

Catching YOUR Memories

THE PODCAST

WITH DIANE ATWOOD

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Diane Atwood: Hey everyone, this is Diane Atwood, and you are listening to the Catching Your Memories podcast. Everybody has a story, a memory, an experience to share if only someone would ask. That's where I come in. In this episode, Carole Starr shares a story about acceptance. A car accident brought life as Carole knew it to a screeching halt in July of 1999. She was 32. Her life as an independent adult had barely begun. The injury that did the most damage is one that you might not notice at first. She's articulate and lively, creative, has a good sense of humor, and is also a keynote speaker and author of the book *To Root and to Rise*.

But when Carole's car was struck the momentum, and how her car spun around caused a traumatic brain injury. She has worked really, really hard to achieve what she has today, but she also had to give up so much. In this episode of the Catching Your Memories podcast, Carole takes us along on her amazing journey of recovery and most importantly, what she learned to accept and what she had to let go of.

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Diane Atwood: Well, Hi there, Carole Starr. It's been about five years since we did an interview.

Carole Starr: Yes, it has been.

Diane: And what we talked about before was this book that you had just published. So, now you're like, internationally known, aren't you?

Carole: Well, in a few countries, I guess, yes.

Diane: Well, tell us a little bit about where people can find your book.

Carole: It's called To Root and to Rise: Accepting Brain Injury, and it's available on Amazon. It's as a print book an ebook, an audiobook. That's one of the things I've been doing over the last five years, is getting it into all the various formats. It's also on my website starrspeakerauthor.com. I wanted to make it available in as many ways that people can find it, to make it easy.

Diane: And we have to say, the first time you said starrspeakerauthor.com, right?

Carole: Yes.

Diane: I'm thinking star like she's a star. And then I had to remind myself, well, yes, she is a star, but her last name is Starr with two rs.

Carole: Yes, I know. I thought that was a really kind of a fun play on my last name. Like with a last name like Starr, you have to do something fun with it.

Diane: You have to rise to the occasion with that.

Carole: Yes, exactly.

Diane: Well, I think you are a star, Carole Starr, I do. And I think a lot of people do, because how many years has it been since you had the accident?

Carole: It will be 23 in July.

Diane: Wow.

Carole: A very long time.

Diane: A very long time and a very rough time. And we have done a podcast episode before in which we talked about that. But I would like to go over some of the highlights is not a very good word to use, but what I mean, where you were in terms of in your life and then the accident and where you were.

Carole: Yes, so it was July of 1999, and it was a car accident. I was broadsided on the driver's side by somebody going about 50 miles an hour. And that accident left me with a brain injury, which changed my life. I was 32 years old at the time. I was building a teaching career. I was also very involved in music as a classical violinist and a singer. And I thought life was going to be this trajectory that mostly went up. I knew there were going to be bumps in the road, but I didn't really imagine that there could be a complete u-turn or such a large divot in the path. One that was going to lead to a completely different outcome, one that I never could have imagined, one that I would not have chosen, but one that nonetheless, given where I am now. I don't wish I had a brain injury. I would never wish that on myself, on anybody, but I am happy with where I am and the ways that I can help, the ways I can use my experience to help others. But it was not easy to get there. And there were many years and years where I didn't think that was ever going to be possible, where all it felt like was this injury has ruined my life.

Diane: It really is all about acceptance, which is what your book is all about.

Carole: Yes.

Diane: But it took you a long time to reach acceptance, and it might not be the kind of acceptance that you might have thought you'd like to reach?

Carole: Right. Yes. To me, early on, acceptance meant I have to like having a brain injury. I have to welcome it into my life. It has to mean that I'm okay with it all. I can dislike what brain injury has done, but it means that I work with it instead of fighting against it. That I accept the catchingyourmemories.com ~ diane@dianeatwood.com ~ 207.415.1315

symptoms for what they are and focus more on what I can do than what I can't do. Because the more that I focus on what I can't do, because there are still, as much progress as I've made, I can't hold a candle to the quote, old Carole. The old Carole, she could work a full-time job and then go to music rehearsals afterwards. Even nearly 23 years later, I can't do those things. I will never do those things again. It's easy to get depressed if I think too much about those things. But if I think about where I am now versus where I was compared to those early years, it's stunning.

Diane: Why can't you do that same pace?

Carole: Mental fatigue is one of the major symptoms I have after my brain injury. Everybody has kind of like a bucket of energy that we start the day with. What I start the day with is much lower than quote neuronormal people do. That the energy that I have. It leaves me fast. It takes more energy for me to do things. So, by just after lunchtime, I'm like, okay, I got to lie down, and the rest can be the rest of the day. It can be a couple of hours. It depends on how much brain power I have used. Our brains are always working, making small decisions, processing noise, processing light, all of these things. And after brain injury, those things get challenging and they take energy and we run out of it. It's the most desperate feeling of tired that I've ever had in my life. It's different than just end of the day tired. Oh, I've got to go to bed. It is like being dragged down. It is confusing. I get confused as my brain kind of goes downhill. I start to lose my words. I can't talk. I will start to lose my balance if it goes far enough that it's better if I lie down early versus trying to push it. Because if I push it, I've just bought myself hours or maybe even days on the couch to recover.

Diane: So, you know, early on, over the years, you figured out, oh, that's a signal that's a very early signal that my brain is reaching capacity?

Carole: Yes. It took a long time and a lot of help from a lot of people to learn those things. For a long time. I would just sort of blast by the signal, thinking I can push through this. I mean, I'm a person who I like to push. Come on, this is all in your head, Carole. Just try harder. And that doesn't work with brain injury. We all have to try. I'm not saying

that we don't have to try because we do. But there's that line of try hard, but be aware of when it crosses that line.

Diane: And the energy that you're talking about, unless somebody's been in your shoes, they might not understand that concept of mental or brain energy. The average person who has not had a brain injury, when they think about, oh, my God, I'm so exhausted. It's usually the muscles are exhausted, their bodies are tired. And maybe we have a slight concept of what it means when our brains start to shut down. But what you're talking about is magnified.

Carole: Yes. The only thing I can compare it to is like pulling all-nighters in college. But magnify that by like 100 times. It's like that, but it's not quite but that's as close as I can get to any experience I had before this.

Diane: Can you talk a little bit about what are the early signs that you get that you used to ignore, maybe because you didn't know, but also because you didn't want to acknowledge them?

Carole: For me, it's a feeling of pressure in my head, pressure in the left side of my head. I start to feel like I call it talking through Jello to anybody who doesn't know me well, they don't hear that my speech is different. People who know me well, they can hear the slight hesitation that starts to come into my speaking because I am working hard to get my words out. Some people feel like it's cotton in the brain like there's a sort of fuzziness that starts to take over. Some people talk about holding the side of their head that's injured. People get more sensitive to light or sound. They can get a headache. Over the last just relatively few years, I've discovered, like, a new sign for me just before the tiredness starts to come out, I get this, it's almost a euphoria feeling. If I'm doing really well at something, I'm thinking, I am not going to need a rest. Look how great I am doing. Today's the day. Today's the day I am not going to need a rest. And I get all excited, invariably, 20 minutes to half an hour later, oh, I'm going down. And now I have learned that that euphoria, that's a sign in itself that I need to pay attention. That that means the cycle has actually started. I don't feel it yet, but the cycle is starting.

Diane: I wonder if it means in the long run, something is changing on a cellular level. That does happen, right? Even all these years later, things get better?

Carole: Absolutely. Oh, yes. And I am better now than I was a few years ago. The changes are small, but small changes make a big impact. Like I can listen to music in the car again, not all the time, but that's a huge thing for me. Being able to, generally, I rest in the afternoon, but if I absolutely have to, I can make it into the mid-afternoon, which is huge for me. That knowing that okay, I'm not doing my best, but I can make it until I get home into the mid-afternoon. It's not every day, and I pay for it when I do that because then I can't cook supper. I'm down for the rest of the day, sometimes into the next day. But if it's something that's worth it, that's okay.

Diane: So, you can decide ahead of time whether something might be worth it or not.

Carole: Yes. And I've had to kind of use it like a formula for deciding, like, all right, how much tiredness is worth it? That if something tires me out into the next day, it better be special because I can't do that all the time, because I can't live life that way.

Diane: Do you have to just go to bed? What is it that you have to do in order to replenish that supply of energy?

Carole: I lie down, I have to go flat. My head has to lie down on a pillow. Just sitting um up doesn't work. My head has to go flat

Diane: And no stimulation whatsoever. If you can manage that?

Carole: it depends on how tired I am. I actually can put the TV on. I was going to say fall asleep with it on. Prepandemic, I had actually gotten to the point where my rest times. I wasn't sleeping. I had to lie down, but I could watch a little bit of mindless television. Since the pandemic, I'm back to sleeping again during my rest.

Diane: Do you have an explanation for that? Is it just the result of the pandemic which has shifted things for just about everybody?

Carole: I think everything takes more thought again, that with the pandemic, all of the routines that I had just carefully created as a brain injury survivor, suddenly so much collapsed when things shut down, couldn't go to the places I used to go, couldn't see the people I used to see. Everything changed and everything all of a sudden it's like, is it safe to go here? Is it safe to do this? Everything required tremendous amounts of thought to figure out, well, how am I going to do this now? And that takes a lot of brain energy.

Diane: I would like to go back to music because you are a musician, and before your accident, you played the violin. Were you in the Symphony?

Carole: I was an amateur Symphony. I was a happy amateur,

Diane: But that changed for you. You've no longer been able to play your violin, play in an orchestra?

Carole: Or sing in a choral.

Diane: Sing in a choral. So, to be able to just listen to music in your car in that closed environment is huge.

Carole: It is, yes, it is.

Diane: How long did it take for that to happen?

Carole: Let's see, it's been a few years that I've been able to listen to the music. It took about 20 years.

Diane: Wow. And how did you discover that you could listen?

Carole: I had periodically tried at various times and I got a car which had the free trial to the Sirius XM radio, which has the classical station because I'm like the classical music geek. And I said, well, here it is. Let's try because I can turn the volume down and see how it works. And it's like I could do this, only on roads that I knew very well. If I was a little bit tired, no, it's got to go off. If it's raining or snowing, no, it's got to go off. But it was just, and a lot of the pieces, I know the kind of music well enough that I know where it's going to go and it's not loud enough that any random cymbal crashes or loud brass playing is going to frighten me. But just to have that back is huge for me.

Diane: But that's another area that affects how you are in the world. You talk about being really tired, having the brain fatigue. So, before listening to music in the car, what kind of a reaction did that cause in you?

Carole: I have a \$10 word for the day. The hyperacusis, the sound sensitivity. I hear things as much louder than they really are. It's caused an overwhelming sense of overwhelm. It overwhelmed my system that it goes beyond just, oh, that's kind of loud to just, overwhelmed is the only word that I can describe it with. This doesn't happen anymore. But in the early days, I have fallen because of sound before, like a sudden loud noise and it would make me lose my balance, and over I'd go. Now I have tilted still because of the loud sound, but not actually fallen anymore. And it's this sort of like disorientation. If it's too loud, it's like I lose this sense of where I am in time and space almost. And it gets hard to talk. All of my symptoms will come out and I used to, I loved nothing more than being in a full orchestra with the orchestra, the chorus could be everything going on. I love being surrounded by sound, which is not something I can do anymore.

Diane: When we were talking yesterday about what we are going to talk about, you said that the music is still in you and you see that it comes out and how you express yourself, how you write. What did you mean by that?

Carole: I think that even if you don't play an instrument anymore, I was a musician for like 23 years since childhood. That doesn't go away. That sense of rhythm, of cadence, of paying attention to the way that things flow and without even being aware of it, that comes out in the speeches that I write, that I pay attention to. How does this all flow together? How do the words sound together? I love alliteration. I like how words go together. That's why to root, to rise, and my Rs. I want there to be a rhythm to the words I write, the words I say. And I think that's the way that I can still be a musician. It's different than it was before. But that's an artistic piece of me that I think will always be there. And I'm very grateful that I had all those years as a musician to instill that in me that I can still get to use those skills. And I think a lot of adjusting to life with a disability is how do we take who we were and graft it onto who we are now? And how do we meld those two things? Because there are pieces

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of our old selves that are still very much there. And then we're also these new people because of our injuries or illnesses or whatever they might be. And how do we meld those two things? I'm still a teacher. I can't be in a classroom. I can't teach the ways that I used to teach, but I'm a teacher. Deep down in my bones, it is who I am. And since the brain injury, I have found ways to teach. It just comes out just like I find ways to be a musician. It is deep down in my bones. I think that's one of the challenges. The early years are about how we're different and adjusting to all those differences. And then as we adjust to that, it's like, well, how are we the same? And how do we marry those two things?

Diane: It's a long journey, though.

Carole: Yes, it is. And it's not an easy journey, and it's a journey that there were many, many, many times when I thought, I can't do this. This is beyond me. This is going to break me.

Diane: And you wrote about all those challenges in your book.

Carole: Yes. Because acceptance was so hard for me. I wanted to write something that could help other people on their acceptance journey.

Diane: And you couldn't do that until you had come to some kind of acceptance yourself?

Carole: Yes. And even beyond that than to have the, I guess you could call it wisdom to look back at my own acceptance journey and to find what are the pieces, what are the nuggets of wisdom that I can share with somebody else? Because it's one thing to go through it, but then it's a thing beyond that, to be able to describe it in a way that's going to help somebody else.

Diane: Did you do any kind of personal journaling at some point maybe you couldn't even think about doing that at the beginning?

Carole: Pre-injury. I had journaled for years. I've been like more than a year without missing a single day. And then post-injury, I would try to write. I could write a couple of paragraphs and actually not even that oftentimes, like a few sentences, and then I would just sort of trail off and I kind of abandoned it. I didn't date anything. I stuffed it all into a

folder because I'm a packrat by nature, which is good that I did because it basically was my that's the word I want, record kind of my acceptance journey, even though it was kind of fragmented. I do believe that journaling is a really helpful way to process things. But people process things through doing artwork, through doing posts on Facebook, through doing video blogs. There's all kinds of different ways that people can process depending on how they like to think about things.

Diane: I'd like to go back to the accident for a minute because I think it might be important to give people some information about concussion. You had a bad car accident, and I'm sure you had other injuries. How did the brain injury manifest itself? From what I know, sometimes those symptoms of a brain injury, they don't show up right in the beginning. They kind of gradually come along and have to be pieced together.

Carole: Yes. And that was definitely true for me. What's interesting to me now is the signs of the concussion, they were there early on, but they were missed and I was asked, do you remember everything? I constantly said yes, but it turns out I didn't remember everything. I thought I did. It wasn't until much later on when other people described accidents they had been and they talked about like, glass breaking and airbags going off. And I'm like, I don't have uh any memory. Still don't, of those things happening. They asked me, did you hit your head? I said, no, but my head hurt. But I didn't tell them that because that's not what they asked me because, in my kind of confused state, I didn't have the ability to extrapolate. My head hurt. Maybe I hit it. So now whenever I talk to medical professionals, I always especially students, I talk about those experiences and how asking the right questions is important.

Diane: Do you know in retrospect, probably, what part of your head got hit?

Carole: The left side? Okay. Because I got hit from the left side. I'm guessing I hit the when it hit the windshield, but I think it was really a glancing blow. I think this is just my guess because the car also spun 180 degrees, and I don't remember that either. I only know that from the accident photos that I saw later on that I think a lot of the damage was done by the spinning.

Diane: Sure. So your brain, they talk about how the brain sits in this bath of fluid, right? And so there's a little bit of room for it to be bouncing all over the place.

Carole: Yes. It was actually the first physical therapist that I saw who recognized it was for the whiplash, I had a pretty severe case of whiplash who recognized that there's more going on here than simple whiplash. And they talked to my doctor who said, yes, you have a concussion, a quote, mild traumatic brain injury. You should recover. For whatever reasons. I am part of the minority, 15% to 20% of people with the quote, mild traumatic brain injuries. I hate the word mild, who go on to have long-lasting symptoms.

Diane: What were your other injuries and you've recovered from all of those?

Carole: Yes. Well, it's interesting because covered from the whiplash, there was a fair amount of trauma, like to my left-hand side that I didn't really even appreciate until much later. My body actually hid a lot of the injury from me. It wasn't until years later I started having pain and I started having flashbacks to something that I don't remember body flashbacks. My body remembers the injury in ways that my cognitive mind does not. So, I've been through a long process over the last quite a number of years now of releasing some of the trauma. And as I've done that, it's helped my brain, it's helped my body to process kind of what it went through because I didn't do fight or flight after the accident. I did freeze. I just sat there. I didn't cry. I didn't shake. I did nothing. I didn't feel it. I was just numb. And I've learned later on that that's a little problematic. I had basically 50 miles an hour of energy that went into me, and it didn't come out. So, it got stuck in me. And so your body can adjust to that for just so long, and then it's going to give you pain. So, I've been very grateful to have help from a whole team of talented people in a variety of disciplines who have helped me to process that.

Diane: You helped found a brain injury support group.

Carole: Yes.

Diane: And that is where I'll bet an abundance of support came your way. And that you also give to other people.

Carole Yes, absolutely. Because it's so important that this injury I mean, it can make one feel so alone that because so many of us, we look just fine, and it can be hard for friends and family to understand what's going on. So, to have a group of people who get it, who when you say I'm tired, they know what you mean. They know that you're not talking about end of the day tired, but you're talking about brain fatigue. And they know what that means, or that if something is really loud or I'm sensitive to light all of those sorts of things, that having those folks and it's having that community, we all need community. People who get us and support groups provide that for others.

Diane: Is this support group still in existence?

Carole: The wing support group is yes.

Diane: Okay. And I will give information at the end of this piece about how people can connect. I'd like to talk a little bit about that physical therapist who noticed some things. What were they?

Carole: To be honest, I'm not sure because I was barely out of it at that time. So I don't know. My memories of that sort of early time are hazy.

Diane: Did they do some cognitive tests just to see how you were?

Carole: I didn't get to brain injury rehab until nearly a year after my injury because I basically and I kept thinking, well, I'm going to recover. I'm going to get better because they told me that I should get better. And some of that was my own stubbornness of not wanting to, like, just believing that I'm going to get better. It was a physiatrist who I saw who actually referred me there because I was not getting better. I had tried numerous times to go back to work. I could never manage more than, like, just a few hours a week. I just kept thinking, I just have to push through this. I just have to get it out of the way.

Diane: So, you had that interfering with your ability to work. You had your orchestra.

Carole: I tried to attend a rehearsal. I lasted just minutes. I couldn't do it because the sound was so loud. It disoriented me enough that I forgot how to get home.

Diane: Wow.

Carole: My stand partner had to leave the rehearsal, too, so she could drive me home.

Diane: And even playing the violin in the quiet of your own home doesn't work because the noise is right there?

Carole: Yeah, the noise is right there at your ear. And I tried in the pandemic they had they had a lot of Messiah singalongs. So I said, oh, I'm going to look at this. This is perfect for me. I'm going to try this. But what I discovered is and even all these years later, I have trouble following this score. I can still read music and everything, but the music goes too fast. That constant having to track with your eyes and going back and forth and following the score. And I was like, this isn't fun. This is too tiring. And I know that piece. I had sung that piece a whole bunch of times and played it, too, but it's like, no, it was probably the same reason why I still struggle with reading that kind of eye-tracking.

Diane: I was wondering about if you're asking your brain to perform different kinds of tasks at the same time, it doesn't appreciate that maybe?

Carole: Yeah, probably. I really thought the only thing holding back the music was the sound. But I realized trying these virtual things, it's like, okay, that's not the only issue. It was a little disheartening, but it is what it is. And it's good information to have.

Diane: So, I'm trying to imagine what it must be like to be in that situation where we're always discovering new things. But the things that you were discovering were not so great. In those early years, did you just keep discovering things that you couldn't do anymore or you couldn't do the same way?

Carole: Yeah. And they were so surprising to me. I remember at an early support group um meeting, I volunteered to write some stuff on the

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whiteboard because I was a teacher. This is what I used to do. I was horrified that I couldn't do it.

Diane: Why?

Carole: I couldn't keep up with the conversation and write what was being said. I lasted like a few minutes, and then they had to find somewhere for me to lie down.

Diane: I can remember when we first met, probably in those years, you're talking uh about going to events, maybe. You laughed about it, but walking from point A to point B and being so exhausted, you had to find the nearest thing, I think, was a park bench to take a nap on because you just couldn't go another step. You're far beyond that now? You still need naps, but?

Carole: Yes. But I think that my days of having to rest in public places are done. I have not had to do that in a while. Of course, we've had a pandemic in there, so I have not spent as much time in public places as I used to. So, I guess we'll see when I eventually get to travel and speak again whether that's true.

Diane: The tide did sort of turn, maybe not dramatically or quickly, but instead of just experiencing one negative thing after another, you began to realize that there were things that were either improving or that, oh, I could do this. How did that transition happen for you?

Carole: It was mostly a matter of finding those things that I could do. And it all started with a paint by number, with a little voice inside me that was saying, make something. Which was really strange for me because I was not a person who made things. I was somebody who taught, who did music, and all of a sudden I wanted to make things. And I tried to ignore that voice for quite a while because that's not who Carole is, not who old Carole was. But it was who new Carole was. I went to Michael's once, got overwhelmed, left in tears, because I couldn't figure out what to buy. And I talked to a friend, and she said, well, try paint by number, I think because her daughters were doing paint by number at the time. So, I went back, got to paint by number. And I loved that little thing. It's like I can only do it for 15 minutes at a time. Then I'd

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be tired. And if I'd take a nap afterwards. But I like seeing the colors come together. I liked feeling successful at it. And then it's like, after that, I did another one. Well, what else can I do? I got into making jewelry that other people saw the jewelry I was making and said, well, would you make something for me? And suddenly I wasn't just this pile of need anymore. I was somebody who made things, people who wanted me to make things for them. And then I started to teach other brain injury survivors through the support group how to make jewelry. And it all began there that I had to start really, really small with that paint by number and build from what I could do. That when I was trying over and over again to do things that were just beyond me, I just kept failing. And that just did a number of my self-esteem. So, the only way to rebuild was to start tiny, tiny, tiny. And whenever I talk to people now, I say, you don't know where you can go if you just start with one little thing, don't worry about where it's going to end up. I had no idea when I tell people, I draw a straight line from the fact that I did a paint by number to I give keynotes., I wrote a book, but I had no idea when I did my paint by number, where it was going to go. It was just I liked doing it. I felt successful. I'm like, all right, well, what's the next thing I want to do? And it goes from there.

Diane: That's pretty amazing because you can see where somebody might stop there because, well, gosh before my injury, I was capable of doing scientific experiments. But you're saying you've got to start somewhere. You've got to reach a point where if you want to go forward, you almost have to go back to the beginning.

Carole: Right. And it's that finding success, whatever that might be, however small that might be because that's what you can build from if you keep having failure after failure, that's a house of cards. You can't build anything from failure after failure after failure. What you can build from is successes. Those can build on one another.

Diane: So this book. That had been floating around in your brain for a while, hasn't it?

Carole: Yes. I have wanted to write a book pretty much my entire life. Never imagined that having a brain injury would be the reason why I

wrote a book. And there were a lot of years, a lot of times when I thought, I can't do this, I did give up on it for a very long time.

Diane: You mean after you started writing it?

Carole: Yes.

Diane: Did you know from the get-go, though, you wanted to write this book about acceptance?

Carole: No. I started writing, it was roughly five years or so post-injury. And I knew the format early on, that I wanted to write short chapters because a lot of brain injury survivors, myself included, don't have attention span, can't read very much. I wanted things to be short. Each chapter would be self-contained. I wanted there to be questions at the end, kind of so that people could think about ideas. But I didn't really know exactly what the topics were going to be. Was it going to be a whole bunch of different things about brain injury? Was it going to be about symptoms? I wrote a whole bunch of, some essays were done, some were half-finished. Some of them ended up in the book. Some of them like, nope, doesn't fit. I didn't have an overarching theme to it, and I couldn't seem to. I didn't have the wisdom yet. Five years ago, I hadn't even figured out my own acceptance journey at that point, and I didn't have the wisdom to help anybody else. I was still figuring out for myself what life with a brain injury meant. And so I wasn't ready to help somebody else. The writing was more for me than it was for anybody else, which is fine. That's a good reason to write. But it wasn't a good enough reason to try and publish something. I wasn't ready. I didn't know that then. I thought I was just giving up. I just thought I couldn't do it.

Diane: How did you know when you are ready?

Carole It was after I did my second keynote on Resilience that it literally felt like a lightning bolt kind of idea because at that point, I had done a number of keynotes. I had been leading Brain Injury Voices and the support group. I had done a lot of things, but that book was sort of still in the back of my head, and it was just kind of there in my head all of a sudden. Acceptance. That's it. That's the glue that holds this together.

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That's my subject right there. I didn't have a title for it until it was practically published.

Diane: And the title, did that come to you like a lightning bolt?

Carole: Well, it was a process because that title comes from a poem. It's the next to last line in one of my poems, actually one of my early poems about acceptance. And for a long time, the title of the book was going to be A Change of mind. But then somebody else wrote a brain injury book with the same title. It's like, okay, now I have to find a different title. So, then I had no idea for the longest time. And I worked with a writing group of other brain injury survivors, and we had gotten together doing a writing retreat, and we were just kind of like batting ideas around and just phrases and things that kind of captured the book because the book was almost done at that point. And one of the phrases that we were batting around was say yes and rise. So I took a walk, and I had that phrase in my head, and I just kind of like, walking and saying, say yes and rise, and all of a sudden To Root and to Rise. That phrase from that poem from years ago, all of a sudden came into my head and I stopped in my tracks like that's it, that's the title of the book. It describes the acceptance journey, that first, we do, we have to put down those roots of who are we now? We have to plant ourselves and find our ground before we can then rise up and help others and find out who we are, all of those sorts of things.

Diane: By the time that you figured out the name, which is a wonderful name, and the book is nearly written, and then you get it published and suddenly five years have passed. You were already doing keynotes, but were you in greater demand?

Carole: Yes, because the book came out in 2017. I hadn't really done, like, national yet. I was just beginning to kind of break into that scene. That has helped with doing more keynotes on the national stage, that I have been able to travel to a number of states, like pre-pandemic. And now with the pandemic, I've mastered the Zoom keynote. I have traveled um all over the country without leaving this room.

Diane: Look at you. You were a teacher, so you did like a form of public speaking. But were you somebody who liked being on stage, being the star?

Carole: You know, I kind of do. I'm an introvert by nature, but I do like public speaking. We did public speaking in junior high. I loved that class. I like pulling something together, figuring out how I can make something work for an audience, how I can take my experience and turn it into something that's valuable. That is more than just my story, but there's a message to it. It's the same thing with the book that I didn't want to just tell my story. I wanted to use my story, yes, but I wanted to make it bigger than that so that other people could see themselves in what I wrote, that other people could use what I wrote. And I do the same thing in my keynotes, but I try to make them useful for other people.

Diane: And who are your audiences?

Carole: I speak to brain injury conferences. I speak to support groups. I speak to student groups, particularly like University or graduate students who are going into various health professions.

Diane: And before the pandemic, you were going in person? That must be challenging. How did you handle traveling?

Carole: Well, I can't travel on my own because there's just too many risk factors in terms of, one loud sound, too much going on could make my brain injury symptoms come out and put the keynote itself at risk. So, I have friends who travel with me. I have one friend who travels when I fly and a pair of friends who travel with me when we drive. And so I use my honorariums that I get when I speak to pay for their expenses and we get to have a little trip.

Diane: Are you able to earn any kind of an income from doing public speaking now and from your book?

Carole: Very small. It's not like a living kind of income. It is a little bit of fun money, basically, which is nice. I called my business Starr, Speaker, Author, and to be able to have this micro business, it means the world to me because I lost my career when I was 32 years old. So. I didn't get the chance to build something. It doesn't matter that I don't make very much

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money at this because I can't. It doesn't matter because it's all about how I feel about it because to me it feels like I'm working a 40 hours job, which is nowhere near that. But it has that emotional feeling to me because I created this.

Diane: You truly created this from your heart, your gut, your brain. You put everything into this.

Carole: Yes. And I'm so grateful for all the help along the way because I didn't get here alone. Family and friends and medical staff and writing group, all of us to get anywhere. We're all a group project.

Diane: You briefly mentioned something about how people with brain injuries, you don't see the injury. I would like to speak to that. Along the way, have you had people who perhaps questioned you? You look fine. What do people say and how do you deal with them?

Carole: There's a phrase that we talk about a lot in the support group, but you look great. And I can laugh about it now that if I'm in a situation where I think that Brainhilde might come out because I will tell people that I've had a brain injury, here's what will happen. And I can see it in their eyes. I can see that they don't believe me because how is it that she's saying these things but it just doesn't jive with them? But then something might happen. There might be a loud sound, something goes on longer than anticipated. I started to get tired and everything that I said happens and they say, oh, now I see what you mean. It used to bother me that I used to try and convince people I really don't anymore because it's not about them. Whether they believe me or not is not, I can't control that. I can say my peace and then the rest is up to them.

Diane: Brainhilde. I'm glad you brought up Brainhilde. I'm familiar with Brainhilde. I have not actually met her personally. I might have seen hints and not realized it, but Brainhilde is like the composite of all the symptoms that you get when you push yourself too far? So, introduce us. At least list her. You don't have to bring her out.

Carole: Yes, I named the injury because some of it feels like there's me, then there's a brain injury. I got two people living in my head and my brain injury, she's a diva. She gets what she wants when she wants it.

She's the one in charge and so I said well let's give her this sort of dramatic kind of a name Brainhilde and so that's kind of my shorthand for talking about it with family and friends maybe my medical team. they all know about Brainhilde. I've completely anthropomorphized this thing but it is a shorthand way of describing like oh, Brainhilde's in the building. That means I'm starting to feel the pressure in my head. It's getting hard to talk. I feel like I'm going to need to lie down to all of those.

Diane: Can doing an interview like this, we've been talking for quite a while.

Carole: I feel it now so we should.

Diane: So, we should wrap it up pretty quickly because I don't want her to rear, I really don't. I'll give you the final word then before Brainhilde comes out. what is it that you hope people will get from this conversation that we've had?

Carole: I think if there are brain injury survivors who are listening to this knowing that you're not alone, knowing that there are others who are going through this and for anybody who's dealing with a major life change knowing that dreams aren't dead, that they might be changed, that life might not go in the direction that we thought it was going to go but different doesn't have to be bad. It's just different. That life can still be rich, meaningful, purposeful, even when it's dramatically different than what we thought it was going to be.

Diane: Well, I didn't know you before you had your accident but I've known you for a while now. I think you're an amazing, inspirational woman. Thank you. Thank you for writing the book, thank you for talking to us and now, I guess you can go rest.

Carole: No worries. It's all good. That was fun.

Diane: That brings us to the end of this episode of the Catching Your Memories podcast. Many thanks to Carole for sharing her life with us. If you'd like to connect with her, visit her website starrspeakerauthor.com. Starr has two rs.

If you'd like to read a transcript of this episode, go to CatchingYourMemories.com/podcast. Be sure to come back in two weeks for another episode of Catching Your Memories.

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This podcast was created, produced, recorded, and edited by me ... Diane Atwood. Catching Your Memories — The interview of a lifetime.