Stroke Dialogues – Jeri Goldstein

Jeri Goldstein is the author of the book Stroke Dialogues: Conversations With Dad which she wrote after her dad who was 85 at the time, had his stroke and struggled with aphasia.

Website
Amazon

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Bill Gasiamis 0:00
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Jeri Goldstein 0:09
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Intro 0:52
This is the recovery after stroke podcast. With Bill Gasiamis, helping you navigate recovery after stroke.

Introduction – Jeri Goldstein



Bill Gasiamis 1:05
Hello, and welcome to episode 202 of the recovery after stroke podcast. Today's guest is Jeri Goldstein, author of the book stroke dialogues, conversations with dad, which she wrote after her dad who was 85 at the time, had his stroke and struggled with aphasia. In those frustrating, long-winded conversations, the family was able to find some funny moments. And those are the stories that she shares in the hope of bringing some awareness and lightness to what is a difficult situation for many families and their loved ones. Jeri Goldstein, welcome to the podcast.

Jeri Goldstein 1:45
Thanks, Bill. I appreciate you having me at this late hour of the evening for me, but I'm happy to be here.

Bill Gasiamis 1:54
What time is it there for you?

Jeri Goldstein 1:56
10:30

Bill Gasiamis 1:57
And where are you?

Jeri Goldstein 1:59
I'm in Florida and South Florida, north of Miami and South West Palm Beach. So smack dab in the middle there.

Bill Gasiamis 2:10
Sounds amazing. I'm in Melbourne, Australia. It's 12:30pm here. And it's one day after you?

Jeri Goldstein 2:20
Yes.

Bill Gasiamis 2:21
So welcome to the future.

Jeri Goldstein 2:23
Thank you. And I know this because I have a coaching client who lives in Queensland. Yeah. And she would always attend my groups, which would happen at three o'clock my time, Eastern and it would be four o'clock in the morning or five o'clock in the morning depending on eastern daylight or whatever's Eastern Standard. And she would always be getting up very early. And I also have a cousin who's moving to Melbourne.

Bill Gasiamis 3:00
Well, that's very cool. Melbourne's good place to live. It's an amazing place to do. You're on the campaign trail to promote your book stroke dialogues, conversations with dad. Before we talk about the book, I love the way that you've just set it up in the background there. And you're making sure that everybody can see it. I love it.

Jeri Goldstein 3:25
Yeah. I thought that since the book, right now, as we're talking today. I don't actually have a physical copy of it yet. I mean, they sent me a proof copy, but they have a great big gray banner, right across the title. So it does me no good, but I did my graphic artists and web designer got me a file. So I was able to print it out so that people could actually see it was a fun thing to do.

Bill Gasiamis 3:58
Yeah, well done. You've got an interesting background. We'll talk about that in a little while. But tell me a little bit about the stroke that your dad had and how you became interested in having a conversation with people via a book about that situation that your dad found himself in?

Jeri Goldstein 4:21
Sure. Well, it came about that in 2012. I get this amazing phone call at 10:30 at night from his then girlfriend that said your dad's had a stroke. And I was not in Florida at the time I was living in Virginia. So having that kind of a phone call late at night was like oh my god, what now and what can I do all the way here not being there?

Jeri Goldstein 4:55
And my dad was an incredibly active, vibrant, creative and, functioned really well in the world. And so the thought of on my side thinking that he had a stroke, I just

could imagine all the things he was going to be upset about, not being able to do any longer, depending on what the outcome was, which at 10:30. At night, we didn't know what was going on. We didn't know what kind of a stroke, we didn't know how serious we didn't know anything. So that started the ball rolling.

Bill Gasiamis 5:44
So how old was your dad at the time?

Jeri Goldstein 5:49
He was 84 going on 85.

Bill Gasiamis 5:55
Okay. So, you know, when I hear about somebody having a stroke at 84 85? It's like, if that's the right territory, that's kind of the right time when you hear about it. And all the young people that I know who have had a stroke, always say, I thought that stroke only happens to older people. And they get really caught unaware. So when you heard that your dad had a stroke, it's clearly not a nice thing to hear. But is it something like "okay, well, that kind of makes sense" or do you go into the same denial that we went into? Because he's your dad, you'd love him in regardless of his age, but you're not connecting stroke to his life?

Jeri Goldstein 6:45
No, I mean, I'm not connecting stroke to age, you know, I've gotten a lot of friends and musician friends in particular, who have had strokes very early on in their career, early on in their lives. But the immediate thought was thinking about the people who I personally knew. So that was my grandmother, who had a stroke at 80 something.

Jeri Goldstein 7:15
And it was my cousin who had a stroke, maybe at 60 something, and was very alone during the time when she had her stroke. So it was going to be a 20 to 25 year period, that she would be riddled with the results of the stroke. Because nobody got to her in time. Like they got to my dad. I mean, within seven and a half minutes, he was at the hospital.

Bill Gasiamis 7:54
Yeah, right.

Jeri Goldstein 7:54

You know, getting TCP, and so he was in the prime window of opportunity to make this be as less harsh as possible. If that could be the term.

Ischemic Stroke

Bill Gasiamis 8:14
Oh, yeah. Well, that is a term. I mean, that's less damaging or less harsh. And what was the cause of the clot that occurred?

Jeri Goldstein 8:26
It was an ischemic stroke. And so, I don't know that they know where it came from. At least, I don't know that we ever got that information. But it was left brain, right side of the body. That was affected. Right. Okay, as well as the expressive aphasia.

Bill Gasiamis 8:56
Okay. And then, were you able to get to him rapidly? When you found out, were you able to be with him immediately?

Jeri Goldstein 9:07
Well, it took me a couple of days to get down there because I heard about it on Sunday. We didn't know what was going on until Monday morning. And then I had to make plans because I had to figure out well, am I flying? Am I driving? How long am I going to be there? What were all the scenarios that I had to figure on in order to possibly stay for a long time?

Bill Gasiamis 9:37
Were you the only family member?

Jeri Goldstein 9:40
My sister did fly down. So it was my sister and myself, we were there, but I got there Wednesday, so it happened Sunday. I had a drive and like finally got there by Wednesday and then my sister flew down and she was there Wednesday also.

Bill Gasiamis 10:04
What's it like seeing your dad in that situation, the first time that you saw him?

Jeri Goldstein 10:10
There he is, in the room right past where my mom had passed away, in the

hospital cubicle. And there was Dad looking small and scruffy not having had his beard shaved. And so that always makes somebody look worse. But he was in good hands. He was in the ICU when I saw him. So intensive care unit. There were lots of people around, so he was being attended to. And then he also had lots of friends that were here in the community, so that he was able to have lots of visitors.

Bill Gasiamis 10:57
Was that a good thing?

Jeri Goldstein 11:02
That was a good thing, because he doesn't like being alone. And it was a good thing, because people who knew him could advocate on his behalf, they could say things like, well, I know him. He likes this, or he doesn't like that, in terms of food choices and those kinds of things. And he didn't feel so alone, compared to how alone he was feeling in his head because he couldn't express himself.

Jeri Goldstein 11:35
You know, at that moment, words, were not coming out that he was thinking they were all you know, the term that came out was plus. Everything was plus. People were plus, everybody was plus, and there were N numbers. Everything was a number. Except for me. He always called me baby. And I was still baby.

Bill Gasiamis 12:10
Wow. That's awesome.

Jeri Goldstein 12:12
It was weird. I never was so excited. I mean, I was very excited to know that was still there. But everybody else was plus one plus two.

Bill Gasiamis 12:29
It's such a strange situation. And I remember my godfather passed away probably two and a bit years ago, and he was in his 80s. And he had a brain tumor. And it was a non-cancerous tumor, but it was just growing and as a result of its growth, and being inoperable, caused every part of him to slowly just stop working. And even though he was on his feet, and able to kind of appear upright, and all that type of thing. He wasn't able to express himself.

Bill Gasiamis 13:05

And unfortunately, the only word he knew, and the only word he would use for everything was a four letter word that starts with F. And it was kind of interesting, weird, strange, funny, sad, all at the same time having to spend time with him, and get him and hear him somehow try to express himself. And that's the only thing that came out was just so strange and difficult to hear you know.

Jeri Goldstein 13:47
Oh, very difficult and very difficult to try to steer the person into some other form of communicating. I'm sure.

Bill Gasiamis 13:59
Yeah. And of course, it's abrasive when you hear that word. I mean, oh, no, I'll say it now. Fuck is abrasive to hear for everything.

Jeri Goldstein 14:10
Right? Every word, every sentence, everything.

Bill Gasiamis 14:14
Every response, every request that's made of him for everything. It's just really abrasive. And it's shocking to hear that coming from him. And then you kind of have to reconcile that and go hang on a sec. This is not the conversation that's happened. It doesn't mean how it's being said. But none of that is relevant. It's just a noise that's coming out of his mouth. And for some strange reason. That happens to be the only noise.

Dealing With Aphasia – Stroke Dialogues

Jeri Goldstein 14:46
Yeah, but I mean, you can imagine I don't know your experience, were you affected by aphasia?

Bill Gasiamis 14:59
I'm not that kind, not in that sense, I was unable begin sentences and finish sentences. At one point in time, I didn't know what I was trying to say. I knew what I was trying to say I couldn't find the words at some point. But it was only for a small amount of time. So my experience was it's really hard for me to even connect to it. It was that long ago, and it was like for such a small amount of time, but it was in the months.

Bill Gasiamis 15:32
And I would get frustrated with my wife because it was so early on for us and didn't understand what I was going through. She'd be waiting for me to finish or start a sentence and be going. Yeah, come on. Yeah, cut it out, spit it out. That was really the hard part is dealing with her reaction to me, because she was completely ignorant about what might be happening. And of course, I didn't actually know what was happening. And what the issue was, because I wasn't diagnosed, I know that I experienced that now. Because I've spoken to so many people about it, and I've reflected on my time. But I wasn't officially diagnosed, because I didn't actually get a neuro psychological assessment, which is the one that tests your cognitive abilities.

Bill Gasiamis 16:30
And I was struggling for about nine months to a year. Just to understand where my cognitive abilities were. And that meant that I had to deal with the speech issue, I had to deal with not being able to type an email read, drive, work. And it wasn't through lack of physical ability. It was all at that time, it was through lack of cognitive ability. And nobody recommended anything to me about getting a baseline for where I'm at, so that I can get some help. I was missed completely.

Jeri Goldstein 17:16
Because one of the things that you mentioned is, about your wife, wanting you to finish a sentence or start a sentence. And I noticed that a great deal with visitors, friends that would come, that would want to visit and ask questions, and not really have a sense of how dad was or was not able to respond or complete a thought. And my sister and I was always trying to get him to work at it, to get to his own conclusion, to think it through if he could think through the lack of language capability.

Jeri Goldstein 18:16
But others wanted to just fill in the blank, like, if they would ask a question, and they knew the answer, they would just fill it in for him. And I found myself being kind of a director of like, "no, no, let dad work at this", you know, give it a few minutes. You don't have to fill in the answer. So it would be teaching, not that I knew what I was doing. But I would just intuitively think he's got to work it, he's got to come to this conclusion. And if it takes a day, if it takes all week, we've got to work it with him. And allow that moment of recognition to happen, no matter when it happens.

Bill Gasiamis 19:07
It's such a terrible habit that people get into, and they do it to children. I know a lot of the people who I hang out with that have young children, and you'll go over to their home, and you'll have a chat. And then you'll see the child and you'll interact with a child. And then you'll say hi, how are you? And then the parents answer.

Jeri Goldstein 19:32
Similar thing, yeah.

Bill Gasiamis 19:33
And it's like, shut up, don't answer for your kid.

Jeri Goldstein 19:36
Give the kid a chance. Right? Yeah.

Bill Gasiamis 19:39
Then I'll say how's school and then they'll answer and then they'll say, oh, so my kids a bit a shy, because your kid doesn't need to speak because you're speaking on its behalf. You really can't say that to them, either because that's a bit rude or whatever, or they might take it the wrong way. So you try and navigate that. And I often get kids on their own, I'll try and get them just where their parents are distracted for a moment and just interact with them, and even if it takes a long time because they are shy or whatever. Or they don't know how to answer. Okay, no problem. If you don't want to chat, then you don't want to chat.

Jeri Goldstein 20:22
Right. But I know with this situation it was, knowing full well that everything was locked in his mind that he knew all of the questions to ask. And he knew all the things he was trying to get to, but didn't have the facility of words. And the ability to put the words together because they just weren't coming out, or the sense of, time or what things were or how do you touch your nose? What is your nose? What are those things?

Jeri Goldstein 21:07
And, for me, it was just sad, but also a challenge to keep working at it, and be there to keep the conversations going. And so that's when all these funny conversations came out of him just trying to get to his answers for all of the missing links that add missing pieces, and understanding all of this stuff.

Bill Gasiamis 21:42
Yeah. So how long was that in hospital?

Jeri Goldstein 21:48
From about a month and a half, that included rehab, so about a week in the hospital, and then the rest of the time was in rehab and doing the rehabilitation.

Post-stroke Deficits

Bill Gasiamis 22:02
And then when he went home, I imagined he was still left with those challenges communicating, was he dealing with any physical deficits?

Jeri Goldstein 22:12
Yeah, his right hand. He couldn't use his right hand. And he was right handed. So most of the challenges, he started coming back with the cognitive. And speech started to come back. In the hospital, he regained his sense of time, regained his sense of how to do certain things. I worked with him and other people worked with him all the time, his conversations became more fluid, but he still had to work at it. And he did speech therapy for almost a whole year to get back to the real life situations and what things meant, and how do you say these things, and then learning how to do everything with his left hand.

Jeri Goldstein 23:13
And I'm sure you've spoken to lots of people who had to just swap over, and so writing with his left hand eating and then of course, not having the two hands, so having other people do stuff for you, open packages, cut your food, so there's a part of it, that was also embarrassing, not being able to have a full facility of what you knew before, and to have to constantly depend on people.

Bill Gasiamis 23:52
And does that also mean that he had tell people to shower him and toilet him and all that type of thing?

Jeri Goldstein 24:00
Yeah, we had an aide that was helping like eight hours a day, and to take him to doctor's appointments and rehab and all of that. So yeah, I was very fortunate that we were able to have a fabulous aide to work with dad, and also helped him with his speech therapy homework. And he worked hard every single day. He

worked for hours and hours at both exercises, dexterity exercises, physical exercises, as well as speech and cognitive exercises.

Bill Gasiamis 24:41
So it sounds like he had a really good recovery mindset. He was really keen

Jeri Goldstein 24:49
After a while, I mean, he was very depressed in the hospital and had to actually get him some anti anxiety meds in order for him to be able to do the work because he was depressed and upset, but when he got home, he was determined, and I was in awe of his determination and how enthusiastic he was to do the work that was required.

Bill Gasiamis 25:29
Was he having emotional outbursts? Did you notice any changes in his emotional expression?

Intro 25:36
If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like, how long will it take to recover? Will I actually recover? What things should I avoid? In case I make matters worse, and doctors will explain things. But obviously, you've never had a stroke before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery.

Intro 26:08
If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery, head to the website. Now, recoveryafterstroke.com and download the guide. It's free.

Jeri Goldstein 26:38
In the beginning, he was crying all the time. And it was super frustrating because he couldn't even push the call button for the nurses to come. And then when they did come, he couldn't tell them what he needed. So that was super frustrating for

him and difficult. So that's why we had to advocate a lot to make sure that he was close to the nurse's station. Instead of being stuck in the room when they first put him all the way down the hall, so that he would be totally alone. So being right in front of the nurse's station, he could just call out in some way, shape or form.

Jeri Goldstein 26:38
Yeah, that's a good move. Actually. I like that one. And it's lovely that they that facilitated that. That's excellent. Yeah.

Jeri Goldstein 27:40
Yeah, I mean, it was an important thing before we even left the hospital first day they moved him to rehab, we definitely had to make that happen. Because it was so evident that he's just going to be stuck there.

Bill Gasiamis 28:00
Yeah, that's really good. I like it, I like that's just a such a different look as a simple thing, but it's such a great approach, just to solve a problem, it's a massive problem, you need a really effective and simple solution. And all it went was just moving his bed, so he can physically express that he needs a little bit of help, because he can't do this other thing, which is press a button or move himself in the bed to get attention that he needs. It's genius. It's so simple, logical and genius. And yet, probably overlooked many times.

Jeri Goldstein 28:42
Yeah. I'm sure. And I can only feel for people who might be in this situation, but that don't have family members. Or don't have the kind of support system that thankfully dad had. And being alone in that situation. You can't express yourself to advocate for yourself. And so you're relying on the medical professionals to help you in whatever way they can. But if you can't express yourself, they're doing things as they know, that need to be done, but not necessarily targeted for that particular person's needs. So that was challenging, but we've had to come up with things on the fly all the time.

Bill Gasiamis 29:41
Yeah, I get to coach people on their recovery journey. And one of the people I've helped in the past was probably in their 70s. And at that time, there's a sense for that particular person there was a sense of, kind of life is almost over and what am I working for? And what am I trying to achieve and overcome? Did you get a

sense for your dad what it was that he was working towards, in his early to mid-80s? What is he striving to do? And achieve and get back to or recover for, what was his reason for recovering?

Jeri Goldstein 30:30
Well, mom had passed a number of years prior to him having his stroke. And he had gotten into a new relationship, even at that age with his longtime friend who also had lost her husband. So they were together, and they were having a great time. They were playing bridge, they were good at it, they had a whole group of friends. And dad, he functioned brilliantly, he would learn computer programs, he was helpful to all of his friends and neighbors, he did everything for himself, except cook, cooking, not cooking.

Jeri Goldstein 31:20
But he was really able to do math, to do with finances, to do everything. And so there was a period when the therapies were done, he was home, it was kind of going towards March or April, I was still decided to be there. And I sat him down, and then said that, let's set your goals for full recovery, what does that look like to you? And what would be helpful for us to know, to help you do so you can reach whatever goals you want.

Jeri Goldstein 32:05
And we just sat there for a good couple of hours and he made a list of the things that he wanted to get back. You know, he wanted to get back use of his right hand, he wanted to get back to doing puzzles in the newspaper, he liked to do the word puzzles in this Sudoku. And he wanted to be able to clearly you want to be able to play bridge with his bridge group. That was a big thing. And he wanted to be able to do math, he wanted to use the computer and use a mouse and things that normally, he wanted to be able to do the dishes again, and iron his clothes.

Jeri Goldstein 32:53
So all the things that were, that make up a life that you do on a daily basis. And these were his goals. These were things that we put on this sheet, this newsprint sheet and magic marker with circles, I call it cluster brainstorming. Or that's the term for it. And I do this with my clients all the time, like coaching clients and musicians, but I just said, this is something that he could do. And then we hung it on the dining room wall when we were finished with the sheet. So that we could we could see it every day. And he could see it every day.

Jeri Goldstein 33:35
And we would check off the things that were being accomplished. And it gave him a sense of purpose. It gave him a sense that he was accomplishing things that were near and dear to him. You know, it wasn't like, "Oh, Dad, you should do this". It was what he decided to do. And I thought that, that was extremely important for him based on knowing who my dad was, and knowing how he was clearly driven to get back to himself.

Bill Gasiamis 34:12
Yeah, that's inspiring. That's really good. Because, look, I know I mentioned the person that I was helping was in their 70s. And they were giving up hope. But people do that in their 60s and 50s and 40s. So it's great, that's a great example. And if anyone who's watching or listening feels that that might be part of their heading down the giving up path, there's really no reason to give up.

Bill Gasiamis 34:41
I mean, you might as well go for gold and have the best experience you can possibly have for the amount of time that you've got left. And you don't know how long that is. It could be short, it could be long. It could be a decade, it could be two. So let's just say assume that it will be and then go for it.

Jeri Goldstein 35:03
Do the best you can.

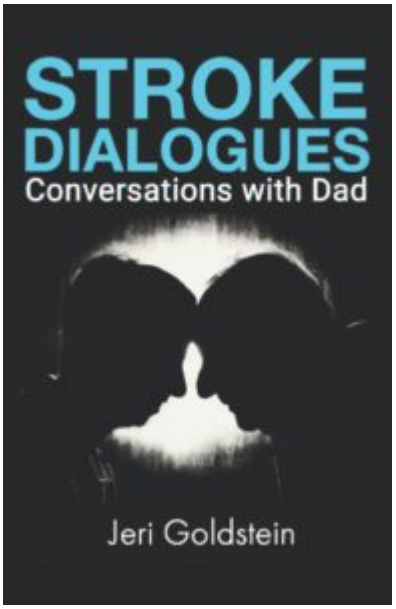
Bill Gasiamis 35:05
Yeah. You're a bit of a, well, I wouldn't say prolific, but you've written a few books and the books that you've written around the work that you do in the music industry and helping, performing artists in different ways. And I kind of understand the reason why you wrote those other books. So one of them says, going to have to be your own booking agent. That's a great thing to sell to a group of musicians is how to get gigs, right, I get that part of solving a problem. And that's your space. And then the other one is get great gigs. And that's your podcast. That's something that you do and help out people with.

Bill Gasiamis 35:52
And then you've got the tiny guide to huge success. And 100 Business boosting Hot Tips to ignite your performing career. And that title is the one that I like the best, because I relate to it, it says, the tiny guide to huge success. And that's

really what it is. Success isn't huge, because you've done huge things to get there. It's huge, because you've done a lot of little things to get there.

Jeri Goldstein 36:24
Absolutely. Step by step.

Stroke Dialogues: Conversations With Dad by Jeri Goldstein



Bill Gasiamis 36:25
Yeah. And I get how they all are great things for people in the industry that you're good at, or that you're working or that you know, like it's speaking to your niche. Right. But then you wrote a book about stroke. And I know your dad had a stroke, but it still seems a little bit out of the ordinary that books, Stroke Dialogues: Conversations With Dad. And before I get you to tell me why you wrote the book. Okay, what I want to do is, I want to bring up the copy. And I want to read a little bit of the introduction, or read the first paragraph to the introduction.

Bill Gasiamis 37:07
And it goes, you can never plan for the moment that upends your life. As you know it. Having a stroke is one of those life-changing moments for dad. That moment was terrifying. It set him on a path in search of the man he knew before his stroke. For me, it reconnected me to family and friends. Together, we began a journey, not of our own choosing. And without a roadmap, insight or knowledge.

Bill Gasiamis 37:41

We grew to respect each other's approach to the challenges ahead. Mostly we lived in a state of patience, and a vision for recovery rooted in optimism, and seeded with hope. That's a really lovely, succinct way to explain what I would imagine most caregivers, family members, partners of stroke survivors go through.

Bill Gasiamis 38:16
Let's talk about that in a little bit. But now, why did you write the book? What was the purpose of it? What was the need for you to write this book, was it personal? What was it?

Jeri Goldstein 38:28
Well, based on the way that we were interacting while he was recovering, and the kind of back and forth, instead of playing 21 questions, we were playing 21,000 questions to get to the answer that he was looking for, and many of the conversations were hysterical. They were really funny. I mean, they were funny, not because, oh, poor dad, he can't express himself.

Jeri Goldstein 39:02
They were funny, because he worked so hard at it, and the back and forth was funny, they were interesting. They were intriguing. And then the final answer was, it's like, we had no idea where the conversations were going. I mean, he would start a conversation like one two, well, what is that supposed to do? And over the course of many hours, sometimes two or three days, we would get to the answer to the question, and I felt really compelled to just keep track of these, because I felt like they were gems.

Jeri Goldstein 39:46
It just felt like they were an interesting journal of his journey to discover the answer to these crazy questions that he was asking. And along the way, we learned a lot about how to communicate, how to ask a question, how to ask one question at a time instead of, so what do you want to do today? And, what would you like to eat and have bunches of questions in the same sentence,

Bill Gasiamis 40:25
Which is what I do in my podcast when I ask a question.

Jeri Goldstein 40:30
But in his case, he couldn't separate them out. And so it became really clear,

really early on, that we can't ask questions like that, that we had to ask one question at a time. And then the conversations got to be really long, because one question at a time, one answer a time, they get to be long,

Bill Gasiamis 40:57
Open ended questions or like closed ended questions?

Jeri Goldstein 41:00
Well, they may not even be questions that he was asking, they would be statements like, one, two, okay, now we have to figure out what does one two mean? What does it mean to him? And so, "okay, one, two, what dad"

Bill Gasiamis 41:17
A little bit of decryption that has to happen

Jeri Goldstein 41:21
Totally decryption, and then he would start off another conversation would be once a day, every day, seven days a week. Okay. Now, what? We worked on that for three and a half days, coming up with, well, what does one do once a day, every day, seven days a week, and you come up with all the regular stuff. And then because he couldn't determine, okay, does have to do with this? And well, he doesn't know, because he doesn't know what that is. You know, okay, if it's this point to the place on your face, that it hurts? Well, you know, is it your nose? Well, he doesn't know what a nose is. Okay, so you can't point so capturing those questions and answer periods made me think God, there's something to this, I gotta write this down, I gotta write down these conversations.

Jeri Goldstein 42:30
So first, I simply started writing down the conversation. And then after a while, I realized, we went through this whole process, there's something here that might be useful to other people who are going through this process, as well. And so that's what got me to write connective tissue stuff, to write not only the conversations, but more information, but yet, it's not a medical book. I mean, I'm coming at this completely from, I love my dad, I wanted to see him get better.

Jeri Goldstein 43:13
So that's ultimately I started writing it very early on, like, the fall after he had the stroke, I started writing these, remembering these conversations before I forgot them, and asking other people to remember the conversations they had with him

that I wasn't there for. And, doing that helped me to pull together all the main dialogue, but then these other little bits and pieces of dialogue to which seemed important, they seemed important to his recovery, and they seemed important for the possibility that other people might relate. And they might benefit.

Bill Gasiamis 44:04
You work in the field of musicians or performing artists, is any of those performing artists, a comedian?

Jeri Goldstein 44:13
Some, I have some comedian. I mean, I have some comedians that I work with, actually quite a few.

Taking Stroke Lightly

Bill Gasiamis 44:19
Yeah. So one of the things that people get offended about is when somebody makes fun about stroke, or makes a joke about stroke, and I never get how people get offended at anything that a comedian says because you're going to actually experience a comedian's view of the world in a way that pokes fun at that thing. And that's what they do. That's kind of the stick right? That's what they do.

Bill Gasiamis 44:59
And I found that stroke's really funny. There's a lot of funny things that happened in my three brain hemorrhages, my brain surgery. And one of the funniest things was I felt after surgery. I mean, it was hours after surgery, maybe it was two or three hours after surgery. I'm in recovery, I've woken up and all that thing. And I've got a fresh, zipper on my head, where they've got I don't know 40 staples or something.

Jeri Goldstein 45:40
The new Frankenstein, right?

Bill Gasiamis 45:41
Yeah, it was pretty cool look for a little while. And then I come out of bed, because they've asked me to go to the bathroom. And I didn't know that my left side didn't work. And the nurses didn't know that my left side didn't work. So I came out of bed on my left side, which is what I normally do. But when I put my foot on the ground, my foot didn't know that it was on the ground, so I collapsed, it couldn't

hold my weight.

Bill Gasiamis 46:10
And that was scary, but hilarious at the same time, like, you come out of surgery, you can't walk. And the first thing that happens is you fall straight to the ground, and you're screaming with your butt hanging out onto the cold floor. And your head, could just as easily have been hit again, which would have been terrible. But now that I reflect on it, and imagine it making my brain leak out and all that kind of stuff. And it's horrific. But it's hilarious. I think at the time, it was hilarious. And another thing that happened that was hilarious was I was having my pre surgery, admission checkup. And we were going through everything, all the vitals or the paperwork and all that.

Bill Gasiamis 47:01
And we just finished that and we left. And we walked out the door. And as I walked out the door, I started to get a numb face, my entire face went numb. And I said to my wife, my face is numb, and I can't feel it. And she goes, let's go back into the hospital. So we turned around and we go back and we go to emergency but because of the procedures that a hospital works by, of course, I'm not just going straight back into the consulting room, I have to sit at the emergency section. And tell them what's going on. And they're gonna go through their whole process, and they just don't get it.

Bill Gasiamis 47:39
I'm a guy who just walked out of a consultation for surgery tomorrow or next week, or whatever it was. So anyway, and I'm sitting there. And while I was sitting there, there was a mum arguing with her son and her son must have been autistic or something like that. Though communicating fine. But she realized that he had gone to the toilet and not washed his hands. For number twos, and he was sitting next to me. So in my concern about me. And all the problems that I was experiencing physiologically from the stroke or whatever was going on in my head on that moment. It still wasn't bad enough. It wasn't that bad that it didn't occur to me that he might have something on his hand that I don't want to touch.

Jeri Goldstein 48:43
So you're thinking that yeah

Bill Gasiamis 48:45

I was afraid that as sick as I was, I still had the ability to get up and just get out of there and go to the other side of the waiting room.

Jeri Goldstein 48:54
That's so funny.

Bill Gasiamis 48:56
I think it's hilarious.

Jeri Goldstein 48:57
No, it's totally hilarious. In fact I have a musician friend who very early in her career, had a stroke, and then wrote a book about all the funny things that happened in the hospital. And had to reteach herself how to play guitar, had to relearn all the music, parts of her career, but that book really captured all of these kinds of incidences that go on, the open gown and all those kinds of things.

Bill Gasiamis 49:37
I know I've got a podcast and I interview people and there's nearly 200 episodes and it can be serious.

Jeri Goldstein 49:46
Yeah, it could be serious. But I mean, you look at how eloquent your speech is now.

Bill Gasiamis 49:52
It's all good. Everything's great. And I celebrate all those things. But what's the thing about it is that I could have a really difficult time interviewing every single person about all the terrible things that happened during stroke and how bad it was, and all that kind of stuff. And it's like, what's the point of focusing all your energy on how terrible and how difficult it all was? There's a lot of things that we could look at, if we look for the Silver Linings that we could reflect on, allow us to just ease the stress and the tension a little bit about all the stuff.

Jeri Goldstein 50:27
Which I think is why this made so much sense to me, is because these conversations were hilarious, you know, we would just be rolling after finding the answers. And going through all that we went through to get to the answers. And I really felt like, there needs to be lightness in this, you know, like, you can have so many, okay, do this kind of informational books.

Jeri Goldstein 51:02
But I felt like why not? Why not capture this? Why not share this to perhaps, in some way, lighten the load for some of the people that are thinking, Oh, my God, this is the end of the world as we know it. And so, that's part of the big reason why I felt like, why not? If one person gets something out of it, I did my job.

Bill Gasiamis 51:36
It helped you dealing with the seriousness of your dad's stroke, right?

Jeri Goldstein 51:40
Absolutely. I mean, the other piece of the puzzle that became very evident to me was having positivity, being positive no matter what was going on, with any kind of depression or negativity that I felt me and the people around dad, friends, family, we all had to come at everything with being positive, upbeat, to comfort him, to calm him, to make it be more likely that he would continue to recover, as opposed to being depressed by his depression.

Jeri Goldstein 52:31
So I felt like that was so important. I had come up with this, this little catchphrase for him in the hospital. I call it the five P's, when you're positive, and patient, what is it? I remember, it was like, so long ago that I couldn't remember what it was. And I had to, like, write it down, because it was a cool thing that got him out of his stuff. And I felt like that was important. Okay, when you're positive and patient, when you persevere and practice then anything is possible.

Bill Gasiamis 53:22
That's terrible thing to say to a stroke survivor who can't talk. It's a tongue twister.

Jeri Goldstein 53:27
I know. It's a tongue twister. And that's why I did it. Because I was trying to get him to practice his P's

Bill Gasiamis 53:36
I'm gonna have to write it down.

Jeri Goldstein 53:38
Okay, when you're positive and patient, when you persevere and practice, then anything is possible.

Bill Gasiamis 53:51
Fantastic. All right. I love that.

Jeri Goldstein 53:55
Go for it, pass it around, but I felt like anytime that I could come up with things that broke his concentration on oh my god, I can't believe I'm in this place. So I would always come up with these kinds of fun things and play games and try as much as possible to distract him from his stuff to get them to work and to see that maybe it's not so bad, and look, we're here, we're working at it, and having my dog there was a major benefit for him.

Jeri Goldstein 54:43
He loved the dog and I would as often as we could bring the dog to the hospital during his rehab. Couldn't go in because he wasn't a service dog even though he kind of was a self appointed therapy dog. But we can go in so dad would meet us, downstairs outside when he was able to do that in the wheelchair. And it just brightened his day all the time. And it was also a really great thing to say he respected the dog, sometimes more than he respected the people.

Jeri Goldstein 55:18
So like we would want to leave, to go home, to eat, or to go to sleep. As long as they said, Oh, we have to walk the dog, then it was okay to leave. But it was just like, I have to go home because I'm tired and I need sleep or I need to eat. He would try to pull up. We always caught him pulling a 8:55 thing where at 8:55, he would ask a big question that would require much time to answer the question. So we couldn't leave until we figured that out.

Bill Gasiamis 55:58
Wow. See, I like the way that you scammed him out of being there for a bit longer. Nonetheless, though, I'm not sure.

Jeri Goldstein 56:09
He scammed us first for three nights, he figured once he figured out how to tell time, he got it. And again, he would watch the clock is like 8:45 8:50 8:55, boom, here comes the big question. That's like, "what is the meaning of life" kind of a question. And it took us three nights to figure out oh, man who did it again?

Self Care Awareness

Bill Gasiamis 56:36
I think the other thing that demonstrates is the importance for you to actually take care of yourself, because it doesn't matter how unwell your dad is, if you're not taking care of yourself, and you become unwell. There's no point having two members of the family unwell. And it's no point, you feeling guilty about taking care of yourself, you've got to take care of yourself. And that stroke survivors has to allow other people to take care of themselves and have time to themselves. Because it's both your journeys, but it's not your burden.

Jeri Goldstein 57:13
Right. Yeah. I mean, but for the survivor, they might not be thinking that way.

Bill Gasiamis 57:20
Yeah. And they might not have the capacity to think that way either.

Jeri Goldstein 57:23
Exactly. I'm sure that that's mostly the case. So it was really important for me, being sort of a health nut, to make sure that I got what I needed in terms of exercise, being outside time away, you know, the ability to cook the foods that were going to be healthy for him and healthy for me, and be able to manage my minimal business at the time, but because it was remote and internet based, I could do it anywhere.

Jeri Goldstein 58:01
But it was very important for self care. And I think that that's a big thing to talk to people about. Taking care of yourself being mentally, spiritually emotionally able to handle the situation because not every situation is going to be as handleable as ours was, many are going to be more difficult.

Bill Gasiamis 58:29
Did you put your life on hold from where you were living to stay with your dad? Why did you hang out and plant yourself there?

Jeri Goldstein 58:39
Yeah. That's why I took the dog and half of my kitchen, all the things that I thought I could fit in the car just in case I had to stay. Well, rather than answering 15 phone calls in every day from home to try to solve problems. I realized it was

just gonna be better for me to be there. I was able to do it. I had my moveable business that I could do anywhere. And I just figured, you know, my house and the old things that I had back in Virginia could be managed long distance. And it was better to take care of business for him.

Jeri Goldstein 59:32
Being there, taking care of the aide managing the household, managing his business, managing my business, it was so much easier to just be there with him to do it. And he appreciated it immensely. Like when I told him that I was going to stay, so I stayed from November to June then I did go back to Virginia for a couple of months to take care of my house and renovating something that I had to do for renting my apartment again.

Jeri Goldstein 1:00:13
And then I came back in November and then just stayed for the next couple of years. Until he passed, but then I just moved down here in preparation to stay with him while he was recovering, and then I moved down here and then a month later, he passed.

Bill Gasiamis 1:00:35
Well, that's inconvenient.

Jeri Goldstein 1:00:36
It was totally inconvenient.

Bill Gasiamis 1:00:40
What ended up happening? Why did he passed?

Jeri Goldstein 1:00:43
Because of end stage renal disease. Kidney failure. Which was something that he had battled even before the stroke, but he was recovering from the stroke really nicely. I mean, he was back able to play bridge and was as good or better than his other friends. So that was a big accomplishment for him. Then all the other health stuff got in the way.

Bill Gasiamis 1:01:16
Yeah, they tend to catch up with you sometimes. And it's great that he was able to have a reasonable quality of life, for the amount of time that he had after the stroke, when he had that little win, and that little battle. And, he overcome some

things. And he gave you and other people around him a good example of how one should approach these things or tackle these things. So everything about it is really positive and really a good outcome. And it's worth the fight. Isn't it? It doesn't matter what age you are.

Jeri Goldstein 1:01:55
That's the point, I think, it doesn't matter, why give up just because you're older, there's still amazing things that one could be doing, who knew that, you're gonna find love again, at 83 84? How do you know that, you don't know until just happens. So it was worth all of the effort that we put into helping him discover ways of, of conquering his challenges.

Bill Gasiamis 1:02:33
Yeah. As we wrap up, I haven't read the book, because I get a lot of books, people send a lot of books across to me, and I don't have time. But I do love going through them and familiarizing myself a little bit with them. And I got stopped at chapter six, the big bird that jumps up and down. Just give me a bit of an understanding of what I'm going to find when I read that chapter.

Jeri Goldstein 1:03:03
Okay, well, sometimes I would have lunch with Dad during his break in the hospital. And where the hospital was, was down the block from where I was going to get my takeout for lunch, and I was going to Chipotle. The one thing he didn't lose was his sense of direction. So I would tell him where I was going. He could not remember names of anything.

Jeri Goldstein 1:03:34
And so this conversation happens between a nurse Estelle, his girlfriend and dad saying, Where was I going? What was I doing? And so he was using landmarks. And the landmark he was using was the Outback Steakhouse. And he thought, I don't know if I should give it away, or if you should just read it.

Bill Gasiamis 1:04:12
It's up to you. It's only one chapter out of all of them.

Jeri Goldstein 1:04:16
It's just because it's too funny. You know?

Bill Gasiamis 1:04:22

Yeah. Just one, just go for it. Let's do it.

Big Bird Story – Jeri Goldstein

Jeri Goldstein 1:04:25
All right. One day, I planned my lunch visit around an errand to the pet store to pick up some dog food and other supplies. The pet store was a couple of miles down the road from the hospital. So I stopped at Chipotle for my takeout. I told him where I was going and mentioned the name of the restaurant and what kind of food they served. He lost a number of things with his stroke, but not his sense of direction and where things were. He knew exactly where I was going and what other stores or restaurants were in the general area. He just couldn't remember their names.

Jeri Goldstein 1:05:08
Always excited about my visits and activities he would tell his therapist, staff, nurses and other visitors what I was up to and when I would be coming. On this day, he tried to describe my whereabouts and activities in the following manner to a staff member and Estelle. She's coming for lunch. "Who's coming for lunch?" My daughter, she had to get dog food. "Where did she go?" Down the street. Then she's getting her lunch. "Where is she getting lunch?" Down the street. You know that place? "Which one?" It's near that other restaurant? "Which one?" It's near the pet food store. It's not from here.

Jeri Goldstein 1:05:50
"What do you mean it's not from here?" It's from someplace else. "You mean the restaurant is from someplace else?" Yes. She's not going there. She's just going near there. "You mean she's not going to this place for her food?" It's just near this place. Yes. But I don't remember her place. My name's My name's I don't remember names. This other place down the block has a big bird. "What kind of Big Bird? Is it outside?" No, it's not outside. It comes from the place where they have big birds. "What kind of place has big birds? How big?" Very big. They jump up and down.

Jeri Goldstein 1:06:33
You know, the bird that jumps up and down. They carry their babies in their bellies. "The bird that carries babies in its belly and jumps up and down? What kind of bird is that?" Very big. Only in that place. Never here, only in that place.

“Okay, the restaurant has a big bird that jumps up and down and carries its baby in its belly. Well, the restaurant come from the same place the big bird comes from. Do you mean a kangaroo? A kangaroo is not a big bird. But it does carry its baby in its belly.” Yes. A kangaroo. That’s not a bird? “No, that’s not a bird. Do you mean Australia? Kangaroos are in Australia.” Yes, Australia. That’s the place. That’s the place the restaurant comes from.

Jeri Goldstein 1:07:27
“What restaurant comes from Australia?” You know they have onions. We’ve eaten there a lot. Lots of steak. “Oh, I know. You mean outback.” Yes, that’s the place that comes from Australia. But she’s not getting lunch there. “Then where is she getting lunch?” Oh, I can’t remember the name. But it’s near Outback? Oy vey, all of that and she’s still not even going there for her lunch.

Jeri Goldstein 1:07:56
Well, we’ll just have to ask her where she went when she gets back. When I returned. Estelle had left and dad and I were all alone to have lunch. “Where did you get lunch?” I went to Chipotle. “Chipo-” Chipotle dad. It’s near the pet food store.

Jeri Goldstein 1:08:15
He tried to say it but had a hard time and didn’t try for very long. But when he tried to explain the recent conversation about the big bird that jumps up and down, we had to rehash most of the conversation, since he had already forgotten Outback. We went through a few minutes of the jumping bird story and when he mentioned that the bird carries its baby in its belly, I chimed in immediately. “Do you mean a kangaroo? Do you mean Outback Steakhouse?”, to his great relief and with a smirk on his face his face he said, “Oh yes baby, yes, outback.”

Jeri Goldstein 1:08:54
I understood that he was using landmarks and he knew to try to describe where he had gone for my steak, my takeout. We both laughed hard when I realized what a crazy conversation this must have been hearing about it later from Estelle I was able to capture the details and we were all hysterical at the retelling, Estelle said that he would not let it go. And he was determined to make his point until someone recognized Outback. I think for dad from then on. Every time he passed an Outback Steakhouse. He thought of that big bird that jumps up and down and remembered his crazy conversation to make himself understood.

Bill Gasiamis 1:09:39
Yeah, that's brilliant. Absolutely brilliant. So when I first read the chapter headline, I thought it was big bird from Sesame Street. For sure he was going to be big bird and then to see the big bird turned into a kangaroo. And how that was the attempt to describe the Outback, which is a very common thing that we say about our desert, in the middle of our country. Here. It's just amazing that somehow, even though that seems like a ridiculous way to get to that outcome, it is a great example of how outcomes can be got to, and the importance of the role that the person is playing that's listening to that conversation and trying to facilitate the memory, or the answer to come right out.

Jeri Goldstein 1:10:35
This is what these conversations are like, similar to that. It starts off with something, and you have no idea where it's going. And then when you get to the end, you go, Oh, my God, it's like, I can't believe that that's that it started with something so crazy like that.

Bill Gasiamis 1:10:54
Yeah, I think this is going to make a big difference and help a lot of people understand aphasia, and understand what people go through to get to be able to communicate and to share their feelings, thoughts, and whatever it is that they need to express. So that's where I see it doing a lot of amazing work and stroke survivors that have been through it will also relate to a lot and be able to appreciate.

Jeri Goldstein 1:11:22
I'll bet, because they know what they were holding in their head and how they were, hard at work trying to make themselves understood if they were going through aphasia. So I'm hoping, I thought I picked out that story to read. And then I went online to just check, to see where is Outback actually from? And it's from right here in Florida. It's not from Australia at all.

Bill Gasiamis 1:11:57
But he associates the name to Australia.

Jeri Goldstein 1:12:01
Well, I mean, well, it's like Australian-inspired food.

Bill Gasiamis 1:12:06

Yeah. And he went all around the world to get that answer. Just for something that was down the road.

Jeri Goldstein 1:12:15
That's right, exactly.

Bill Gasiamis 1:12:21
I really appreciate you reaching out Jeri and sharing your story and letting us know about the book, I think it is going to be something that does shed some light on a difficult time that people go through and then makes it a little bit funny and allows people to see the possibility for humor, and to embrace it, and to feel good about having a laugh about some really difficult times. And I would just like to ask you, if people wanted to get in touch with you, or find a copy of the book, when it's available? Where would they go?

Jeri Goldstein 1:12:59
Well, it will be on Amazon, and it will be on Amazon Australia, as well as every Amazon wherever it is. And they can also go right to strokedialogues.com, my website and there'll be links to get either the PDF, and eventually I'm going to do an audio version. So hopefully, I keep procrastinating on that one. But I've got my little studio set up in my closet right next to me here and I've got that microphone that you've got there. And I'm all ready to go. I just gotta find quiet space when they're not cutting trees in front of my answer.

Bill Gasiamis 1:13:44
Which is every single moment you sit down to record something.

Jeri Goldstein 1:13:48
Absolutely, but this is a brilliant time, at 10:30 at night, my time, there's nobody's doing any work outside. It's great.

Bill Gasiamis 1:13:57
Well, there you go. Now you know when to sit down and record.

Jeri Goldstein 1:14:01
Now that I know that I can make it to this time, and be lively and bubbly. I can probably go ahead and do it now.

Bill Gasiamis 1:14:09

Yeah, well done. Well, thank you so much for being on the podcast.

Jeri Goldstein 1:14:12
Thank you so much. And thanks for doing the podcast after your situation and thinking hey, I couldn't talk, I couldn't think, I think I'll do a podcast. That's pretty amazing thing to come to that

Bill Gasiamis 1:14:30
It was a ridiculous idea. I don't know why I even thought of it or how I got to it. I just felt like I needed to connect with people and I used as an excuse to talk about stroke more often. And it was just like, it was about me at the beginning and then it really rapidly changed and it's still about me but about everybody else and all that.

Jeri Goldstein 1:14:55
Brilliant. It's brilliant. I mean I listened to many of your episode. And each one really touches, obviously on different topics with different people's experiences. But your ability to pull stuff out of people is brilliant and sensitive and lovely, quite lovely.

Bill Gasiamis 1:15:22
Thank you. It means a lot to me, I get a lot out of it. And I always love it when people reach out to me and say they want to be on the podcast that's even better than me trying to drag them.

Jeri Goldstein 1:15:36
That's great. I don't know how I came to it. But I was looking up all kinds of resources so that I can get the word out and so that I can hopefully make a difference. And yours was one of the first ones that popped up, and I loved it. And so I just started listening and paying attention to what you're doing. And it was brilliant.

Bill Gasiamis 1:16:03
Thank you. Thank you so much.

Jeri Goldstein 1:16:04
You bet. Thank you. Thank you so much for having me on.

Bill Gasiamis 1:16:08

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Intro 1:17:36
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