

Brooke Parsons: Transforming Stroke Recovery Through Resilience and Advocacy

Introduction

Brooke Parsons is more than a stroke survivor—she is a beacon of hope and resilience for the global stroke survivor community. Experiencing a major stroke at just 13 years old, Brooke's journey over the past 30+ years has transformed her into an advocate, educator, and leader in stroke recovery. As a Stroke Foundation Ambassador and a lived experience consultant, Brooke has dedicated her life to reshaping stroke rehabilitation and advocating for better outcomes for all survivors.

A Stroke at 13: Brooke's Life-Changing Experience

At the tender age of 13, Brooke's life changed in an instant when she suffered a major stroke. The impact was profound—her parents found her unresponsive, unable to walk, talk, or care for herself. Despite the initial misdiagnosis of a migraine, Brooke's family persisted in seeking answers, eventually leading to a diagnosis of a significant stroke affecting a large portion of her brain.

Her recovery journey was arduous and complex, involving six weeks in a hospital, learning to navigate life with new physical and emotional challenges. Yet, Brooke's story is not one of defeat but of perseverance and triumph.

Deficits and Strengths: Living with the Effects of Stroke

Brooke lives with long-term deficits, including mobility challenges requiring a wheelchair, occasional speech difficulties, and fatigue. Despite these hurdles, she has embraced her “new Brooke” identity—a version of herself that she describes

as fierce, stubborn, and resilient. Brooke's ability to adapt and find purpose has been instrumental in not only her recovery but in inspiring others.

Advocacy and Leadership: Brooke's Role in Stroke Research

As a Stroke Foundation Ambassador and a lived experience consultant, Brooke has become a vital voice in the stroke survivor community. She has been involved in numerous groundbreaking research projects, including the AVERT trial, which explored early rehabilitation interventions. Brooke's input ensures that stroke survivors' perspectives are considered in the development of treatments, hospital practices, and support systems.

Her advocacy extends to co-designing projects like the Young Stroke Service, which addresses the unique needs of younger stroke survivors, such as returning to work, maintaining social connections, and navigating life milestones after a stroke.

The Importance of Community and Peer Support

Brooke emphasizes the power of community in recovery. By sharing her story and mentoring others, she creates a ripple effect of empowerment among stroke survivors. Whether speaking at conferences, collaborating with researchers, or supporting fellow survivors, Brooke embodies the importance of connection and shared understanding in overcoming life's challenges.

Philosophy of Resilience: "Drop the T"

One of Brooke's most inspiring messages to stroke survivors is her philosophy of resilience: "Drop the T." Instead of saying "I can't," Brooke encourages survivors to say "I can." This mindset shift has empowered her to tackle challenges head-on, whether it's participating in daring activities like the CN Tower Edge Walk in Toronto or representing stroke survivors on an international stage.

Brooke's Vision for the Future

Brooke is committed to ensuring that stroke survivors are not just heard but valued in shaping the future of stroke care. She advocates for meaningful

involvement of survivors in research, grant applications, and policy-making, emphasizing that lived experience is as crucial as clinical expertise.

A Legacy of Advocacy and Support

As Brooke looks ahead, she remains dedicated to mentoring the next generation of stroke survivors, researchers, and advocates. Her focus on succession planning ensures that her impactful work will continue to benefit the stroke community for years to come.

Conclusion

Brooke Parsons is a shining example of what it means to turn adversity into opportunity. Her journey from a 13-year-old stroke survivor to a global advocate and consultant is a testament to the power of resilience, community, and purpose. Through her work, Brooke is not only shaping the future of stroke recovery but also inspiring countless others to believe that life after stroke can be meaningful, fulfilling, and extraordinary.

Call to Action:

If you're a stroke survivor or caregiver seeking inspiration, support, or community, follow Brooke Parsons's journey and learn how you too can turn challenges into opportunities. Connect with the Stroke Foundation or explore the resources available to help you on your path to recovery.

Brooke Parsons: Inspiring Stroke Recovery Through Advocacy and Resilience

Brooke Parsons, a stroke survivor inspires with her journey of recovery and advocacy, showing how resilience can shape life after a stroke.

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Transcript:

Introduction - Brooke Parsons



Bill Gasiamis 0:00

Welcome everyone before we dive into today's extraordinary conversation, I want to thank you for being part of this incredible community. Your support, whether it's sharing the podcast, leaving reviews or simply tuning in, makes a huge difference. Together, we're creating a space where stroke survivors and caregivers feel seen, heard and inspired. Since 2015 I've been personally covering all the costs of producing the recovery after stroke podcast to ensure stroke survivors and their loved ones have access to free valuable resources.

Bill Gasiamis 0:37

Last year, I asked for help from those who feel they've received tremendous value from the podcast by supporting it on Patreon, at patreon.com/recoveryafterstroke. Your support helps keep this podcast alive, and I'm grateful for everyone who listens and engages and contributes in any way they can, as always, I'd love to remind you about my book, *The Unexpected Way That A Stroke Became The Best Thing That Happened*, is a resource for offering practical guidance and hope for stroke survivors and their families.

Bill Gasiamis 1:16

If you haven't already, you can grab your copy on Amazon or at recoveryafterstroke.com/book. Now, I'm thrilled to introduce today's guest,

Brooke Parsons. Brooke is a stroke survivor, a Stroke Foundation ambassador and a lived experience consultant who has spent more than three decades advocating for stroke survivors and shaping the future of stroke research, she shares her inspiring story of resilience the challenges of living with deficit, and her work to ensure stroke survivors have a voice in the recovery journey. Let's jump in.

Bill Gasiamis 1:58

Brooke Parsons, welcome to the podcast.

Brooke Parsons 2:01

Hi Bill. How are you?

Bill Gasiamis 2:04

I'm really well. I am excited to have you on my show. We've met a couple of times in person.

Brooke Parsons 2:10

Haven't we? We've been social butterflies.

Bill Gasiamis 2:15

We have, and more so lately than ever, because I have always known about you, but we just never cross crossed paths.

Brooke Parsons 2:25

Is that a good thing that you've always known about me?

Bill Gasiamis 2:28

Yeah, because I've never heard anything terrible, always nice, lovely things and and it's all correct. And then when I met you, you know, when they say, don't meet your heroes and all that kind of stuff, when I met you, I was like, I hope she doesn't let me down and disappoint me, and you didn't.

Brooke Parsons 2:47

We were just sitting on the couches having a bit of quiet time, having a bit of a yarn.

Bill Gasiamis 2:53

Yeah, that was at the conference that we were both at Smart Strokes.

Brooke Parsons 3:01

That's right, it was on the Gold Coast.

Bill Gasiamis 3:03

On the Gold Coast, and I had a little bit of time to do a presentation. I did about a 15 minute presentation, and you did a few presentations, if I remember correctly.

Brooke Parsons 3:13

I did one presentation.

Bill Gasiamis 3:15

One, yeah, what was your presentation?

Brooke Parsons 3:19

On my presentation was about the young stroke service, which is who I'm employed at the Flory Institute. So it's a project that I'm working on, and I'm one of many. There's a huge team involved. And I was very fortunate to say that I was going to smart strokes. So I was happy to present on behalf of everyone.

Bill Gasiamis 3:45

Yeah, what is Smart Stroke? What is the Young Stroke Service about?

Brooke Parsons - Early Life and Stroke Experience

Brooke Parsons 3:51

So, the Young Stroke Service is about meeting the needs of people who have strokes when they're younger. So you would understand yourself bill that your needs and wants when you had your stroke may not have been met immediately, because our needs and wants as young people having strokes are much different to society that are generally met in the hospital when they have strokes. So as a young person, it was about, how do I get back to work? How do I reconnect with my friends and keep those connections going, how do I be a fulfilling auntie?

Brooke Parsons 4:46

How do I do all those things? Get a house or rent or I was very much at the very beginning of my life, and we've got an amazing medical system here. But when you're discharged from hospital, that's it, right? You're out in the big, wide world by yourself. And although, over the years, I've been very fortunate to meet so many, who have helped guide me, I've learned a massive lot as well. So it's about

addressing the needs and the wants of young stroke survivors in today's world, we are between Victoria and South Australia at the moment. And it's currently going well, I think.

Bill Gasiamis 5:46

So you definitely were a young stroke survivor, if I remember correctly. You had your stroke at around 13. So tell me about that part of the process. What happened? What do you remember? How did it evolve? Not evolve? How did you kind of go through those early days of stroke with your family and yourself?

Brooke Parsons 6:14

That's a really good question, Bill, because I guess you know, I've got a lifetime now as a stroke survivor, 31 years, almost 32 years as a stroke survivor. So I've lived more than half of my life as a stroke survivor, that as a kid, I was very studious. That probably doesn't surprise you, but I would always do my school work. I never missed school, I didn't like missing school. I was always the eighth grade student, and then bang, I had my stroke. I was home alone, talking on the telephone to a friend about going to the local shops the next day to perv on boys, as girls do at 13.

Brooke Parsons 7:05

And my life changed. My parents came home and found me on the ground surrounded by shattered glass, and they had to pick me up off the floor. At the time, my dad was a butcher, so he was used to dead weight, thankfully. He picked me up, I was 50 kilos at the time. He picked me up and he put me on my bed, and from there, my parents decided to take me to the local hospital, where I was given a migraine tablet, and my parents were told to actually take me home, and that if I had a good sleep, I'd be okay, but I couldn't walk, couldn't go to the toilet, couldn't do anything.

Brooke Parsons 8:02

And as a 13 year old, you're also going through the 13 year old changes, hormonal changes, etc. So my parents stood their ground and said 'No, we're not taking her home because she can't walk, this isn't our daughter. I could barely string a sentence in any word that I was blubbering out. It was a blubber they weren't clearly concise words. So I was then taken to a hospital on the outskirts of Melbourne, where I had a CT scan. My parents remained vigil beside my bed for that night, and neurologist came in at round 2am in the morning.

Brooke Parsons 8:54

Said I'd suffered a major stroke affecting a size of a 20 cent piece, my brain being completely dead and surrounding areas damaged, and that if I survived the night, I'd be transferred to the Royal Children's Hospital. Now that became home to me for six weeks. I was in there as an inpatient. I was then out for weekend leave for a few weeks in a row to make sure mum and dad could cope with me being at home. Because I think it's important to remember Bill that, yes, my life changed, but so did bears, so did my younger brothers.

Brooke Parsons 9:42

Because, you know, before they went out, the day of my stroke, I was a pain in the bum. I'm not putting any disclaimer on that, because I'm probably still a pain in the bum, but you know, I was this, a grade student that everyone just idolized and looked up to, never did anything wrong. So then to come home in a wheelchair, unable to really talk, while not articulate my words like I used to needing my mum to help feed me, barre me, do everything for me.

Bill Gasiamis 10:30

It was a change of life for all of us. Let me take a quick pause to reflect on Brooke's incredible journey so far, her story of resilience, advocacy and community building is why I started this podcast to connect, inspire and provide hope for stroke survivors and their families. If this podcast has been a source of value for you, I'd love your support on Patreon, by becoming a patreon at patreon.com/recoveryafterstroke.

Bill Gasiamis 11:00

You'll not only help keep this podcast going, but also join a growing community of people dedicated to recovery growth and making a difference in the stroke survivor space. Now let's get back to Brooke and hear more about her remarkable journey.

Brooke Parsons 11:18

And then you got another layer on top of that, where you had my school community, so I'd grown up like we generally do with our friends at school, and then one day, I was stuck in a hospital bed, and all my friends at school found out that I was paralyzed, and they didn't know what was going to happen. And then when I did come back, there was this whole adjustment around, you know, how do we treat her? She's now got, we were just kids, okay, so she's got plastic legs on

her legs. What do we do? Do we give her extra time? Do we not play with her? Do we invite her out anymore?

Impact of Stroke on Life and Family of

Brooke Parsons

Brooke Parsons 12:11

So there was, I think there's several levels of complexity to that, but above it all, and this is what I always try to remember to say, this is that I was 13. At 13, you're still a baby. So in the big world, if your parents say 'Go and brush your teeth, you go and brush your teeth. You don't question it. You do it, because that's what your parents have told you to do. I was very much that person. If I needed to go to the bathroom, I would say 'Mum, I need your help. I need to go to the bathroom. If I wasn't feeling well 'Mum, I don't feel well.

Brooke Parsons 13:01

If I was at school, it was all about open communication with the teachers on how they could assist me and what they could do to very much make my life regular, to make it normal, because I still wanted to be that BROOKE I was before the stroke, I still wanted to be that Brooke that would get a grades, that Brooke that would be in the music band, the Brooke that everyone loved to hate. Didn't understand why that had to change, but it did, and I think, if anything, I've gone from strength to strength.

Bill Gasiamis 13:49

Now, we're going to talk about that. I definitely think you have, but you know, navigating that experience at any time in your life's hard, navigating it as a 13 year old, like it's even harder. Your the thing about it is, like you mentioned, the thing that really stood out, which is that your life changed, but everyone else's life changed in your family as well. That is a really important point, because I said, you know, I probably wrote about it in my book as well. I probably said, you know, the day my life changed. And every time I speak to a stroke survivor, it's always the day my life changed.

Bill Gasiamis 14:36

You know, they it was kind of the line in the sand moment from this before that line, it was like this. After that line, it's like that. But very few of us, it's not that

we don't acknowledge the people who have supported us, helped us all that stuff. It's that they're not front of mind. They're not front and center, remote, because we're going through our own experience, and we're thinking about like how our life has become harder and more difficult, but our family and our caregivers are going through it with us together, and they have to pause everything.

Bill Gasiamis 15:14

Their identity changes, and their work situation has to change, and their entertainment part of their life has to change, and the way that they occupy themselves and the hobbies they have and the people they hang out with and all that, it is a complete it's a disruption of everybody's life, yours, theirs and separately and as individuals, but also as a collective.

Brooke Parsons 15:41

Absolutely and if you think about it, Bill, I just said then about my school friends and my school teachers and the school community. For yourself, it might have been the work community that you belong to, like you may be the stroke survivor, but the effects of your stroke go way beyond you, yeah, and they go way beyond me. And I can even say almost 32 years on that my stroke still affects people today.

Bill Gasiamis 16:16

Yeah, okay, how I get it? But tell me how.

Brooke Parsons 16:21

When I'm fatigued, they may find it harder to understand me because my speech is still troubled at times. We all say we change as people when we have strokes, and I guess I'm a bit of a a tough nut, like, there's not much that shakes me, but when I'm shaken, I'm shaken to the core. So if I'm having a bad day, and I've let things build up and up and up, and then I just sit there and cry, whoever's around me is affected by that, and that at times, has been work colleagues, unfortunately, and they've just had to, you know, go, okay, well, that's you today, goodbye.

Brooke Parsons 17:14

We'll try again another day, or, I mean, I was just on the phone to a friend who didn't wish me a happy birthday three weeks ago, and that was the first time in the entirety of not knowing her that she hasn't done that she didn't even register until the last five minutes, and I went 'Well, look, we can all be a little selfish.

Brooke Parsons 17:44

And I was trying to relay it back to her situation, but I said 'You didn't even wish me a happy birthday like and then is that me being selfish because it's Christmas and we're all under the pump to get everything done, or was that me being a friend and really just laying it out on the table to a friend who didn't want to hear it? It's a little bit. It's a double edged sword, I think.

Bill Gasiamis 18:17

Are you any different from any other person on the planet, honestly, because I get what you're saying, because it's partly your stroke affects you and the other people around you every single day. But quote, unquote, normal people, they and like, have their meltdowns in a different variety or?

Brooke Parsons 18:41

Absolutely, think about it. Everybody has a crappy day at work, everybody has disagreements with friends or family. Everybody in today's day and age is looking for extensions on bills and all sorts of things. So I am no different. The difference between me and some others is that I carry the burden of the stroke. Yeah, okay, and that is obvious because I'm in a wheelchair.

Bill Gasiamis 19:17

That's unique, right? In one way, maybe in a community where you hang out and there's not a lot of survivors, because we both hang out in communities where there aren't survivors of stroke, and then we hang out in communities where there are tons of them, but when you're in a community where there's not a whole bunch of other stroke survivors or people with disabilities or any challenges like that, it's kind of like of the way I feel it is people who are not directly impacted by a medical situation touch wood.

Bill Gasiamis 19:54

Because they're healthy and well and nothing's gone wrong with them. It's, you know, they're ignorant, and not willfully ignorant, but they're ignorant. And then it's like, how do you know? Is it our job every time to educate people or not? Is it? I don't think so.

Brooke Parsons 20:13

It shouldn't be our job. But I'm sure you've found over the years, Bill, just as much as I have, that it ends up being our job.

Challenges and Adaptations Post-Stroke For Brooke Parsons



Bill Gasiamis 20:26

Some people deserve it. Some people deserve it in a way where, if you can nicely, kind of bring them back into reality about something, then I think it's really necessary. Some situations, I've found myself being tempted to say something and then about my situation where, because I don't look like I've had a stroke, the assumptions about me are huge, you know, and it's like, maybe it's not the right time to tell you in this particular forum what I'm what it's like to be me, what I'm feeling, what I'm going through.

Bill Gasiamis 21:03

What my left side feels like, and maybe you're not being mean spirited or anything, and I don't need to really correct you or pull you up or anything. But then at the right time, it's just a little bit of information. I feel like it's better to give people information about me so that they have an awareness, even though they don't relate and can't understand but it's more about supporting them to understand me better.

Bill Gasiamis 21:30

I think it's like that, that I prefer to do that where I'm supporting you, so that we can interact in a way that's not hard for both of us and and awkward for you, because I don't feel awkward or anything, but you might take it like that if I give you a bit of a hard truth that you wouldn't expect.

Brooke Parsons 21:54

You know, Bill, I think one of the big words you said right at the very beginning of that was "Assumptions", people make assumptions all the time about everything and anything I'm sure it's all in our makeup, right in our genetics. I found in the very early days, I would go and speak at Rotary groups, and I would sit in rooms, and I would just tell my story. I was the girl with the damn it doll, the doll that was lifeless limbs, and, you know, the fight that I had on my hands and I would look around the room as I was speaking, and no matter what I thought of my speech.

Brooke Parsons 22:41

There would be these men crying, and I could never understand why, right? Because what happened to me happened to me, not them. But I think what I've learnt over the years is that, yes, it's taken a lot of education on my behalf to give out. But how much better are those people for knowing that education you've had a helping hand in that everyone we know has had a helping hand in that which has had a roll on effect, because assumptions can be horrible things.

Brooke Parsons 23:26

Assumptions, you know, I could have made my mind up about you before I'd even met you, you know, but thankfully that one day, I saw you sitting there alone, and I just said 'Are you okay? And then that sparked a conversation. That's all it needs.

Bill Gasiamis 23:48

Yeah, I agree. And it's like, and same here. You know, I had heard about you. I'd seen some of your stuff on socials and what have you. I knew that you were involved with the flurry. I didn't know what capacity or what you were doing. A friend of mine told me that he met you because he works at the flurry, and he was just, he was there because his role is to scan people's brains when they come in for diagnosis or for different research projects or whatever. And he's in the thick of it, with survivors of loss of neurological conditions all the time, and recently for him, just a little while after.

Bill Gasiamis 24:39

He started working at the flurry, and he's been in hospitals his whole life like he was in a senior position at the Royal Melbourne Hospital in the Radiography department, amongst other hospitals that he's worked at. And just after he joined the flurry, his daughter. Had a brain hemorrhage, and she was 17, and he was in near my hospital bed, next to my hospital bed when I went through it, you know, in 2012 and he's the one that guided my recovery via the introduction to the person who would eventually become my brain surgeon, and all those things.

Bill Gasiamis 25:32

Cris was in awe of the role, I suppose that stroke survivors, not Brooke Parsons, yet he wasn't like that were playing in the bringing light to this condition, awareness to this condition, breaking those assumptions down, and explaining things in a way that non stroke survivors would understand. And he was talking about how you guys met, that you guys spoke your presentation, what the project

was about, and even me at that time, previously, when I say previous, me, pre-stroke me, would have made a decision about you, and because I wasn't in the frame of mind.

Bill Gasiamis 26:21

Because I was actually very similar to what I am now, but I was a little bit kind of like, what's the word like, front when somebody saw me, I was glass half full kind of guy, but in private, I was glass half empty kind of guy. So I had this kind of Jekyll and Hyde thing that I used to do. I used to present really well in front of people and then make assumption and then and then not do the same thing for myself in the background.

Brooke Parsons 26:52

Yes.

Bill Gasiamis 26:54

So when I met people who, when I spoke with people who had done different things in certain areas of what I where I couldn't picture myself or hang out.

Bill Gasiamis 27:06

I was threatened to buy them, or I was whatsoever, like I would put them on a pedestal, and then I couldn't interact with them, because then I would think that they were better than me, and I like so many weird things that came out of these interactions, which were so false, right? And the stroke, what the stroke has taught me, and the podcast has taught me, is that all the things that I tell myself about me and other people are all rubbish. And unless you have the opportunity to sit and speak to somebody and get to know them about what they are like.

Bill Gasiamis 27:41

Imagine being negatively impacted by somebody I haven't met because they're talking on a stage about a topic that's dear and near to them. Because I don't have the skills to do that yet, and I think that, and I've put them on a pedestal, and I think I'm not good enough yet. I mean, seriously, that just bring myself back down to earth, settle down, calm down, take a breath and just go and say hello and meet this person and formulate your own actual thoughts about this person, and from an interaction, not from far you know, this afar thing.

Bill Gasiamis 28:20

Social media, this afar, thing that we do is terrible, and I've found that the

podcast has helped me just have no thoughts about people, bring them on and then go for it. I don't know anything about anything, and I'm just going to, we're going to discover about each other in the moment.

Brooke Parsons 28:42

You know, Bill, I think that. I think people are afraid these days to make friends, and I think that's exactly what you're describing there. You know, not making an assumption about anyone being willing to sit down and have a bit of a chat with them, find out what you can and work with what you've got, whether that's becoming great mates or colleagues or, you know, the person you might see once a year or once every few years. It doesn't matter, but there's some sort of workable relationship there.

Brooke Parsons - Inspired by Mentorship

Brooke Parsons 29:29

I'll never forget 21 years ago when Julie Bernhard rang me and introduced who she was, and that's how I actually got into the flurry and into research. Up until that point, I was just one of these little people that went around and said 'Hi, I'm Brooke, I had a stroke. I heard Julie B's voice on the phone, and at the end of it, I just went, yeah, I'm going to give this a go. And I'm going to give this a go because she sounds like she's a woman who knows what she wants and how to get it. And she was one of those people like I was talking about right at the very beginning.

Brooke Parsons 30:18

Who said to me, who's your adult neurologist? If you've left the children's now, where are you going? And I went, do I need someone? But it's people like Julie B and Vincent and people way smarter than I could ever be including your friend, Chris, because I know exactly who you're talking about, that I admire, that I look up to. I've been so fortunate to be guided by I asked for their opinions, and I remain open in in the feedback that I get from their opinions. But as a person, if you ask me to go outside and speak to a stranger, I'd have no idea on how to do that.

Bill Gasiamis 31:16

Yeah, I think where we're getting at is is that this particular moment in time, with regards to stroke recovery, is bringing stroke survivors into the research field and

treating us as equals, that's where we're at. We're starting there equals in that what we've got to offer from our perspective, and what the researchers or the doctors have to offer from their perspective are actually both very useful things, and they need to be combined where previously it was, that was the part of my assumption about who these people were and what they did, was that they're going to tell me what to do.

Bill Gasiamis 32:00

And I'm going to have to go along with it, whether I like it or not, no. And that kind of does, that's the part that doesn't work for me. And I always had that while they're in a white coat, I know what that means for them, you know? Or do you know what I mean? So it was like that kind of assumption that I was making is I thought x of certain people, and then I thought that they had assumptions about me, and it was just too messy in my head and to break down those.

Bill Gasiamis 32:27

Those my ignorance by embedding myself into a podcast and then into the community by meeting tons and tons of stroke survivors, doctors, researchers and all that kind of stuff. What I realized is that I think we're moving to that phase where there's equality in what, in how we're seen by the research and the doctors who work on solutions for stroke survivors, whether they are physical therapy solutions or neurological solutions or emotional issues.

Brooke Parsons 33:06

Med solution, I think that Bill that you know, you talk about, maybe the professors being up here and us down here, that's it. Anyone years ago, I was very much like that, yeah, so I'd speak if I was spoken to as we're now, you can't shut me up, right? Because Julie professor, Julie Bernhard, Julie be to me, yeah, he's taught me over the years that my voice is actually really powerful, and that if I don't agree in something that the professors are saying, I need to tell them now. Otherwise it could change research. It could change the way things are done. Guidelines are done, policies are made.

Brooke Parsons 34:03

It could change the way stroke survivors are treated in hospital, and maybe not for the better, but because people like you and I have been through it, we can say, well, actually, that didn't work. Or have you thought about it from this perspective? And that helps fill the gap that what the researchers don't see from

day to day in a hospital room or in a hospital or even in a home setting that we see because we as stroke survivors don't get the opportunity to take our stroke off and have a holiday from it. Okay, that's the sad reality of it.

Brooke Parsons 34:47

It's with us. 24 hours a day, seven days a week, 365, days a year. For the researchers, they may be researchers 9:00 to 5:00 I know they do accept, allow us, but let's say 9:00 to 5:00, they get to go home to their families and have a life outside of research. So I think for me, that equality is coming to an equal because if I don't speak up, or if I don't speak up, on behalf of those who can no longer speak up. Unfortunately, then our messages and our words are never going to get across.

Bill Gasiamis 35:32

Yeah, nothing will change and not only the people who can't speak up, the people who don't know what to say when they're faced with the situation, I feel like what we're doing, you and I right now, is what we're doing is we're encouraging all the stroke survivors listening to get involved and to speak up and to be part of research and to be a part of whatever the Medical kind of world needs from stroke survivors.

Bill Gasiamis 36:02

Whether you're presenting, whether you're speaking, whether you're involved in research, what we're saying, I think, to everybody listening and watching, is we need to get involved. We need to make ourselves heard and our issues known so that people can start knowing that there's more work to be done.

Brooke Parsons 36:27

There's more work to be done, but also from a funding perspective, and I don't mean to bring up dollar value, but at the end of the day, researchers need funding to do research, and often to get funding. Now, more than not, you need to have a consumer involved in your steering committee or on your board of your research, and that needs to be shown in the grant application. And I think if we can get consumers involved even before grants are written. So I know I was consulted about the Young Stroke Service before it was even written up as a grant application.

Brooke Parsons 37:13

And then I was asked to check the grant application before it was submitted. And then I was one of the first handful to find out we were lucky enough to get the grant to run the project at every step of the way I've been consulted and that, to me, has been real, true co design that's being having a consumer involved in every twist and turn of the project. I think, you know, I've been around a long time now, sadly.

Bill Gasiamis 37:56

Not sadly.

Brooke Parsons 37:57

I don't know, the gray hairs is starting to show.

Bill Gasiamis 38:00

I just turned 50. I'm excited about that. Are you serious?

Celebrating Milestones and Navigating Fatigue

Brooke Parsons 38:04

Absolutely, good on you. What a milestone, right? The other week, I turned 45 and it's like I woke up excited, but then my day just got on with meetings and all the normal things, but then I made a cake. So when I went into work two days later, I had a cake to share with the researchers and the colleagues there, who are my friends, my work buddies, I call them. And you know, that was nice. That's what I needed, because we can talk about all of this, and I'm very surprised it hasn't come up yet.

Brooke Parsons 38:52

And I'm not sure how you find it, but I find as the year goes on, full steam, beginning of the year, my puffing Billy ready to go right? And then as the year gets on and on and on and on, I start to slow down because I'm fatigued. So as a stroke survivor who's been around for a very long time, there's new stroke survivors coming through the ranks to do what I started 21 years ago, and to do what I'm doing today in different projects, etc. And you're right, it's about breaking down those those those equality walls, to realize that it's you're just as valuable.

Brooke Parsons 39:47

And your input is just as equally as important as what the researchers who use

but at the same time, you need to remember, and when I say you Bill, I mean all stroke survivors and researchers need to remember at times we can all get fatigued, and that when a stroke survivor gets fatigued, it may show in different ways. And then I guess I would be asking that members of the team around that stroke survivor would pick up the slack for that stroke survivor at the time of their fatigue.

Bill Gasiamis 40:23

That's fair. So are you full time employed in this role?

Brooke Parsons 40:38

No.

Bill Gasiamis 40:39

How many hours a week do you do?

Brooke Parsons 40:42

Too many? I am okay, so I probably do about 5 to 10 on the books, but there's a lot I do off the books.

Bill Gasiamis 40:58

No doubt, and how many years have you been doing this type of work for, or have you had this role, I suppose.

Speaker 1 41:10

So, with a monetary reward of being paid probably the last two and a half years for that, for 21 years, I've always been volunteering of some way, shape or form.

Bill Gasiamis 41:28

Wow, such a long time you would be the most prolific volunteer ever. I mean, you're I'm saying that now being a little bit funny as well, but realistically, if you think about it, the amount of impact that all your work has had for 21 years, you know, and evolving with somebody who was very young, you know, very, very young when they had a stroke, and then bringing you along for the journey for 21 years mean that you got to influence people and explain to people what it's like as a 13 year old, as a 23 year old, as a 33 year old, and so I like, Do you know what I mean?

Bill Gasiamis 42:13

And move through the whole life cycle that you've had since very young, that's really going to that's going to be very insightful, and it's going to make Wow. It's going to make what you can offer researchers so much more man rich in information and experience and all that kind of stuff. Does that make sense?

Brooke Parsons 42:41

Like it does make sense, but I think we've all got a lifetime that we can explain. So where you were pre-stroke, to what happened with your stroke, to straight after your stroke, to the next little bit, to meeting others who have had strokes and how that's made you feel, etcetera, will be different to my journey of the last 30 something years.

Bill Gasiamis 43:09

Yeah, but your journey has been, your focus has always been about making and improving the lives of stroke survivors.

Brooke Parsons 43:18

It has, yes.

Bill Gasiamis 43:20

Yeah, and mine, and I'm not saying that it should have been. What I'm saying is your version, only because you had a stroke of 13, no other reason. You know, you've put a lot of time and effort into improving the lives of stroke survivors, which includes you, but that's alright. That's the whole purpose. You need to be your own advocate, and while you're advocating for yourself, other people benefit, and that's awesome.

Brooke Parsons 43:49

I think Bill there that you You're right, but I think I do what I do not only because I love it, but because, unfortunately, stroke is an illness that we're not going to be able to stop. We want to be able to stop it, but we can't. So if I can have an impact on research now, that's going to help someone who has a stroke in the future, I've done my job. That's what it's about. It's not about going our strokes exist, and now they don't. I want to be able to do that, but we can't. So if it's about just making life a little easier for somebody who has had a stroke, then all the better.

Brooke Parsons 44:48

Like, if we think back to the day that you and I met, and you just need a quiet time and poor Bill, you get me come up. Are you okay? You didn't need to be open to a

talk, you didn't. You could have just said 'Oh, bugger off. I want some time to be by myself. I would have had to have respected that, but I was concerned, because you were by yourself.

Bill Gasiamis 45:17

And I look really pooped, didn't know you did.

Brooke Parsons 45:22

Although in Adelaide, I thought you looked more pooper.

Bill Gasiamis 45:26

Yeah, I think you're right.

Brooke Parsons 45:28

Yes, so when looking back at that first conversation that you and I had, what did you take away from that talk?

Bill Gasiamis 45:40

Look, I just felt like you were, like you knew me more than anyone else, so you tuned in. You exactly knew where I was at. You didn't even have to actually ask me. You knew and my quiet time was, I think, in that foyer when there was no one in there, it's really nice and quiet, it's large, it's got good light and that and the sensory overload that I was experiencing when I was in the rooms where there was presentations happening and one after the other, after the other. So we're talking about fluorescent lighting, lots of light coming through the windows as well.

Bill Gasiamis 46:21

Which we were right were right there details on the on the board, on the screen, where the presentations were happening, the sound from the microphone system and the PA system. And it was like, I am just nothing sinking in anyway. So it doesn't matter who was presenting or what they was saying. I was like 'I can't be in here. I've gotta be elsewhere. I've gotta give my time, my brain, time to settle down, because we've got another half a day to get through, and the next day to get through. And I get energized emotionally and mentally being there, but I get drained physically.

Brooke Parsons 47:03

So completely agree.

Bill Gasiamis 47:05

I've got to play that game, right? So when you came over and we had that chat, firstly, I wanted to meet you. I was hanging out to meet you because Chris told me about you earlier, and I knew about you from before Chris told me about you. But also I knew you were going to be there and you, you were going to be presenting in some capacity, and that was my goal, was to get there and meet more stroke survivors. So I met you, I met Adrian O'Malley eight. I bumped into booth again, Brenda booth again, and a bunch of other people, right? And I thought, excellent.

Understanding and Addressing Oversights

Bill Gasiamis 47:42

This exactly what I want. And not only do I want to meet people just for the sake of meeting people, but meeting people who get me, who I don't have to explain stuff to, is just such a like it's such a relief to just be in a space where people just totally get union have to say anything, and that helps, because when I'm with my family and friends who've known me my whole life, and even though they know that I had a stroke or two or three in 2012 to 2014, they still default to my regular how they knew me. How they knew me before stroke, and they treat me like that.

Bill Gasiamis 48:24

And I've gotta always kind of massage them into like, I'm having a bad day bill, or I'm not up to this kind of, you know, whatever Bill. And I've gotta keep telling them and reminding them, by the way I had a stroke once, you know, and I don't mean to do it and be nasty anything. I just gotta keep reminding them that I am having one of the things that happens to people without a stroke, and it hasn't gone away yet, and it's been 14 years, or 10 years, or whatever. It's been 12 years.

Bill Gasiamis 48:58

So when I'm in a space where people get me, it's strange that it happened to be I had to go through stroke for people to really get me, but I love it. I love it even though I'm wrecked, even though I'm tired, even though it's just, I don't know, it's easier, but, and you know where I was disappointed, I've got to say, right? So you know, when we went to Adelaide for the Asia Pacific Stroke Conference, we're in a whole place where everyone is there for stroke. They've traveled from all over the world, and talk about not getting us right.

Bill Gasiamis 49:36

There was a lady who did a presentation at the very opening of the event, and she had a stroke, and she had deficits. I'm pretty sure it was left side deficits. She wasn't able to walk.

Brooke Parsons 49:55

Right.

Bill Gasiamis 49:57

Was it her left?

Brooke Parsons 49:54

Right.

Bill Gasiamis 49:55

Right? She had deficits. She couldn't walk, she couldn't move her arm, etc. And she was meant to get on a stage, and they brought and she's with her caregivers, etc, comes to the stage, to the edge of the stage, and there's no ramp, I know, push her wheelchair up the stage to get her to the podium where she could stand, and it's like, are you guys serious?

Bill Gasiamis 50:27

We are at a Stroke Conference. Everyone is talking about how they're going to help stroke survivors overcome all these things and improve outcomes, and, you know, have better results in hospital and all that kind of stuff. And the one thing where should have not even been a thing.

Brooke Parsons 50:49

That shouldn't have even been a consideration.

Bill Gasiamis 50:51

Yeah, there should have just been a ramp there, part of the stage, yeah, and there was no, no one there. So I so that gave me that, that view of what it's still possible, what it's still like, even in the stroke medical world, and when and I felt like I wasn't understood in that room, even though it wasn't me or about me, like I felt you still don't get me. You guys don't get me, you spent 30 years doing this stuff, your professors, and nobody thought about a ramp for stroke survivor.

Bill Gasiamis 51:30

What do you mean? Whereas, when I was in the room with at the smart strokes conference, I felt like you guys got me, everyone got me. You know, you definitely did, but just generally, that was a way better, like it was a way better experience, there was ramps everywhere, it was accessible.

Brooke Parsons 51:54

Just interesting. Feel that there was more peer support at Smart Strokes.

Bill Gasiamis 52:01

Yeah, the intimacy of that event may have been what enabled that. So I get it, and there was a lot less international flavor there, so I totally get that, and it was a very well organized event. It was a great event. The presentations were awesome, and so they were at Asia Pacific Stroke Conference. But I just feel like I don't know if it was the organizers or the people who run the Asia Pacific Stroke Conference, but it's very telling when the most important thing is overlooked access.

Brooke Parsons 52:45

For a stroke survivor, this brings me to accessibility. We've all had accessibility issues in one way, shape or form or another, you bring up a very good point. Was it the organizing committee at Asia Pacific strokes conference that overlooked around to you and I, it's just natural. It's what should be there, but did anybody in that organizing committee have had a stroke, none.

Bill Gasiamis 53:29

That says a lot. I agree.

Brooke Parsons 53:31

Therefore, it brings us back to our original point that humans need to be involved in every single aspect, agreed, not just from a uni giving their input, not just from an institution giving their input, not just from an organizing committee, but from every angle, consumers are so needed and wanted.

Bill Gasiamis 54:02

Yep, I totally agree, absolutely. I mean, that's the only thing that could possibly explain why they missed such an obvious thing. It's like the elephant in the room. How can you not see it, honestly, but at the same time, maybe that's there'll be a learning from that, surely, because I think people would have told them, what are you guys doing? How come you didn't have a ramp there?

Brooke Parsons 54:25
Did you give feedback?

Bill Gasiamis 54:28
Not about that issue, no.

Brooke Parsons 54:30
Okay.

Bill Gasiamis 54:31
Yeah, but I imagine that others would have surely.

Brooke Parsons 54:36
Yes, I'm hoping so.

Bill Gasiamis 54:41
So that's interesting. I thought that others would, and I thought maybe I don't need to, but I feel like now I should have, even though others might have made a point of that, I feel like I should have made a point of that just nicely in an email saying 'Hey guys.

Brooke Parsons 54:59
Important to us.

Bill Gasiamis 55:01
Yeah.

Brooke Parsons 55:01
It's important to you, you need to voice it. She could all live by the rulings of, someone else will mention that, or someone else will give feedback. But what if nobody does because someone else is thinking 'Oh, Bill will give that feedback. Bill will do that. He was really upset about that when I saw him. I'm sure he'll give that feedback, but you are thinking someone else was going to give that feedback. So no matter how many times these people hear it, they need to hear it.

Bill Gasiamis 55:34
Yeah. I agree. I suppose the more people saying it, the more it'll sink in absolutely.

Brooke Parsons 55:44

Yeah, we've all been in those shoes where we wouldn't have given ramps a second thought.

Bill Gasiamis 55:50

Oh yeah, I definitely was that quiet.

Brooke Parsons 55:55

Moved into an SDA, a Specialist Disability Accommodation, and yeah, the doorways are wider, and it's very much catered to my needs. As I think I've picked up two things so far in four months that ain't right with the place. But my point that is, I've gone from renting a one bedroom apartment to this 1.5 bedroom SDA apartment, the bathrooms bigger, so I'm able to get my wheelchair in, wheelchair out. I'm able to shower comfortably here, all these things I wouldn't have thought of just as I didn't think of when I first wanted to move out of home.

Brooke Parsons 56:46

But until you're faced with those challenges, you just think 'Oh, someone else will deal with that, but someone else's issue that's not mine. So we're all my point is we're all made to be like that, but if we can just remember, have that little voice in our heads going, but my voice is just as important. And if I thought that in the conference, I need to relay that.

Brooke Parsons Empowering Stroke Survivors



Bill Gasiamis 57:16

Yeah, that's the point of the conference, to bring stroke ideas, information together, right?

Brooke Parsons 57:21

Absolutely, and consumers are more and more playing a role. So a couple of years ago, you would never have seen the the level that we saw at Smart Strokes of consumer involvement.

Bill Gasiamis 57:38

You're literally talking about a couple of years ago.

Brooke Parsons 57:41

Actually, two years ago, yeah, you might have had one stroke survivor. Might

have opened up the conference, and that was about it. Now this year, what did we see?

Bill Gasiamis 57:53

Yeah, they were front and center in every part of the conference, stroke survivors, every part of the conference.

Brooke Parsons 58:00

Absolutely, yep.

Bill Gasiamis 58:03

And Saran opened up quite a number of those main morning presentations. It was great, actually, absolutely,

Brooke Parsons 58:16

So I know last year I gave like, a three page letter feedback of all the things they could have done better for Smart Strokes, most of it was taken on board. This year my pet peeve was about the accommodation, but we won't even go there. So I haven't really provided feedback per se, but I am sure if I was that stroke survivor who had to get up on stage, maybe I'd be a little different, because it would have impacted me directly.

Bill Gasiamis 59:04

Yeah, I had to move so Asia Pacific, Stroke Conference. I had to move from the hotel room I was at that was suggested as the place to go for affordable accommodation near the venue where smart, where the Asia Pacific Stroke Conference was, and I think the organizers didn't actually go and check out the accommodation that they recommended.

Bill Gasiamis 59:35

And let's just say it was old, which is not relevant at all, because that doesn't bother me in one bit, if something is old, but it wasn't clean, and there was a lot of dust and debris in the air vents, and you could see places where furniture had been moved, and there was like a thick layer of dust that had a main vacuum.

Brooke Parsons 59:57

I wonder if we were talking about the same place.

Bill Gasiamis 1:00:01

We may have, we won't mention the name, and then, as a result, I had to relocate and move because I was so unwell with my sinuses. And I made a note to the organizers and said 'Hey, guys like you made a suggestion, and it seems like it's been a while since you've gone and inspected that property that you're suggesting to us to go and see, to go and stay at because the standards are not good enough, these are all the things that I've experienced, these are the photos to prove what I'm saying.

Bill Gasiamis 1:00:43

Like the dust was caked onto the air vents, yes, and I'd like to let you know that you need to do more in inspecting a place when you recommend it. So that was received well, and then I changed accommodation. The hotel wasn't very supportive, but the organizers were a little bit upset, horrified that it would event would have that that thing would have happened. So I suppose, like I spoke out about that, because I know that a lot of other people were may have been impacted by that.

Bill Gasiamis 1:01:24

And it's just that I'm still defining my role in how, what kind of role I'm playing in the community, in stroke survivors community, very powerful one. Well, I hope so, with the role, as in, like I have been, I have been a little bit not distant, but I have taken purposely a slow approach forward and, you know, stayed in the background because I didn't know whether it's an old, this is old Bill again, you know, going, I don't know if it's appropriate for me to talk to people like this, who are in these positions, who have these types of qualifications, and, you know, tell them what I think.

Bill Gasiamis 1:02:15

You know. So it was, I'm kind of about getting over that, and I don't need to tell people what I think from I know everything perspective, it's just from a you guys are missing the obvious thing, like the ramp at a Stroke Conference. You know, I'm feeling more and more comfortable about being in that position, and I think I owe my listeners and my guests the responsibility of taking what I'm learning from them.

Bill Gasiamis 1:02:44

When they offer me an hour of their time to listen to an episode, I think I owe them a responsibility to sort of take it to the next level and go 'Hey guys, this is

what I'm hearing from 330 stroke survivors that I've interviewed. This is what you need to be aware of.

Brooke Parsons 1:03:03

Yes, but I think Bill, you already do an incredible job.

Bill Gasiamis 1:03:10

Yeah?

Brooke Parsons 1:03:10

What you do? So, Bill, can take a hike for a little bit.

Bill Gasiamis 1:03:15

Yeah.

Brooke Parsons 1:03:18

The only bit of advice I would give if I'm allowed to give you advice is, choose what you want to make a difference in. And by that, if you want to talk about ramps and stages and conference centers, you might be thinking more along the architect side of things, accessibility side of things, that if it was a peer support thing, you might go.

Brooke Parsons 1:03:52

I might just put you in contact with Adrian O'Malley and Brenda Booth, or The Flooring Institute, or whoever that would specialize in that, and then you could proactively do the whole conference stage sort of thing. I'm only using that as an example. What I would tell you is that you can't do it all.

Bill Gasiamis 1:04:18

No, no, none of us can do it all right? That's very important.

Brooke Parsons 1:04:22

Because if we don't look after ourselves, we're unable to look after each other. And at the end of the day, as a peer support group, who do understand each other, we need to be able to look after ourselves.

Bill Gasiamis 1:04:39

I appreciate that. You know why? Because I haven't actually really thought about what where I want to play most at that's so that's a really good point that you made there, and this might encourage me to sort of think about where that might

be, whether, like you said, whether it's accessibility, whether it's something else. That's the first time I've actually heard it like that. And why? Perhaps I felt like I can't really comment about all these other things because I haven't picked it as my hobby horse.

Brooke Parsons 1:05:13

Maybe and look, we're all here to help and to guide you and to listen and to pose questions that probably mean nothing to you, but to get you thinking about what you would like, where you feel that you can make the biggest difference.

Bill Gasiamis 1:05:38

Yeah, that would be good to know that. Oh, my God, I think about that.

Brooke Parsons 1:05:47

Ring. You can always email.

Bill Gasiamis 1:05:51

Thank you. So what can you talk about some of the work studies, research that you're involved in currently? Can you give us a bit of a idea?

Brooke Parsons 1:06:03

Absolutely. So obviously, I started out 21 years ago as the consumer representative for the avert trial, which is a very early rehab trial. It was an international trial run out of the flurry under the direction of Professor Julie Bernhard. At the time, she said 'Can you give me three years of your life? And at the 15 year mark, we presented the results of that trial. So there's no time frame on research. I think that's the biggest thing I've learned, is that you know, if you're going to do something, you do it properly. From that, I'm now the consumer consultant for the avert dose trial.

Brooke Parsons 1:06:54

So we've learned that you can get a stroke survivor up out of bed, but we're trying to get the exact dose right, because it wasn't necessarily correct in a vert. I was also the consumer consultant for pesto, which was a drug inserted into a person's spine to break the paralysis cycle. I was a part of the novel project. Novel is an architect project, actually, and that had me hook, line and sinker. That was if we had an unlimited budget, how would we build a hospital? What would it look like for stroke survivors?

Brooke Parsons 1:07:48

And I had Rosie from the Jetsons, for those that aren't too young to remember the Jetsons on TV, and they had Rosie, the robot that would clean up after them, etc. And we would have lighted walls. So if I put into the keypad on a wall that I had to go to physio, the walls would light up all the way to the physio room, etc. So that was really cool, because you could think outside the square as to what you wanted to do.

Brooke Parsons 1:08:23

I'm now involved in the Young Stroke Service, which we briefly touched on at the beginning, and there could be something coming up, but I'm under wraps at the moment someone stay tuned.

Shaping the Future

Bill Gasiamis 1:08:47

Alright, okay. Well, I think I know part of the, some of the stuff that you're working on not going to mention it. That's alright, and I understand why you might keep things under wraps, It's important to do that. So what does it look like for you going forward in the next five years and 10 years in this space, do you still see yourself hanging out, playing, supporting, being involved?

Brooke Parsons 1:09:21

There'll always be a spot for me. It'll just be however big or however little I'll want it to be, the way I'm looking at 2025, it's going to be a massive year.

Bill Gasiamis 1:09:37

Okay, for research and stroke survivors for what specifically me, for you.

Brooke Parsons 1:09:44

For me in the research world. But let's keep in mind that whilst I know where I'm heading, personally in the research world, I'm always thinking that, if I wasn't around, would my role still go on? Who would do my role? Who's coming up through the ranks? How do I want my role left from me for the next person to take over. So there's always that going on in the background.

Bill Gasiamis 1:10:31

I like that. I like that you're thinking about that because then we don't want any of this to stop.

Brooke Parsons 1:10:40

No, because it's much bigger than you and I, right? And life is fleeting, that's the truth of it. So I mean, stroke research was always around before I started, but the consumer voice wasn't as powerful as it is today, and I've had a real helping hand in making it powerful. So what can I do to ensure that that powerful voice of the consumer stays alive well and truly beyond my days when I decide, right, it's time to retire, I've had enough need to go and sit on the Whitsundays.

Bill Gasiamis 1:11:31

Yeah, I like that. You're thinking of that. What do we call that? Not it's like, what's the succession plan?

Brooke Parsons 1:11:42

Absolutely, yeah, we definitely need that everything we do, in research, there needs to be an outcome, but there needs to be a plan beyond that. So if we want consumer voices to be sustainable, beyond me, beyond you, what needs to be put in place for those for that to still happen, and it is happening. It's happening with grants. Now you can't get a grant without consumer involvement.

Bill Gasiamis 1:12:27

So, it seems like has there been a policy change or some kind of a change in the way that these organizations do research that kind of embeds that or cements that in? If this doesn't happen, then nothing happens.

Brooke Parsons 1:12:41

It's starting to but I still think there's an element of a way to go. So a researcher may approach someone and say, will you be on our board? And they the stroke survivor can say yes, but then often penciling in the monetary awards of having that stroke survivor on the board is forgotten about. So you've got the element of having the stroke survivor committed. Yep, you've got them. But then it's making sure the grant reflects the consumer's involvement.

Bill Gasiamis 1:13:26

So it's not just about ticking the box. No, you spoke to a stroke survivor. Technically, they're on the board, but then that's about it.

Brooke Parsons 1:13:35

Yeah, because if we think 20 years ago, it was very rarely heard of that a stroke survivor was on a board. Now that's just expected you have a stroke survivor on

your board. Okay, it's taken us a while to get there, but we're getting there if it's written into grants, the monetary reward side of it all, then in the next 10 to 15 years time, that'll just be ordinary. And therefore, why wouldn't it be sustainable?

Bill Gasiamis 1:14:20

All the up and coming Brooks will just fall into the program as per normal, as part of the normal running of a grant process of a research program. And then there won't be that whole like the battle. It's for lack of a better word, the lack of the like the Battle of the stroke survivors, being heard, being included, being part of the program where that's just expected. It's standard every time there's a grant provided or people asking for money. Your research is happening is just okay, stroke survivor involvement number one starts there and then going forward from everything else.

Bill Gasiamis 1:15:10

That's such a great way to position research, especially it's a great thing for other people helping survivors of other conditions to also imagine if we could kind of put that broadly into, you know, cancer. Cancer survivors are involved at day one day dot. Heart patients, they dot this patient, you know, that patient always that they dot, that'd be great.

Brooke Parsons 1:15:43

I think so, and the other thing to remember is that writing a grant or being in research takes a team. There's no I in team, and that motivates me every day to get up and do what I'm doing, because it really does take a team, a team of exceptional humans, whether they are strict survivors, family carers, researchers and their Families and everyone needs a little bit of someone, and that's where that peer support and that common understanding comes in.

Bill Gasiamis 1:16:31

Yeah, it's that party I've got a part in my book that's all about community. It's like, find your community and get involved so that you can feel understood, heard, that you can feel like I'm playing a role, playing a part. You have purpose, meaning. Tell me a little bit about that for you, like the purpose and the meaning side of it does. Have you ever had that thing in your mind, like, you know, what's my purpose in life? Have you done that? How have you? Because for me, I had a purposeful and meaningful life before stroke. It was all about my kids.

Bill Gasiamis 1:17:08

It was all about raising them and all that kind of stuff, and then they let you down when they turn 18, because they don't need you anymore, and that your purpose, you have to redo it, I suppose, revisit it, and work out how you're going to go forward. And one of the big things in my recovery was when I discovered the purpose was to help other stroke survivors, when I kind of stumbled on that and then I did the podcast and began that, then the meaning came after.

Bill Gasiamis 1:17:43

But at the beginning, the helping came from just attending the Stroke Foundation, Smart Stroke, Safe stroke speakers, course, that I did to learn how to present for them. And then we did a lot of awareness raising campaigns and all that kind of stuff to different community groups, corporations, a whole bunch of places. And it gave me, you kind of turned this horrible thing that happened to me into, man, I could actually turn this into something helpful, meaningful, purposeful and supportive of other people.

From Survivor to Mentor: Evolving Journey Post-Stroke

Bill Gasiamis 1:18:27

That's not so I'm not going to decrease the amount of time that I'm going to be feeling sorry for myself. You know about what happened to me? Because it's about other people now, right? Yeah. So what about you? Where are you with that type of thing.

Brooke Parsons 1:18:45

Pre-stroke, I wanted to be a music teacher. So that was pre-stroke. I knew at the age of 13 what I wanted to be when I grew up, and then at the age of 18, when I was looking at uni subjects and uni choices and courses and what I was doing in BCE and where I wanted to go after school, I really had no idea, because I knew I couldn't become that music teacher I'd so desperately hung on to throughout the first five years post stroke, that was good.

Brooke Parsons 1:19:26

Mind you, hanging on to that idea for five years post stroke, in those very early initial days, gave me a purpose to keep going, to get up, to try again. Get up after every fall, and now I'm going to be okay from that, I would say luck's been

involved, because I was asked by the Children's Hospital to be a chapter in a novel written by Neil Mitchell. Who was a 3 AW radio presenter, and then somebody at the Stroke Foundation read that chapter and said 'We've gotta get her as an ambassador. And then the CEO at the time, Erin Layla, nominated me to be on Julie B's project.

Brooke Parsons 1:20:22

And so it's sort of gone around and around in a circle. Now you may have noticed Queensland in Adelaide, I often take a back seat. And by that, I mean I'll sit there and I'll be amongst everyone. But if you said to me 'Oh, Brooke, I don't agree with that, or I do agree with that, and for these reasons, I'd say 'Bill, please, say it, they're really good points, because you've told me, right? You might just need that little bit of a push. For me, it's about mentoring and bringing everyone else up through the ranks. Now, to do what I do.

Bill Gasiamis 1:21:09

I love that. That's so great. So it's kind of evolved, and it still involves your original participation, helping other people, be they researchers. As a result of helping researchers, you help stroke survivors, that's all still there, and now it's about mentoring other stroke survivors to sort of step in and play a role. I love that.

Brooke Parsons 1:21:30

Yeah, so I think I've always been giving. I think there's always been an element of leadership there. I'm one of these people that always seems to know what's going on, even when I don't want to know what's going on, like around places and things and all of that's well and good. I'll always have a little bit of a burning desire in me, I guess, to be a leader in one way, shape or form. And many would probably say I am a leader in what I do.

Bill Gasiamis 1:22:07

Yeah, there's definitely a leadership quality there that it seems to come natural to you.

Brooke Parsons 1:22:17

I think, yes, yeah. But my purpose isn't so much about me or doing what I do to fix me, because the cold truth is that's never going to happen. But a deformed arm, that's the way that's going to be, got deformed legs. Sadly, that's the way they're

going to be. But those that know me, those that have relationships in whatever form, with me, that's because they know Brooke, the Brooke who lights up her room when she enters.

Brooke Parsons 1:22:58

The Brooke who has a sparkle in her eye every time she smiles, and the Brooke who will give her absolute most even on her worst day, just to get through the day. That's why I do what I do. I think that's what gives me purpose, and it keeps me going.

Bill Gasiamis 1:23:28

Yeah, that's good to have something to keep everybody going. Anybody going? I as we come to the end of the episode and wrap up, I ask stroke survivors these three questions at the end of my episode, which I'll ask you. But usually the stroke survivors who I ask are very new to stroke. When I'm saying very new. It didn't happen 30 years ago. It happened say, you know, two months ago, six months ago, a year ago, they're still in that very early sort of part of their journey.

Embracing Change: The Transformation After Stroke

Bill Gasiamis 1:24:02

And the first question goes, what is the hardest thing about stroke for you? So I'll be very interested in in that perspective from somebody who's been living with stroke the majority of her life.

Brooke Parsons 1:24:20

Do the hardest thing for me was accepting the fact I lost old Brooke. However, I gained a Brooke who is fierce, who is stubborn, who can be a loud mouth and still have most of the qualities that she had beforehand. So what I'm describing to you is, I can still be a pain in the bum.

Bill Gasiamis 1:24:48

So, you can be old Brooke. And then there's this new version as well that's also still emerged and taken the old Brooke with her.

Brooke Parsons 1:25:05

Absolutely, I think, you know, I could say I'm the old Brooke, but I'd be denying

myself the fact that I'm in a chair now, and that I've had a stroke and that I've got limbs as much as I want them to work, don't work. So that's what I mean by old Brooke had limbs. Used to run around on a Saturday morning in a netball skirt and play goal shooter and then come home and study for six hours. New Brooke can't do that, and that's okay, but new Brooke is just as powerful as the old Brooke was. She's just had to find those qualities that make her equally, if not, better.

Bill Gasiamis 1:25:56

More powerful. I love that. So then the next question goes, what has stroke taught you?

Brooke Parsons 1:26:10

What has stroke taught me? That's a really good question. I this is going to sound weird, but we are all human, so therefore we all have the right to have good days and bad days for people like yourself, Bill and for like myself, despite being in a chair, our stroke is the burden that we carry every single day. So for example, I might say to you 'Hey, let's catch up and do lunch. And you'd say 'Yeah, I'm just going to make a salad sandwich. I don't know. I'm just making this up, by the way, the way you make a salad sandwich would be completely different to me.

Brooke Parsons 1:27:14

Ringling the support workers downstairs going 'Hey, can you come up and make Bill and I solid sandwiches. Although it's done differently because our abilities are different, we're still people, and we have every right to express how we're feeling and our opinions and be accepted and loved just as much as the next person. Does that make sense at all?

Bill Gasiamis 1:27:51

It does. Do you feel that society, this is such a general question, and it probably deserves a general answer and nothing specific. But do you feel that society still overlooks the needs of people that are different because of, say, their appearance, their disability? Does that still happen? Do you get a sense that I think overlooked, etc happens.

Brooke Parsons 1:28:24

I don't know if it's overlooked. I think we as individuals, though, need to find an acceptance that's okay for us to go. This was the old me, this is the new me, and

I'm still equally as important, and I'm still okay.

Bill Gasiamis 1:28:47

So it's a personal thing to develop.

Brooke Parsons 1:28:50

I think so because, you know, it would be fair for me to say, people see me in a wheelchair, and they must go 'Oh, poor bro, she, you know, she's in a chair, her life must be so terribly hard. But did they see me get up and speak in Queensland? No, have they seen the process of me being in a novel? Absolutely not, but a person who's been in a novel will completely understand the process of being in a novel. So I just accept how you do things may be different to how I do things. Yes, we've both had strokes, but they're like our invisible friend that just tag along for the journey.

Bill Gasiamis 1:29:46

It's about how you turn up, isn't it? It's about how we turn up to a place, and how we put ourselves out there, and the vibe that we're giving off, as to how people are going to interact with us and classic example I always go back to this guy is Stephen Hawking, yes, in all of his challenges and disabilities and inabilities and all that stuff, he was still when he turned up, he paid attention. You need to listen to what he had to say about the particular topic that he was talking about. And it did make it made no difference.

Bill Gasiamis 1:30:20

He was the expert in his field, no matter what his condition was like, looked like, you know, nothing. So that's, I think, where you're getting it is like, it's how we turn up, regardless of what we've been through or what we're going through, absolutely. I like it. And then the last question is, and we may have already kind of gone over it a little bit, it's like, what I don't like the word advice particularly, but it's like, what would you tell other stroke survivors?

Brooke Parsons - From 'I Can't' to 'I Can

Bill Gasiamis 1:30:52

Usually, they're going through it early on, they just started their journey. Some of them might be, you know, a few years in, they're still grappling with all of the changes, the differences can What do you tell them? What do you tell other

strokes survivors who are listening?

Brooke Parsons 1:31:08

Yeah. Look, I think this is a really powerful question, because if I recall back those early days, and I'm sure we all can, in one way, shape or form, we hear the word can't a lot. So the first thing I say to stroke survivors is, well, let's drop the T and it's I can. And if you can, you will find a way to do it. And an example of that is in 2023 I went to the World Stroke Congress in Toronto, where I spoke, and I said to two of my colleagues who happen to be physios, let's go and climb the CN Tower, and let's do the sky edge walk.

Brooke Parsons 1:32:07

Now these two physios clearly thought that I wouldn't have thought of any dare devil activity, and that would be all safe because Brooke's mentioned it. So they went 'Yeah, yeah, no worries. So I paid for the three of us to do it. When we got there, they went 'Holy Lord whose idea was this again? And I go 'Oh, very happily. And then we got out onto the sky edge walk, and one of them hung over the edge and went 'Yeah, I'm free, this is lovely. Another one would barely put a toe over the edge. But then it came to me.

Brooke Parsons 1:32:56

Here I am in the wheelchair, and I'm hanging over the edge, well and truly going, I'm free. This is wonderful. I don't want to get down from here. That would have been very easy for me to turn around and go, no, I'm not doing that. But I didn't, because who knows if I'll get back to Canada. Hopefully I will, but it was something, then that evening, I sent the little clip to Julie B said 'The only thing missing was you. And then it became the talk of the conference. Everybody knew that there was a girl in a wheelchair who did the CN tower climb.

Bill Gasiamis 1:33:47

Yeah.

Brooke Parsons 1:33:49

And that would be so easy to just sit back and go, I would like to have done that, but I'm in a chair.

Bill Gasiamis 1:33:56

I can't there's, I suppose, what you're getting through is, there has to be, like, a willingness to participate in life. And it's pretty obvious that when you do like, big

things can come of it. I mean, you represented stroke survivors at a conference in Canada from Australia. That's huge, and that's possible, right? That's, I'm not saying that the goal should be to be a stroke survivor who specs on a on a international stage, maybe, but it doesn't have to be that. But that's what I get from what you just said.

Resilience and Advocacy

Bill Gasiamis 1:34:00

So by participating in life and doing the scary things, one of them is, you know, looking over the edge of a massive drop, it kind of is a similar thing, to participate and then end up on a stage, which is a big thing in another country, doing a presentation. I see why you've achieved so much. It's because of that willingness to do scare you well, maybe calculated, risky thing, but scary nonetheless.

Brooke Parsons 1:35:06

Yeah, I think it's about dropping the T and believing you can when you can, believe you can anything is possible, because you're willing to go to all lengths to make it, in itself is anybody can choose to if they want.

Bill Gasiamis 1:35:31

On that note, thank you so much for joining me on the podcast. I really enjoyed our chat, and it's great to connect with you again, since we connected in the conferences, which always happens in very small bursts, because everyone's rushing everywhere, and no one really has time, so much time. So it's been lovely. Thank you.

Brooke Parsons 1:35:54

Thank you, Bill. Thank you so much, and I'm always around.

Bill Gasiamis 1:35:59

Well, that brings us to the end of this inspiring episode with Brooke from surviving a stroke at just 13 years old to becoming a fierce advocate and lived experience consultant, Brooke's story is a testament to resilience, advocacy and the power of community. Her work is shaping the future of stroke recovery for survivors everywhere. If today's conversation resonated with you, I'd love to hear from you. Please like, comment and subscribe on YouTube, if you're listening on Spotify or iTunes, leaving a five star rating or review would be amazing.

Bill Gasiamis 1:36:38

It helps others discover the podcast and join the growing community. Remember to check out my book, *The Unexpected Way That A Stroke Became The Best Thing That Happened*, available on Amazon or at recoveryafterstroke.com/book, and if you'd like to support the podcast directly, please visit patreon.com/recoveryafterstroke. Thank you for being here and listening and making this podcast part of your recovery journey. I'll see you in the next episode.

Intro 1:37:08

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Intro 1:37:38

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Intro 1:38:03

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Intro 1:38:30

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