Weasilience-Handling Life's Wild Moments Brain Injury Survivor - Carole J Starr

2021 Virtual Speakers Series: Moving Forward: Personal Perspectives on Life after Brain Injury

*** Originally recorded on September 23, 2021. *** Listen to it here.

JOAN BANKS-SMITH 00:04	[music] The Northern New Jersey Traumatic Brain Injury Model System proudly presents Moving Forward: Personal Perspectives on Life after Brain Injury, a virtual speaker series for individuals with brain injury, family members, and friends sponsored by Kessler Foundation and Kessler Institute for Rehabilitation.
JEAN LENGENFELDER 00:25	This series is sponsored by the 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 Carole Starr. Before her brain injury, Carole Starr was a self-employed as a corporate trainer. She was also a classical violinist and singer. In 1999 while in her home state of Maine, Carole was broadsided on the driver's side by a vehicle going 50 miles an hour resulting in a brain injury. Carole was unable to return to work or music and still lives with daily brain injury symptoms. One small step at a time, she's reinvented herself. Carole is now a national keynote speaker, the author of the award-winning book To Root & To Rise: Accepting Brain Injury, and the founder and facilitator of Brain Injury Voices, a nationally recognized survivor volunteer group. Thank you, Carole, for being here with us today.
BANKS-SMITH 01:39	Weasilience: Handling Life's Wild Moments, Brain Injury Survivor. This is presented by Carole J. Starr, MS, author, advocate, and brain injury educator, co-founder of Brain Injury Voices, and her website, starrspeakerauthor.com. This was presented on Thursday, September 23, 2021.
CAROLE J. STARR 02:00	Thank you so much. I am delighted to be able to talk to you all today. One of the silver linings of the pandemic is being able to get to talk to groups from all over. I'm coming to you today from Maine. And so I wanted to mention that Jeannie mentioned we're going to be doing Q&A at the end. So if questions come up for you during my talk, feel free to put those into the chat, and I'll be handling those at the end. Jeannie and Angela will kind of be curating those and keeping track of those for me so that we can kind of cover them towards the end. So I want to get started by finding out a little bit about all of you, about who's here. One of the joys of this technology that we're all using today is that we can do polls. We can find out a little bit about each other. So this is kind of also our opportunity to practice a poll because I have several of them interspersed through this speech. So Angela, if you want to launch the first poll, it's going to just ask you kind of who you are. You get to choose however many descriptions fit you, and then when you finish the poll, you just hit submit. And then once everybody has had a chance to participate, Angela will put up the results for us so we can see who's here in this group. For all these polls, your answers are always anonymous. All right. So our breakdown is we got 38% of folks with brain injuries, 63% folks as professionals, and 6% folks as other. So wonderful. So I'm so glad just to know kind of who is here.

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STARR 03:52 So let's get started. Weasilience, some of you might have seen the title of my talk and wondered, "What kind of wackadoodle word is weasilience?" It's actually a play on the word resilience, and that's what this speech is all about. And I promise you won't have to wait very long until you too know the secret of why this talk is called Weasilience: Handling Life's Wild Moments. So what is resilience, and why is it an important topic for all of us here, whether we're brain injury survivors or professionals? I looked up the word resilience. I'm kind of a word geek that way, and I learned that it comes from a Latin verb that means to leap back. I think that's important information to know because that relates to the traditional definition of resilience. Traditionally, we think of a resilient person as somebody who adapts well to adversity, somebody who bounces back after tragedy. Well, no offense to the ancient Romans, but I've got a bit of a problem with that definition, and here's what I don't like about it. I don't like those words bounce back because they imply that resilience means going back to normal, going back to the way life was before a tragedy happened. And so much of the time that just isn't possible. STARR 05:26 Adversity whether it comes from brain injury, whether it comes from something else, it changes us. I know that in my own experience, I kind of think about brain injury like a meat cleaver that just sliced right through my life, and it sharply divided it into a before and an after, an old Carole and a new Carole. As much as I wanted to, as hard as I tried, I simply couldn't bounce back to the old Carole because I am forever changed by my brain injury. But yet I am still a resilient person. All of us here are resilient people. So I'm going to tweak our definition of resilience just a little bit. Resilience doesn't have to mean bouncing back after brain injury, after adversity. Instead, resilience can be about learning how to bounce forward. And why is bouncing forward an important topic for all of us here no matter who we are, no matter what our role is in the brain injury community? If you're a brain injury survivor, resilience is something that can make the difference between a life spent looking backward at what was and a life spent moving forward with what is. It can mean the difference between a mournful life and a meaningful life. If you're a brain injury professional, resilience is important because when you're working with survivors who have had our lives shattered by brain injury, we have no idea how to cope with these unexpected, unasked for new lives that we're leading. We're lost. So no matter what your title is, we're going to look to you for guidance. We're going to look to you for strategies to help us to rebuild our lives. STARR 07:27 Resilience is also important for all of us outside of brain injury because every single one of us here has been and will be challenged by wild moments in our lives, those life events that shake us to our core, that change us forever. Think about things like the death of a loved one, the end of a relationship, a job loss, a medical crisis, a global pandemic. All of us right now have been in the midst of a shared wild moment for the last year and a half. Unfortunately, it seems that adversity is just part of the human experience. Bad stuff is going to happen to us. But here's the good news. Resilience is

also part of the human experience. We can find a way through life's challenges and

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even grow stronger because of them. And that's what we're going to focus on today, strategies for bouncing forward and growing stronger after adversity.

- STARR 08:33 So normally, at this point, when I give this talk in person, this is when I move away from the podium. I have a story to tell you. There's props. I'm moving around, and I thought about, "Well, okay, how do I do this now in a virtual setting?" because moving around with props doesn't work so well when I'm sitting here in front of a virtual camera-- or a stationary camera. So what I am going to do instead is I'm going to show you a video. This is a video of me telling this story because this story, it is best told in front of an audience. So the video I'm going to show you is from when I gave a version of this talk for the Vermont Brain Injury conference a few years ago, and this story will also clue you in as to why my speech has this unusual title. So here's the video.
- STARR 09:33 I have three points that I'm going to make about resilience in this speech. But I'm going to access those points by telling you a story. I like to do my storytelling away from podium. So I'm going to step away here. So the story that I'm going to tell you, it is a true story. Everything happened. This story happened 10 years ago, actually, exactly 10 years ago. It was early March, 4 o'clock in the morning, and I woke up because I heard this scratching noise. And I was half asleep, and I thought, "Oh, there must be some kind of an animal outside my bedroom window." But as I continued to wake up, I had the horrifying realization that that sound, that wasn't coming from outside. That was coming from inside. There was something running around underneath my bed. So in a panic, I turned on the light, and as the light filled the room, I saw something dash out of my bedroom. I jumped out of bed. I closed the door. I jumped back into bed, pulled the covers up around my neck, and I sat there shaking. What in the world had gotten into my house? And what in the world was I going to do about it? It was 4 o'clock in the morning. It was much too early to call anybody for help. I could hear the thing in the next room and also realized that I couldn't call anybody because it was in the room where the phone was. So I sat there for a while and eventually said, "Well, Carole, you need to figure out what this thing is."

STARR 11:02

So I gathered my courage, and I turned on every light in the house as I went, and I tiptoed into the next room, which was my office. And there, running along the back wall, was this little creature. It was maybe this long. It was pure white. It had a black tip on its tail, looked like this. For those of you who are closer to the stage, I have a prop with me today. I had no idea what this thing was or what in the world I was going to do about it. And as sometimes happens when I don't know what to do, I kind of froze for like 2 hours. I just sat there, and I stared at the thing. I wasn't afraid of it. It wasn't ferocious. You can see it's kind of cute. It didn't seem very scared of me either. I noticed that it liked spending time underneath the spare bed that I have in my office. That's where I store my gift wrap tubes. So it would go in and out of those gift wrap tubes and just kind of look out at me. And as I watched this thing, I thought, "You know, I think this is a ferret. I think somebody's pet ferret has gotten into my house." I had never seen a ferret before. But I had seen pictures of them, and this



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kind of looked like it. And I remembered that the day before there had been a big snowstorm, and I had gone out to shovel snow, and my storm door had gotten propped open with the snow. I said, "I betcha that's how the thing got in here." Now, the improbability of one of my neighbors being out in the middle of a snowstorm walking their pet ferret did not occur to me at that moment. But I was comforted to think, "Okay. This is somebody's pet that's in my house."

STARR 12:51 So somewhere between 6:00 and 6:30, I decided to call my parents for advice knowing that they would be awake at that hour and would not mind a phone call from me so early. So they had two pieces of advice for me. One, call animal control, and two, stop staring at the thing. So I took both of their pieces of advice. I shut the door to my office trapping my furry friend in there. I took a shower, had breakfast, read the paper. I called the town office as soon as they opened. They were able to come right away. I was the first call of the day. Animal control man arrives. We open the door to my office. The little creature is no longer there. Apparently, he could go underneath the door. So we started to search my house for this thing. At first, we couldn't find it, and I kind of half hoped maybe it was all a dream. Maybe I hallucinated the whole thing. But no, we did indeed find the beast again. It was back in my bedroom on my bed, behind my pillow, looking out at us. I did a lot of laundry later on that day. Animal control took one look at the thing and said, "Ma'am, that's no ferret. That's a wild weasel." Hence the title of my talk, Weasilience. I think I went just a little weak in the knees when I realized I'd spent the early morning hours communing with a wild animal.

STARR 14:17 Now, animal control man, by all rights, he could have left right there because his job is dealing with unwanted domesticated animals, not wild ones. But he was a nice guy. He said, "Well, I'm here. I've got nowhere else to be. Let me see if I can help you catch this thing." So we proceeded to chase this thing through my house. I now have a new appreciation for the phrase to weasel one's way out of something because this little weasel weaseled its way out of every trap and snare the animal control man had with him. So eventually, we chased the thing into my kitchen where, apparently, between the baseboard and the cupboard is a little space. In went the weasel. At this point, animal control man's radio crackled. He had another call. He had to leave. That's when all the emotion that had been building up in me since 4 o'clock in the morning just came spilling out, and I sobbed in front of animal control man. I think I scared the poor guy. He took pity on me. He said, "Well, I know somebody who specializes in wild animal trapping. I will give him a call for you." I'm not sure, but I think it was hearing the word trap because suddenly my mind went back to my early morning hours spent with the weasel, and I remembered how it liked my gift wrap tubes. And I said, "Can we set a trap for it?" So we got one of those gift wrap tubes, and we ducttaped the end. We put it in that corner hoping that there was only one way in and one way out.

STARR 15:50So animal control man leaves. I'm alone with my wildlife. I pulled up a chair, and I sat,
and I stared at that corner. I cried for about an hour. But eventually, the weasel did
indeed come out and went right into the tube. Admittedly, I had not fully thought out



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the next phase of this plan. To this day, I don't know whether it was bravery or stupidity, but I grabbed the end of that tube, and I rushed through my house with a tube of weasel. I got to the front door, flung it open, and I launched that tube right out onto a snowbank. And then I watched shaking from behind the safety of my closed door as my dazed little weasel eventually exited the tube, went bouncing across the snowbanks never to be seen again. I'm sure I gave that weasel the ride of its life. Later on that day, the wild animal specialist that animal control man had contacted did indeed call me, and he was pretty impressed when I told him how I had got that thing, and I will never forget his words of congratulations to me. He had a very thick Maine accent, and he said, "Well, now, aren't you a good little trapper?" So that's my story.

STARR 17:28 All right. So I hope that you enjoyed that story. You might be thinking, "Okay. Carole, yeah, that was a funny story. But what is that story doing at a brain injury conference? What does that story have to do with resilience?" Well, as it turns out, my little weasel friend is actually a surprisingly good symbol for resilience. I looked it up, and I learned that in Native American culture, the weasel is a symbol of fierce courage. All of us here know how much fierceness, how much courage it takes to face the life-changing challenges of brain injury. The appearance of the weasel is also an invitation to observe deeply, to find the hidden meanings of events, all of us to find resilience. You have to be willing to look deeply at our own experience to find your own unique path to resilience. So I promised you three lessons from my weasel story that relate to coping with adversity, and here they are. In order to bounce forward after brain injury, after other life challenges, it's important to overcome denial, to observe the situation, and learn from the experience. For the rest of this talk, I'm going to be unpacking those lessons and sharing specific resilience strategies within each one. And I've put those strategies as well as a list of resources together on a handout, and the handout will be emailed to you after the conference.

STARR 19:10 So my first resilience lesson is about overcoming denial. Now, in my weasel adventure, even though I could plainly see that little creature that was running around my house, I still kind of tried to deny it. I didn't want to get out of bed to face it. I decided it was somebody's pet ferret instead of a wild animal. I hoped it was a hallucination at first when animal control man and I couldn't find it. Denial is a really common experience after adversity when something bad happens to us like a weasel, a death, a divorce, a job loss, a scary diagnosis, a brain injury, a pandemic. Denial, it's often where we go first because reality is just too hard to process. It is too much to bear. It's that feeling of this can't possibly be real. This is not happening. After brain injury, did any of you have thoughts like that? I know that I did.

STARR 20:14 Denial can actually be good for a while. It's protective. It gives us space that we need in order to eventually move towards acceptance. For example, in my weasel adventure, I think that I needed the time in bed with the covers up around my neck in order to process what was happening. What was I going to do next? However, the problem comes when we stay in denial for too long because eventually it will get in the way of moving forward. I couldn't stay in bed forever. I had to reign in my fear,



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gather my courage to face an unknown creature. When we're dealing with a challenge, be it brain injury, be it something else, there comes a time to accept what is to move forward with a new reality. Letting go of denial, that's the beginning of resilience. It took me a long five years to stop denying my brain injury, the symptoms, to let go of returning to my old life. It was about eight years until I reached full acceptance of my new self, my new path.

STARR 21:22 When I think back to my own journey with denial, what that was like to me, here's the image that comes to mind, a big old rock. Denial can be like a gigantic wall of rock. It's a boulder that gets in the way of progress, that gets in the way of moving forward. Here are some of the ways that denial showed up in my life after brain injury. Maybe some of these will ring true for you too. There was this frantic voice inside me yelling, "No, no, no. This is not real." Every night before I would go to sleep, my last thoughts would be, "Maybe tomorrow. Maybe tomorrow is going to be the day that I wake up normal, and this nightmare of symptoms is just over." I didn't want to admit just how confused I really was. So a lot of the times I tried to minimize and hide my symptoms from my family and friends and medical professionals. I flat out refused to use strategies to get things done. I was going to do things the way I had always done them. I thought that the only way to move forward was to continue to push and push and push to get back to my old life as a teacher, as a classical musician. Even though every time I tried to do that, I failed.

STARR 22:47 Overcoming denial, it is a process, a slow process, one that can be particularly difficult given the realities of brain injury. I know that it was for me. I like to think about things in terms of metaphors, and here's how I think about the process of overcoming denial. I think about it in terms of planting seeds, planting seeds that eventually can take root and grow. And over time, those seeds can grow strong enough to break through stone, to break through that rock of denial. When I look back at my experience, I've identified, well, I thought about, "Well, what were some of those seeds that helped me break through my rock of denial?" And I think that these are seeds that apply not only to brain injury but to other forms of adversity as well, and they are to learn about the challenge, connect with peers, and reflect on failure. With any challenge, we have to understand what it is that we're facing. Knowledge is a seed that can grow to break through denial.

STARR 24:01 My own knowledge journey began-- it was about eight months or so after my injury. That's when I bought my first book about brain injury. Due to my symptoms, I was struggling with reading. I still often do. But despite the struggle, I saw myself and my symptoms on the pages of that book. That recognition, it was both terrifying and comforting to me kind of both at the same time. There were so many times when I wanted to run away from what I was reading in that book. But yet I kept coming back to it to learn more because I was learning about myself and my injury at a slow pace that I could handle. And I think that's an important point that overcoming denial, it has to happen at our own pace because trying to rush the process, all it does is overwhelm us. After all, seeds grow in their own time. So whatever the challenge is, learning about it, that's a step towards resilience.

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STARR 25:03 There's a special magic that happens when brain injury survivors talk to one another because we get it. We have a shared experience. Peers can plant seeds that grow towards overcoming denial. It was a fellow brain injury survivor who helped me, who planted that first seed that helped me to get over my own denial about needing to use strategies. We met as part of brain injury rehab. Her injury was several years older than mine, and she modeled a level of acceptance that I wanted to get to, and one thing that she talked about was that she needed to use strategies. And that reinforced what my therapists, my family, friends, what everybody had been trying to tell me, that hard truth that I had struggled to accept. Sometimes I think it's easier to hear those hard truths from our peers, from people who share our journey than it is from family, friends, or even professionals. There is tremendous power when we can connect with others who share our journey, whether that's one on one, in a group, whether it's in person or nowadays virtual because resilience grows when we connect with one another, when we swap our stories, when we share our heartbreaks, share our triumphs, when we know that we're not alone in this. STARR 26:27 After brain injury, many of us, we try to go back to the way life used to be. Our old lives are what we know, so we try to get back there. We struggle. Many of us fail over and over and over again. Being able to reflect on those failures and learn from them, that's another seed that can break through denial. For years, I tried and failed so many times to return to my teaching and my music. Then one day I was meeting with my counselor, and I was sharing with her a whole laundry list of return to old life failures, and she asked me this bombshell of a question. She said, "Carole, is it possible for you to accept that you're not going to make a full recovery?" And oh, that question, it hit me like a ton of bricks, and I instantly started sobbing. And in that moment, the fact that my old life, it really was over, it just seared through me in a way that it never had before. And suddenly, I understood my failures. I had thought

learn from our failures, resilience has taken root.

STARR 28:24

So before we move on to the next section, I'd like to get some interaction going via breakout rooms, another Zoom tool that we have at our disposal. One of the things I miss about in-person conferences is the ability to talk to each other, to share our learnings, to share ideas. So I'm going to attempt within this speech to do that virtually. What we're going to do is we're going to send you off into breakout rooms in small groups for about five minutes to give you an opportunity to talk about these resilience strategies, to talk about, "Well, how do these apply to your own situation?" This is the discussion topic here on my slide just to talk about the ways, how do these resilience strategies apply to you? How do they apply to your own life? So what's

that I was failing because I wasn't trying hard enough. I've always been somebody who believed if at first you don't succeed, try, try again. But trying again, that wasn't the issue. I was failing because what I was attempting, it was simply too much for me. It was too much for my brain. Huge chunk of my rock of denial got blasted away that day, and that was when I finally stopped trying to go back to my old life, to go back to the old Carole. So my focus changed towards accepting and learning, "Well, how do I appreciate my current life? How do I learn to live with the new Carole?" Every failure has something to teach us once we're willing to look at it, to examine it. When we can



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going to happen is Angela is going to set up these breakout rooms. You don't have to do a thing. When it comes up on your screen to join the breakout room, just click yes, and off you go, and then the computer does the rest. And I will put into the chat this discussion question too. So if you get there and think, "Ah, what are we supposed to be talking about?" it will be in the chat for you as well. So you'll have five minutes to talk about this, and then we'll come on back. So Angela, if you want to do your breakout room magic.

STARR 29:54 All right. There we go. So now that you've had a chance to talk about those strategies, I'd like you to pick one of them, to pick one that is most helpful for you right now. The idea behind this is that by the end of this talk, I'd like for you to have basically your own personal roadmap to resilience, kind of three of the strategies that are most helpful for you right now. So Angela is going to put up a poll of these three strategies where you'll just pick one. One that's most helpful for you at this moment. So it looks like we've got 33%, learn more about the challenge. Connecting with others was 56% and learning from failures, 11. And there are no right or wrong answers to this. This is just to kind of see where people's heads are with this. It's all about what's most useful for you. So I encourage you to write down whichever one that you picked because, again, that will give you that road map for yourself for strategies that are most useful to you. So let's continue on.

STARR 31:05 All right. So overcoming denial, that was about clearing the boulder. Now what? When we can't go back because adversity has changed us forever, the path forward seems empty. What do we do? We build a brand new structure. We build a brand new life. But how do we do that? Where do we start? One place to start is with observation. That's my second resilience lesson, observed situation. My weasel story, I caught my furry little friend because I observed that it liked my gift trap tubes. There's no way I ever would have come up with that idea for a successful trap if I hadn't spent all that time in the early morning hours just observing the weasel's behavior. Learning to observe ourselves is a critical skill for building resilience, for building our new lives after a brain injury, after other forms of adversity. The importance of self-observation, it has been recognized for millennia. It was the ancient Greek philosopher Socrates, among others, who said, "Know thyself." I think that one of my most profound and life-changing know thyself moments came all the way back in 2001, 20 years ago, about 2 years after my injury. And it was the selfobservation that, over time, it led to this new life that I'm leading now, one that includes this speech today. And the story of this observation, it is also the story of building resilience. And as I share my journey, I encourage you to think about how my resilience experience might relate to your own journey.

STARR 32:52 And what I observed way back in 2001 was there was this new desire in me that I wanted to use my hands to create, which was really strange because old Carole didn't care anything about using her hands. This was all new Carole. There was this little voice inside me that was whispering, "Make something." I think that no matter what challenge we're facing, we all have a little voice inside that whispers observations, that whispers self-knowledge to us, that can guide us towards resilience. That little



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voice inside, it's a quiet voice. It's one that we can't hear if we're living in the past, if we're trying to get back to the way life used to be. The little voice inside is the voice of the present. It's a voice that can point us in a new direction. When I listened to that quiet voice inside me all those years ago that said make something, that was the very first time that I turned away from the beating unsuccessfully against the closed door of my old life and toward quietly walking the open new one. And I think that's an important point that it isn't enough for us just to observe the little voice inside. We have to act on it because observation without action, it doesn't get us anywhere. And one of the things that I've learned is that even the smallest of actions can crack open new doors.

I started out really small, really simple with this paint by number. Because of my STARR 34:29 difficulties with fatigue and concentration and attention, at first, I could only work on this for about 15 minutes at a time. But I'd be so tired I just had to take a nap for an hour or two. But yet I loved doing this. When I successfully finished this paint by number, that made me think, "Well, what else can I make?" So I got into other crafts including jewelry making, cross-stitching, photography. Our actions build on one another. I don't think it matters what we start with, where we start because once we take just one action, more can follow, momentum builds, and resilience takes root. I think that one of the reasons that the crafts worked so well for me is that they gave me an opportunity to experience success after I'd failed so many times to get back to my old life. I can't stress enough how important it is to find something we can be successful at. After brain injuries, many of us, we fail so often that it just sends our self-esteem, our self-confidence just plummeting towards rock bottom. Success, it can be like a shot of adrenaline. Success can help move us forward. The more success I observed myself having with the crafts, the more motivated I was to continue to build my new life. I think this observation applies to dealing with many of life's challenges. Start small, find success, and build on it.

STARR 36:09 It was through the crafts that I also started to observe my sense of self returning. For a long time after my injury, I felt like all I am was a professional patient. All I had to talk about with others was my brain injury, everything that I had lost. Crafts, they gave me something else to talk about. They gave me another identity. Now I was a person who made things. By making gifts for others I could give to others instead of always being on the receiving end of help. I participated in an art show at the rehab hospital where I received my outpatient treatment. People actually bought my jewelry, which was so rewarding. So by volunteering at that hospital, I taught other brain injury survivors how to make jewelry. That led me back to teaching, which has always been one of my core identities and another way to give. I began to observe that I am more than just a professional patient, that I can be useful in the world. It's just different than it used to be. Getting outside oneself and finding ways to give to others, that builds resilience.

STARR 37:22In 2003, I participated in a workshop on creativity at the Maine brain injury
conference. As part of that workshop, I had a table where I displayed my crafts. It was
also my very first opportunity to speak publicly about my brain injury. My speech was



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all of five minutes long, and I was so nervous that my knees shook the entire time I was up there. Sharing my story in front of others, being vulnerable, it was a risk. But I've learned that resilience doesn't build unless we're willing to take on some risk, unless we're willing to feel the fear, and we choose to move forward anyway. Resilience grows when we break new ground, when we push our boundaries one small step at a time. When I spoke at that conference, it increased my self-esteem, my self-confidence. It showed me there was power in my story, but I could use my story to help others, and it made me feel like maybe there could be some value, some purpose in everything that I had been through. And even though I was so nervous, I had this overwhelming feeling of, "I'm home. This, this is what I'm supposed to do. This is where I belong." And for the first time since my accident in '99, my way forward was clear. I knew what I wanted to do. I knew that I wanted to do more speaking about brain injury.

STARR 38:50 Sometimes I think that when we're in the midst of adversity, it can seem like the steps we're taking, they are so small, they are so slow. It can seem like we're not moving at all. But small and slow can grow into big and unexpected, and here's how that concept has played out for me over the course of my own brain injury. It's now been 18 years since I did my first five-minute, knee-knocking speech about brain injury. Since then, I've gone from being part of brain injury panels to giving short talks to organizing workshops to delivering keynotes. In 2010, my mentor and I founded the Maine-based survivor volunteer group Brain Injury Voices. You can see the statistics of what we've accomplished together in 11 years. We're proof that when brain injury survivors, when we work together by focusing on what we can do, we can make a huge difference. It was by focusing on what I can do one small step at a time that I wrote my book To Root & To Rise: Accepting Brain Injury. Took me 12 years to write this book. It is a book and workbook designed to help brain injury survivors move forward with their new lives. That's the very definition of resilience that we're talking about today.

STARR 40:09 The journey that led me to this moment talking to all of you, it began with an observation. It began with listening to that little voice inside me all of those years ago that said make something. Those words, make something, they are about so much more than just doing something with my hands. I didn't know this back then. But what I know now, those words make something, they also refer to making something out of tragedy, turning suffering into something meaningful. Now, I certainly did not choose to have a brain injury. None of us choose to have adversity visit our lives. But one thing we can choose is to make something out of it. Making meaning, that's another part of resilience. I'm choosing to make meaning as a brain injury speaker, a book author, the leader of Brain Injury Voices. I never would have expected it, but through this, I have found my life's work. But there are so many ways that we can make something out of adversity. It's about whatever brings us a sense of purpose. That could be time with family and friends, volunteering, creative pursuits like arts, crafts, music, or writing, helping somebody, caring for animals, tending a garden, devoting time to a spiritual practice. However it is that we choose to make meaning, the process begins with self-observation, with listening to our own little voice inside.

Weasilience-Handling Life's Wild Moments Brain Injury Survivor - Carole J Starr

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STARR 41:43 So it's time again to stop for another breakout room session where now you get to talk again in small groups about these resilience strategies and how they apply to your own life, to your own journey. So Angela is going to Zoom you off into the breakout rooms, and I will type this into chat again so that you have what you're going to be talking about. And because there are more strategies here, we're going to give you about seven minutes so that you can talk in your small groups about how you can apply these resilience strategies. Looks like find success and build on it was the most popular one at 37%. But again, there are no right or wrong answers to this. It is about whatever is most useful for you right now. And again, I encourage you to write this down as part of your own personal roadmap to resilience.

So let's keep on going. Now, within this speech, I've kind of been building a resilience STARR 42:45 structure, and I've been moving from the ground upward. Overcoming denial, that was the demolition phase. Observe the situation, that was the construction phase. My third phase, learn from the situation, that's about the big picture. That's about gaining perspective. There's always learning to be found in any life-changing event. That is one of my core beliefs. It's also an attitude that contributes to resilience. Now, learning from life challenges, of course, it doesn't change the fact that the challenge, whatever it is, is extremely difficult to cope with. Having a weasel in my house was not easy. Having a brain injury has been the greatest challenge of my life. But when we can figure out what adversity has to teach us and then use that learning to keep moving forward, that increases our resilience. When something bad happens to us, it's really common to ask, "Why did this awful thing have to happen to me?" How many of us have said something like that to ourselves? I know I have. The problem is that that question doesn't have an answer. That question tends to lead to sadness, to anger, frustration, disappointment. It doesn't lead to insight. Here are some questions that you can ask that lead to resilience. What can I learn from this situation? What does this challenge have to teach me?

STARR 44:27 So can a weasel be a teacher? Absolutely. The biggest lesson that I learned from that weasel, it actually has to do with resilience. And what I realized after that whole situation is that it doesn't matter how I handle situations. It is not always pretty. It doesn't matter if it takes me a long time to figure things out, if I cry while I do it, if I get confused, if I have to spend hours or days on the couch resting afterwards. What matters is that I know without a shadow of a doubt that I will continue to persevere and that I will slowly find my way. Brain injury has been the greatest teacher of my life. Here are three lessons that brain injury has taught me that relate to resilience. Brain injury has taught me to look for silver linings, to find humor, and to express gratitude. Research supports that these are perspectives that contribute to resilience. It doesn't matter what challenge one is facing. I found these perspectives to be especially helpful during this time of pandemic.

STARR 45:45 I've always been a big believer in the concept of silver linings, that something good can come from something bad. Brain injury put that belief to its biggest challenge ever. It is so challenging to find silver linings in something as life-consuming as brain injury is. It's so much easier to list all of brain injury's negative consequences. They



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are very numerous, very real. They turn our lives upside down and inside out. It took me years to find the silver linings of my brain injury. At first, all I had to hold onto was my belief that they were there, even if I couldn't see them. And I'll be honest, there were times when my belief in silver linings, it was one of the things that kept me from ending my life in the early years. I had to believe there was something good that was going to come from all that I was going through. So if you're in that place where you can't see how there could possibly be any silver linings to what you're going through, please have faith that you can find them. You will find them. I think of silver linings as being on one heck of a balance scale with brain injury being that enormous load on the other side. We need something that can counterbalance some of the downward weight of brain injury.

STARR 47:05 Here are a few of my silver linings. Because of brain injury, I understand better what it is to struggle. I think I'm a better person for it. I have more empathy, compassion, perception, wisdom. Because of brain injury, I've become less of a perfectionist. I've always been kind of a type A hard-charging person, and now I say, yeah, I'm more like a type A-minus kind of person. Because of brain injury, I have a clear purpose in my life. Brain injury gave me a passion for a cause that my life didn't have before. Now some of those silver linings might make it sound like, "Well, jeez, brain injury was the best thing that ever happened to her." It wasn't. It was the worst thing that's ever happened to me. Silver linings, they don't erase all of the many challenges of brain injury, but they do make them a little bit easier to live with. They even out that balance scale just a little bit. Being able to see the positive within the negative is a hallmark of resilience. So I encourage you to think about brain injury, think about any other challenge you're facing and try and find a silver lining.

STARR 48:22 Adversity is not funny. Brain injury is definitely not funny. We can't change the bad stuff that's happened to us. But over time, we can learn to view pieces of it in a different light from a different perspective. It was Mark Twain who said, "Humor is tragedy plus time." Humor is an age-old strategy for coping with adversity. When life is falling apart out of our control, sometimes all we can do is laugh. Humor, it's like WD-40. It's the grease that makes everything move just a little bit more smoothly. Now, just like silver linings, humor, it doesn't change the challenges of brain injury one iota, but it can make them more bearable. It took me time, but eventually, I learned to view my brain injury symptoms more lightheartedly. A lot of the time, it seems like there are two very different people living in my head. There's me and there's a brain injury, and I'll tell you, my brain injury, she's kind of a diva. She's the one in charge, and she gets what she wants when she wants it. She's kind of a drama queen. So I decided to give my brain injury a name, a kind of dramatic-sounding name. I call her Brainhilda.

STARR 49:40 A lot of my Brainhilda humor centers on my most challenging symptom, which is extreme and oftentimes unpredictable mental fatigue. I have rested every day, oftentimes multiple times a day, for more than 22 years now. As a matter of fact, I had to rest before giving this speech. I will have a rest after giving this speech. Due to my mental fatigue, that has meant that sometimes I have to rest in public places



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because when Brainhilda is taking me down, I pretty much have to obey. It does not matter where I am. So here are some of the odder places that I have had to take a nap. I have had to rest in a classroom at a craft store, in the coffin display room at a funeral home. I did not rest in a coffin. I rested on a couch that was there. I kept my eyes tightly shut because the coffins were all around me. I rested in the bedding department at a furniture store. I just did that just a couple of weeks ago. At a hotel bar, I had not been drinking and the sign did say bar and lounge. I rested at a golf course pro shop, on a fishing boat, and in the Washington, DC, conference room of my US Senator. So given all that, I tell people I sleep around. My motto is one that any Star Trek fans would appreciate. To boldly nap where no one has napped before. Humor is a healthy choice we can make for ourselves. When we can laugh, we are resilient. So I encourage you to look for ways to laugh, to choose to be amused. STARR 51:27 It's been my experience that when life is at its worst, that's when expressing gratitude can be most beneficial. Given that we're living through an especially stressful times these days, I thought it would be beneficial to try a group gratitude exercise. So I'm going to ask you to think about the following statements. If you'd like, you can type your answers into the chat or you can just keep them to yourself. Today I'm grateful for this person in my life, this simple pleasure I enjoy, this thing that makes me smile or laugh, this information that I learned today. As you think or write about your answers, how do you feel? Take just a moment as you think about what you're grateful for and pay attention to what's happening to you physically, mentally, emotionally. I know that when I focus on what I'm grateful for, I can feel my muscles relaxing. I feel a smile growing. I feel a lightness that starts to take over me. STARR 52:46 Gratitude, it is one of the simplest yet most powerful resilience tools that we have. Looking forward expressing gratitude is a choice. It's a choice we make for ourselves. It's about choosing to find something to be thankful for even within the midst of the darkest of feelings. It's about letting the sadness, the anger, the fear of what's happened to have their place. It's not about denying those feelings, but it is about making a conscious decision to turn away from those feelings, at least for a short time, to focus on being thankful. It's about finding a way to live with the harsh realities of brain injury, of adversity. So I invite all of you to look for regular opportunities to express gratitude, most especially during those times when you're struggling. It's time for our last breakout room session. We're going to do this for about five minutes, and again, the opportunity for you to talk in your small groups about these resilient strategies, silver linings, humor, and gratitude, and how they might apply to your life. All right. So it looks like finding ways to laugh was the one that got the most votes in this one, and again, no right or wrong answers. These are all wonderful resilient strategies. It's about whatever is most useful to you wherever you are in your journey. STARR 54:19 All right. So we've been on a resilience journey today. We began with my funny

weasel adventure, and then we moved through the bouncing forward lessons inspired by that, overcome denial, observe the situation, and learn from the experience. To close, I have a little poem. Something that combines my serious topic of resilience



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	with a little bit of weasel-inspired whimsy. So here's my closing poem. When life throws you weasels, what do you do? First instinct is to hide because you don't have a clue. Emerge from denial. Look it square in the face. When you choose to turn forward is when you really start the race. Strategies are possible if you observe with care. Help can be found when you look everywhere. So learn from this moment, and you'll manage with brilliance. Then you too can proudly say I have weasilience.
LENGENFELDER 55:28	Thank you, Carole. That was a wonderful presentation.
BANKS-SMITH 55:34	This Northern New Jersey Traumatic Brain Injury speaker series was supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research, grant number 90DPTB0003. Interested in joining a study? Go to kesslerfoundation.org/join.
	For more information about Ms. Starr, the Northern New Jersey Traumatic Brain Injury System, research at Kessler Foundation, and Kessler Institute for Rehabilitation, links are in the program notes. This podcast was recorded on September 23, 2021, remotely and was edited and produced by me, Joan Bank Smith, creative producer for Kessler Foundation.
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