

# The Worst Thing That Happened To Me | Annika Luke

Annika was 44 when an almost two-week unusual headache was finally diagnosed as an ischemic stroke. Annika describes the stroke as being the worst thing that happened to her.

Facebook

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I was in occupational therapy thinking everything was fine, and she pulled up a big monitor it was just like a Where's Waldo type thing with she had pictures of cows and hearts and churches and bells. And she said I want you to hit all the bells.

Annika Luke 0:22

And so, oh, okay, yeah, that's fine. And I did it and I started doing it. And then I broke down in tears. That was my realization, like, oh my gosh, something is wrong with me. I couldn't do it. I could see how easy it was, but I couldn't do it.

Intro 0:48

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

Bill Gasiamis 1:00

Hello, and welcome to the Recovery after Stroke podcast. If you are a stroke survivor with a story to share about your stroke experience, now is the perfect time to join me on the show. 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 in the hope that it will help somebody else who is going through something similar.

Bill Gasiamis 1:24

If you are a researcher who wants to share the findings of a recent study, or you are looking to recruit people into studies, you may also wish to reach out and be a guest on my show. If you have a commercial product that you would like to promote, there is a path for you to join me on a sponsored episode of the show.

## Introduction - Annika Luke



Bill Gasiamis 1:41

Just go to [recoveryafterstroke.com/contact](https://recoveryafterstroke.com/contact), and 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. In today's episode, I am joined by Annika Luke who experienced an ischemic stroke at age 44 That she describes as being the worst thing that happened to her. Annika Luke, welcome to the podcast.

Annika Luke 2:06

Thanks. Thanks so much for having me.

Bill Gasiamis 2:09

My pleasure. Tell me a little bit about what happened to you.

# The initial stroke symptoms and series of misdiagnoses

Annika Luke 2:13

Oh boy, I just jumped right into it. So I guess about a year ago, June 14, 2022. I was exercising down in my basement, as I pretty much do almost every single morning. And it was not an intense workout. I wasn't doing anything crazy. I was doing a hit workout from Apple.

Annika Luke 2:36

And I don't even remember exactly what I was doing something like jumping jacks or lunges or something. And suddenly the room sort of spun a little bit. And then I got a headache. So I thought okay, this is weird, but I've gotten migraines before.

Annika Luke 2:53

So maybe this is just a migraine, I stopped while I tried to keep going for exercising. But I thought I should probably just chill because the room calmed down. It was just a headache at that point.

Annika Luke 3:05

So I went upstairs and I took some medicine like I normally do and just continued on my day still a headache, but you know, sometimes you just have a headache. So that day was just as it was with a headache. And then the next day came still a headache. So I just again kept going and texted my boss saying, Hey, I'm just gonna be working from home, I got this bad headache.

Annika Luke 3:33

And I'm gonna say it was probably the next day or the day after that the headache was still there. And so I said, you know, this is kind of unusual, I'll go to urgent care. So I went to our local urgent care center. And I said, Hey, I've got a migraine. I've had a migraine for about two days now.

Annika Luke 3:58

This is unusual for me. Usually, they start to go down in intensity. I'm not feeling that I'm still feeling really bad. And she said, Well, it's probably a cluster headache. Let me give you some sumatriptan and maybe you'll start to feel better. And so I did, I took that sumatriptan and made the headache worse.

Annika Luke 4:20

So then the next day I called, still had a headache. I called back to urgent care and said hey, you know I've got this headache. And she said well, why don't you go ahead and go to the ER they have a migraine cocktail, and they can get you there. So okay, so I you know, at this point, the headache was so bad I was just vomiting and it was horrible.

Annika Luke 4:45

And I went to the ER. They gave me the migraine cocktail. It did make it feel better, but it still wasn't anything. I still had a headache. And you know, I told them. I said, my hand feels funny. My left hand feels like it's numb or disassociated from my body.

Annika Luke 5:08

And they were just like pass that off and said, Okay, well, you can go home. And so I went home. And I want to say it was three days later was still a headache. I got in to see a neurologist. So, I went to see her and told her all the symptoms, and I said, you know, there's something kind of weird too, is that I feel like I hear breathing.

Annika Luke 5:35

It's like somebody's breathing in my ear. And I said, you know, is it normal? And she's kind of just shrugged her shoulders. And I said, well, Am I hallucinating? Because I don't like mouth noises. So I thought maybe that was just my way of being even more annoyed.

Bill Gasiamis 5:59

Are you talking about chewing mouth noises?

Annika Luke 6:01

Yes, I do not like mouth noises breathing, or chewing close to my ear. Yeah, so I said, you know, she kind of just shrugged that off and thought, nothing much of it. And she looked at me after she examined me she did like a stroke assessment and said everything there was normal.

Annika Luke 6:25

And I think you just have a long migraine, and you're gonna continue to have it for maybe 10 more days. And then she just sent me on my way with this new drug that they have for migraines. So she gave me quite a few sample packs. And I

said, you know, I'm headed to Colorado in a few days.

Annika Luke 6:49

And I'd like to be able to go and she said, Well, here's enough sample packs, take one of these just as prophylactically. So that while you're there, you take one every other day. So she gave me enough samples for that. I went on my way. And then I'm gonna say it was probably a day or two after that, where the headache was still there still intense.

Annika Luke 7:20

And then I was trying to go to bed. It was the 22nd of June. So I started the headache on June 14. And then on the 22nd of June, I was going to bed, I couldn't sleep, and my head hurt so badly that I ended up sleeping on ice packs. Just I got a bunch of ice packs, and I put them on a pillow and tried to sleep on them.

Annika Luke 7:45

And I still had a hard time sleeping. And I went downstairs and I wrote my family a note because you know, I have two kids. And the husband said, hey, look, I'm not sleeping, well just know that I haven't slept well. And you know, try to be quiet in the morning. Because I thought they're gonna get up, make a bunch of noise, and think, Hey, where's mom? Why isn't she making our lunches or whatever it is that I normally do?

Annika Luke 8:09

And so I wrote a note. And then they kind of got off on their own. They went to school or camp at that time. And I kept sleeping. And then my husband came in and checked on me and he was concerned, definitely was concerned. But it was nothing. I wasn't acting that unusual. That morning, I did get up and I let the dogs out. I walked outside.

Annika Luke 8:35

And you know, I remember thinking, go to the bathroom dogs because I want to go back in I had to like, sit down, I felt nauseous and sick and bad. And so I did that quickly. went back upstairs and went back to my bed. And so anyway, my husband noticed after he took the kids to school, that I was acting a little odd, but nothing that couldn't be explained by lack of sleep and having a headache for that long.

Annika Luke 9:07

You know, it's just eventually getting to you. So that was kind of where we were. And he called the neurologist and said, You know, I think she's getting worse. Is there something more we should do? So she called in a prescription for prednisone. Then he went back to pick that up. And then she said, I know you're leaving soon for Colorado or he said that he said we're leaving tomorrow at this point.

Annika Luke 9:43

How are we going to leave? Is that okay? That she still has this bad of a headache? And she said yeah, you know since you're traveling maybe we should get you a CT scan. So you know we're leaving. I can't remember When it was, but it was very soon after he had been talking to her.

Annika Luke 10:03

And so he called her back and said, You didn't make it for today like she prescribed the CT scan. But we couldn't get in today because she needed to write it for the stat. So anyway, he called her back and said, Yeah, I am concerned. And I think that she needs to get in to see that do the scan today.

Annika Luke 10:28

And so she did that. And then he drove me there. As he was getting me ready for the CT scan, he noticed, like things were just really not right, that I seemed to be uncoordinated. I was like, kind of walking into walls on the left side of my body. And so he was concerned.

Annika Luke 10:58

So anyway, he drove me to the CT scan place, and he got me in there. And he said, Hey, I think there's something wrong, I think she might be having a stroke. And they did a couple of little stroke tests, you know, had me smile and maybe put my hands up. And they said, Yeah, I do think it is a stroke, and they did a scan, and they confirmed it. So then, after they confirmed it, they're like, Okay, we need to get her to the ER now.

Annika Luke 11:30

And we were close to an ER, closer than it would have been for an ambulance to come rather than my husband to take me. So my husband ended up driving me to the ER, they called ahead and said, Hey, we have this patient coming. And that is when they confirmed the stroke. And they started doing all the tests that needed

to be done. And they said It's really bad. It's not good.

Annika Luke 12:03

And I can't remember what hospital we were in, I guess it was the ER where they, they thought that my brain was swelling to a point where it was really dangerous, and they were going to have to do a craniotomy. So they medivac me to a different hospital. And I was in the ICU there for a few days. And then I was still in the hospital for another week or so about a week total.

Bill Gasiamis 12:37

We've been going for around 10 minutes. And

Annika Luke 12:40

That's a long story. Sorry.

## The stress of not getting proper treatment



Bill Gasiamis 12:43

And the tension, I could feel the tension building and building and building and building and I'm thinking, okay, at five minutes, I thought they're gonna get help, she's gonna work it out. That was a stretch. At seven minutes. I thought, no, no, they're gonna work it out, it's gonna be a stroke, they're gonna work it out.

Bill Gasiamis 12:59

And that 10 minutes, and I'm thinking you're one of the people who's gone out of their way to make sure that you got help, which is usually the opposite is

happening in the stories that I hear people say it's nothing, I'm going to avoid it.

Bill Gasiamis 13:21

I'm gonna go to work, I have this trip to go they do everything except go and get help, you've done the exact opposite. And it's still taken around 10 days or two weeks to get a diagnosis, which is amazing that you are still able to keep going after that amount of time and then still turn up to the hospital in a condition that was reasonable enough for you to even though you need help to be on your feet and to make your way to a hospital. That's pretty amazing. So yeah, they've discovered a stroke, what kind of stroke was it?

Annika Luke 14:06

It was an ischemic stroke, due to a carotid artery artery dissection. So we think that happened during the exercise. To me, I'm not 100% sold on that is the cause of it, but it must be there's no other thing that I mean, the only other thing is that I was lifting 15-pound weights, doing overhead presses, maybe the day before. So maybe I weaken the artery at that point. But yeah, it was surprising to me because I wasn't doing CrossFit or you know, crazy amounts of exercise. I was rather tame and what I was doing.

Bill Gasiamis 14:52

These pesky carotid arteries sometimes, you know, just don't behave the way they're meant to and The tears do occasionally hear about it's very, very common. But some people you hear that they had a massive collision, in a motor vehicle. And that caused a big, like a whiplash-type injury. And then that caused that. And then I've heard people and occur that have just sneezed and caused a stroke.

Annika Luke 15:25

So leave me walking around feeling very happy about like, how is it that I'm not going to do it again, you know, and I keep asking, I've gotten to so many specialists, I'm talking to right now because I'm going to get a stent in my carotid artery coming up here. Because since the stroke, I've heard my heartbeat every single time. It beats beats, it sounds like a squeak. And so talking to an interventional radiologist about, you know, that they, they focus on these type of things, and like, how did it happen? And they don't know. They just don't know.

Bill Gasiamis 16:07

Yeah. You know, the thing you said about listening, being able to hear your



heartbeat. Is that disconcerting?

Annika Luke 16:16

Yes, it's horrible. It's not like a tongue. It's a squeak squeak. Every single time, my heartbeat, I can't sleep. So what I do is I wear an earbud in this ear, so that I can sleep is just playing pink noise or brown noise all night long. And if it falls out, it'll wake me up.

Bill Gasiamis 16:40

Right. Okay. Now, I know there are actual hearing aids, specifically designed for people who have tinnitus, and maybe four similar conditions that you're experiencing right now that cancel out noises for some people in some conditions. So they do stay in a bit better than an ear but headphones, for example. Yes.

Bill Gasiamis 17:07

Now, the other thing that's interesting about what you said is one of my coaching clients reached out to me and said, Well, I've been speaking to her for a couple of years about all her stroke-related experiences. And just recently, she said, I don't know what it is, but I hear voices.

Bill Gasiamis 17:26

I thought, oh, what kind of voices are good or bad? When she says, No, they're not those types of voices. She just said, she hears like, it's like background talking. And she might be in her room on her own. And she can hear the background talking. And I thought, oh, that sounds a bit weird. I wonder if you need to go and see somebody about that. Anyhow, I reached out to the stroke survivors who follow my recovery after stroke page on Instagram.

Bill Gasiamis 17:54

And I asked the question, and because I didn't want to freak people out. I asked it like this. I said this might sound like a strange question. But did you start hearing sounds of voices in your head after the stroke that you didn't hear before the stroke? And you won't believe the number of people who responded and said yes.

## **Requiring a stent to prevent another**

# stroke

Annika Luke 18:17

Well, that's weird. I have never heard of that. It doesn't sound like a murmur or anything. It sounds like a squeak. But that's because however, my carotid artery healed, and I've seen images of it, it's fascinating to me because they've done an angiogram. It healed very, very narrow. So it's more narrow, I think than it was before.

Annika Luke 18:41

And so that's why just that blood getting through there is a problem. And that's another reason why I'm gonna get the stent is that you know, as things build up in your blood, because of that narrowness, I mean, it's like 90%, closed off. That could lead to problems down the road. So the stent will help later on, for potentially not having a stroke.

Bill Gasiamis 19:10

Yeah. So it has healed and because of the way that it's healed, it has taken up more space inside the blood vessel. I think so. Yeah. And therefore, it's got a 90% reduced capacity. Yes, yes. Okay. All right. And therefore, you're probably being asked to take a blood thinner, or of some sort. All day.

Annika Luke 19:37

Yep. I'm not all day. Every day. Yeah. And, you know, if I get a stent, then I'll have to do two blood thinners. I'll do the aspirin and Plavix.

Bill Gasiamis 19:47

Yes. Okay. And how old were you at the time?

Annika Luke 19:52

I was 44 at the time, so I'm, I'm now 45.

Bill Gasiamis 19:58

Have you ever heard of anybody Having had a stroke before then did you know anybody?

Annika Luke 20:04

No, not. And, when it happened, even when they said it was a stroke, I didn't believe them. And I would say I was delusional about it for, I want to say, two to

three weeks, like even in the hospital. And while I'm being medivac, I just thought, why are they blowing this out of proportion?

Annika Luke 20:28

Like, I'm okay. I mean, I went into the ER, and I said, you know, I react to iodine contrast. But we're doing scans, but you can give me gadolinium. And so obviously, I had my wits about me, I was able to walk. So I thought, what, they're overblowing this, this is not a big deal. I will come back from this.

Bill Gasiamis 20:55

Yeah. And that's a great thing to think, especially during a potentially difficult, scary time for a lot of other people. But I'm curious. You're going through that? What are you? Like, you know, how do you comprehend though you are in hospital, you are unwell? I know you don't feel unwell, or you don't sort of see yourself as being unwell. I was like that, for the first blade that I had, I experienced a similar kind of what's the word? Not delusion, but a false sense of security. And people were coming to visit me.

Bill Gasiamis 21:42

And I was walking around, and I looked fine. But I had a blood clot in my head. The doctors and nurses were trying to emphasize the point, you need to sit down, you need to rest you need to settle. You need to not be walking around. You need to stay in our ward. Because I was always done at the hospital cafe, catching up with people who were visiting and all that kind of stuff. But your husband didn't, he wasn't so he wouldn't have been so nonchalant about it.

Annika Luke 22:21

Like, you know, no, he was he, he was worried. I mean, he was talking to doctors. And they were telling him how bad it was. And, and he was kind of beside himself, he called my neighbor, who is a doctor, and said, you know, this is happening.

And my neighbor, a super, super nice guy. He actually came to the hospital to visit not to visit, but more to like, help my husband because he wanted to talk to the doctors himself, and then give it in normal speak to my husband so that he could sort of help interpret that, you know, English to English.

Bill Gasiamis 23:03

Yeah. Okay. And so the kids, how old were they?

Annika Luke 23:10

My son is now 15. He was 14 at the time. And my daughter is 11. But she was 10.

Bill Gasiamis 23:20

Okay, so my kids were the same age. How did you guys manage that part of the process? I don't remember dealing with that part of the process too much. Because I wasn't really in a good state to be doing that type of thing, although I was probably trying to allay their concerns. And just don't worry, I've got a bit of a just kind of play it down. How did you guys manage that?

Annika Luke 23:43

Sure. So I remember my husband talking to me about this when we were in the hospital. But basically, we were going to go to Colorado. And we were going to go with some really good family friends. And they have two kids. And we decided that the kids would go to Colorado, with the family friends to you know, they didn't need to be there. And that was, you know, baby nervous for making them nervous. So we just thought, Alright, let's go ahead, let them enjoy their vacation.

Annika Luke 24:17

And I being as delusional as I was that I'll meet them there they'll go. And then we'll go to we'll just go a couple of days later after all this blows over. And even while I was in the hospital, I was saying, all right, where are we going to Colorado? And my husband was pretty, pretty blatant about Nope, we're not going to Colorado and I said, But why not? I'm fine. And he said because it's not here.

Annika Luke 24:47

This is where you need to be like they have healthcare in Colorado. It would be fine. So I thought I was gonna go and even after he said, No, I thought well, we can just do arrive there, maybe you don't want me flying. Because, you know, I know that that's a potential problem. And even while I was in the hospital, I bought compression socks, thinking that I was gonna go to Colorado and have them delivered to my house.

Bill Gasiamis 25:16

Wow, that's so cool. I like it. It's not so bad that you're delusional, that kind of helps the situation. I felt like my being a little bit disassociated from the seriousness of the situation made it easier for me. When I was in the hospital. It

didn't help the people that were visiting me, my family. My parents didn't help any of them with the situation. But it certainly did help. It's an it did help me to be more. More, more calm. I suppose the word is? Yeah.

Annika Luke 25:53

Yeah, I would say calm. And that's true. I was, I was pretty calm and chill about the whole thing. Yeah, I mean, this is not my first go-around with health problems. So I just thought, it's just a little blip. You know, everybody has a little blip and keeps going.

Bill Gasiamis 26:11

Yeah. So at some point, you went through the whole hospital process, and you were sent home. Were you when you went home? Did you go home with any deficits? What did the stroke do to you?

Annika Luke 26:25

Yeah, so I went home. Not, like I said, about a week after. And so they did outpatient therapy for me. Even though my husband wanted them to do inpatient therapy. I think outpatient was the right way to go.

Intro 26:41

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

Intro 27:11

If you're finding yourself in that situation, stop worrying, and head to [recoveryafterstroke.com](http://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](http://recoveryafterstroke.com), and download the guide. It's free.

Annika Luke 27:44

I did outpatient therapy, both occupational speech and physical therapy. So I did all of that. And I would say it was actually that when I broke my delusion. The delusion was broken. Because I was in occupational therapy thinking everything's fine, everything's fine. And she pulled up a big monitor. And that was just like a Where's Waldo type thing with pictures of cows and hearts and churches and bells.

Annika Luke 28:24

And she said I want you to hit all the bells. And so Okay, yeah, that's fine. And I did it. And I started doing it. And then I broke down in tears. I just that was my realization, like, oh, my gosh, something is wrong with me. I couldn't do it. I could see how easy it was. But I couldn't do it. And you know, I remember thinking, I've never been the smartest person in the room, but I held my own. I was capable. And now all of a sudden I can't find the bells. So that was a tough blow for me.

Bill Gasiamis 29:08

Right? That was the moment that you realized there was something wrong with your head. What specifically was the thing that you realize, for me, I remember introducing myself into a course that I went and set in about three or four months after my second bleed. And I was cognitively affected. And I remember my biggest concern was that I didn't know if I was going to get my brain back or to the way that it was when I took it for granted, but I didn't know how to brain and I just went about my business. What was your specific concern?

## **Annika Luke getting back to work after the stroke**

Annika Luke 29:55

Yeah, getting my brain back and being able to do all The things that I used to do and wanted to do. And I even tried working shortly after that, because I worked from home. And I struggled.

Annika Luke 30:15

I couldn't do something simple. And then I just took a break and said, Okay, hang on. Let's see what happens. And just let it chill. I tried too soon. I want to say I was out of the hospital for a week. And I was trying to go back to work, and everything's fine. Nothing to see here.

Bill Gasiamis 30:38

What kind of work?

Annika Luke 30:40

I'm a web developer. So I work for a company doing all their websites.

Bill Gasiamis 30:45

That's intense.

Annika Luke 30:48

It's just a lot of thinking.

Bill Gasiamis 30:49

Focus, concentrate, and monitor time.

Annika Luke 30:56

Yeah. And my typing wasn't great. At first, like, I could type. But it was my left hand that was a problem. And anytime I went to hit the A button, I would hit the Caps Lock and everything after I'd be shouting.

Bill Gasiamis 31:14

That's exactly my situation still.

Annika Luke 31:18

It's frustrating. It's like, No, I think I've overcome that. Now. I don't remember it happening recently. I think I can type okay, now.

Bill Gasiamis 31:27

Yeah, that's still my situation, because I've got numbness in my left hand. So my hand doesn't know where it is on the keyboard. And thank God for autocorrecting for me, because I just right-click, and then AutoCorrect. Because if I had to go back and stop all the time to spell correctly, it would be a lot longer process to do an email or type of paragraph or whatever.

Bill Gasiamis 31:58

So I just allow myself to type the whole thing, even though it's wrong. And just autocorrect so that it's quicker. Otherwise, if I had to look down at the keyboard all the time, it would just be too annoying. You're a web developer. Does that mean you were coding?

Annika Luke 32:18

Yeah, I was coding. And just doing like, front-end stuff. Yeah.

Bill Gasiamis 32:26

And coding is a language is it not?

Annika Luke 32:33

I do less coding. Now more management of the websites, I mean, I can still get in there and do the code. And I do from time to time. But that's less intense. It's when we're building the sites that you do a lot of coding. And then as the sites become more self-sufficient, for lack of a better word.

Annika Luke 32:56

Yeah, there's more management and seeing, you know, what products are up there. Let's change this. Let's change the description. Let's make this one out of stock, that type of thing. So it was more just making it look different.

Bill Gasiamis 33:14

So you attempted to go back to work immediately after you went home from the hospital? That was about a week later. The kids? Are they still in Colorado at that time?

Annika Luke 33:25

No, they came home. And then I was just working from home.

## **Parenting after getting home from the hospital**





Bill Gasiamis 33:36

How did you handle the kid's situation? Because they would have thought a stroke was not a big deal. We left she was in hospital, we came home, she's back? How did you manage that whole thing with the kids because teenagers are a pain in the butt? Under normal circumstances, when you've had a stroke, it's even harder for me it was even harder to cope with teenagers. How did you transition? When they came back? Was it difficult? Did you have to change the way you went about things?

Annika Luke 34:08

I don't think I did so much. No, I mean, I feel like we weren't great about explaining what was going on. And because I seemed to be healing. Okay, we just sort of kept going. And I did have a hard time with times. Like, especially if somebody told me you know, 445 or quarter to or the quarters, those drove me crazy and that I would have to leave 45 minutes before that, or 30 minutes before that that time calculation was hard for me. Anything with those 15-minute intervals just really got to me. So they kind of had to help with that.

Annika Luke 34:59

I'm They knew obviously that things were wrong, but feel like we could have done a better job explaining to them. And I think we did. My husband was wonderful, like, beyond wonderful. My sister was staying with us for a little while too. So she helped out quite a bit. With just like picking kids up from camp or getting dinner ready. And I also had a great group of friends that organized meals. For us I want to say we had meals for two months afterward, just so I didn't have to do any of that, which was great. That's a big relief.

Bill Gasiamis 35:42

That's

Annika Luke 35:43

one of my pet peeves. I hate making dinner.

Bill Gasiamis 35:49

Don't think you're gonna lose friends by announcing that most people are probably going on with you, Annika, I hate me either, as well. I'm one of those people, I'm home earlier than everybody. So I'm home from 330 to four o'clock in the evening. Nobody gets home before me. And I thought that was an advantage when I was choosing careers and creating a work, my own business, and all that kind of stuff.

Bill Gasiamis 36:17

It's not an advantage. Because I get I get to work at 730. And then my day doesn't stop until after 630 when everyone comes home. And as I get older, I'm starting to resent it more. I'm starting to resent my decision to be the guy who's at home who has to prepare everything and make dinner because there's no point doing it when my wife gets home at 630, and then starting the dinner preparations because I'll never end that will still be going at nine. So

Annika Luke 36:50

Yeah, and they want to eat dinner every night. It's bizarre. Again,

Bill Gasiamis 36:59

Oh my God, these kids. It's ridiculous husbands and wives and oh, man, it's unnecessary. And it is I know a big issue with people who have stroke and try to then explain that to the family. Cause I appeared normal, the way I'd always appeared. And then trying to get through a task work, dinner was really hard. But it became important to me because I would be at home doing nothing all day. And then making sure that I had the energy to go out, pick up some of the ingredients, and then make dinner.

Bill Gasiamis 37:32

So at least we ate together when they were when they were still eating dinner at home with us. And it was a good thing to have to do as an I'm not sure if the words as rehabilitation or as to have something to do because I had a lot of downtime in almost three years that I went through the process before my brain

surgery, I had a lot of downtimes, so I needed to occupy my time with something. But it was a lot more of a chore because it was also around the same time that I was really tired. My day was coming to an end. And fatigue was kicking in. It was a real challenge.

Annika Luke 38:18

Yeah, I think that was a challenge for me at the beginning. But I wanted to prove that I could do it. So you know, when the kids went back to school, I made it a point to get up with my son. He goes to school at 7 a.m. His school starts at 715 or something. And I made a point to get up and see him off. Because and make lunches during that time. Because I felt like that was what I did. You know, I was a mom.

Annika Luke 38:55

And that's what I wanted to do. I wanted to make sure that I kept that up. I didn't want the stroke to make it come to an end I was so tired. So, so tired. I've never been as tired as I was after my stroke, and you know, I've been pregnant, and that is tiring. But this was a whole other level. But I did try to keep that up and keep the routine in.

Bill Gasiamis 39:24

Yeah. So even to me, you seem pretty calm, and mild-mannered. It's been about a year. You seem to have come a long way. I suspect though, that there's a little more still going on under the surface. Did it change the way you think about life? How did it impact you? On a personal level, on an emotional level?

Annika Luke 39:53

No, impacted me. So I would say you know as far as like, speech, occupational Um, physical, all that stuff came relatively easy. Like I had to have a walker for a little bit. But, in the physical therapy, I was talking to her more about what I can not do, like hurt my carotid artery again, not, how I get back to walking because I was able to walk.

Annika Luke 40:25

I carried the walker around just as, lifting it, because I didn't want to fall down and not have something to fall on. But I didn't need it to walk balance. So yeah, all of that came relatively easy. And then for a long time, as we mentioned before, I was tired. That was my biggest problem. And just being around people socially,

was hard and draining.

Annika Luke 40:54

So that was difficult. And then I would say October was when really, everything just crumbled. October was, it's normal to have this apparently, but where my stroke hit, it's in my parietal lobe. And the specific part of it was not in my Thalamus, but it did hit that somatosensory cortex, which does impact how you feel things. And because my body can't feel correctly, it's just sending the pain signal. So I have pain down the left side of my body, the entire left side of my body is tingly and feels as though it's been burned.

Bill Gasiamis 41:48

That's how I describe it. Yeah,

Annika Luke 41:51

It's and that, to me was crazy, because I thought things were going well. And you know, little numbness, not a big deal. But in October, when this started creeping in, that was a tragedy, I couldn't imagine that I was going to have this pain for my entire life.

Annika Luke 42:12

And at that point, I put my foot on the gas, like, Okay, we're going to fix this, we're going to do therapy, and how are we not going to overcome this, of course, we can overcome this, everything I've read tells me that, you know, the brain is this amazing thing, and you can grow it at any time, you can change it.

## **Non-invasive brain stimulation and mirror therapy**

Annika Luke 42:30

And there's Neuroplasticity. And I thought, Okay, I'll fix it. So I did a lot of research. And I've tried a lot of different things to overcome this pain. So I tried something called non-invasive brain stimulation, which is trying to hit your motor cortex in a way that makes the pain feel better. It's worked with people with fibromyalgia. And so I tried that. And I did that every day. I did it paired with mirror therapy because I wanted to try to train the left side of my body to feel the way the right side of my body does.

Annika Luke 43:21

So I set up this thing in my basement, where I had a mirror set up, and then I put my hand in, so that they looked like it was a mirror image of it, and did that every morning for about 20 minutes every day. And I would wear the device on my head while I exercised because this is the thing like I did go to Johns Hopkins and I said, Hey, I want to be involved in your nibs program, your non-invasive brain stimulation program. And they said, No, you don't have any deficits that we can fix with this.

Annika Luke 44:01

And I thought that was insane. I have a deficit. This is a big problem. It hurts. And they just said no. So I took matters into my own hands, I got, my own tDCS unit, and I found out where my M one motor cortex spots are measured in my head, and put them into a place where I thought would be where they needed to be. And so I did that while I was exercising. And then I did it while I was doing mirror therapy. I would say I wore it for about 60 minutes every day.

Bill Gasiamis 44:41

What did you notice? Nothing. I was hoping you weren't gonna say that. But I was expecting it.

Annika Luke 44:48

I know. I know. I still am hoping that that's not the case. But yeah, I did it for probably three months. They're about. And then I went on vacation where I couldn't do it. And I didn't notice any difference. And I thought, no if I'm doing it all this time, and I haven't noticed any improvement, I thought maybe I would notice that when I stopped, that more pain would come, but I didn't.

Bill Gasiamis 45:20

The cerebellum and the motor cortex are probably in, they are kind of near each other in some parts of the brain. And I imagined that when they operated on my head to remove the faulty blood vessel, they may have gone in via the motor cortex, or they were near it, or they interrupted, or they did something to it because when I woke up from surgery, I had exactly what you described on the left side, tingling, numbness, burning, all at the same time.

Bill Gasiamis 45:49

And that meant that I couldn't walk because my leg didn't know where it was in

the world. And it wasn't sending feedback from the floor to my head to tell my head that it was on the ground. And therefore my work properly and all that stuff. So the rehabilitation has worked well. And I've got movement back, back all that stuff. But the thing I experience is, that the left side gets tenser and tighter because it's overcompensating all the time to make sure that I stay upright. After all, it does feel completely different from the right side.

Bill Gasiamis 46:29

And, and then that makes the muscles tense, and then that makes my balance, go off. And then that has a cascading effect of things that interfere with the way that I feel stability. So the solution to that is to get a massage, and try and loosen, loosen all the tension from the left side and then try and balance it with the right side. And if somebody if I go to a massage, and you know, you get these fluffy, gentle massages where they barely, barely touching, they're killing me.

Bill Gasiamis 47:11

That is so hurtful, so painful, that I need to go, I book in for the deepest, hardest, whatever you want to call it version of a message that I can get because then that doesn't hurt as much. What that does is relieve the pain of the muscles and creates relief instead of causing sensory pain and sensory burning, the right type of response. And I remember going into physical therapy without teaching me how to walk again. And they wanted to retrain, they said, my, my left side so that it's not interpreting soft touch as burning as difficult, etc.

Bill Gasiamis 47:58

So the way they would do that is that we'd get a rough tell that's come say, out of the washing machine without fabric softener. And then they would just rub that up and down my leg and my arm for 30 minutes to desensitize supposedly my left side so that it doesn't say that it's not so that they're reprogramming this sensation that you and I are feeling into.

Bill Gasiamis 48:32

We'll call it normal. I don't know what, you know, something that is less painful. No, not at all. And it was so frustrating because I would have to go there and say to the guys, this is not working. I did this for about 10 or 11 sessions or something. And I would just sit there and just be completely irritated. You know, on my left side, I would just annoy the heck out of me and make it painful the whole time.

Bill Gasiamis 49:01

And I would get zero results. And then recently, so for me, I went through all of that in 2014 and recently my friend helped me through my because he's a radiographer who helped me through my recovery. My MRIs or my scans through the hospital that he was working at, at the time. His daughter who was 17 had a bleed in the brain almost in the same spot as me and she has the same deficits now on the left side. And I was talking to my friend who's very well medically aware because he's a radiographer and has been a radiographer for his whole professional life.

## Accepting the permanent deficits from the stroke



Bill Gasiamis 49:37

And he said to me that the doctors told his daughter that we're going to retrain the brain so that it stops thinking that sensitive touch is bad etc. And they were just telling her this routine that they told me about how I was going to get my sensation back on my left side. And I just had to break the news to him, I said to Chris, I'm not sure that you're gonna get a result.

Bill Gasiamis 50:11

And that you guys need to keep pushing that because I have not met anybody who has had the deficits that we've got now his daughter and I and you that we're talking about, that has been able to get back the normal feeling on the left side or the right side. It just hasn't happened, it doesn't happen. It looks like it sounds like and I don't want to be the bearer of bad news sounds like that. It's the one thing that's permanent is the way that my left side is always going to feel.

Annika Luke 50:43

And I'm trying not to believe that though. I still feel like I can get better.

Bill Gasiamis 50:54

You can I agree with you, you can improve. And one of the things you also can improve with is the way that you experience your left side, it doesn't have to make you down as much as it does. And that's where I've improved. So some days, believe it or not, Annika, I don't notice my left side.

Bill Gasiamis 51:16

And that's a cognitive thing, right? That's a mental thing. It's not that my left side has changed. It's that I've changed the way that I respond to it and experience it. And then I have to catch myself every once in a while again, I have a nice one that said, Ah, damn it. Now I've noticed that.

Annika Luke 51:41

Yeah, no, I Well, what I do all day is I alternate between hot and cold, because I can feel hot, and I can feel cold, I cannot warm and I cannot feel cool. So I have ice packs that I touch. And I have like things you put in the microwave, a heating pad and type things. And I play with them. And that's one of the ways that I like relaxing at night is I'll sit there and touch them with both my hands.

Annika Luke 52:14

So that they're trying this, the left hand is trying to learn what the right hand is feeling. Yeah, I've noticed that it makes it feel better. Because especially when it's really cold, it's a sensation that is not getting a sensation. So when it does, it's really happy about that. And I've thought of, you know, like they sell those little mats that you can lie down on there, like acupuncture, puncture math. Maybe I should try that. Because sometimes I'll just take a brush and brush my hand to get that sensation on my hand.

Bill Gasiamis 52:54

Is that a sensation? okay to feel? Is it annoying? Is it painful little?

Annika Luke 53:01

It doesn't bother me I would, I would say like you the light. Touch really? does. So like, I wear only tights now basically, or shorts. Because if my pant leg rubs up against my little left side, it hurts. So that's bothersome to me. So yeah, I don't wear all my clothes anymore.



Bill Gasiamis 53:30

I've argued. I'm not sure if it's possible for anyone on the planet to ever have this type of argument with my wife about the bed sheets. Because some bed sheets that were gifted to her by her mother made me feel uncomfortable in bed and I couldn't sleep. Do not put these pitches on the bed anymore. They are terrible. Blah, blah, blah. Yeah,

Annika Luke 54:00

Yeah, they have a nice smooth

Bill Gasiamis 54:03

cotton, you know, whatever. And she thought that I was saying her mother's bedsheets were terrible. Throw them away. I can't sleep with this. bed sheets that make my left side feel uncomfortable and painful. As a result of that feeling on my left, I also sleep on my left side now because if I'm sleeping on my left side, the weight of my body is creating that hard sensation. While sleeping on my right side, the shades are creating that soft touch sensation. And it's a really big problem. I can't deal with it. And it stops me from sleeping.

Annika Luke 54:43

Well, be careful with your neck. You don't want to get in some weird position. No Carotid Artery Dissection is for you.

Bill Gasiamis 54:48

No, I can't sleep on my back. So I do have a pillow that supports my neck and all that type of thing. But yes, it is such a dramatic thing to have the wrong bedsheet. For me, it's such a problem. And I understand travel. I try to avoid all things that make me out of my comfort zone. But that's probably not a good thing either. Do you know? I don't want to end up in my 50s being one of those Grumpy Old Men who are bothered by everybody and everything.

Bill Gasiamis 55:23

It's way too early to be like that. I'm only 50 I don't want to get there. Until I'm 80 or something. You're so you're able to exercise, walk, run, are you able to have you been able to get back to that, even though your left side feels a bit strange?

Annika Luke 55:45

Yes, yeah, well, I don't, I've never, I stopped running a long time ago, I was a runner, right after college. And then, when I was 34, I had my hip replaced

because I had hip dysplasia. So I don't run anymore. But I was doing HIIT workouts and strength workouts, and I was trained as a personal trainer. And I taught spin class and Pilates for a while. And so yeah, I've gotten back into my exercise. I don't teach or anything anymore, but yeah.

Bill Gasiamis 56:24

How does the looking forward from here? How does the future look? What are you excited about?

Annika Luke 56:34

Um, well, I think I've come to realize what I'm grateful for. So for a while when the pain really hit in and then I realized, like, this is, this is it, this is the rest of my life, I'm gonna be feeling this. I took it to go to meditation. So I started doing meditation and gratitude meditations, in particular. And so I'm, I'm just grateful that, you know, I have everything that I have. I have a wonderful family, really good family and friends. And, you know, I'm just so happy that I have that. And I want to enjoy that. And so I really, want to travel a lot.

Annika Luke 57:26

I, we've done a couple of trips recently, and it felt good to be able to do that. And I know my husband likes to travel. So he and I will be doing that in our retirement future if we get to that point lucky enough.

Bill Gasiamis 57:44

Yeah, perfecting out was the hardest thing about stroke.

Annika Luke 57:50

Um, just the loneliness of it, you know, like, not wanting to burden everybody with like this. I mean, my poor husband had to hear me talk about stroke, for every walk we went on for a long time. But even though he's so empathetic and so good. It's just, and I have great friends that I could lead on to, but there's just still something so isolating about it.

Bill Gasiamis 58:23

Wow. A lot of people describe exactly what you said that it's stroke is isolating. And I'm not sure how I haven't been able to understand specifically why it's isolated. But I felt, I still feel that I felt that I still feel that I still have moments where I'm not trying to be annoying, or painful or weird or anything. But you just don't get it. I just can't express and I don't want you to get it.

Bill Gasiamis 58:54

You know, these are conversations that I'm having with people, right? I just don't want you to get it. But I need you to get it. And I know you're never gonna get it. But it's so hard to be me. And yeah, I've never felt it harder to be me because I felt like previously when it was hard to be me it was because of something I concocted that wasn't a real thing that if I changed my mindset, or if I had another opinion, I could redirect and take a different path and it'll be fine. I could resolve that particular matter.

Bill Gasiamis 59:27

That was ailing me. But right now, this thing that happened to me is not something I can divert away from. It's following me everywhere I go doesn't matter what I do. Yeah,

Annika Luke 59:43

And you always wonder, if I said something stupid was that because I had a brain injury? Or did I just say something stupid because sometimes I say stupid things like you never know? I mean, I always fumble over my words and stuff.

Annika Luke 59:58

So that has nothing to do. With the fact that I had a stroke, it's probably just who I am. But you always question your own choices and your mentality. Like, are you okay? Yeah, fear of having another one that does loom over you. You're like, I don't want to do anything stupid.

Bill Gasiamis 1:00:21

Does that mean that you're making different decisions about how you go about being physical?

Annika Luke 1:00:30

No, because I'm back to doing HIIT workouts and stuff. And in some ways, I even think about it as therapeutic. Because where it hit in my brain when you hit that parietal lobe, there's a lot of in there that does, like not only feeling and sensation, but it's also where you are in space. So oftentimes, when I'm working out, I'll sort of stop and guess where I am, and then look down, just to test myself.

Annika Luke 1:01:02

Because I feel like that, and also, balance is important, too. So I think that when you're working out if you're gaining that balance, you're growing that part of your

brain as well. Yeah, so there's a lot that is beneficial to the exercise, I don't lift heavy weights anymore, especially over my head. But I still do work out daily. Yes. And I walk quite a bit, I would say, I do about a mile in the morning and a mile in the evening.

Bill Gasiamis 1:01:38

Exercise is so important, it's one of the most important things if you can get any version of exercise done, no matter what your deficits are, don't matter how bad stroke has impacted you, if you can just get physical in some way, shape or form that does support the brain to grow new pathways to recover, to heal, to do all sorts of things to useful.

Bill Gasiamis 1:02:06

In the last 12 or so months, have you had many trips back to the hospital thinking, oh my gosh, what is this in my head? What's happening? I should go to the hospital and get it checked out.

Annika Luke 1:02:19

I have not gone back to the hospital. But even just this morning, I had a headache that seemed unusual. And I thought what is this? And I think it's just allergies, quite honestly, but made me pause made me think twice about it. And I feel like I should go talk to migraine sufferers about the possibility like, hey, this could be a problem. Because it's you're so easily dismissed if you're a migraine sufferer.

Annika Luke 1:02:49

But if I just would have asked, I want to scan, I think they would have found it sooner. And I think the whole thing could have potentially been avoided because it was the clot that broke off that caused the stroke. So had they discovered the dissection, which really the big tip-off there was the breathing noise that I was hearing was actually that the carotid artery was making a wishing noise as it was going past the tear.

Annika Luke 1:03:22

So that and I sort of kicked myself a little bit too because I know, I know that I need to do my research. And be my best advocate. Yeah, I should have done more.

Bill Gasiamis 1:03:38

Yeah, but you never planned for having had a stroke and needing to research that.

Annika Luke 1:03:46

No. Never knew. But if I had researched hearing a noise whooshing noise in my left, I would have potentially been able to figure that out. But you know, not medically trained.

Bill Gasiamis 1:04:01

Just a regular person. Are you hard on yourself because of that? Do you

Annika Luke 1:04:09

Always just question your own what you could have done differently. And I think I should have just asked for more. And I think being who I am, which is like no, everything's fine. I think I was accepting of their answer if you're fine. Go home. Here are some sample types of feelings where I should have said no, I'm not fine. This is not a normal headache.

## Lessons from the stroke



Bill Gasiamis 1:04:38

What has stroke taught you?

Annika Luke 1:04:42

Oh, gosh, what has it taught me? If anything, to keep going, you know, grit is always been important and something I hope I instill in my children. But that's a key part of life in general. And that's how you are successful, you just keep going. Just put one foot in front of the other and do the next right thing.

Bill Gasiamis 1:05:08

Yeah. And if someone listening is early on in this journey, they've just had a stroke, they've just come home. Let's say they stumbled across our interview,

what do you want to tell them? About? The journey ahead,

Annika Luke 1:05:24

Sir. Enjoy the things that you can enjoy. Try not to think too much about what the future is gonna hold. Because you just don't know, enjoy those little things. You know, I've been so happy to have my children, my husband, my dog, you know, I get a lot of joy out of them. And I think that everybody has those little joys

Bill Gasiamis 1:05:57

about those moments, isn't it? It's about the moment that you're in right now. For example, right?, I'm enjoying our conversation. And I get to do it once a week at least, have done it for the last nearly three years, once a week for the last three years. And I'm grateful that I had a stroke that led to a podcast, that is me, speaking with other stroke survivors who get me makes me feel less alone. And it makes me not have to tell my wife about it. Again, and again. And again and again for 10 years solid.

Annika Luke 1:06:42

Yeah, yeah, I was a little worried about coming on here. Because I always feel like all your guests seem profound. And, like, almost happy that they had a stroke, I, I still am going to hold the stroke as the worst thing that ever happened to me, and I'm going to keep it there.

Bill Gasiamis 1:07:01

Do you do that? You do that and let it. Let's see what happens with it. The reason I say that is because you might know that I'm about to release a book called Stroke The Best Thing That Happened to Me. But the very beginning of the book makes it very clear. When a stroke happened to me, that was not the best thing that happened to me.

Bill Gasiamis 1:07:23

It was the worst thing that happened to me. And it's the evolution of my life and how I've grown and developed that led to stroke, in hindsight, becoming one of the best things that happened to me because my life has a clear trajectory change. And it would never have happened. If it wasn't for the stroke, it never would have happened, I would have just gone about being my Neanderthal old self.

Bill Gasiamis 1:07:56

And I would have struggled with all of the pretend pretending and all the stories that I said to myself about why life was hard. And from a physical health perspective and a mental health perspective. It motivated me to do better in every aspect of my life, to look after my nutrition, better to look after my mental health better, attend to my emotional health, mend my relationships, make better connections with people to let people go from my life that was not serving me.

Bill Gasiamis 1:08:50

So it is an opportunity for growth is what I'm trying to sell to people is, you know, this is an opportunity for post-traumatic growth. And you might not see it yet. And you might not know how and you might not know where it's going to come from. But the simple fact is that you decided to reach out and get onto a podcast and share your story. I mean, that's a cool thing. And if you listen back to the podcast, you might find that some of the things that came out of your word out of your mouth are profound words.

Annika Luke 1:09:32

Possibly, but well, maybe leave it at that because I still think the worst thing, but you know what, even if it is the worst thing, it still means that everything else is better. And isn't that happy?

Bill Gasiamis 1:09:48

Isn't that great? Yeah. See? There you go. That's perfect. Well, on that note, thank you so much for being on the podcast.

Annika Luke 1:09:57

Thanks for having me.

Bill Gasiamis 1:09:58

That's a wrap. We're done.

Annika Luke 1:10:00

A great buy.

Bill Gasiamis 1:10:01

What a lovely chat. Thank you so much. I'm going to edit this and put it up, it'll go up in a couple of days, there's not another podcast ahead of this, and I'll use the images that you sent me for promotion. And even though you've sent submitted images already, you will receive an automated email because I'm dealing with

stroke survivors, and I have to completely remind them all the time, you will receive an automated email that asks for all this stuff again, but if you've already done it, just ignore it.

Annika Luke 1:10:34

Okay, that sounds good.

Bill Gasiamis 1:10:36

Enjoy the rest of your day.

Annika Luke 1:10:38

Thanks, you too. Bye. Bye.

Bill Gasiamis 1:10:44

Thanks for joining us on today's episode 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](https://recoveryafterstroke.com/episodes) If you'd like to support this podcast, and I would love it if you do, please leave a five-star review and a few words about what the show means to you on iTunes and Spotify.

Bill Gasiamis 1:11:08

If you are watching on YouTube, comment below the video, like the episode and to get notifications of future episodes, subscribe to the show on the platform of your choice. Also, if you are somebody who has already left a comment and responded to one of my episodes, thank you so much. I truly appreciate it.

Bill Gasiamis 1:11:27

It makes a massive difference to the algorithm. And what that does is put the episode in front of people who need to see the episode. For example, stroke survivors who are searching for this type of content. Once again, thank you for being here and listening. I appreciate you and see you on the next episode.

Intro 1:11:48

Importantly, we present many podcasts designed to give you an insight and understanding into the experiences of other individuals. The opinions and treatment protocols discussed during any podcast are the individual's own experience and we do not necessarily share the same opinion nor do we recommend any treatment protocol discussed.



#### Intro 1:12:05

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#### Intro 1:12:18

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#### Intro 1:13:10

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