

Vertigo Turns Out To Be STROKE

- Joy Alliy

Joy Alliy was a lawyer who had persistent dizzy spells that were misdiagnosed as vertigo before being diagnosed as an ischemic stroke. Joy was 42 years old.

Instagram

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Bill Gasiamis 0:00

What motivates you to come on to the podcast? What's the point of it?

Joy Alliy 0:04

Well, I've been on other podcasts too. But this one, I felt that because of you I wanted to reach out specifically to stroke survivors as well, especially the new ones. So they can know that they're not alone. You can recover, it might not be 100%, but you can recover. And being in a wheelchair doesn't mean that it's the end of the world, you can still do so much in a wheelchair.

Intro 0:33

This is the Recovery after Stroke podcast. With Bill Gasiamis, helping you navigate recovery after stroke.

Bill Gasiamis 0:46

Hello, and welcome to the Recovery after Stroke podcast. As mentioned in the last few episodes, I'm putting the final touches on my book and have made the first chapter available for free for anyone who is curious to check it out and wants to grab a copy. If you go to recoveryafterstroke.com/book and fill out the form, you will receive the first chapter in your email a few moments later.

Bill Gasiamis 1:12

The book is called "The Unexpected Way the Restrict Became the Best Thing That Happened" and it took four years from concept to completion. Now in the final stages, it will be available for sale in about six weeks from now. So go along to recoveryafterstroke.com/book. Grab your copy of the first chapter free today. If you are a stroke survivor with a story to share about your experience. Come and join me on the show.

Bill Gasiamis 1:37

The interviews are not scripted, you do not have to plan for them. All you need to do to qualify is be a stroke survivor who wants to share your story. If you are a researcher who wants to share the findings of a recent study or you're looking to recruit people into studies, you might also reach out and be a guest on my show. If you have a commercial product that you would like to promote that is related to supporting stroke survivors to recover there is also a path for you to join me on a sponsored episode of the show.

Introduction - Joy Alliy

Bill Gasiamis 2:05

So whoever you are, just go to recoveryafterstroke.com/contact. Fill out the form explaining briefly which category you belong to. And I will respond with more details about how we can connect via Zoom. Now this is episode 272. And my guest today is Joy Alliy, who was a self-employed lawyer who had the signs of stroke for several months before she went to the hospital. Nonetheless, was given the misdiagnosis with vertigo.

Bill Gasiamis 2:37

Joy Alliy, welcome to the podcast.

Joy Alliy 2:39

Thank you Bill for having me.

Bill Gasiamis 2:40

Tell me a little bit about what happened to you.

Vertigo Turns Out To Be STROKE

Joy Alliy 2:42

Where should I start? Well, okay, basically all this happened during the pandemic. And first of all, It started around February 2020, I went to a funeral because I lived in Tanzania. So this is from Africa to Scotland. I lived in Tanzania and in February one of my friends from uni passed away, they had a heart attack at 42 now sorry from high school. So I went to Kenya for the funeral. In Kenya the funerals in Africa the funerals are not like in the UK where they are just all subdued there's a lot of crying they are just very sad was a lot to take in because there were children there crying and everything.

Joy Alliy 3:29

So I came back home and then I continued working and then around May, I started having dizzy spells. One day I just woke up and I had the middle of the night and I had a really bad day I woke up and had like a spell that was like feeling dizzy hot and cold, feeling nausea, feeling like I was going to throw up. And you know, because I didn't during the pandemic I thought maybe it was going to be to do with to do with maybe COVID The thing is, I was extremely careful because I'm asthmatic.

Joy Alliy 4:00

So I made sure I was self-isolating. And I've done all this stuff I can't get COVID now. So the next day it calmed down. Then I continued working in the more I continued working the dizzy spells continued. And so I just thought you know what, I'll go to the hospital. So I went to the hospital and they referred me to an EMT specialist. The specialist looked at my nose and they said that I had vertigo so they just gave me anti-vertigo medication. So I continued working but then I continued having the dizzy spells to the point where I just had to stop driving as I had to take taxis to work.

Joy Alliy 4:47

At one point I even went out one time when I was driving it almost crashed my car when I was trying to park. This was in the parking lot of the building, but then I

just thought there was something wrong. And so this time my partner was Scottish. He was in Scotland and I told him all this stuff and he was like, I'm so sorry, this is happening. I wish I could be there. And of course, at that time, the restrictions on traveling in Scotland so you couldn't leave the country.

Joy Alliy 5:19

And luckily, you know, around around August that's when the that's when the, the air pass, the airways were like open so that you could fly. So my partner decided to come stay with me. And when he was there one day, he went to see a friend of his who was just sitting at home watching TV. And basically, I lost my vision temporarily. Because I used to wear glasses, I wear glasses, and the time was very important. I thought maybe there was something wrong with my vision. So I made a note to like, maybe I could see a, would call it opticians.

Joy Alliy 5:56

As I continued, continue that, and then another dizzies will happen and what's going on, there must be something wrong. And then and then one day, about five days before the stroke. My father was cooking me a meal and I vomited as I was going on, um, I mean, is it food poisoning? What's going on? Am I having these things? Then the last time I had the dizzy spell, I was actually in the pool with my nephew. My nephew was six. And I was teaching him how to swim in the pool.

Joy Alliy 6:27

And I didn't want to scare him. So I just got off and I sat on the edge and we're going to come down. The next morning I had I had this I woke up the next morning, was supposed to go to an island with my partner woke me up at 7:30 to go to the so we could go in had a stroke. So I forgot to say that the night before. I got up at 4 a.m. to go to the bathroom.

Joy Alliy 6:51

When I woke up, I decided when I went to the bathroom, I switched on the light and I couldn't see I looked in the mirror because you know, people just look in the mirror like just normal I looked at it and I just couldn't see my reflection at all. Well, I must say because if my brain told me like, there's nothing to see here. And it came out.

Bill Gasiamis 7:12

You could see walking, walking through the house.

Joy Alliy 7:15

But could see myself walking through. But then when I took it I looked at it my brain said, We don't want you to see this. I don't know what happened. And then I just tried to I just tried to make a noise and nothing came out. And I thought you were having a bad dream. And so I just went back and I went back to bed. Then the next morning when I woke up, that's when the stroke could happen. I think the stroke started happening around 4 a.m., so that time the stroke was happening and I didn't know and I went back to sleep.

Bill Gasiamis 7:45

So did you work out what the underlying cause was?

Joy Alliy 7:50

They looked there and they couldn't find anything and, when he came here, they did all those tests to do with what do you call it? The bubble test to check if there was if I had a hole in my heart. They checked my atrial fibrillation, they checked arteries, everything. And I'm not underweight, I don't have high blood pressure. I don't have what you call it. I am not diabetic, none of those things. I got a stroke I was 49 kilos. And then obviously, and I was always, I was always, I was always working out. I worked out four times a week, I did kickboxing and I believe it must be stressed because of the nature of my job.

Bill Gasiamis 8:42

Okay. Can we talk about the nature of your job? What were the events like leading up to the stroke?

Joy Alliy 8:49

Well, I am a lawyer. I'm a corporate lawyer. And I run my firm. During the pandemic, you can imagine it was difficult. All these, all the companies representing the all grade much trying to find ways to keep their stuff going. At the same time, I had to deal with just what I had to do. And so and my staff, some of them didn't want to go to the government offices, I was running around trying to sort out everything out. And family wasn't taking COVID seriously, or having panic attacks because of that. So all this stuff just kept building and building up.

Joy Alliy 8:57

And how many people do employ?

Joy Alliy running a business after a stroke

Joy Alliy 9:31

I used to employ three people. I say used to because I recently closed my business after five years, but before that, I used to be I used to work in a law firm for about, for about 12 years. Then I decided to have my business thinking that things would be better it will become, but it's worse.

Bill Gasiamis 10:04

Yeah, it's hard hard run a business and manage people to keep on top of everything.

Joy Alliy 10:11

It is very hard.

Bill Gasiamis 10:13

As a result.

Joy Alliy 10:14

you can hear people saying that so when you hear people say that they want to start a business, you're like, okay, good luck.

Bill Gasiamis 10:20

I completely understand that. Tell me about when you decided to decide to stop the business to close it down. Was it? What's related to the whole situation? But is it because you have deficits as well that makes it hard for you? Or was it more of a lifestyle?

Joy Alliy 10:45

Yes. Yes, because I have, I have cognitive issues, I have aphasia. And aphasia has to do with expressive aphasia. And of course, it was really neat to be able to express yourself on the bat, just like that bat problems are spelling, grammar, and numbers. How am I supposed to be with clients, when I can't do my simple math properly? And also, I decided, after my stroke, six months after my stroke, I went back to work. Six months.

Joy Alliy 11:21

When I went back, I couldn't even read, I couldn't even read the legislation was like, it was just like, the numbers, the words were just like all over the place. And

it took me some time to learn how to read again, properly. And then at the same time, so then, when that happened, I decided to basically, first suspend my lessons. Because it is not a good idea to continue practicing when you have a stroke.

Joy Alliy 11:47

I didn't want to be sued for any I didn't want to perfect any lag measures. Then I suspended it. And then my staff were associates, they will continue the firm. Then because I wasn't there, we weren't getting any clients. Because I was doing everything marketing, and running the business. I was wearing so many hats. Because they weren't doing enough marketing. We started losing and weren't making any money.

Joy Alliy 12:11

So I was just paying salaries, but no money was coming in. So I just thought, you know what, there's no point in. So because I was recovering, and I was trying to recover and run the business at the same time. It wasn't working. Yes, yeah. And doing it remotely.

Bill Gasiamis 12:31

And doing it remotely. It's that trying to run the business and recover at the same time kind of doesn't work together, you have to do one or the other. And after you've had a stroke, you can't run the business the same way. And it does get in the way of the recovery if you focus on other things instead of your recovery. I'm interested to hear about your journey in kickboxing.

Bill Gasiamis 12:55

I think that kickboxing is not necessary in life, that you do not need to do kickboxing. I see people perform the sport. They're athletes, they're amazing. They can take a beating, they can give a beating. But I don't understand how people can get involved in it at all. Just seems so bizarre to me. But tell me about your journey with kickboxing to what extent were you involved?

Joy Alliy 13:22

Well, when I first started as a lawyer in one of the firms, of course, it was because when you're doing it, they just give you so much work. It was just becoming too much for me and I was getting so stressed I started getting problems with my back. And I was even I was getting carpal tunnel syndrome. All these back issues

back muscle spasms. And so when I went to see a doctor in South Africa, they said when she was porters relaxing, and you know your kickbox on your kickboxing your body has to be completely relaxed.

Joy Alliy 13:58

Also one or the other reason why I chose kickboxing was because I wanted to learn how to defend myself. Because I had issues in the past with an ex. So it's okay, to combine two different things. Self-defense and Saturday we'll find relaxing. Also, when you're punching the bag, if somebody annoys you at work, you just take it out on the punching bag later on. And the next day you're in there.

Bill Gasiamis 14:24

Okay, that completely changes my view on kickboxing then. So it's, it was a sport, it was relaxing, it enabled you to take your frustrations out. Did you perform? Did you compete at all did you get to the stage where you competed?

Joy Alliy 14:40

No, as you can imagine competing and coming to work with a black guy and wearing a suit. Those who don't work. So I didn't I didn't get to the competition level but I was quite good. And I think that helped me because when I was at the hospital when they were trying to lift my leg to see how I was doing, I was quite flexible, and so they were surprised. They asked, they asked my sister, is she a ballerina? And she said, said no, she kickbox.

Bill Gasiamis 15:08

So you had real long, long reach if you kicked like?

Joy Alliy 15:12

yes, yes. And people say I have a mean left hook.

Bill Gasiamis 15:21

So are you? Are you left-handed or right-handed?

Joy Alliy 15:25

Right handed. I don't even know how that happened.

Bill Gasiamis 15:28

Well, so what you do is you use your right hand to set, up set up the punch, and then.

Joy Alliy 15:35

Yes, people think it's gonna be right and then it's just left.

Bill Gasiamis 15:42

I especially started to struggle with martial arts kickboxing, and UFC, watching particularly after my brain surgery. And I had brain surgeries, and my head was tender. Even now I'm talking about it. And it feels like I have to touch my head, you know, to make it feel, I'm not sure to protect it. As soon as I had brain surgery and came home, and then I was very cautious about my head, and people touching my head, I just couldn't understand why somebody else would willingly get into a ring and allow other people to try and hit them in the head.

Bill Gasiamis 16:20

It was just so bizarre to me. I couldn't understand I still can't, and I cringe watching those types of sports. But of course, I appreciate the athleticism. I mean, and the agility and the absolute just amazing human ability I do I appreciate it. I just can't watch it. The joy it just makes me squirm and feel uncomfortable.

Joy Alliy 16:47

It's not for everyone, but I still watch it all the time and I still box as part of my physics.

Bill Gasiamis 16:54

Okay. And how often how many days a week were you, were you at the gym?

Joy Alliy 17:03

There four times a week and during the weekends is do yoga and swimming.

Bill Gasiamis 17:08

Okay. Do you feel like that had a lot to do? All of the stuff that you did to take care of yourself? Do you feel like it had a massive role in your recovery? That it's a ploy too.

Joy Alliy 17:25

To a certain extent. it did, because I also ate well, and all those things. And in terms of I think it helped a lot in terms of the physio because people are surprised at how much I'm able to lift. After all, I also do a little bit of weightlifting as part of my physio, and people are surprised how much I can lift, I'm only 5 foot 2. So

tiny person lifting quite a lot of weight, they're surprised and it's all because of the conditioning that my body had before.

Bill Gasiamis 17:54

Yeah, I think it's a good foundation to have if you're fit. And you put a lot of effort into maintaining your body and you're eating well and you're doing all those things, creating just the right bit of a better environment to sort of start from in your recovery.

Bill Gasiamis 18:14

Rather than having an environment that's been unhealthy in the past and feels like you already gave yourself a real positive place to go from and you were doing it to protect your health you're doing it to look after yourself and to stress less than to make sure you didn't get carpal tunnel syndrome and all these things. So isn't it interesting that exercise is prescribed to avoid certain things? And also prescribed after a stroke because it helps with rehabilitation and helps the brain recover.

Joy Alliy 18:54

It is and so I'm surprised when people say like they find it difficult or people who are I say normal or difficult to exercise and like guys, it's going to help you in the long run. might find it painful now but in the long run you enjoy it and help you even if you have an injury it helped you write a good base for your recovery.

Bill Gasiamis 19:16

How did you go back to the gym? Did you find it easy? Was it difficult to go back after the stroke? Did it feel like it was harder? How did that go?

Joy Alliy 19:27

Well basically because what happened is I came here to Scotland and then I had a different physical home back home. So the physical heavy is a sports physio. So here's a little some equipment there and so I use a lot has also been to the gym a couple of times with my partner but I can't go it independently. I think it's it's probably a confidence issue more than anything.

Bill Gasiamis 19:53

And you go to the gym with your partner because he helps you, he spots you with the weights Oh, he's just your sparring partner?

Joy Alliy 20:03

No, he's just there so that I know I'm coughing, there's somebody there, but I'm gonna start going on my own soon as a place to go on my own all the time, is to go to the gym at 6 in the morning.

Bill Gasiamis 20:15

Is it because you need somebody there in case something goes wrong?

Joy Alliy 20:21

No. Just somebody there to just say, you're fine, we'll be fine. Because you know, like, when is the first time you go to the gym Oh, when you get a bit nervous, especially in the past, like my gym back home, it was like, Sorry, buddy, there was a lot of testosterone in there. When you went in, it was like all these men started looking at you all these things.

Joy Alliy 20:45

Back then because I used to kickbox and they knew that I kickbox as soon as they walked in, they just didn't mess with me. Then when I came here, it was still that so that confidence disappeared. And so when I came here just like still a bit nervous, worried that some of my training was something.

Bill Gasiamis 21:02

I hear or he, okay, and you wanted to you originally started going to protect yourself as well. Because you're in a situation where you need to protect yourself. Okay. So it's just going into a new environment. And you're not certain about what goes on in there. And what happens and you have a previous history and you figure, let's just take this slowly and easily and get to know what's happening. Have somebody there with me? I think it's a good idea. There's nothing wrong with that. Especially because you are back in the gym. I mean, that's a great idea. If it's getting you back into the gym now, does your partner go to the gym and participate as well?

Stroke recovery and hospital experience in Tanzania

Joy Alliy 21:41

He's been twice. I get trying to get him back and I'm like, I'm like, please just

come with me. And he's like, No, I'm fine. But so when I don't go with him, I just work out, you know, you know, flat, I just do it on my own. We have some ways we just use that I use all my equipment that I have.

Bill Gasiamis 22:03

So he just turns up just that make it possible for you to go. That's so cool in itself.

Joy Alliy 22:10

Sometimes he does sometimes he does exercise. I don't want him to think that I don't say something bad because going to hear this right.

Bill Gasiamis 22:19

Now I know. But it's such a good thing. It's such a cool thing, even though he doesn't want to participate at the gym. It turns up just to help you. Do what you've got it. It's so cool. I like it. I like it. So tell me about what it was like in the hospital system. Was it was it in Tanzania? Yes. What was it like when you presented a hospital with a stroke?

Intro 22:45

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. How long will it take to recover? Will I recover? What things should I avoid? In case I make matters worse, and doctors will explain things but, you've never had a stroke before, so 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 23:15

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.

Joy Alliy 23:48

Well, first of all, there are no public, no ambulances, and no private, public ambulances in Tanzania. They're all private. And when you call an ambulance,

basically they ask you if you can pay first. If you can't find your way to the hospital, and because we because of that because he was the one who discovered me and he didn't know about ambulances. So he's the one that drove me to the hospital. Luckily, we first went to a clinic where there for about half an hour and they had no clue that I had a stroke.

Joy Alliy 24:24

This was a clinic that was run, this was a clinic for experts. And they didn't know. Then this is just a we got one of the hospitals which we did. And luckily it was one of the one of the really good hospitals in Tanzania. And as soon as we got there was almost like a scene from ER, I was wailing in and people were standing over me asking me questions, all this stuff. And then they just they just said that I had a stroke. Because they did all the little tests, initial tests there I discovered I had a stroke.

Joy Alliy 24:58

Remember I kept saying I don't know what happened, I don't know what happened. Like our feelings like, like feeling sorry for what's happened to me, even then. And then they, they said, we have to do more tests. And then they took me to do the MRI, the CT scan, and all those other things. But then as they were doing that, they were also telling my sister like, prepare to pay, go get your insurance, and also before the insurance kicks in, you have to pay a deposit, then she had to go get a credit card and then pay the deposit.

Joy Alliy 25:31

And because it's all doing COVID, and at that time, they weren't taking it very seriously. So I was at the back of my mind, I was still very nervous about COVID, the Lord had a stroke, but I was more concerned about COVID. They said, Okay, you need to stay here, but we'll put you in a private room. So then I was in a private room for six days. So yes, six nights.

Bill Gasiamis 25:54

So you're, you've had a stroke, you're in Tanzania, you feel like the hospital system in Tanzania is not taking COVID seriously enough at that stage. And you're more concerned that you broke a check COVID rather than the fact that you've been told that you've had a stroke?

Joy Alliy 26:12

Yes. Because of all the stuff we have heard on, we've seen on TV about people getting COVID. And just because I'm asthmatic, I was worried that it would go to my lungs and all this stuff. I wasn't thinking about a stroke. And also, when I was there, the first night, when I was there, I got up and started walking up and down the corridor. And this is what I finished, you just had a stroke, I think it was just nervous energy. So then later on, they had to put all these tubes in, in me, that stopped me from going anywhere.

Bill Gasiamis 26:45

So I can relate to that part, the first time that I ended up in hospital after the first bleed. I turned up and they, I didn't look like somebody who had a bleed in the brain. But, there was a bleed in the brain, I was talking just like I am now walking, and my left side felt a bit strange. But I was in hospital for seven days, and there was a lot of waiting time in between. So I would just get dressed get up and go down to the cafeteria at the hospital. And they'd be looking for me. And they'd say to me, you can't leave your hospital bed.

Bill Gasiamis 27:22

And I would be organizing with my phone for people to meet me at the cafeteria. So my friends would come and see me with ketchup have a coffee, whatever. And it was I didn't take it seriously. Because of that. I felt like, well, I don't know what this bleeding the brain thing is, but doesn't seem to be doing much. And I didn't take it too seriously. But the doctors and nurses were freaking out. They couldn't believe that I wasn't in, in my ward. It was kind of nervous energy, but it was also on board, I needed to be up and about I was getting tired lying down.

Bill Gasiamis 28:05

So I needed to stretch my legs. It was not the normal presentation of somebody who's had a stroke, and then people would come and visit me. And again, they couldn't connect it because they would hear he's had a brain hemorrhage. And they imagined that that should be more serious. And they just weren't seeing it from me. And I couldn't convince people that I was unwell. And I couldn't even convince myself that I was unwell.

Joy Alliy 28:39

When I think the fact that you're meeting them in the cafeteria and made them think that oh, he's fine.

Bill Gasiamis 28:45

Yeah. Yeah, I was getting people to say to me, you know, sometimes these things happen. And one of the people who one of my cousins said to me, you know, boxers, and UFC fighters and all that sometimes that gets more blades on the brain, you know, and usually they, they go away and they recover, and they're fine. So everyone's just was pretty relaxed about it except my parents, they weren't relaxed about it, they were losing their marbles. But it was, it was interesting.

Bill Gasiamis 29:20

With the cultural differences, I'm curious to know how you guys go about things. So in my Greek family, when somebody has a stroke, or or any kind of minor or major incident, it becomes everybody finds out about it in about three minutes. And then you're dealing with 1001 questions about everything and then there's constant phone calls and it's a way that they get together to support you. It's their way of supporting you but it becomes overwhelming and too much. What's it like with your family?

Joy Alliy 29:59

In Tanzania is different. Like when you when somebody gets sick, you won't know about it. They just basically, it's like, it's especially if it's something major like that. They just basically want to keep it to themselves, they will tell very few people. I don't know why that is, you just feel like you need to just keep it as small as possible. So I didn't have that many people know about it. And even even when I left Tanzania, later on, still not many people knew about it until I came here. And I set up my acid, or something on my Instagram pages when they realize.

Bill Gasiamis 30:43

Wow, that's interesting. So, is it, is it? What is it? You know? Is it sort of, is it shame? is it, pride?

Joy Alliy's experiences with support and hidden deficits

Joy Alliy 30:57

It's a shame. And it's like stigma. It's like, you know, when you even when you had COVID, people were like looking at you and saying, I don't want to go

anywhere near that person. It's like, remember, when people first had HIV, you didn't want to go anywhere near them. Because it's like, all those things. If you have HIV, if you have cancer, if you have all the things. You just people just don't want to go near you. You think it's catching.

Bill Gasiamis 31:20

So unwell people, do they lack the support that I got that I thought was amazing, but overbearing, but still amazing, where people rally around you and bring food and all that stuff? Are you not sure if it elicited direct family? Do they get involved?

Joy Alliy 31:44

Define direct family, I think if you say direct family, as in your immediate family, yes. But any other family members? No. And of course, I got the financial support. But that's about it. It's just one of those things that they just, how do I describe it? I think we're a bit. It's part of the culture. And it's just something that just hasn't evolved in time. This is sad, because there were there were people that I knew who had had strokes, and I told my family should reach out to them to get more information. So they could better take care of him. But they didn't do that. Then one at that many people have had a stroke.

Bill Gasiamis 32:29

I see, that's interesting. Does that make it harder when people don't know that you've had a stroke? Because you're behaving a different way? Do you have cognitive issues, you have speech issues? And then I imagine you're still trying to communicate? Are you pretending that everything's normal? Are you letting people know who you ask or who you run into that this happened?

Joy Alliy 32:58

Well, I would, because at the beginning, they would see me in a wheelchair, or they would see me walking with like a limp or something. But if I but if I didn't tell them, they wouldn't say, say anything. It was me who made people aware. But people and imagine when I had the stroke, I reached out to some people who were stroke survivors, and they didn't call me back.

Joy Alliy 33:21

Because I wanted to know, like, what's your experience? Can you tell me if all these things that are happening to me are okay? Is this normal? should I expect

this but nobody came to me to tell me, only one person came. It had to do with my emotional ability.

Joy Alliy 33:36

And it wasn't the right way that they told me how to deal with it. Either. They didn't understand that. It was normal. It was only when I came here. And when I read about it more in the Stroke Association, that was when I learned more about my defects. But in Tanzania, not really. But my partner was very good at trying to get as much information as possible they could, because he became a full-time carer, my partner.

Bill Gasiamis 34:02

I see, so when you left one hospital, what were the deficits? There were some cognitive ones, and there were some speech ones, what else?

Joy Alliy 34:13

There's a slight weakness. I had swallowing problems, which I still have sometimes, like when I'm tired, or if I'm sick. I have sensory overload. Which doesn't help the fact that I'm here in Edinburgh Scotland. And I also had, obviously I had temperature issues. So temperature regulation issues. So there are temperature regulation issues, and I have some hidden ones as well. I have anxiety, depression, and PTSD.

Joy Alliy 34:50

When people see me they don't see those. Those hidden ones. And those are things that they didn't pick up on in Tanzania. None of them, If enough, didn't pick up on that.

Bill Gasiamis 35:05

How long were you in Tanzania before you left the hospital and before you went to Scotland?

Joy Alliy 35:11

I was in Tanzania for six months. Then I came, then we came over here, which was quite difficult because it was getting in the middle of a pandemic. We had to, we had to go to Kenya first for 10 days and then go to London and then take travel by car to Scotland. Six hours.

Joy Alliy dealing with anxiety and depression

Bill Gasiamis 35:33

Yeah, was the anxiety and depression something that you experienced before the stroke? Or is it something that occurred after?

Joy Alliy 35:44

Before the stroke I had, I was what you call a highly functional person with anxiety but also highly functional. But I didn't know that. It's something that I'm learning now but I didn't know that I had that back then. I used to get a little panic attacks as well at work.

Bill Gasiamis 36:05

And you hadn't worked out that you had anxiety, you lived with a so-called condition or the symptoms of it, and you just thought it was your normal life?

Joy Alliy 36:17

And I knew there was something wrong with my body. But I just didn't know sometimes you hear about it, but you just don't think it applies to you. Later on, you sit there and you have time to read and you're like, Oh, so that's what it was. Luckily, when you have this period of recovery, it's given me time to sit and read more. That was before the stroke used to read just anything stuff to do with the law, nothing else.

Bill Gasiamis 36:47

And the depression, how do you describe that? What? Is this something that has set that off? Because of the condition again? Or is it something that was from the past? And how do you experience depression? How do you describe would you describe it to me?

Joy Alliy 37:04

Well, with depression, I mean all the stuff, I'm taking medication for it as well. And it's the doctors who the doctor in Tanzania, that's why I saw, well what they call it, therapist in Tanzania and she was the one who diagnosed that I had PTSD, anxiety and depression, because when I was in Tanzania, I couldn't sleep at night when I came back home.

Joy Alliy 37:31

It's all because of the fear of getting another stroke because whenever it was time to sleep, I just didn't want to go to sleep. After all, I knew I was going to have a stroke to just staying up until 4 a.m./5 a.m. and depression I just didn't want to do anything I just didn't feel motivated.

Joy Alliy 37:50

Felt like my world was crumbling, I just didn't want to do anything. And it affected my eating as well. So just wouldn't eat as much. Which is still a problem now because I'm I've lost quite a lot that much weight. Considering that am I quite small. It's quite a lot. My trainer, the physio says that I've lost 30% of my body, my body weight. So that's so that didn't help either. It's just a feeling of doom and gloom. A feeling like, you're like in a sorry, a deep well that you just can't get out of.

Bill Gasiamis 38:42

So, the, it's a feeling, is it a thought or a feeling?

Joy Alliy 38:49

Feeling, feeling, and sometimes thoughts. Have also been in thoughts of suicide as well. That was quite bad because I remember when I had it. And when I finally told my partner, he freaked out. I didn't tell him for a while because I was afraid. Again, with my thinking. I thought that now with anxiety about depression and suicidal thoughts, I was thinking about how it was back then.

Joy Alliy 39:18

Because back then when you had suicide they would take you and take you. I thought the same thing would happen now I didn't want to tell him. When I told him he was like; right, you're going to get you to see another therapist here, right away. I used to find one.

Bill Gasiamis 39:38

Is your partner from Scotland or is it from back home?

Joy Alliy 39:42

He's Scottish, he's Scottish,

Bill Gasiamis 39:45

Very different cultural approaches to that kind of issue.

Joy Alliy 39:50

Yes. Luckily is actually because he took a year out once and traveled to parts of Africa so he understands the African culture as well. sometimes both worlds.

Bill Gasiamis 40:02

Yeah, okay, so he's confident sort of reading between the lines, and understands what might be going on. That's not obvious to the regular person who's not from or spent time on the continent. Okay, interesting. So, how is your motivation these days?

Joy Alliy 40:27

Well, I just celebrated by, I mean, when it comes, I just celebrated my third anniversary. So you can imagine what it's like when you're the days before and the day or every day is the same thing. Wake up, are you worried that you're gonna have another stroke, all these things, then luckily, people will help you. Then obviously, sometimes I get a bit depressed, like, for example, and it was closing my business, otherwise have been quite motivated.

Joy Alliy 41:00

I mean, when people see my Instagram page, they're shocked. Because I've done so much since I've had my stroke. I've done wall climbing, I've done growing. I have so many things I've always been active, both in physio and out on physio.

Bill Gasiamis 41:22

And you decided to share your story, you've come on a podcast that I was going to make a point of that because I do get a lot of people who told me that they go through anxiety, depression, difficulty doing stuff, and getting stuff yet, they somehow make an effort A to find a podcast B to come onto the podcast and share their story. What motivates you to come onto the podcast? What's the point of it?

Joy Alliy 41:50

Well, I've been to have been on other podcasts, too. But this one, I felt that because I wanted to reach out specifically to stroke survivors as well, especially the new ones. So they can know that they're not alone.

Bill Gasiamis 42:07

Do you think there are a lot of stroke survivors who might be from a similar cultural background to you? That might be listening, and therefore, being encouraged to take different actions on the recovery and get over the stigma.

Overcoming challenges and finding community after a stroke

Joy Alliy 42:31

Because you can recovery might not be 100% but you can recover. And being in a wheelchair doesn't mean that's the end of the world, you can still do so much in a wheelchair. Remember, when I used to be in a wheelchair and people looked at me, I'm like, What's wrong with you? And because the thing is, maybe I'm different. But I went to university to school in the UK when I was young, and through Uni as well.

Joy Alliy 42:59

So my mentality is a bit more Westernized. So when I go back home, I still struggle a lot with playing to just an African culture, and my Western upbringing was a big clash there.

Bill Gasiamis 43:15

Yeah, I imagine it would be really difficult to try and traverse the world and say something simple to implement or to talk about in Scotland, for example, that would be very difficult to implement, and difficult to talk about just a few 1000 kilometers away in another direction.

Joy Alliy 43:37

I used to have such heated discussions with people about basic human rights, I'm like, But why? Why is this not allowed? And I'll be like, Okay, I give up. It's just the basic things that just people can't get their minds off. And this can make people even highly educated, they just don't believe that. There are still so many people who don't believe in therapy. People still think that certain diseases are to be stigmatized, all these things. This is a shame, because in the 21st century now need to wake up.

Bill Gasiamis 44:12

Yeah, it is a shame. You do say that some, in some pockets of the great culture as well. You do say some people who will not share will not tell you everything is a secret, usually in the older generation. I think one of the good things about social media perhaps, is that, well, maybe people oversharing these days, but there's still this desire to express and share. So people have a voice, and they have a way

to express it and they can find their community. I mean, the stroke community is the perfect community, we wouldn't have had this level of community.

Bill Gasiamis 44:52

When I experienced my first brain hemorrhage in 2012, there was nothing like this there were surely there were some books but I found them online and read books from other strokes of oversharing. So it was quite difficult. Now there's a proliferation of them. Because access to self-publishing is so good. And it's effective, and it's cheap. And distribution is perfect because Amazon does it all. And it's such a different world that we live in, in literally 10 years that things have changed so much that we're able to feel that it's beneficial to express.

Bill Gasiamis 45:35

So we also feel it because we're doing something good for other people. Other people are reaching out to me every week and saying thank you for that episode. That was a great episode, I appreciated listening to Joy, for example, who or whoever else. And, and it's I don't think I could be here without it, I actually with this ability to share if I couldn't do it, honestly, I don't know where I'd be today, I don't think I'd be around.

Bill Gasiamis 46:02

It's just necessary for me to get on and talk about it almost every week because I interview one or two people a week. And when I do, I feel like I'm having a free therapy session, every time Joy, it's, I have to talk about it so much that I couldn't possibly talk to my wife about it this much, because she's not equipped to listen to it all over and over and over again. And, for example, if you were a stroke survivor, and I spoke to you about it every single day, every single week, you would get sick of me as well.

Bill Gasiamis 46:40

But the beauty of the podcast is I get to hear from you, we talk about it once. And we both benefit from that our people listening and watching on YouTube benefit from that. And then I get to move on to the next person and have a therapy session with them. And then hopefully, I'm doing the same for them. Hopefully, it's a mini-therapy session for them as well. Do you feel some kind of? Do you feel that when you get onto podcasts, and talk about what you went through?

Joy Alliy dealing with PTSD, stroke, and therapy

Joy Alliy 47:13

I don't know. I remember at the beginning when I talked to people I called a few people that I talked to, I used to say sometimes Joy, maybe toned down the talking because you don't want to re-traumatize yourself. Now I was like I need to talk about it. Because if I don't work for me talking was almost like accepting that this has happened to me. Because if you just don't talk, they just face in and you just don't accept it to me talking was a way to finally come to terms with the fact that this is my new life.

Joy Alliy 47:47

This is why I now need to embrace it. And the fact is the fact that there isn't a very good, a very, very big stroke community in Tanzania doesn't help because after my stroke when I moved here, who started texting me saying okay, I'm sorry, but my, my brother or my uncle or somebody who's had a stroke, what can I do? They would ask me, call me all the way here asking me for stuff. And I'm like, How am I supposed to do that? Now? I can't remember, I can't remember which hospital you should go to or whatnot. But if there was a big stroke community, then they can easily reach out to them.

Bill Gasiamis 48:25

Yeah, people who have been through it before know the lay of the land. Yeah. I do. I do. Enjoy it. You're a lawyer. So you talk for a living, right? So you're really good? Yeah. So you're good at it. It's a skill and to not talk about something that's a topic that's important on your mind would be difficult. I encourage people to talk as well. I think it's one of the best ways to get through it.

Bill Gasiamis 49:00

It also feels to me, like it's a good way to support dealing with Post Traumatic Stress Disorder. I'm not sure because I've never had PTSD, so to speak. I know a few people who have experienced it. But does it help to calm that down to settle the PTSD? How do you deal with PTSD?

Joy Alliy 49:23

Well, when I was in Tanzania, I finally tried to reach out to a therapist and they

said that though you shouldn't you shouldn't approach a therapist because it's not the African way. But he just said no, we're going to get some help for Joy because she exhibiting symptoms of PTSD. So I found this one therapist who was Tanzanian. She knew how to deal with PTSD. She used a method called EMDR I don't know if you've heard of it.

Bill Gasiamis 49:53

Tapping.

Joy Alliy 49:56

This was not a use-your-finger EMDR eye movement processing. Yes, yeah. So then when you're doing that you have to talk. You have to recount the events that happen when you have a new stroke, and you keep repeating it until it just becomes a story. I don't know how it happens, but somehow you train your brain to just think of it as a story rather than a memory.

Bill Gasiamis 50:21

Yes. And then when you think about it next time, you're not traumatizing yourself every time you think about it. Yeah, yes. So I think that's what talking to nearly 270 people on the podcast has helped me do. It's helped me to remember it as an event that happened in the past, but not an event that's continuing to happen to me every single day, even though I had three brain images in the same spot, even though I had brain surgery, and had to learn how to walk again and do all of that.

Bill Gasiamis 50:54

I talk about it now. And it's like, I read it in a book, it doesn't feel like I went through it. And it's a bit strange, to have a conversation with somebody about my experience, because I no longer feel it. Although I'm left with a deficit, it has left me with left-side numbness and balance issues. And sometimes, you know, my cognition is a little bit slow. I'm really tired. Last night, we had a late night, and I woke up early this morning to come here. So all my deficits are telling me more.

Bill Gasiamis 51:30

They're going hey, do do less today don't do so much today. So I love that explanation with you in terms of I was gonna say I love that explanation of what EMDR does and how it changes the story about what's happened to you to not re-traumatize you. So for people who are watching, and listening EMDR according to a Google search that I just did is a psychotherapy treatment that aims to reduce

distressing emotions associated with traumatic memories.

Bill Gasiamis 52:12

EMDR stands for Eye Movement Desensitization and Reprocessing. And how is it, Joy? If you can answer this? I'm not sure. Maybe you can't. How is it that eye movement helps to settle PTSD?

Joy Alliy 52:31

I think when you follow on, I think, I don't know. But I think we follow the eye. You just You just focus on one particular thing and somehow it's connected to your brain? I don't know. The therapists know about that. When he was talking about cognitive defects, you said you had a late night and I was wondering whether you had sensory overload issues.

Sensory overload and its impact on daily life

Bill Gasiamis 52:53

I did. I wasn't partying. I'll tell you what happened. So in Australia, we have Australian football. It's a little bit different from the NFL and it's very different from round-ball football, what everyone else calls football. It's like a rugby, kind of like a rugby game. Anyhow, my team made it to the final. And they won. So we were watching it here at my house. The team is called Collingwood and we are mad Collingwood supporters, our entire family.

Bill Gasiamis 53:29

My wife's side of the family happened to be Collingwood supporters when I met them. So it was just a bonus. So there's just there are about 25 Crazy Collingwood people just here, you know, in this part of my world, you know my house near my house. So we all got together with my parents and my in-laws. Everyone was here, and we were watching it. And I was screaming and yelling. And it was emotional. And of course, because I have somehow a little bit of an inability to control my emotions.

Bill Gasiamis 54:02

I think I discovered about pseudobulbar effect, you know, when I cry at the drop of a hat now, I've been crying for two hours yesterday. You know I can't during

the game. Just because one of our players did something. I mean, I'm tearing up now, just because one of our players did something amazing. I would start crying and everyone was giving me a hard time. Because part of the part of the therapy for me is I cry. I don't hide it. I let everyone see they all get uncomfortable and then they start teasing me about it.

Bill Gasiamis 54:35

Look, Bill's crying again because somebody did something good in the game. And I just tell them all to get lost and leave me alone and it's just how it works. You know it's become one of those things that we can joke about and laugh about. Because, because that that's me now that's what I do. I just cry at the football. So I am overloaded. I can feel it physically in my brain, I can feel it, and I can feel that after this interview, I'm going to have to do nothing for the rest of the day.

Bill Gasiamis 55:12

As I said, I woke up at seven in the morning to make this Zoom call at eight. And today is going to be a ride of what I call a ride off. And our guests, our guests last night, they did not leave until one in the morning. And I was hoping that they would leave earlier, but they wouldn't.

Bill Gasiamis 55:33

And I couldn't tell them to leave. And when they left, I told my wife, why didn't you make them leave earlier? Why couldn't you get them out of the house a bit sooner? Not because I wanted them to go. Because I wanted to be able to do this podcast and be in a good condition. So yeah, I do get sensory overload and I have this particular room that I've set up in my house that has been treated so that I've got a good sound for the podcast. So there's no background noise and things like that. It's like a little quiet room.

Bill Gasiamis 56:10

And when I feel like there's too much noise, it's overloaded. My head's overloaded, I come in here. And even though I've got my computer screens up here, and this is where I do my work, and my recording and my editing. It's really quiet. If I close the door, I can't hear the outside world, it's just really quiet and helps me to calm my brain down and, relax everything. So that's a long answer to yes, your question. I'm overloaded.

Joy Alliy 56:46

I'm glad you say that because I think some people just don't understand the concept of it. So hopefully, when they hear this about you and me, they might understand more about what sensory overload means.

Bill Gasiamis 56:56

Yeah. And you know, I avoided going and watching my team for many years. Because it was too hard. It was too loud. And when I'm at the ground, we had 100,000 People at the stadium yesterday. And when you go and play when you go and watch my team, they regularly have 80-90,000 people at their games. So it's just three hours, of way too much information for a stroke brain to handle. So when people used to ask me to go to the football for many, many years after the first incident, and then after brain surgery, I said no. And I have this memory of an event. So my whole health issue started in 2012.

Bill Gasiamis 57:47

But I believe that there was an event in 2010. Okay, and again, it's related to the football. Again, my team made it into the final. It's a big deal because they don't get there that often when your team makes it into the final. And it's like the playoff series for people who are from the United States who are listening. It's like the playoffs at the end of the at the end of the year. So they come to the final game.

Bill Gasiamis 58:13

They needed to win the final game to win the championship to be crowned the champions, and I met the final game 20 in 2010. And it's in November, early November, and I'm watching the game and I go home after the game because it was a draw. They didn't get a result. And in the old days, if you didn't get a result you came back and played the next week. Okay, so I had a ticket. I was there, there were 100,000 people, I was yelling and screaming all day and I was sick for the entire week.

Bill Gasiamis 58:46

After the game, the whole week, I was sick, I couldn't stand up, and I had nausea. I went to the doctors, I went to the hospital, and they did a lumbar puncture. They scanned my brain to see if there was a blade or anything wrong. And they couldn't find anything at that time. So the following week, I had a ticket to go to the game. And I had to give the ticket away to my dad I said to him, I'm not going because I feel too unwell.

Bill Gasiamis 59:12

You need to go I watched the game at home on my own so that I would not be in that space where I was going to get high blood pressure and yell and scream and give myself another headache because this headache was like never a headache I've never had before. So I think that it was the first sign of what was to come nearly one and a half years later when I ended up in hospital because that blood vessel in my head that burst was there from birth.

Bill Gasiamis 59:47

So it wasn't something that I created or that just happened later on in life. It was always there and it was always waiting for something to go wrong. This arteriovenous malformation And that's what they do. They just sort of sit in the background until they start playing up. So, yeah. That question you asked me just reminded me of that whole part of the story and yesterday made me feel makes me feel my head today's not as bad as it was in 2010. But it kind of reminds me of that event back then.

Recovery and self-improvement Joy Alliy

Joy Alliy 1:00:27

You know, it's funny, you were saying, we're talking about yelling and how it increased your blood pressure. Well, before the stroke, my blood pressure was, was actually on the low side. But unfortunately, because I'm a bit of a perfectionist, and get very frustrated, there's a lot of yelling, I was almost like, you know, the chef Gordon Ramsay, I was a bit like that. Constantly yelling, frustrated with people needed to get everything perfect.

Joy Alliy 1:01:01

They got something Oh, just get very upset. I'll start like, cursing all these things. I'll get angry when I was when I was driving, to work and back road rage, all these things. So I did kickboxing.

Bill Gasiamis 1:01:12

At work as well?

Joy Alliy 1:01:20

Yes, this was at work. Yeah. Because when you have your firm, you can do anything. Yeah, when you're when you're employed, you just have to, like keep it

in, but you're still very frustrated. But when you go to the office, and you just start screaming or whatever.

Bill Gasiamis 1:01:35

Yeah. I also did the anger thing. Absolutely. And I tried a lot, a lot of the work that I'm doing now with myself to myself, it's trying to not be as ridiculous as I was angry, yelling and screaming. And it's such a silly tool, because it just, doesn't achieve anything. It just makes you rage, and it makes the other person shut down or rage as well. And in that state, you can't create anything meaningful or, you know, come to some sort of an understanding or an agreement. It's a really difficult way to try and make communication work. I don't know.

Bill Gasiamis 1:02:19

I don't know why I go there. But I try not to kickboxing would help with that. And a little bit of yelling and screaming at the television. I feel like does help release some of that stuff. But it still causes a headache. Like it's caused a massive headache.

Joy Alliy 1:02:36

When people see me now they just see this docile person and like, you should have seen me before stroke. I was a completely different person. You would have liked that person.

Bill Gasiamis 1:02:47

Yeah. Would you be in difficulty? I was gonna say would have been difficult to work with.

Joy Alliy 1:02:56

Only when I had my firm, but before that I was brilliant. Because I was I just had a paycheck. That was it. I just had to do my work. Look after my clients and then go home. When you have your law firm. There are so many things that consider paying taxes, paying salaries, dealing with, staff when you have your little disputes, all these things.

Bill Gasiamis 1:03:21

Yeah. Dealing with clients and difficult situations at work. Yeah. Yeah.

Joy Alliy 1:03:28

Clients that don't want to pay

Bill Gasiamis 1:03:30

clients that don't want to pay. Yeah. Oh, yeah. That's terrible. Hey, I was wondering, as we get to the end of the podcast episode, I was wondering if you could share with me. What's the hardest thing about stroke?

Joy Alliy 1:03:52

Trying not to push yourself too much, keeps you out of the recovery.

Bill Gasiamis 1:04:00

trying to not push yourself too much. Yeah, fair enough.

Joy Alliy 1:04:06

Because I'm still thinking with my old Joy brain.

Bill Gasiamis 1:04:12

And you have to take a different slower approach to life. Yeah. What has stroke taught you?

Joy Alliy 1:04:25

It's taught me to slow down because I had such a life that was so chaotic before. He's taught me that. overworking is not, it can be dangerous. Like you need to take time off you need to rest. You also need to be kind to yourself. Need to Be kind to yourself love yourself and appreciate the little achievements that you make especially during the stroke journey.

Joy Alliy 1:04:52

And also, if you have any issues, any anger any anxiety anything, get help. Those of our law know that love conquers everything. Because that my partner I won't be here. I mean, we've been we've been together for nine years now. And he looked after me for three years. And he's done everything, everything. I'm almost tearing up.

Bill Gasiamis 1:05:23

Yeah, that's a good thing. I love it. And if other people who are just starting the journey to recovery, are listening today, what's the one thing you would like to tell them?

Joy Alliy 1:05:39

Don't give up. If somebody tells you, you can't do something, try. Be surprised.

And you'd be surprised how strong you are. Your mind can do so much. If you put if your body can do so much, you just put your mind to it. And don't don't, don't. Don't worry about pain. Because pain is required. Because some people worry about doing stuff to increase or because they think it's painful. Well, you have to exhibit you have to be in pain to get better. Just also because of feeling something is painful. Just keep going.

Bill Gasiamis 1:06:23

And on that note, thank you so much for joining me on the podcast and reaching out to be on the show.

Joy Alliy 1:06:28

Thank you so much for having me.

Bill Gasiamis 1:06:34

Thanks again for joining me on another episode today. Remember to grab your copy of chapter one of the book "The Unexpected Way That a Stroke Became the Best Thing That Happened" by visiting recoveryafterstroke.com/book Have a look around the page also explains what the rest of the book is about. And then fill out the details and get your free chapter.

Bill Gasiamis 1:06:57

As always, to learn more about my guests, including links to their social media, and other pages. And to download a full transcript of the entire interview, please go to recoveryafterstroke.com/episodes Thank you to everybody who has already left a review. It means the world to me, and I appreciate it. People must review the show so that the algorithms and the people who decide how popular a podcast can be see that there is a positive response to this podcast so we can put it in front of other stroke survivors who are perhaps having a hard time.

Bill Gasiamis 1:07:41

And what that might do is help them have a better stroke recovery. And that would be amazing. Leaving a five-star review on iTunes and Spotify would be amazing. If you're watching on YouTube, comment below the video, like the episode and to get notifications of future episodes, subscribe to the show. And also hit that notifications bell on YouTube because then it will notify you that the next episode is available. Thanks again for being here and listening. I appreciate you see you on the next episode.

Intro 1:08:16

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Intro 1:09:01

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