evidence of a slight brain bleed and cheering on some imaging. Trust me, a mild TBI does not mean it's going to have a mild effect on your life. The adaptation to it can take years.

BISSELL: 17:49

During the first days and weeks after my accident, one thing I could not detect temperatures, I'd come out dressed in shorts and a sleeveless top to find my husband sitting there wearing jeans and a heavy sweatshirt and he'd tell me the temperature and suggest I go change, but I couldn't feel it. I couldn't drive for quite a while after the accident. And when I got the okay, I had in-town permissions only. When I was cleared with a neurologist to finally drive myself to one of my appointments in the next town over, I stopped my car about two miles away from my house and called my husband at work and asked him how to get there. I had no idea which direction to go in, north, south, east, or west. And I've lived in this town all my life. When I finally got the okay to venture into a family-- sorry, not a family grocery store, a familiar big grocery store, a chain grocery store, but it was familiar, a few months after my accident, I had a list from my SLP to only get six items on-- to have six items on my list, no more. I just thought that's going to be a breeze. Finally get to go to the grocery store. I only have six items, familiar grocery store. And I did emerge successfully with my six items an hour and a half later. And I was laden with a migraine. I was fatigued beyond belief. I just remember when the doors parted and I walked into the produce department and I think I saw every single fruit and vegetable in there. I was just trying to process everything at once.

BISSELL: 19:25

At the beginning, I was pretty emotional. I was tired all the time. I napped very often. People would visit me and then make a comment about their visit at a point later in time. I'd have no recollection of their being at my house. I used to be an avid reader, but couldn't read after the accident and to this day prefer a puzzle or a podcast or a book on tape because reading and comprehending text can be quite a challenge. But I keep working at it though. I experienced sleep issues, speech issues. All of a sudden I stuttered, almost always stumbling on words with the letter P in them. And my theory behind that is that it's from the trauma around hearing 30 or 40 times in a row that my friend Pat was no longer with us. I developed an auditory processing disorder, significant light and noise sensitivities, memory issues, unpredictable stamina and cognition. My physical health was compromised. I couldn't calibrate time. Doctors tried all sorts of medications to minimize all of this without much success. Does any of this sound familiar, folks? And I constantly asked what happened to me. I didn't believe that any accident had occurred. I knew something wasn't right and that I had a cast, but I couldn't remember anything about a fall. So I actually literally thought one of three things. I thought maybe I was in a coma and having sort of this out-of-body experience. I thought I had died and I was watching this scene unfold from some other place, or I thought people were lying to me.

BISSELL: 21:10

And this drives home the point that many times survivors do not have insight after a brain injury has occurred, especially immediately following. And it's extremely important to have someone or a team around you who can kindly and respectfully remind you of what you need to know, where you need to be, and most of all, that everything will be okay. For me, the first insight that some trauma had actually occurred was when I saw an X-ray of my arm and I saw the break in it. And I said to

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

myself, "Well, there's some evidence." And I began to sit up and take note, not only of the physical stuff, but especially of my other diagnosis of traumatic brain injury. I began to finally believe that I had a condition with a name, TBI, even though I didn't know much about TBI. And I couldn't remember why or how I got it. And I definitely didn't know what it would mean to my life. At the time of the accident, I had just taken a new job in my school as an assistant to the principal and an academic coach to the teachers. I had been a math teacher and math coach for about 20 years. I went to school and earned an undergraduate degree in mathematics, and then a graduate degree in education. I was ambitious, passionate, and knowledgeable in this field of work. I had just become licensed as a middle and high school principal the same year of the bicycle accident with aspirations of running my own school in the near future. This was my craft. This was my future. This was my interest and my income. And I was good at it. I saw myself retiring with pride in a party at 65 and then continuing working, maybe consulting for schools or the State Department of Education. That entire chapter and vision is over.

BISSELL: 23:06

My accident occurred after school on a Friday afternoon. And I called my principal, I think, as the story goes that weekend, and told him that I'd return to work after the weekend. In all reality, it was eight months before my neurologist let me go back. And that was only for three hours a day. And she made it clear it was a trial basis only. And I realized now that it was actually an exercise in getting me there dressed appropriately on time. It was not actually about being that productive once I got there. In fact, I was often drained by the time I arrived at 7:30 AM from doing just that, being there on time, dressed appropriately. And many days, at the end of my three-hour shift, which was only 10:30 in the morning, I go to my car and I'd have to sit in the parking lot for quite a while trying to find the stamina to drive the two and a half miles home, where I then have to crawl up the stairs and lay down and rest. During my eight months off, there was a lot of testing, during which time I know now I was being prepared for the likely permanent impairments that I didn't want to hear about. All in all, I had about 80 appointments during that time. The usual neurology, orthopedic, chiropractic, primary care, physiatry, psychiatry, PT, talk therapy. I went to EMDR therapy, craniosacral therapy, and rounds and rounds of cognitive rehab with a wonderful speech and language pathologist named Katya. All of these appointments now became my new social life. My friends were thinning. Between certain friends and family members from my family and my husband's family, I was actually called names.

BISSELL: 25:00

I was asked if I was faking it. I was mocked openly the first time I went out socially because I couldn't read the menu. And one former friend who works with special education students, no less, told me if I would just get up off the couch, get moving, and do more, I'd get all better. And while cocooning isn't the right answer, neither was that theory. And I tell you this to remind you that sometimes when you go through something like this, you learn that sometimes your circle sort of decreases in size, but often that can increase its value. I share this to make the point that sometimes it's hard for those in your circle to see and understand exactly what is happening after a person has suffered a brain injury, that their goodness and intellect is still there, but their processes for doing things is what has changed. Maybe they have less stamina. Maybe their emotional foundation isn't as steady as it was. Others

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

have to resist the temptation to minimize the survivor's symptoms and remember that resilience will grow from their support. I recognize that it's hard to accept that the role that family and friends have played in the life of a survivor has also changed drastically sometimes. There is an abundance of frustration, grief, and loss going around after a brain injury. Probably the largest forfeiture being that the survivor's present and future identity is fundamentally altered. A survivor's life plan may not go the way it may have been mapped out. But remember, this doesn't mean that life won't be good, great, even better in some or many ways.

BISSELL: 26:44

So in this virtual room today, we should all just take a moment and offer empathy for the survivors and the caregivers through that shared and not so simple experience of having a life disrupted. I continued with Katya in cognitive rehab where I was for a long time. I think I counted once I had something like 36 or 40-- up to something ridiculous, like up to 40 appointments, call it, where I was taught how to do simple everyday things again, like cook, clean, grocery shop, go out successfully in public, efficiently plan and sequence my day, manage fatigue and migraines, help navigate speech and hearing issues, and many, many other things. As you can see, there was no way I was returning to work after the weekend to work after the weekend of my accident. I had a lot of work to do, and an equal amount of that work revolved around the emotional piece of gaining acceptance of the fact that the very capable of me was very different now, and that I had to adjust and find ways to be comfortable wearing this new pair of shoes, metaphorically speaking, that pinched my toes and rubbed the wrong way. I had walked away with a number of post-concussion symptoms. The quantity of my disorders has not changed in 13 years. I have all the same symptoms now that I had then. Other than I can now sense temperatures and my daily headaches have gone.

BISSELL: 28:27

The quality has changed because having a TBI means that I have to work daily using the strategies that Katya taught me in cognitive rehab. She said if I would stop fighting my injury, start accepting it, and begin working hard at managing it, I might recover more. And I was scared enough and hopeful enough to listen to her. Thankfully, I listened to her. At one appointment, I remember failing miserably at a task that Katia had me do with a deck of cards. The task was such that when it was completed, I would turn the cards over to see if I put them all in the right piles that matched the suits. But they were all scrambled up. And this was probably one of the most insightful and pivotal moments for me. The results were in. Every suit was in every pile. And they didn't lie. I could see it in front of me, black and red. And that was uncomfortable for me. This really gave me insight into what was going on inside my brain. And that's the day I went home and said to myself, "Okay, Stacia, what are you going to do about this?" Basically, I knew I needed to wear these uncomfortable brain injury shoes and start walking. And I also realized that if I twisted my ankle or fell down, I needed to get back up and keep climbing up. It was because of Katya and also that particular event that that day, I made three goals. I put myself on a mission that day. Number one, to educate myself as much as I could about brain injury in general. Number two, to become as insightful as I could about the specifics of my brain injury.

BISSELL: 30:25

And three, to also be a voice for brain injury, to educate where other survivors cannot. And these three things keep me moving today, even on the days when my feet are sore from wearing those not-so-comfortable new shoes. My husband of 30

Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd  
2024 TBI Summer BrainStorm

years took on more and more on top of his demanding job. But sadly, about a year after my bike accident, when I wasn't really on this earth yet, when I was still in survival mode, and I was really struggling to connect the dots in many areas of my life, our marriage took a turn and we separated and eventually divorced. Statistics show that this is a common relationship story post brain injury, sadly. We continue to co-parent together as necessary, but this unfortunate layer caused my healing to be on a much slower path with negative residual effects that can't ever be measured. I mentioned I went back to work for three hours a day after eight months of being out. Finally, at 12 months after the accident, I went back full time with a number of accommodations, written accommodations, and I struggled. In a busy middle school, there's a lot of stimulation. Thankfully, I had a boss who did a great job following my accommodations and then some. For example, he made sure that my office was away from classrooms and the hallways where 600 kids would loudly storm through multiple times a day. He had the fluorescent bulbs taken out of my office ceiling. He magically made the 24 bells a day not ring in my office. He would turn down his walkie-talkie whenever he'd walk into my office or be in my company.

BISSELL: 32:20

He knew that when someone said something on the walkie-talkie, it would startle me. He admitted that when he heard I had had a concussion, he had an athletic frame of mind and thought it would resolve like so many of the athletes that he had coached over his career who had had concussions, or so he thought they resolved. But he quickly understood it was more than that for me and became committed to helping me succeed. I loved the mission he put himself on. He said he felt lucky to be able to provide as many of these accommodations as he could. He knew I had always been a good employee. I was sensitive to my craft, proud of my reputation, and he knew I wouldn't exploit the accommodations. I knew that the better I got and the stronger I got, the longer my day would eventually be and the more productive I'd be. He told me many years later down the road that he also saw that during this time I was doubting myself, which wasn't the norm, that I had anxieties that he hadn't seen before, that I was somewhat emotionless and not as quick to laugh as I used to be because I was working so hard at concentrating, always trying to keep up. But he understood that in order for him to get the most out of me, he had to be adaptive to the unique set of circumstances that I came back with. And I tell you this because I want you to see what concussion in the workplace can look like. It can be really respectful and kind and valuable for the employee and the employer. I say this for those of you who are at work or trying to get back to work. Even so, at the end of my first year back full-time, my neurologist could tell I was struggling. I was tired. I was unhealthy. I had a poor quality of life. And she told me, "You're not going to go back." I begged her to let me stay.

BISSELL: 34:14

I was experiencing so much loss from everything else familiar. I mean, I was different. My husband was gone. My kids happened to me empty nesting me at the same time. Family and friends were avoiding me because I was different, and they didn't know what to do with that. I think that my neurologist could see that this job was, in a way, keeping my feet on the ground. So she cut me a deal for allowing me to return the second year and said that I needed to rest over the summer and that at my first appointment with her in October, after school started, if she didn't like what she saw, she would pull me from my job. And I had to agree to go quietly. So I agreed to that.



## Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd

## 2024 TBI Summer BrainStorm

And then in August, right before school started, she closed her practice and moved to Pennsylvania. And I didn't have a doctor in October when I was already in trouble, and the school year had just begun. So that second year was marked by naps. I would nap every day when I got home, usually twice a day on the weekends so that I would be ready for Monday mornings. And I worked at home late every night to get my work done from that day because I was slower now and not finishing things while I was at work. I would have just about enough energy in my spare time to get groceries, clean a little, make food, and take care of a house, a yard, and bills that used to be maintained by someone else. I was not social, no time or energy, so I was fairly isolated as well. I barely made it to the end of that second year back at school. There was an accumulated effect going on by now, and I had no doctor during that second year who could officially decide how to help me.

BISSELL: 36:03

But because I'm a glutton for punishment and didn't know what else to do for myself, I decided I would rest over the summer and try it again year three. My principal retired over the summer. And when a new principal took over that third year, she did not follow my accommodations. In fact, she gave me a new office at the top of a busy stairwell where hundreds of preteens loudly ran by multiple times a day. I heard those 24 piercing bells ring every day, startling me out of my skin practically. And I was given an office mate, something that I wasn't supposed to have so I could have some quiet time to think and do my work. In addition to maintaining my job as the academic coach of the building, I was now given two different math classes to teach in two different grades, grades that I hadn't taught in years. I was given the role of math department head and expected to cover the in-house suspension room every day one period and keep up with the job that I had been struggling with. After just three weeks of this incredibly difficult situation, I then received my first ever letter of misconduct from the new principal. And let me back up. I was struggling, keeping up. A colleague and I put our heads together and decided to combine and co-teach our two small classes that occurred at the same time every day to relieve some of the pressure off of both of us. Co-teaching is a great model in schools and it was working. It was about the only relief I got every day. But in that letter from my new principal, it said that I had failed and/or refused to comply with my work schedule and that my conduct could have jeopardized the well-being of my students and negatively impacted other staff members.

BISSELL: 37:52

And the letter further stated that an investigation would follow. Wow, I was so angry. I was so ashamed. I had always had stellar performance reviews even in the two years prior-- at post brain injury, but prior to this when I was struggling. Thankfully, I just got a new, smart and intuitive doctor, and he pulled me that day. And I've never been back. But what followed was a very, very low point in my life that I had to climb out of. I guess it was because it was the final connection lost to the woman in the glass box. I hadn't realized how tightly I had been hanging onto that piece of her. I didn't want to be this new person wearing this uncomfortable pair of brain injury shoes, but it was what I was dealt. It was the pair of shoes in my closet now. And it was the beginning of a big climb in those shoes. What followed was the start of navigating disability retirement systems, years of a difficult moments engaging in our legal system as well. This is a common story also, a sad one, and a wrong one. There really is a lot of education to be done out there. And I am so, so grateful for organizations

## Look Closer. My Brain Injury Is Invisible- Stacia Bissell, MEd

### 2024 TBI Summer BrainStorm

like this one that help folks like us navigate things like this. And these are exactly the reasons why it's imperative for all of us to get involved in organizations that support brain injury, advocating, volunteering, participating, donating, writing, and speaking our stories so that the world becomes less ignorant and more educated about this silent epidemic and chronic epidemic.

BISSELL: 39:50

So, let's talk about rebuilding. Let's talk about putting on the damn brain injury shoes even when you don't like the way they fit or look on you and using acceptance and hard work and determination to hike as far as you can into this new wilderness. For me, the end of my beloved career was the point when I stepped foot into the Brain Injury Association of Massachusetts. At the urging of a close friend, I attended my first support group. And that was a game changer. And I can honestly say if you're a survivor and have been avoiding them like I did, don't delay any longer. Give them a try. After leaving my job, I saw a decline in my headaches. I had had a headache every single day for three years and sometimes migraine spikes in between that would last for days. But the daily headaches finally subsided. I started to exercise more. I began volunteering at the Brain Injury Association of Massachusetts. I started writing my story down and I started doing speaking engagements. I co-founded a support group for survivors and caregivers in a neighboring town. And I always love sharing that when that group of specific survivors and caregivers were canvassed by me for what TBI meant to them, they collectively came up with this statement. And I'm quoting here, "TBI is invisible and non-discriminatory. It can be about loss, shame, missing yourself, discovery, courage, and persistence while pioneering your own new direction." Oh, my God, spot on, right?

BISSELL: 41:37

I also helped spearhead a coalition with interested legislators, the Brain Injury Association of Massachusetts, an area pediatrician to develop and deliver a professional development package to teachers. A handful of my articles have been published in Hope magazine, which is David and Sarah Grant's gift to us all. And earlier this year, my brain injury story titled Breaking the Glass Box was published in the best-selling book, Deserts to Mountaintops: Choosing Our Healing Through Radical Self-Acceptance. I'm a brain injury coach and mentor for hire, helping those who want to make sense of their brain injury journey. You can learn more about me on my website, [tbimmentor.com](http://tbimmentor.com). And I believe that and the book will be placed in the chat. Okay, so don't get me wrong, I still have my days. And those are the days I have to be especially determined to work harder to help myself through them, to remember self-care and recall what I learned from the defeats I encountered while relearning things and finding new and meaningful activities and contributions to society. I know that suffering well is not the answer. Finding meaning is what helps tolerate any discomfort. Admittedly, I'm afraid of my future a little, but I haven't been afraid to start over. In fact, I've gone down paths that have proven that and some have worked out and some haven't. I was on a fairly predictable path before my brain injury. And now there are many unknowns. And it's a known fact that survivors of brain injury don't acclimate easily to changes. So feeling insecure or anxious about the unknowns is common and normal.

BISSELL: 43:16

I can admit that I'm sad about potentially not remembering important conversations and moments with important people in my life. I'm concerned about making wrong decisions because I can't sequence steps or understand consequences or simply

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cannot see the whole picture of something at one time. And my migraines and fatigue levels can still kick the crap out of me at times. But this is what I hope for. I hope not to be a burden to anyone. I hope to be independent, to learn lots of new things in my life, to feel worthy of good things again, and to have my children witness me be successful at something again. Thankfully, I've learned that I can make and sustain meaningful relationships with quality people who are doing the hard work in their lives too. I've learned that traveling builds a stronger brain just by having new experiences. I've learned how to grow some of my own food and take down trees for firewood thanks to the chainsaw that my sister gave me on my 50th birthday. I'm still a mom to my amazing three children and their spouses and now three grandchildren. And those grandchildren, my goodness, they have revived feelings of deep joy within me. I'd say the deepest in 13 years. I camp in the White Mountains of New Hampshire every year with my growing family. I love to kayak and be in the woods hiking or walking or on horseback whenever that opportunity is available. And yes, I've gotten on my bike again. I've learned to say yes to things like zip lining and public speaking. I finally learned how to say no. And I've learned to say no way to an expiration date on my recovery.

BISSELL: 44:56

At one talk I did a few years ago, someone from the audience asked me if I was glad that this happened to me. No, I'm not here as an advertisement for brain injury. Just bang your head and you can have it all too. No. But seriously, some of the greatest gifts I've had in my life are ones I've been given since my TBI. I've been given the gift of slowing down. I didn't really have a choice, but I've been afforded that space to notice things like butterflies or the way the breeze feels on my skin and to read people's faces better because I take time to notice. I think I'm nicer and more empathetic. I've learned to be grateful and hopeful and to provide hope and insight through my mission and passion for coaching and educating and speaking to those living with a brain injury or whose loved one, client, or patient may have one. I'm grateful for the days when flourishing Stacia is present and TBI Stacia is nowhere in sight. I'm grateful that some folks have a memory of the old Stacia in terms of the home she built and the relationships she cultivated and the children she raised and the holidays she hosted and the students she taught. And I'm really grateful for the kindness and acceptance of the people I've met since my brain injury. You guys are my heroes out there. And even for the people I don't know anymore, who knows, maybe their misunderstanding of brain injury will clear up someday. My message to the other survivors out there today, I'm encouraging you to flop at times until you make it. The first three to five years are the toughest. Work hard at understanding your brain injury, strive for balance in your life, quiet your mind and move your body however you can. Surround yourself with quality people, fresh air, and good food.

BISSELL: 46:52

Find your acceptance of this tough thing. Acceptance is a miraculous cure. This thing is going to be invisible to others, but not to you. It will be what you make it to be. Take good care of those brain injury issues because they will be the shoes you wear for a long time. And to the loved ones and caregivers out there, the same list goes for you. Take care of yourself and also allow for some kind, respectful and guided floundering to take place with your survivor. It may lead to insight and progress, and also remember that their resilience grows from your support. Last, let me just simply say that I realize my brain is still injured and I'll always have to manage it wisely, but

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there is nothing wrong with my heart. So thank you. Let's do some Q&A and talk together. Jeannie, I'll let you lead the way on that.

- LENGENFELDER: 47:53 Thank you so much, Stacia, for the wonderful presentation and for sharing your story with us.
- FEMALE 1: 47:59 So I had a TBI. It was four years ago and just wondering if certain things or everything with a TBI are forever or it just makes things a little harder sometimes.
- BISSELL: 48:17 Are you asking me if your symptoms will be there forever?
- FEMALE 1: 48:21 I guess so. I kind of feel like I'm still trying to figure out part of me, which feels silly.
- BISSELL: 48:29 No, not silly at all. My take is it that your healing journey never stops. There's no expiration date. I feel better this year than I have, and I'm 13 years out than I did three years ago. I feel like I'm stronger. So I do think that you're four years out, I mentioned earlier, the first three to five are the toughest. Keep working at it. Keep protecting your brain. Keep managing it wisely.
- LENGENFELDER: 49:02 We had a question that was sent privately in the chat. Could you repeat your mantra for survivors that you had mentioned before?
- BISSELL: 49:12 Yeah. I encourage survivors to flop at times until you make it. I mentioned that the first three to five years are the toughest and to work hard at understanding your own brain injury. I mentioned striving for balance in your life, to quiet your mind, move your body however you can, surround yourself with quality people, fresh air, and good food, and find your acceptance of this tough thing, and take good care of those brain injury issues. I think that was what I was being asked. And I can certainly put that in-- I don't know, give that to Eugene, and you can pass it on.
- LENGENFELDER: 50:09 We can do that, absolutely. And then I have one more from the chat, and then we'll go to some more hands being raised. One of the questions was, how do you see your life going forward in the next 20, 30 years? What do you think your future looks like?
- BISSELL: 50:27 Oh, that's such a great question. I see a lot of-- well, 20 or 30 years, I hope. I'm going to be 60 next year, so I'm hoping. So between 60 and 90, a lot of family time. I want to continue helping the brain injury community. I hope to share my life with someone at some point. I think that I want to continue learning new things from everything from art to technology. I want to bring more time in the woods and on horseback. So these are sort of some of the things, and traveling. Those are how I see myself going. I think there's something else also in the world and work of brain injury. I haven't figured it out yet, aside from coaching and speaking and authoring. But follow me on Instagram and check in with my website. Stay tuned. It's a great question.
- LENGENFELDER: 51:34 And I also see that Zena has their hand raised. So Zena, if you would like to unmute.
- FEMALE 2: 51:42 Yes, hi.
- BISSELL: 51:43 Hi, Zena.
- FEMALE 2: 51:43 Thank you for sharing your story. And I just want to give you a little bit of background. I work for the Office of Vocational Rehabilitation in Wansport, Pennsylvania. And I logged on today because our office is getting ready to sponsor a traumatic brain injury

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symposium. And so this has definitely kicked off some of my education and dealings with someone who has a traumatic brain injury. And I also worked for a provider who provided services to individuals with brain injury. And it always seems to be very common that the supports of people who have the brain injury feel like they're flailing around and don't have as many supports as they would like. And just like you had mentioned earlier about your husband and you had separated because they're just not given enough tools to learn how to deal with the new person that has developed after the injury. And on top of that, you're going through disability adjustment for yourself in the meantime. So the symposium is to help provide guides and tools and not only for someone with a traumatic brain injury, but also their supports. And I kind of feel like for someone who is experiencing a traumatic brain injury, you always want to educate yourself on that topic and find out different resources.

FEMALE 2: 53:31

And as I was combing through the resources, I found that they weren't very easy to find. And so if I had a traumatic brain injury and I'm getting overwhelmed and I'm tired and I'm trying to research supports, it's just really not there and it's a big, huge puzzle piece. So that kind of frustrated me. And I wanted to know if you experienced the same.

BISSELL: 53:57

Yes. Yeah. I think the education never stops. So that's why I mentioned for survivors to learn as much as you can about your brain injury, brain injury in general. There is a lot-- there are a lot of different therapies and things you can try. There is no one magic thing, but try a lot, read a lot. Just keep trying, keep reading, keep educating yourself. And Zena, thank you for the work you do.

FEMALE 2: 54:28

Yeah. I wanted to let that I also connect with you on LinkedIn. So I would like to keep in contact with you.

BISSELL: 54:36

Okay, thank you.

FEMALE 2: 54:37

You're welcome.

LENGENFELDER: 54:38

I think we have time for one more question. There were some other questions that came in in the chat, and I know others have their hand raised. So I would just encourage everyone to reach out through [tbimmentor.com](https://tbimmentor.com) to Stacia directly. But Kathleen, why don't we get to your question next if you want to unmute yourself?

FEMALE 3: 54:58

I just have to say for the whole group, this woman is amazing. I got a chance to work with her one-on-one, and it was absolutely phenomenal and game-changing for me. It helped me see that there was hope. And I think that's the biggest word that, in fact, a friend, I have nothing on now, but gave me a bracelet that said hope. Because I feel like there is hope. One of the first questions I ask you, will I ever be able to get on an airplane? And she said, yes, with modifications, with support, but you'll be able to do it. But the question I have here, I've participated in LoveYourBrain, Brain Injury of America, some little different groups here and there. And I think the support is so incredible. But it's like, how do you find maybe that-- how do you develop a group where it's like, other than one-on-one, I'm doing a little bit, but where you're getting together more consistently, but have a facilitator and kind of have some group of people that you connect with, but that is more consistent and regular. LoveYourBrain

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is amazing, but it's six weeks little chunks. But it's facilitated very nicely. And I think I like the limited size, like 6 or 8 people versus 15 or 20.

FEMALE 3: 56:24

So just wanted to throw that out because I find tapping into those supports to be huge at recalibrating, like, "Okay, I'm not strange. I'm not weird. I'm not losing my mind because I get the whole thing." "Oh, well, you're 62. That's normal." Or, "Oh, you look so great, or look how you can move." And you're just like, "You don't know what it's like with my head pounding, my ears ringing, but I'm still getting up and doing something because I have to or I'll lose my mind."

BISSELL: 57:06

Wow. I think your question is, how do you find those small group social supports that understand brain injury? And I am confident that any one of us in this Zoom room today could probably answer that. I would definitely look-- if you're looking for in-person, you're going to need to obviously know Zoom. Are you looking for a virtual?

FEMALE 3: 57:28

Virtual, yep.

BISSELL: 57:29

Virtual. There are a number of virtual support groups for brain injury out there. I happen to know of one on a Tuesday that I might be able to get you into. And then you can always choose-- two or three of you could break away and do an extra one a week without that facilitator. You can choose to do that. You could spearhead that or you could rotate.

FEMALE 3: 57:54

All right. Thank you.

BISSELL: 57:57

Good to see you.

LENGENFELDER: 57:58

Thank you so much, Stacia. We really appreciate you for your presentation today. And again, anyone who would like more information or be able to connect with Stacia, please visit [tbimmentor.com](http://tbimmentor.com) to connect with her. So immediately after this presentation, there's going to be a survey for you to answer about today's presentation. We'll also be following up with an email survey if you're unable to complete the survey now. And for anyone who's local to us in New Jersey, we hope that you can join us for our TBI conference on Thursday, September 26th. More information about that can be found on the Kessler Foundation website. Again, thank you so much, Stacia, for joining us today. We really appreciate you and appreciate your time with us.

BISSELL: 58:44

That goes both ways. Thank you, everyone, for being here and taking time out of your day. It was a pleasure speaking to you.

ANNOUNCER: 58:49

Did you miss our Mind over Matter live event? Not to worry! Tune in to our inspiring podcast series dedicated to embracing a positive outlook after a traumatic brain injury. Join us as we learn from experts, connect with fellow survivors, and explore strategies for maintaining a healthy mindset. Whether you're a survivor, caregiver, or healthcare professional, this event offers valuable insights and support. Don't miss this opportunity to empower yourself and others on the journey to recovery!

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