

The Stroke That Took Everything - And What Came Back

What Does Stroke Recovery Really Feel Like?

Recovery after stroke isn't a straight line, it's a winding, unpredictable journey that challenges not only the body but the mind and emotions. It's easy to think recovery ends when rehab does. But for most survivors, that's just the beginning.

There's the grief of lost abilities. The confusion of waking up in a body that feels foreign. And perhaps most misunderstood of all, **the kind of fatigue you can't sleep off.**

The Hidden Weight of Stroke Fatigue

Post-stroke fatigue is not the same as being tired. It's deep, cellular. A kind of heaviness that sleep doesn't fix. You can wake up exhausted. You can rest all day and still feel drained by evening. It doesn't come and go; it lingers.

This kind of fatigue makes small tasks feel enormous. Putting on shoes. Taking a shower. Holding a conversation. Everything demands energy that your body no longer gives easily.

And the hardest part? It's invisible. To the outside world, you might look fine. But inside, your brain is still working overtime just to keep up.

From Paralysis to Progress

For many stroke survivors, recovery starts with relearning: how to walk, how to speak, how to navigate a world that suddenly became unfamiliar. Whether the stroke affected the left side, the right side, or speech centers, it leaves an imprint.

Some people regain skills quickly. Others move slowly, step by step, using devices or therapy to support their progress. What matters isn't speed, it's consistency,

compassion, and staying in the game.

When You Look Fine But Don't Feel Fine

One of the most disorienting parts of stroke recovery is **not looking sick anymore**.

People stop asking how you are. They assume you're back to normal. But maybe your hand still doesn't work like it used to. Maybe stairs are still terrifying. Maybe your brain feels foggy by lunchtime, and you need to nap every afternoon.

These hidden deficits are real. They affect your work, your relationships, and your self-esteem. And they're often the part of recovery no one talks about.

Tools That Support Recovery

Many survivors face mobility issues long after hospital discharge. One common issue is **foot drop**, where the front part of the foot drags or doesn't lift properly. It can make walking feel awkward, slow, and even dangerous.

There are technologies that help, orthotic devices, functional electrical stimulation, and targeted rehab. For example, devices like Bioness can provide electrical signals to assist foot movement and improve gait. Some clinics even offer free trial sessions to see if they're a fit.

The right tool won't solve everything, but it can be a stepping stone toward greater independence.

Why Emotional Support Matters

Physical therapy is only one piece of recovery. **Emotional support is just as essential**.

Recovery can be isolating. Friends may drift. Work might not feel possible. Your sense of identity can blur.

That's why connecting with others who understand stroke, not in theory, but from lived experience, can be life-changing. Whether it's an online group, a local meet-up, or a comment section under a podcast, having a place to feel seen and understood is part of the healing process.

Final Thoughts: You're Not Failing, You're Rebuilding

Stroke recovery is slow. It's messy. It's frustrating. But above all, it's **possible**.

If you're still using a cane, still wearing an AFO, still struggling with speech, still waking up tired, **you are not behind. You are rebuilding.**

The fatigue, the grief, the tiny victories, they all count. And no matter how long it's been, recovery is still happening.

Stroke Recovery and Fatigue You Can't Sleep Off

Alyssa reveals the raw truth of stroke recovery: the fatigue, the grief, and how she's rebuilding life after a stroke at 31.

Instagram

TikTok

Support The Recovery After Stroke on Patreon

Highlights:

00:00 Alyssa's Life Before the Stroke

05:17 The Onset of the Stroke

12:43 The Stroke and Its Immediate Impact

19:50 The Road to Recovery

28:44 The Heart Surgery and Its Aftermath

39:37 Life After the Hospital

45:28 Fighting Through the Pity Party After Stroke

59:46 Reflections on the Experience

1:08:49 Alyssa's Coping Strategies and Daily Challenges

1:15:26 Fully Healed, But with Scars: Alyssa's Message to Stroke Survivors

1:26:80 Introversion and Adapting to Social Environments

1:32:42 Support and Community Building

1:39:06 The Role of Podcasts and Personal Stories

1:42:54 Final Thoughts and Gratitude

Transcript:

Alyssa's Life Before the Stroke

Bill Gasiamis 0:00

Before we dive in today, I want to thank Bioness for supporting this episode. Today's conversation features one of their patients, but more importantly, it's a story about resilience and recovery. This is not a paid testimonial, just an honest look at one person's journey and the role technology played along the way.

Bill Gasiamis 0:19

Alyssa Van Steen was 31 when a rare bacterial infection attacked her heart valve, leading to a hemorrhagic stroke and eventually open heart surgery. What followed was months in hospital, re learning how to walk, speak, and function with her dominant side offline. This conversation isn't about easy answers. It's about the days that don't get better overnight.

Bill Gasiamis 0:45

It's about the kind of fatigue you can't sleep off. And it's about what it means to rebuild your life when the world thinks you're better, but your body still knows the truth if you're in it right now, if recovery feels heavy, endless or invisible. Alyssa story might be the reminder you didn't know you needed. Let's get into it. Alyssa Van Steen, welcome to the podcast.

Alyssa Van Steen 1:11

Thank you.

Bill Gasiamis 1:14

Thank you for being here. Tell me a little bit about what life was like for you before stroke.

Alyssa Van Steen 1:25

Life with before stroke, so I was 31 when it happened, and I was just working, and I don't know, just doing my life. I think I was at a point where I was, I think in like, your 30s, you kind of know, like, okay, this is who I am now. And I kind of was, like getting that sense right before everything happened. So I was in a good place in my life, when things happen.

Bill Gasiamis 2:01

what kind of work were you doing?

Alyssa Van Steen 2:06

Just our local grocery store down the street?

Bill Gasiamis 2:09

Yeah, so very locally focused, focused in the community. I imagine that it's pretty rewarding meeting the locals. Everyone knows you. You know them. Is it a small type of community? What's it like?

Alyssa Van Steen 2:26

It's smaller, but I'm still in Orange County in California, so it's, I mean, it's busy. There's a lot to do and but the where I live is a little bit more slower and family driven. But yeah, the grocery store that I work at is the more sought out, I think, the sought after grocery store, so it's busy, busy, yeah.

Bill Gasiamis 3:01

And what did you do to for downtime? Did you have some stuff that you did on a regular basis that you enjoyed doing, getting out and about? What? How did you occupy time other than work?

Alyssa Van Steen 3:13

So other than work, I am an artist, so I work with cut pieces of paper, and I'll do like hand painted and at the mouth and and I did that as well for work as well. I was on the in the art department for my work as well. And so that was kind of like what I spent a lot of my time with as well, as well as gardening.

Alyssa Van Steen 3:46

I'm a big gardener, and yeah, I've transformed my yard, the front yard and the backyard, many times. So yeah. And then other than that, I love to walk my dog. Um, my dog's a 75 pound dog, so I, you know, he needs a lot of walks. And I love to walk and so that is a, yeah, that's where I was at, right now.

Bill Gasiamis 4:19

You walk dogs, you or you walk your dog.

Alyssa Van Steen 4:23

Oh, my dog, my dog, yeah.

Bill Gasiamis 4:25

But it's if it's a 75 pound dog, you're not walking it. It's telling you.

Alyssa Van Steen 4:32

no, he's a good he's a good listener.

Bill Gasiamis 4:39

Fair enough. So did you study the arts?

Alyssa Van Steen 4:44

I didn't. I actually went to school to become a teacher, and I graduated, and I ended up kind of thinking like, Oh, that's not really what I want to do. So I was like, Oh, I'm just going to do. Work, and I'm just gonna do my art on the side and garden and do my thing. And, yeah, that's where I was at.

Bill Gasiamis 5:07

It was just like a hobby that turned into something that you were getting paid to do.

Alyssa Van Steen 5:12

Yeah, yeah, that's pretty cool.

The Onset of the Stroke

Bill Gasiamis 5:17

So tell me. Do you recall the time when at 31 something went wrong. How did that day unfold? What happened?

Alyssa Van Steen 5:28

Yeah, so my stroke happened on Well, I guess all before everything happened, it was April 23 was the first day that I went into the hospital. So it was about a day and a day, maybe a day and a half, before April 3 that I I just kind of started to feel like I was sick. And I have had COVID before, and it really felt very much like COVID.

Alyssa Van Steen 6:03

I had body aches, I had chills, I had a migraine and no appetite, and I am someone that I have had migraines my whole entire adult life, where I've had anywhere from like three to four a week. And it was always under the under control, pretty much, where it was just kind of like, this is just what happens.

Alyssa Van Steen 6:31

Like, my mom gets migraines, and it was just like, oh, some people just have a more prom or, yeah, they're just more prone to it and so, yeah, and so. But this migraine didn't feel like any other migraine I've ever felt in my whole entire life. This was a migraine that I was trying to take, like, an ibuprofen, just to like help, and I was screaming and crying on my floor like I didn't know what to do.

Alyssa Van Steen 7:14

So it was that evening that my mom took me to the urgent care to see what was going on. And Urgent Care basically just gave me a shot of ibuprofen and sent me on my way, and I could, like, barely walk in. It was so it was so excruciating, I don't I never want to ever experience that type of migraine. It was, it was crazy. So when I got home, my mom was trying to get me to eat, and I just couldn't.

Alyssa Van Steen 7:52

And so she ended up, like, having to, like, spoon feed me spaghetti, because I just couldn't even, like, lift my arms. It was, it was weird, and that was the last thing I remember. I only I remember her feeding me spaghetti in the dark because I couldn't take any kind of lights. And the next thing that I remember, I'm waking up in a hospital bed. Wow. So what had happened was my my blood pressure went super low, and I guess I was starting to scream and be incoherent, I guess.

Alyssa Van Steen 8:42

And that's when my mom and my brother had to call for an ambulance, and they also were saying that my heart rate was very high. And so it was about two days in the hospital where we were just testing and testing like and we we just, we couldn't figure out what it was, what happened, and I was still having like, constant migraines. It wasn't that same migraine, but it was migraines, right? I started to have a bladder infection.

Alyssa Van Steen 9:22

My kidneys were failing. They were talking about it was possibly ms, it was just I was on oxygen. It was like I was then I was starting to go septic. It was just like, nuts, intense. And yeah, and so it it, it took a couple of days. No, it was, it was actually two weeks, but I was in the hospital and we found out what it. It. It was so basically, I had an infection that was attached to my heart valve.

Alyssa Van Steen 10:12

So it was a rare bacterial infection that went into my bloodstream and attached itself to my heart valve. And it was deteriorating my heart valve, and so it, it was, they were like, Okay, well, we can, we can get some strong antibiotics to help this, and we probably don't have to go in for heart surgery or anything. We could probably just like, kill it on the spot.

Alyssa Van Steen 10:46

And so that's what we were doing. So we stayed in the hospital. I was on antibiotics for a couple of times a day. Very strong. Was like, making my hair fall out. It was crazy. So that was, and they were kind of, they were kind of, now looking like, Okay, this is the problem. And then you're also, you're having many strokes, and there's lacerations on your brain. So I was like, okay, so this is but they're like, but we're, we're killing the and the the bacteria, so we'll be okay.

Alyssa Van Steen 11:29

So it was a while, and then I had to, it was May 1. Is when they were like, Okay, you can go home. And what we can do. You still have to be on antibiotics for couple, like, another six weeks or something, but we can have a nurse come out and once or twice a day and do your injection and then, or whatever, or the drip, and you'll be fine, like, you can go home.

Alyssa Van Steen 12:06

And we're like, okay, so I'm getting ready, ready to go home. Um, we're waiting to be discarded, discharged. And I went up to go to the bathroom, and I was like, and I was feeling better. I was starting to feel better too. So I was like, okay, like, I'm like, things are things are looking at. Wasn't on oxygen or anything like that anymore. And so I went to go to the bathroom, we're waiting for to be discharged. And I come back from the bathroom, and I was like, I feel kind of weird.

The Stroke Recovery and Fatigue and Its Immediate Impact



Alyssa Van Steen 12:43

And my mom was in the room, and she's like, What? What do you mean? And I was like, I don't know. Like, something's weird, and I don't know how to like, describe it. And she's like, Okay, we'll sit down. Let's have the nurse come in. A nurse comes in. She's like, kind of checking me out. All of a sudden, my whole

right side gets super heavy, and I know exactly what it is. I was like, I'm having a stroke, and I've never had any type of scare with like, stroke or anything, but I just knew, like, I knew that that that happens with stroke.

Bill Gasiamis 13:18

Let's pause for a moment, you've just heard Alyssa describe one of the hardest pivots of her life, from being days away from discharge to suddenly realizing she was having a stroke her right side when heavy, her speech disappeared. Her world flipped. If you've been through something like that, the suddenness, the shock, the feeling of your body no longer responding. I want you to know you're not alone, you're not broken, you're rebuilding.

Bill Gasiamis 13:47

Now this is recovery involved layers of trauma, rehab and fatigue, and most people never see it. And like many stroke survivors, she faced something called foot drop, that dragging, uncooperative feeling that makes every step harder than it should be. If you're dealing with that, there's a device that might help the bonus system. It's not fit for everyone, but there's free one hour trial.

Bill Gasiamis 14:13

You can try No pressure, just a chance to see if it works for your recovery. You can schedule it at locations across the United States. Now let's get back to Alyssa as she starts to make sense of the stroke, the Aphasia, and the first steps towards healing.

Alyssa Van Steen 14:31

And so, um, once they kind of were like, I said, I'm having this stroke, it was like gangbusters. Everyone came in. There was like people were moving me around. They and then they took me to to what do you call it? The I can't think of it to test your brain, am I right? MRI? Thank you. Yeah, I remember going into the MRI machine. And I don't remember coming out.

Alyssa Van Steen 15:04

And so I had had a hemorrhagic stroke, and it affected my right side. I wasn't talking much when I woke up from my stroke, and a lot of this is like things that I've had to be filled in from my family members, because I don't remember a lot of it. I remember bits and pieces of when you're in the hospital, but you don't remember it like it happened. And you it almost it remembers. I remember it in

like, little seconds, here and there.

Alyssa Van Steen 15:48

But I can't say that like this second happened before this one and then this one was it's just scattered. So I wasn't, wasn't really talking. I could say like yes or no, but I couldn't do much more than that. I couldn't say my name when they after a couple of days, they were trying to get me to say my name, and I just said my birthday for and that went on for a couple of days as well, where I just what's her name, November 17, 1991 just so There was that. And, yeah, so pretty. So that was, yeah, so it was, it was a lot.

Bill Gasiamis 16:47

What was going through your mind at the time. So before that, you're having a migraine. They come, they go, no big deal. Okay, we're going to a dark room. Bit of ibuprofen. Things settled down, but then you went on this ridiculously wild journey in that time.

Bill Gasiamis 17:11

And then at some point, the news is getting worse and worse and worse, and then you think you're on the way out and back home, and then you have a hemorrhagic stress. What are you thinking? Are you able to comprehend? What is going on? Are you going? How the hell did I end up here? What? What's going on in your mind during that time?

Alyssa Van Steen 17:34

I don't think I really like clued in that this big thing happened until, like, maybe a week or two later, when I was kind of like, oh, this happened to me. I think also like, I and I was also transferred to a different hospital. After I went into the MRI machine, they transferred me to another hospital that was specifically for, like, stroke patients. And I just, I don't know if it was a combination of, you know, because when you have a stroke, I feel like, when I woke up, my brain was like scrambled eggs, like it just didn't.

Alyssa Van Steen 18:20

There was no like, way to, like, sort out what I couldn't even say in my mind, like, what's happening to me? Like, I couldn't even say that. It was just everything was broken. Yeah, and I it took me a long time for me to be like, Oh, okay. Like, this is what happened. And I and I also had, and I had aphasia as well. So that was, like,

really difficult for me to try to even try to talk, because it wouldn't really come out.

Alyssa Van Steen 18:59

I would say, say things, and I could say, like one little thing, I couldn't say, like a sentence, or I couldn't even say, like three things, three, three words in the order, you know, I could only say, like, one or two things. So it was, it was difficult to, like, have my family talk to me and me communicate, respond, yeah.

Bill Gasiamis 19:30

So what was so sounds like, life after stroke changed dramatically, right? What was like? What was it like? What could you do? What could you not do? How did your body feel? What deficits did you have? How did it change?

The Road to Stroke Recovery

Alyssa Van Steen 19:50

Well, I couldn't walk anymore. Couldn't go to the bathroom by myself anymore. My whole right side was completely. Uh, numb and limp. So it was it, it wasn't until so they also, they kept me, I, you know, I kind of went moving floors, ICU and different things and, and then they were like, I think because her age and the type of stroke that I had, they were like, you would do really well on a rehab floor.

Alyssa Van Steen 20:30

And so I was like, okay, like, and I remember, I do remember, actually kind of saying, like, I just want to go home. Like, saying something like, I just want to go home. And my parents were like, no, no, you're going to go to the rehab floor, because this is going to be better for you in the end. So like when you do go home, you need to be able to have a little bit, like a leg up on your rehabilitation.

Bill Gasiamis 20:55

And your mom, did your mom promise to bring you food and feed you pasta while you were.

Alyssa Van Steen 21:03

Yeah, well, my family was really good, too. Also, like, a little bit about me. I'm terrified of any type of doctor's office, so this whole thing was so already, the fact that, like, I had to go into on like an ambulance and I'm in the hospital, was traumatizing, yes, and so I'm so squirmish around like needles or whatever. And

so the whole time that I was at the hospital, my parents made it a priority to like, no matter what, like, at least one person stays with Melissa, whether it's just my parents or my brother, like there is one person that will be there with her.

Bill Gasiamis 21:50

Can I a little bit just be just sorry to interrupt? Can I unpack a little bit so my wife is not afraid of doctors and needles and all that kind of stuff. She doesn't really enjoy needles, etc. I'm the opposite, right? So I love doctors because doctors make you better, because hospitals is where people go to help be patched up and fixed up and then sent home.

Bill Gasiamis 22:18

So my I don't get how people are afraid of doctors, doctors, surgeries, hospitals. Are you able to unpack that a little bit and just give me an insight so I can kind of understand.

Alyssa Van Steen 22:30

I think, you know what? I think from my own experience, I can't really say about like my family, that that were also going through with me. But for me, I think the the only times I would ever be in a hospital was when I would be watching my grandparents die. Okay, and so I'm like, this is where people die. Got it?

Bill Gasiamis 22:59

I completely get it. So I don't I know that people have to pass away at a hospital from time to time, and that's kind of where they end up. I get that, and I know what you're saying. So it's just literally, it's like your experience probably also as you were younger, with older grandparents, and you have to go and see that and experience that.

Bill Gasiamis 23:22

Go through that process with them. Okay, yeah, I totally get it. Now I know exactly why. All right, let's pick up on your in hospital. Mum's bringing you food, and everyone's staying with you. One person is staying with you all the time because of your experience, let's and then what?

Alyssa Van Steen 23:46

So I was on the rehab floor, and we were doing rehab, and that's, you know, there's speech therapy, there's occupational therapy and physical therapy. And the way that I it was set up in this hospital that they had a schedule put out for

you the next the night before, and they'd say, like, 7am you're going to have speech, and then at 730 you'd have so and you're, you're going, going, going.

Alyssa Van Steen 24:22

And I think because, also because I was younger, they were like, We're gonna work her as much as she can. And I think when I got to the rehab floor is when I start to remember my memories. I don't remember a lot from before that, but I also was starting to talk a little bit more when I was on the rehab floor, and it so I remember being like, I'm here to work. Like, this is like, no, bring it like you're gonna if you want to.

Alyssa Van Steen 24:59

If you want to have me, like, two different PT sessions in one day, like, we're going to do it. Like, let's do it. Um, and I was so like, I get I'm just, like, so grateful for the the rehab floor and all of the people that work there, because, oh my gosh. Like it's crazy. How much, how, how much knowledge they have to fine tune little things for every little need that you might have.

Bill Gasiamis 25:11

So you embraced it so there's no denial of your condition, There's none of that stuff. No resistance to what you needed to do, the hard work that was coming up, that you needed to do. You were just up for it.

Alyssa Van Steen 25:53

But I also wasn't, you know what? It's funny, because I really was just kind of focused on, like, right now. I wasn't thinking, like, Well, when I go home, what's gonna happen? Can I am I gonna walk when I go home? Like, I just didn't even think about that. I was just so focused on, like, no, no. This is what's going on right now. Like, let's just focus on right now.

Alyssa Van Steen 26:14

Because I think I didn't even there wasn't there was a like, towards the end of my stay, there was a moment where I was like, wait, I can't even, you know, my right is my dominant hand. And I was like, I can't write with my I don't, I can't write right now, like, and I, that's what I used to do for work, like write and draw and, you know, cut paper and like, I was like, I can't do that. And I remember breaking down and like, and, yeah, it was, it was rough.

Bill Gasiamis 26:53

So one stage, the majority of the time you're going day by day, it's about focusing on the task at hand. I did something similar. I never once thought about what it would be like when I went home. When I went home, I was more capable than I was when I started rehab. I could walk and I could use my left arm again. They weren't perfect at all, but they were I was still able to make breakfast and a cup of tea and that kind of stuff.

Bill Gasiamis 27:22

So all the usual stuff were okay. I couldn't walk work. I probably couldn't work. So I didn't occur to me at all, not once in my head, like, I'm going to go home next week and I'm not going to go to work, I'm not going to do anything, I'm just going to be at home waiting for more rehab. I had a patient rehab to go through, but you'd you'd had that realization, it was like The what now moment like, how were you afraid that you weren't going to rehabilitate further, that you were going to be at home. What was the, what were the thoughts or the concerns in your head?

Alyssa Van Steen 28:10

Yeah, because I was like, I can't even go to the bathroom by myself, like, you know, like that didn't like I even when I when I got home, like, I still didn't, like, I could go to the bathroom, but I had to have, like, someone watch, like, kind of watch me walk in, make sure I'm okay. Like, it was not it, yeah, there was so much more to go that I think I was it. It's better. I think it was better for me to just stay focused on, like, what's going on today?

The Heart Surgery and Its Aftermath

Alyssa Van Steen 28:44

Because I think when I had that moment of like, wait, I can't even write my name, like it, that just like, destroyed me. And so I worked and worked and worked, and I was also still being given the antibiotics for the bacteria in my heart, and it was not working. They were saying that, well, we killed the germ, but it destroyed that heart valve. So you're going to have to have open heart surgery, and you're going to have to have a valve replace.

Alyssa Van Steen 29:31

And so I was like, I think that day, I was like, it was like, I think I only had one more, one more thing on my to do list, and it was physical therapy, and it was at the end of the day, and one of my doctors came in and was saying, like, Yeah, this

is like, this is happening. Like, we have to do it sooner rather than later. You are going to have a lot of restrictions and things that you can't do once you have the heart surgery.

Alyssa Van Steen 30:10

You're going to have to be on the cardiac floor for a week. You won't be able to raise your arms, you won't be able to push out of bed, you you and so there was so much in my head. I was like, I won't be able to I have, I already have all these restrictions with losing my right side. I can't even, like, do any I can't do things. I can't even get up out of bed. And now you're I have more restrictions. And it was like, it was really hard.

Bill Gasiamis 30:44

Full on. So what kind of timeline did all this stuff happened? So from that crazy headache to the bacteria being found, and by the way, I still have to ask you about the hemorrhagic stroke, then the hemorrhagic stroke, and then the heart valve surgery. What's, what was the timeline?

Alyssa Van Steen 31:06

So I went into the I went into the first hospital on April, in April, and my heart surgery was on June 7. So that whole time I was still in the hospital. So I was in the hospital for a while. And so, yeah, and I remember that day too, when they were kind of, they told me about the heart surgery, and I was really, like, distraught about it, and then, and I just knew I was like, I don't want to go to physical therapy.

Alyssa Van Steen 31:39

And that was the first and only time I've ever said no to one of my therapies. And my mom was like, okay, when she was walking down the hall and she saw one of my therapists, and she was like, she doesn't want to, she's really distraught, like, she doesn't really want to go. And she's like, Okay, well, I'm gonna, I'm still gonna, like, peek my head in, in like, 3030, minutes and see what happens.

Alyssa Van Steen 32:03

And she peeked her head in, and she's like, how are you feeling? And I wipe my eyes. I'm like, let's go. Like, I was just like, Nope, we're gonna go. And I ended up having the best session that day. I walked a lot more than usual. We did steps like it was just, and I think that was like, that was just like, one of the things that

really, like, solidified in my brain that, like, you're gonna have to work hard, but the payoff is going to be so much better.

Alyssa Van Steen 32:36

If you just keep going. And so I was just like, I think from, I mean, I was already in that headspace, but even when I was not wanting to do things, I was just like, you're never going to say no to any of this now, like, I'm never going to say no to any of my therapies. I'm always going to try, because even even the things that you don't want to do is going to benefit. You in one way or another, even if it's the smallest amount.

Bill Gasiamis 33:08

I love that. It's a great attitude to take into the next phase of your surgeries, of your medical interventions. We know what caused the heart valve issue. We know what caused the massive headache. It was the bacteria, what caused that brain hemorrhage.

Alyssa Van Steen 33:27

So the heart valve was not pumping enough oxygen or blood to my brain, and it is it caused me to have a stroke.

Bill Gasiamis 33:41

Did it cause an actual bleed in the brain? Yes, that's so bizarre. How would it do that? I mean, maybe you don't have the answer, but that's okay.

Alyssa Van Steen 33:52

I don't know. And it was also, I was, you know, it was also like the infection was in my blood. It wasn't just in one place, so I don't know if it was, yeah, I don't know. It was crazy. And then the fact that, like, the type of stroke that I had, people would walk in, like nurses, and they'd be like, Oh, this is not what I was expecting.

Alyssa Van Steen 34:18

And so I was like, Oh, okay. And I didn't get it until I was out of the hospital where I was like, oh, a lot of people don't survive this type of stroke. Like hemorrhagic strokes are not like they think it's like, 2620 25% survival rate. And I was like, okay, like, now I get it. But at the time, I was like, What? What do you mean?

Bill Gasiamis 34:46

It's a big deal that they're treating a hemorrhagic stroke survivor. It is a big deal. The numbers are not that good in the favor. They're not in the favor of. The person having the hemorrhagic stroke, that's for sure. So you know that last PT set or that therapy session that you had was that kind of like a mind shift? Was that a moment? Did that help you prepare better for the heart surgery? How did that change the way that you were going to tackle the heart surgery. Did it help?

Alyssa Van Steen 35:24

It totally did. I think that was like, and that was when I was in that therapy session, and I was working hard, and I was having that revelation in my head afterward, too. I was like, okay, like, this is my one day of like, I'm like, down the dumps about having to have all these things happen to me. The next day, I woke up and I was like, I'm ready. Like, I'm ready when, when's the surgery?

Alyssa Van Steen 35:52

Like, let's do this. And up until I went into surgery, I was like, in good spirits. I was like, people are they're going to take care of me. Like, this is what's going to happen. I have to do it anyways. Let's just put a smile on and let's do it like and we had, again, I had such a great team of people that were preparing me, and it was just, it was great. And then coming out of the surgery was really rough, because open heart surgery actually does feel like you got hit by a truck.

Bill Gasiamis 36:33

And opening up your your rib cage.

Alyssa Van Steen 36:39

Yeah, wow, so you're when I woke up, it was just like, I could barely speak. I couldn't even, like, breathe without hurting. And it was intense. And the next day, they have to, they get you like, you gotta, you gotta stand up. You gotta be moving. And I was like. I was like, okay, someone's gonna have to, like, Help me up, because I can't get up. And, yeah, it was, it was rough. I was in pain for a while.

Bill Gasiamis 37:17

What was the biggest challenge that you faced during the recovery, after all of that stuff that you've been through, this was the last hurdle, a massive hurdle, but the last one, what was the, what was the, what was the hardest part about that

recovery? What would you say?

Alyssa Van Steen 37:44

I think I don't know if anything really sticks, other than the fact that, like I it was, it was all very challenging, and it was, but I don't have anything that really sticks out where I'm like, that was the hardest, because it was, it was all hard. And they were, and, you know, when I went to the cardiac floor too, they were like, sending physical therapists to make me walk around the halls, and I had, like a pillow on my chest to make sure that, like nothing was going to happen to my chest, if anything, if I were to fall.

Alyssa Van Steen 38:28

You see my walker, and I had my AFO at this time. And so I was, I was able to walk. I every once in a while I'd have to sit down in a wheelchair and have to rest a little bit. But it was, everything was doing well. And my heart was, everything was looking up. They, they had a put, like a pig implant in my my valve. So it's a pig valve that they and it's, it's working great.

Bill Gasiamis 39:02

You're one of those modern miracles. You know, just the fact that you went through all of that stuff, a little bit of a piece of this here, and a piece of this there, and a intervention here. I mean, everything that you went through to get to where you are today is an absolute medical miracle. Is a religious miracle, whatever you want to call it. I don't mind what you call it. It's sensational, isn't it that, yes, you went through all of that trouble, and here you are. We're on a podcast. We're talking about it. I love it.

Stroke Recovery and Fatigue - Life After the Hospital



Alyssa Van Steen 39:37

It really is. And I know and I knew it from the very beginning, because I didn't, I think it, it wasn't until I got home from the hospital that I was like, starting to go through the ups and downs of coming home. You know, when you it's, it's rough. You. And because I really did believe that I wasn't supposed to be here by the time I got home. But in the hospital, I was like, no, no.

Alyssa Van Steen 40:10

Like, this is good. Like I'm I can do this, but then when I got home, you know, life changes significantly. Like, we have a we have a tri level house, and I can, I couldn't do the stairs, so we had to move my bedroom downstairs. And it was, I was sleeping so much and like I, you know, it's hard for me to put, even put on my shoes. And it was, and there was so many medication I went home with 10 different medications.

Alyssa Van Steen 40:41

It was so rough I had, and you might know this too, like, when, when? Because you had a little bit, you had your left side was affected, right? Yeah, yeah. So when you're the side that's affected tries to, like, come back online, and your it almost feels like bugs are crawling up your legs or your arms. But it's painful.

Bill Gasiamis 41:10

Yeah, I get, I used to get, like, little electrical shock, things happening, coming through, and, like, I know, like, zapping my hand and kind of trying to bring it to life, you know, like, I don't know. Like, yeah, I can't explain it. Like, there you go. It was just some electrical impulses that zapped my hand, made made it feel like it was, like, there and it was painful and it was annoying, but it wasn't constant, and it was twitchy. It would twitch.

Bill Gasiamis 41:47

And that would happen. I would lie down, sometimes in my bed, sleeping or just about to nod off, and then my entire left side would do this massive like jolt, and it would just move for something. It did heaps of weird things when it was coming online and I had to get my coordination back. And my left leg, I have numbness and sensory issues on my left side, and the muscles are tighter, and my left leg would buckle, so the knee would just kind of collapse and buckle when I walked.

Bill Gasiamis 42:25

And then my eye. Because up until from the age of five to 40, I wore glasses, and I was used to doing the old push up the glasses, up your nose routine as they slide down. Just push them up, push them up. And at 40 in June, on my 40th birthday, June, July, somewhere there, mid, mid year, I had surgery, cataract surgery to remove the cataracts in my eyes to which then restored my vision, and I didn't need glasses, but I was used to pushing the glasses up my nose, and I kept doing that for a long time after I had finally gotten rid of the glasses.

Bill Gasiamis 43:17

So in November 2014 this all happened. In 2014 I had the brain surgery my left side's not working properly, but I'm lying down in hospital, and I remember being in the rehab facility, and I go to fix my glasses, but because my coordination wasn't right, poke myself in the eye, and then I would continue to poke myself in The Eye regularly because I went to fix my glasses and missed the middle of my head and got it into my eyeball. So that took a little bit of getting used to both the not fixing my glasses that weren't there, and also dealing with the poking of my eye.

Alyssa Van Steen 44:01

Yeah, it I was so thankful I didn't have any kind of, like facial anything with my stroke. I think it was like a day or two like my stroke happened. I had a little bit of slight, like, down, turning on my on my right side, but it kind of corrected itself. And so I was so thankful for that, but oh my gosh, the at night, I would just feel like bugs were crawling and biting me on my right side, and it was so painful.

Alyssa Van Steen 44:37

And my I was also like, I also lost quite a bit of weight when I was in the hospital. So I was only about 100 pounds, and I'm five eight, so I'm I'm pretty tall. So they were like, well, we can't give you any more medication, so you really just have to put a bunch of ice packs on you.

Alyssa Van Steen 44:58

So I was like, laying. Bed, just like a bunch of ice all over me trying to sleep, because that is just it's so painful to have, like, your body is responding but doesn't know how to, like, come back online and like, Hey, I'm here now, like I'm I was asleep, but I'm awake now. But they don't, they don't know how to react.

Fighting Through the Pity Party After Stroke

Bill Gasiamis 45:28

Did you ever do the pity party? Did you ever want to give up and say, oh, forget this. I'm not doing this anymore. Did you ever have moments?

Alyssa Van Steen 45:34

When I got home? Yes, I had a lot of days where I was like, throwing my cane around, like, and I was just mad that this was my life now I really, like, you know,

and then like, I'd go to, like, trying to wean myself out of off the medication, but the because I wanted to not have to take so much medication, and I would try to wean off, off of the medication, but then it wasn't working, so then I have to go back on it, or, like I was trying to hold out.

Alyssa Van Steen 46:12

And I would just, like, collapse into, like, this breakdown where I was like, I just, I didn't want to be here anymore. I really didn't want to live, I didn't want to live this type of life like I didn't think that I was supposed to be here anymore. But it, and it took me, like, a good month to, like, get out of that headspace. I got home on she June, June 26 is when I got home. It took me a good month for me to like, get out of that headspace.

Bill Gasiamis 46:53

What year was that?

Alyssa Van Steen 46:56

2023.

Bill Gasiamis 46:58

It's very, very recent.

Alyssa Van Steen 47:01

So, um, but that I also, I think you it's, it's, I don't think that, like, I don't look back on, like, the little pity parties and saying, you're like, oh, I shouldn't. I should have just, like, sucked it up or anything, because you have to go through that because, but also, like, I wasn't. I wasn't saying, like, No, I'm not going to, I'm not going to do therapy, or, like, No, I'm not going to practice my hand movements, no, I'm not going to, you know, work with my Play Doh today, or, like, whatever. Like, I was like, I still did all that.

Bill Gasiamis 47:38

So it was more of an expression of your frustration and the realization that I'm in this completely different world than I was three months ago.

Alyssa Van Steen 47:49

Yeah, because I was like, how am I supposed to, like, go to work, how am I supposed to do anything? Like, how am I supposed to I don't know how long this is going to last. Like, because in the hospital, I was kind of like, I think I got the

idea of, like, no, no, I can do this. Like, I can ill. I think the misconception with like strokes, I think if you haven't had one yourself, or if you haven't had a loved one, had it, had one, you you're under this impression of like, oh, okay, oh, well, he's driving again, so it just comes back, like, or you're walking again, so it just comes back.

Alyssa Van Steen 48:28

It doesn't, it doesn't just come back. You have to find new pathways in your brain to now learn how to walk, learn how to drive, learn how to talk. It's it doesn't just come back.

Bill Gasiamis 48:45

And often not in the same way that you had it before. It's not the same. It's different version, and it's usually different on one side of your body, which makes you focus on the difference. Like, my left side feels like this. My right side feels like that. For me, that's kind of the part that's still kind of I grapple with. It's like, I wake up in the morning. I gotta get out of bed. My right side's up and awake and ready to go. My left side still needs another half an hour. That's why we when we connected at around eight o'clock Melbourne time, I was still half asleep.

Bill Gasiamis 49:20

Because, literally, half asleep. How about that? Yeah, because my left side just it doesn't want to move at the same pace as my right side. Actually doesn't want to do that at the same pace. Needs a lot longer. My leg needs to wake up so that it does come back. And everything appears normal to me if people look at me.

Alyssa Van Steen 49:43

Yeah, that's so funny that you said that, because that's like, that is so what you feel like, even today, when I got up, I was like, oh my god, I'm so tired, but I'm like, ready to wake up, but like, I need to lay down a little bit longer. And there's, there's days where, like, I'm getting ready for work, and I. Day and I'm like, I have to sit down. Like, I can't, like, I can't just, like, get up and go, like, like I used to, like, I have to, like, take it easy. You need to, like, have rest days.

Bill Gasiamis 50:11

Those running late days, running late days, right where you used to wake up, no breakfast, throw your clothes on, yeah, either jump in the car or walk to the train station or wherever, and just go to work, no big deal, and just, there's just

another day. They they don't happen for me like that. I've got to be up, I've got to have time. I've got to settle into the day before I even get started.

Bill Gasiamis 50:39

It takes a while. I'm curious, so you would have been, you sound like you were a person who had a bit of a social life. You would have had friends. You would have had people in your life other than work. Then you're in hospital for three months. How do your relationships change? You know, did some people step up extraordinarily, like, what happened there with your personal life?

Alyssa Van Steen 51:06

I think that, um, I'm I have a lot of family friends, but I have two really good friends that they were actually on a cruise when all of this was happening, oh my gosh, and so and they were like, you know, I'm sure they were like, so distraught by it, but then when they came back, I had told my mom and my family, like, I don't want people in the hospital with me. I don't want, I just want my immediate family. I don't want aunts and uncles, and I don't.

Bill Gasiamis 51:47

The whole extended family in there.

Alyssa Van Steen 51:51

It's just too over stimulating. I think it's like, yeah, and it's just, like, too much for me when I could, you know, and I was, at the time, like, I was still not able to, like, speak that great and like, I just, like, didn't want people to see me, like, you know, it's just it wasn't my thing.

Bill Gasiamis 52:14

It makes sense. Well, firstly, it's, it's hard. We're the same, like my family, Greek family, like everybody was there. Everybody actually came. And I didn't have the opportunity to think about that, because I went from, you know, being two, two brain hemorrhaging in within six weeks. That's a little bit but upright. But see two brain hemorrhaging, but upright in some kind of a strange way.

Bill Gasiamis 52:45

So when people saw me, they didn't really have the deep desire to completely overwhelm us with love. They were just okay. He looks all right, like mustn't be that bad. But then, after the brain surgery, when they find out that I can't walk and, you know, my head has got a massive scar on it, and I'm in hospital and I'm

lying down, well now they can see that that's more dramatic than what the two brain hemorrhaging looked like early on, it looked way more dramatic.

Bill Gasiamis 53:21

So they all came, and I didn't have the opportunity those first few days to think about, who do I want there? And they were all there. My wife was overwhelmed. I was overwhelmed, and it took about two or three days before I realized we can't have that many people in the room. It's way too many people we can't be dealing with everyone else's emotional baggage that they bring without knowing that they're bringing it and making it burdensome. They don't know. Yeah, they come for the right reasons, but it's the wrong time to turn up for the right reasons. You need to come later.

Alyssa Van Steen 54:00

Right and, and my best friend actually said she said this to me multiple times afterwards. She's like, I I just know you and I know that you wouldn't want me to go to come in anyways, because I remember my my mom had said something like, why don't you just come anyways, even though she doesn't want and she didn't, and I'm glad she didn't, because she knew me, whereas my mom was more of like, I just want people around her. Maybe it's going to make her feel better.

Alyssa Van Steen 54:33

You know, you don't, she doesn't. You don't understand it, unless you're in the hospital bed and then when and when I was having my stroke, there were people that were around me, but I, I mean, they said that I was No, I didn't even know, and so I, I don't have any, I don't have memories of those people being there, but they were just like, I mean, they all. Had said, like, it was really terrible. I'm like, yeah, it's not great. It's not really like, what I don't I don't want people to, like, remember that time.

Bill Gasiamis 55:12

That's cool. I totally get it. So you're back into the land of the living everything is going great. As far as the medical stuff is all behind you, the actual critical, urgent, acute medical stuff is all behind you. How does life evolve now into what you're doing now into how it's got you to where you are today? So I heard you say a little earlier that you're back at work. So tell me a little bit about that transition from bedroom after the hospital bed, bedroom downstairs to outside world.

Alyssa Van Steen 55:51

I think I was determined. By the time I got home, I was like, determined, like, I will go I will get upstairs, I will get back into my room. I will do these things. I will drive again. And that was, those were my goals. I was like, that that was more my set. I set my sights on it. And I was like, even if I'm going to be struggling up and down the stairs, I'm still going to be doing it.

Alyssa Van Steen 56:20

And so I moved back upstairs when it was very difficult for me to go up and down the stairs, but I could do it safely with my hand handrails, and I had, I was still wearing my AFO, and I could do it. It takes me, it takes a lot out of me to just go up down the stairs, but I'm gonna do it. And I did. And same thing for the driving thing. I now drive with my left foot.

Alyssa Van Steen 56:50

I have my my pedals are reversed on my car now, and I have, like, a little steering knob, yeah, and that was really exciting. So once that, once that happened, once I got back into my car, which was, um, last fall. It was like, September, um, 2024, I was like, the minute I am able to drive around, I'm going back to work. So I was like, even if it's too soon, I'm doing it, and I will figure things out when I get back to work once I'm in the job, if I if I need little leeways here and there. I know that they're gonna be there for me.

Alyssa Van Steen 57:44

Let's just go. Because I didn't, because I think you can, you can say like, Oh well, I don't know if it's time yet. And it's like, you're never gonna know when the time is. You just gonna jump in the deep end, right? And so I also was, oh my gosh, was that? I think it was last summer as well. Yeah, it was last summer as well. So I was 2024 I also ditched the the brace and a device on my leg that by an S device that helps me walk, and I was able to put down the neighborhood that I can, I can do more.

Bill Gasiamis 58:36

Sounds like you're it sounds like you're driving.

Alyssa Van Steen 58:39

I'm gonna. Now, I don't.

Bill Gasiamis 58:45

Connection issue, it sounds like the driving was your I'm back moment. It sounds like that was the kind of defining moment you got into the car, you became independent again, and you were going to find a way to overcome all the other stuff as well.

Alyssa Van Steen 59:03

Yeah, I was like, once I'm driving, I feel like I got a sense of my life back, like I was able to, like, go and go to therapy by myself, like, or because I was doing outpatient therapy as well. And I was like, it was, it was crazy. And so I felt like, Okay, I had my independence back. So I went back to work in last October, and it was a, it was a transition. It was, it was difficult, but it was great.

Reflections on the Stroke Recovery and Fatigue Experience

Alyssa Van Steen 59:46

And I could have asked for shorter days, but I didn't. They were just, they were all eight hour days, and I was like. If they that, I just knew that they the way my work is. They're just so accommodating for anything and anyone, really. So I just knew that, like if I needed a shorter day, they would help me. If I needed to work less days, they would help me.

Bill Gasiamis 1:00:20

And so as your role remained the same.

Alyssa Van Steen 1:00:25

My role has been, yeah, it's the same now I've, I am able to, I can, I can write and I can cut. And the way I my my writing, it looks nice, but it's not. It doesn't look like my writing. You know what? I mean? Like, it's gonna, it's gonna take me some more time, but I can do the work at work for it, and, and, yeah, and it took me a while to, like, be able to, like, get on ladders.

Alyssa Van Steen 1:01:05

And a lot of you know, we work, we work with, like, a lot of boxes, and sometimes heavy boxes and but there's always people around. So if I really needed to, if I really needed someone to, like, help me with anything I could. But now I feel like I'm at a good place where, like, I really don't need people to help me.

Bill Gasiamis 1:01:30

Yeah, that's excellent. What is what have you? What have you learned about yourself during this time? What a stroke taught you, or the heart condition taught you, or everything that you've been through taught you, my gosh, there's so many things that you've been through. What are they taught? What are some of the lessons?

Alyssa Van Steen 1:01:48

It's funny too, because I was listening to one of your your vlogs that you had put up, and you said something that I've always said to my mom, is that this stroke has been the worst and best thing that's ever happened to me. I don't think I would have known a sliver of how strong I am until I went through this. I have this, like, listen, we also we, I still have my bad days. This is not, like, you know, I'm not, I'm not saying that I don't have bad days.

Alyssa Van Steen 1:02:30

There are days and I there's a lot, a lot of things that I still have to work on. But I just, I, I'm, I am, I am capable of doing so much more than I thought I would have ever been able to even think about doing. So it's been, it's been really eye opening, especially for my age as a person.

Bill Gasiamis 1:02:58

You've changed as a person as well. So how have you changed as a person?

Alyssa Van Steen 1:03:07

I think I don't like, I don't have the trying to say it, like, kind of nicely, there's, I don't, I don't have the time for any of the BS, you know what's, you know what I'm talking about. I don't have, yeah, like, I don't have, I don't have that in my brain where I'm like, this, doesn't it? That doesn't matter. It's not for me, you know? It's not. I think when you go through things like we both have been through, it's you're like, that little in this big world.

Bill Gasiamis 1:03:52

It sounds like your focus has changed from the little things to the more important things, whatever they are for you.

Alyssa Van Steen 1:04:01

I mean even if something for me is to, like, go out with, like, go buy tickets to a concert or something, it's not. It's what's making me happy right now, and it's

not, I think you kind of get stuck in this, like, oh, well, is this?

Alyssa Van Steen 1:04:30

Should I be doing this? Or should I be saving my money for this? Or should I be doing this? Or should I be worrying about the next thing that's going to happen? And I feel like, with a stroke, you're just kind of like, No, you're just gonna, you have no guarantee. There's no guarantee, like, for anything. So it's like, who cares? Like, go.

Bill Gasiamis 1:04:52

There has to be money or whatever. I agree. I agree. There's part of me that's like, all right, save for a rainy day. I. Yeah, but, but say for just a few of them, not for 1000 rainy days, right? Just say, for a few rainy days, so that you know, you get into the habit of not blowing every single dollar you made the last week, which is cool, but also experiences. I think it is, for me, like it's about experiences and people. So if you give me your time, oh my gosh, like I'll do anything for somebody who gives me their time.

Bill Gasiamis 1:05:29

I value time more than I've ever valued it, and that really is something that I see as being the only true i it rich. Riches, the only true riches is time, how much time we have, and we don't know how much time we have. So that's the problem, right? So, yeah, which I experiences? Can we have this experience like, say it's a traveling overseas experience. It's like, well, we could, we could do it on a budget, which means we still travel overseas, we still see that place, thing, those people, or we can do it five star all the way, which we'll never be able to do.

Bill Gasiamis 1:06:18

We'd be broke in no time, and we wouldn't be able to experience anything else after we came back from that event. So for me, it's like going all right, how can I do what I want to do? How can I have that experience in a way that supports me what I want out of it, and allows us to also be able to buy food next week or tomorrow or whatever? And that before, I used to be in this pattern of, we can't go anywhere, we can't do anything, because something might happen down the track, and then if we are not, you know.

Bill Gasiamis 1:06:57

Five years ahead on our mortgage, or 10 years ahead on our mortgage, or any of

that stuff, well, it's going to be all ridiculous and terrible, and oh my god, we can't spend any money on anything. And then I got the sickest you could possibly get. Things were so terrible. Everything was so bad for such a long time, for at least three years for us. And even though we I had created that buffer of if something goes wrong, which I want to be okay for 10 years without working, if necessary.

Bill Gasiamis 1:07:30

Even though I created a buffer like that, it actually meant nothing, because I didn't know whether I would be here tomorrow or the next day. So or fantastic. You don't have to work for 10 years or forever. You might never work ever. You might not come out of the hospital after your brain surgery. So it's like it meant nothing. Things didn't seem to have the importance that I imagined in my head that they needed to have. Now I'm not saying that a lot of people don't have a different experience than us. They definitely do, and I get everyone has a different way of approaching that.

Bill Gasiamis 1:08:07

But for me, it helped me break down some negative thinking patterns and barriers where I was missing out on life while trying to preserve my life. If my life went wrong, it's just it was backwards. It didn't make sense. I wasn't living for my life right now, while I was in it, I was preparing for a life I wouldn't be living kind of thing so weird. I don't know it's so weird, I can't explain it, but like you, yeah, I look at opportunity to have an experience is something that I need to make happen, rather than not make happen.

Alyssa's Coping Strategies and Daily **Stroke Recovery and Fatigue Challenges**



Alyssa Van Steen 1:08:49

Yeah, it was. It does put this like perspective in you, and you're like, I can't get rid of that perspective anymore. There's no way of like going back to the way I thought before. So it, yeah, like I said, like to put the nice, nice way, like, there's just no room for the there's no room for that type of thinking of you. We're just never promised anything. So it's, it's just better to, like, at least have some time to have fun while we are we're here.

Bill Gasiamis 1:09:30

One of the things that was really cool recently is somebody was watching one of the interviews I was doing, I think, or maybe one of my vlogs while they were in hospital recovering from a stroke.

Alyssa Van Steen 1:09:44

I heard that one that you were, what you were telling me, that while your video was telling me, yeah, I did. I did hear that. I thought that was so cool, because I really, because you were kind of saying, like the way. That you in the hospital and you were almost you were already thinking of doing this podcast, basically, in one way or another.

Bill Gasiamis 1:10:10

I had rolled out. I had rolled out of surgery, couldn't walk. The first day of not walking, they hung me up on a on a on a device where I was attached to the ceiling so that my feet are touching the ground, but I'm not at risk of falling or collapsing or anything like that. It's to take the weight off of the therapist so they're not holding my body up while I'm trying to learn how to walk again. And

we knew then that things were pretty serious. I couldn't walk, and they needed to put me in a month of a two months of rehab they were going to put me into.

Bill Gasiamis 1:10:47

So I'm going through this after seven days of being in the hospital, in recovery, day one day one of therapy was moving me just from hospital to the therapy room. And while they were putting me through, I go through this door, and on the top of the door, it says the transit lounge. And I'm like, Wow, that's pretty cool. I've been to transit lounges before. They were all for a trip overseas or somewhere exotic that I hadn't been before. This one was a little bit weird. The name of the room was a bit bizarre.

Bill Gasiamis 1:11:19

But I knew what it meant for me was I'm going from where I don't want to be, where recovery has sort of paused, it's not happening much more, to a place where recovery is going to continue and I'm going to get better. And I thought, wow, that's cool. And that became the first name of my podcast, and it was the transit lounge podcast when I first started. And that podcast was about 10 or 20. Was about 20 episodes, I interviewed people who weren't stroke survivors. We were talking about recovering from something serious.

Bill Gasiamis 1:11:55

And when we got to the end of that, I didn't feel right about it. And then I realized I should be interviewing stroke survivors, and then their recovery after stroke podcast happened. And I don't know, I cannot remember how I joined the dots between about 2015 when the podcast started, middle of 2015 somewhere there, to November 2014 where I saw that lot sign and said, Oh, that's a cool name for a door for a room. I had no idea how I connected the dots and then turned it into a podcast.

Bill Gasiamis 1:12:33

But was happening in my mind, and I was doing a lot of those things in my mind that that helped me with my recovery. One of those things I was also doing was, um, I was imagining myself walk. I mentioned that in the vlog, and didn't know exactly how that was helping, but I know that it was firing off the same neurons as if you're walking. So that was like, oh, in my downtime, without any physical effort, I can create pathways and reroute and get it all going.

Alyssa Van Steen 1:13:09

I wish I would have had that video of you talking like that when I was in the hospital, so that that makes me so happy that someone was in the hospital that was hearing that. I really wish I would have heard that, because me, I'm, I've always been such a walker. And I just walk like multiple times a day, and I just, I love it. I can't get enough of it. And the fact that you have this thing that is taken away from you in a split second, and now you have to work so hard to just get it somewhat back.

Alyssa Van Steen 1:13:53

You can't even so it was just it was really hard for me when I was, like, not able to, like, go on walks, I worked really hard, and the first time that I walked without my brace, I was on the Halloween and like, I'll never forget it, because we went at night to walk around the the street, and I was like, I'm not I'm Not wearing my brace anymore. My brace was like, pinching me, and it was just like, just like, I'm so over this, like, I want to walk more.

Alyssa Van Steen 1:14:29

And, yeah, you just, I think, also, like, I have so many and I remember in the hospital too, I had dreams of me walking and so that made me like, think it was crazy. When you said that on the on the vlog, I was like, well, it's crazy. I wonder if that was actually 100% right. It's so crazy.

Bill Gasiamis 1:14:54

You've woken up from James before and felt like it was a real experience. Well, that's why. Why? Because you're actually living your your your mind, your body, your soul, your spirit, everything is re is experiencing that dream as if it's actually happening. The fact that you're unconscious in sleep and you're in a bed matters not the same parts of the brain are firing, the neurons are firing, the neural pathways are wiring up. It's all happening, right?

Fully Healed, But with Scars: Alyssa's Message to Stroke Survivors

Bill Gasiamis 1:15:26

And that's the thing I wanted to ask you about, like, what we might be chatting about this right now, but there could be a stroke survivor listening right now, who's in the hospital, but what would you say to them?

Alyssa Van Steen 1:15:44

I think that I was under the impression that I would be like healed at some point. And now it's 2025 I'm approaching my two year and you had said something in one of your vlogs, and that really stuck with me is that you, especially now, like in in where I'm at right Now, I still wear my device on my leg every day, um, but you can't really tell that I, you know I'm wearing pants too. You won't see it. You and I'm not wearing a I'm not using a cane, unless it's like nighttime, or if I'm really tired, then I'll, I'll use my cane. It doesn't really look like anything happened to me.

Alyssa Van Steen 1:16:45

I talk, you know, you wouldn't know that I had lost my speech, you know, you you wouldn't have known any of that, and you had said, fully healed, but with scars. And that's but I don't see the scars being and I don't think that you meant it in this way either. But I think a lot of people think like, scars, like, it's a like, it's a bad thing, and I see it as a good thing. These are, these are like, we want these scars, because you'll never forget the things that you have went through with these scars, even when you look like you're fully healed.

Alyssa Van Steen 1:17:34

And when people say, like, when people ask, like, oh my gosh, how are you doing? Okay? And they do say that they're like, Okay, so you're fully healed. And I'm like, yeah, like, like, sure, because I think like you had said in one of your vlogs. I think a lot of people say like, they want to hear, they just want to hear you saying and, and that's fine, because I know that there are certain people that, like, want to ask more questions.

Alyssa Van Steen 1:18:02

And then I will tell them, like, yeah, no, I'm not fully healed. I don't know if it will ever happen, but like, for right now, like, this is what's going on and, but I'm doing really good. Like, there's probably no healing. But for the MO, for most people, I'm just, I just say, Yeah, fully healed.

Bill Gasiamis 1:18:22

Qualify a little bit what I meant by that, because you're you're right about what I meant is that I actually have a physical scar on my head. Everyone's because of where my hair really, really short, like a number one. Everyone sees it all the time. And it's not why I wear my hair a number one, but they see it. So there's

that, then there's emotional scars that are there. And let me tell you, when I did the book launch, I'm in a room, there's about 40 people there. I I was supposed to do a 20 minute speech. I cried about four times, and I was like, Oh my gosh, I didn't plan for this in my speech.

Bill Gasiamis 1:19:02

It's ruining the flow. But, you know, it's heartwarming, and people kind of made, probably made them buy an extra book or something, I don't know. So it was okay. So that little emotional thing, I didn't realize it was there until I got up to do this presentation in front of friends, family, loved ones, people who came to support me, and it just came out of nowhere. So the trauma that I went through is basically has been dealt with.

Bill Gasiamis 1:19:31

But you know, there's a little niggling bit that needs to come out every so often and say, Hey, remember me, and I'm okay. I remember you, and then there is the mental scars as well. So again, healed from them, but I had to grapple with I'm not going to be here. Maybe tomorrow. I don't know if I've said the things I need to say to my family, to my friends, to my wife, to my children "Oh my gosh, I haven't got time. I need to get all that stuff done and sorted" and then I think my healing really started to take the a turn to the next level.

Bill Gasiamis 1:20:14

Where things started to improve a lot, despite my pain, despite my numbness, despite falling over, despite not being able to work the same as I did before, when I started doing stuff for other people, helping people, I didn't realize that at the time it was a little bit selfish. When I started this whole podcast and book thing and everything, because I wanted to, I wanted to use what I'd learned and the people that I met to help me, which was cool, right? Because I was at least advocating for myself, and at least I was leading my own recovery.

Bill Gasiamis 1:20:55

I was in charge of it somehow, right? There was other people involved, doctors, therapists, they were all involved, but I was leading the charge. But then when people reached back through the podcast, comments on the YouTube video or from the book, and said, This really helped me. I don't know that just took everything to the next level that made my whole experience that really tough stuff that we had to go through worth going through. I don't do that kind of stuff from

normally.

Bill Gasiamis 1:21:27

That's not what I do. I used to do all selfish stuff. It was all about me, me, me, me, me, how much money am I going to make, how much, what car I'm going to drive, and how many houses I'm going to have, and all this stuff, and now all that, all those ideas went away, they went away, they just, they fizzled. And I'm content. I have contentment, which is a gift that I've never had before.

Alyssa Van Steen 1:21:51

Oh my gosh, yes, that's such a good way to describe it, like the contentment, I think because I, um, I also have a scarf, but you can't really see it because I have hair. It likes to pop out every once in a while, but yes.

Bill Gasiamis 1:22:10

On a bad hair day.

Alyssa Van Steen 1:22:15

Yeah, I also think, like when we go, we go back to, if we can come back to what to tell people to. I also think that, like the it was the first, I think it was the Okay, so it was the September after I got home from the hospital. So I got home from the hospital in June, right in September, I had purchased about a year in advance. Well, I I purchased Cold Play tickets with my best friend, and the pandemic happened, and then they canceled their tour, and they were like, but we'll keep the tickets, because when we come to LA, we'll give we'll let you have first pick, like, where you want to see.

Alyssa Van Steen 1:23:07

And so we're like, okay, so it just happened that, right? It was probably the month before my stroke happened that we were like, We got in, we got tickets. It's coming. It's in September. And I was like, I'm not missing that con concert. I waited for that concert, and it was also like, it was going to be special, because it's my friend, it's my best friend's favorite artist. And so I was like, I'm gonna go. It's gonna be really challenging for me, especially because I'm wearing my, I was still wearing my brace.

Alyssa Van Steen 1:23:41

It was at the Hollywood Bowl, which, if you're familiar, it's just not, it's old, it's very it's it's muddy, where we had to park there. It was a lot. It was a lot. And

then there was a lot of people, because it was, everyone was stoked that it was only there for like, two nights too, and they were going to go overseas. So it was, like, it was a lot people were bumping into me. It was I got home, and while I had a great time, I got home and I just collapsed and, like, bawled my eyes out, because it was just so over stimulating.

Alyssa Van Steen 1:24:21

But I'm so glad I did it, because the next concert I had was like two months later, and I was like, I'm gonna go. I'm gonna do it because it was really traumatizing, but I'm gonna do it again, and it was so much better the next time I went. So I feel like a lot of people that are sitting in their hospital beds, maybe right now, where they've gone through their stroke, and they don't think that they can do things like you can do things we can do it like you might have to change your seats. You might have to whatever it is. It doesn't have to be a concert.

Alyssa Van Steen 1:24:58

But I think like, and also for me, like, I'm such an introvert too, to like, go to a concert, it's just already overstimulating. But then the with the stroke, it's, like, so much more over stimulating. But I got little earplugs, and I had, like, a little safe zones, like, planned out. Like, okay, if I need, if I need to go and, like, have, like, some quieter time I'm going to go over there, like, or whatever it is. Like, I like, made little plans to make sure that I was going to be in the safest environment for me to also, like, live my life, though, like, I'm not going to say no to things.

Alyssa Van Steen 1:25:44

Yeah, and I don't think people should say no to anything like, especially when it's it's really hard to it's really hard to like, say that you're going to get up and do all your exercises and do all of your words, scrambling and little things that I have to, you know, that I've done, and it's hard to, like, get up and be like, Okay, I have to do this today. I have to do this like, there's no there's no negotiation, like, I need to go for a walk today because it's going to help me, because then I'm not going to be as stiff. My spasticity is not going to be as stiff the next day, and it's just, yeah.

Bill Gasiamis 1:26:25

I love it, there's, I don't know who said it, so I'm not going to be able to credit them. But on the social somewhere, I picked up this video where the guy was saying, do something for yourself today that your future self is going to thank you

for and so, yeah, okay, I love that. I love doing it for my future self, because my future self really appreciates all the hard work that I did today.

Introversion and Adapting to Social Environments

Bill Gasiamis 1:26:50

And it sounds like they're two different people, and they almost are. They almost are two different people, but we benefit together, and the hard the person who's doing the hard stuff might really hate it, but Bill of the future is so glad that I did the hard stuff when right, I had to do it. Yeah, yeah, I love it. So you said you're an introvert. I don't get that. I don't get that. Is it just a tendency where you prefer quiet time, alone time, that type of stuff.

Alyssa Van Steen 1:27:27

Yes, I prefer quiet time, alone time, yeah, but I, I also just, I think I because I also worked when I was younger. I worked at Disneyland, and so when I worked at Disneyland that I was, like, I was they, they push you to, like, get out of your shell. And I really wanted to stay working there so, and I think that kind of helped me. That was, like, a long time ago, but, and then now, like, the work, the place that I work now, very extroverts, and so I can go, go in and turn it on, but I definitely have to go to my car and take my break in in silence.

Alyssa Van Steen 1:28:12

I think also, like the for me, like the biggest things that get me on a daily, day to day to day basis, is the fatigue and the over stimulation of anything and everything, even if, like, certain lights, or even if it's just like, oh, like a lawn mower going in the backyard, or something like, I just like, can't There's Certain times the day, or, like, whatever it is, and then fatigue, just, you just, you don't know when that's going to happen. It's just going to happen whenever it feels like, because it's like, sometimes you think, like, I'm going to beat the fatigue, like I can. I can do this, like I can.

Alyssa Van Steen 1:28:56

I can take a little easy here, and then I can. But it No, there's no, I think, like a traumatic brain injury, you can't beat the fatigue. I have to, I have to keep learning that and to say that out loud, because I know.

Bill Gasiamis 1:29:12

Beat you down. You can test it, and you can push the limits of it a little bit. But then it's like, not even me. I've been at this for 13 years now. I come home sometimes at, say, 330 or 4pm and I've got a list of emails, stuff to do, send, and my brain's going, you're not getting any of that done today. Absolutely none of it. Don't even think about it. Sit down and do nothing. Otherwise we're not going to have a good day tomorrow, and then the fatigue wins. But I've come to terms with it.

Bill Gasiamis 1:29:47

I think introversion is actually a really good skill, because when you're comfortable being on your life, on your own and with yourself and. Having quiet time while you've practiced it for so many years, you know how to do that really well and switch it on, whereas I'm not like that. I was always out and about with somebody doing something. I'm a total extrovert. So then when it came to alone time and me time, it felt weird. It felt weird. Ah, okay, I'm alone and all right, what now this is boring, and I can't occupy myself and I can't stimulate myself.

Bill Gasiamis 1:30:27

I've gotta get out and about, and that's where I struggled. I struggled with the fact that even in hospital, after the the first bleed, my doctors and nurses were looking for me because I was never in my hospital bed. I was never in the bed. And they're like, You are not well. There is a blood vessel bleeding in your brain. You have to be in your bed. And I'm like, No, everything's fine. I would meet up with people at the cafe. We would chat.

Bill Gasiamis 1:30:56

They would send search parties down to the cafe to look at look, look for me so they can take me back up to do blood tests, scans, all that kind of stuff. So I I see introversion in this scenario as like being a skill that gives you guys the opportunity to really give you, give yourself that time of No, I don't want people around, I don't want noises. Just wanted to be me quiet place. I always felt like I wasn't productive enough.

Alyssa Van Steen 1:31:29

No, but that's so true. But then I will say, like, although like, I'm also the type of person that, like, I can't just sit still, like, I need to be doing something like, I and I think that's why I like, I like gardening, I like walking, I like, like, like, going out

with my dog. Like, I I'm introverted, but I'm also, like, if I'm sitting and watching like a movie or something, I'm working on my hand. Like, I'm working with my hands. I'm I'm cutting paper, I'm doing like, art or something, because I can't just sit still.

Bill Gasiamis 1:32:04

You're occupied that.

Alyssa Van Steen 1:32:06

Yeah, I need to be occupied. But that also, in turn, like, doesn't really help me when I'm, like, supposed to be resting, and I'm like, I'm like, already thinking, I'm like, Okay, I have to do this. Okay, then I'll do okay. I'll do that. When I'm rest, I'm resting, and, you know, it's like, I'm trying to lay in bed, but I'm already, like, making lists of all the things that I can do this week and like, and so it probably doesn't really help that I'm like, not great at, like, Resting, resting, but yes, I can be by myself alone, no problem.

Stroke Recovery and Fatigue: Support and Community Building

Bill Gasiamis 1:32:42

I love it. Well, hey, I really appreciate reaching out. Thank you for sharing your story. Is a wonderful story of overcoming and recovery and moving forward, and thanks for following my vlogs and, yeah, supporting me the way that you have. It's brilliant. And I look forward to hearing how things evolve from here and how life improves further.

Alyssa Van Steen 1:33:11

I am too. I do want to like Leave, leave. I guess the audience with this, when I got home from the hospital, it was really hard for me to find anyone like me that have gone through a similar thing, um, any type of stroke, or at least, you know, any kind of stroke or I would love to find, I would have loved to find, like, a hemorrhagic stroke person that was like posting, like, day in the life of how, like, you know, healing from I couldn't find it. It was really hard. And, and then when I, if I do find it, they're not in my area, so I don't have people that around me that have that similar interest.

Alyssa Van Steen 1:34:13

But I found it online when I started posting videos on myself, and I got so many messages over like, I think it was like one or two episodes, or episodes of posts on Tiktok, and I had so many people like, say, like, oh my god, I'm a hemorrhagic stroke survivor as well. Like, blah, blah, blah, or, you know, or whatever, even ischemic stroke or and it was like, so crazy, the amount of people that reached out to me, and they were like, Oh, thank you for posting this. This is so cool. Like, I'm so I'm so surprised you can do this, or, like, whatever it is. And I was like, Okay, this is cool.

Alyssa Van Steen 1:34:54

And I had this, like, similar thing that you kind of had, where it was like, Oh, I. Wow, I really love this, but it's also like, helping me as well. Like, I'm, it's like, very selfish, but like, it is true. Like, it makes me feel so good when I'm like, I can't, I didn't find it for myself, but I'm going to be it for someone else. And I think that, like, there's, there's so many people that have strokes younger and younger right now, and they've been, they've told me this in the hospital. They were like, we're seeing more and more like younger people with strokes. And it was really hard for me to find people.

Alyssa Van Steen 1:35:39

So I was like, I'm gonna, I'm gonna break that wall, or at least, like, maybe, maybe I wasn't looking hard enough, or whatever. But, you know, it's like, you need it, because I think, like, your podcast is so it's it. There's so many episodes of people.

Bill Gasiamis 1:35:58

Yeah, nearly 350.

Alyssa Van Steen 1:36:01

Right? It's crazy, like, and when I found out, you, I found it, you're, I was like, Oh my gosh, look at all these people have had different types of stroke. I was like, and it's so it's so lovely to have someone different podcasts, but they all say the same type of things that I went through, and it's something that's like, Oh my gosh. It's very meaningful. It really is. So I also, I also have, like, this little quote that I have been telling myself that I kind of like remind myself every day that the toughest gems are the hardest to mine.

Alyssa Van Steen 1:36:47

And I really feel like when you're when you go through any type of stroke, I feel like you feel that, that that you feel that like the whatever it is that you had to get back to to give you, like a some a little semblance of your regular life, like it's really hard, but it's so rewarding. Um, yeah, and I just, I appreciate I appreciate you, and I appreciate the things that you're doing. And I can't wait to listen to more podcasts.

Bill Gasiamis 1:37:30

Thank you. I'm gonna, I'm vlogged, yeah. Thank you so much. I'm definitely be following your journey on Tiktok. We're going to have the show notes. Anyone who wants to connect with you will be able to go and connect with your community. Is so important I was missing that I created the same thing. And that's the part of it like that's what our responsibility is. You need to create your own community the way that you're comfortable doing, in the format that you want to do it.

Bill Gasiamis 1:37:57

And then people will will be attracted to that, because it's you, because you're unique in the way that you tell your story. Even though we are stroke survivors and we've had similar things, we're totally different. There's only thing we have in common, is stroke but also, then we also have the understanding in common of each other. It's like, okay, and that is, that's what you can you imagine the amount of people that I've spoken to, the different political views, the different ideological views, and all that kind of stuff. I've never spoken about that at all.

Bill Gasiamis 1:38:33

I'm not interested any of that. I'm just interested in people's stroke journeys, what happened to them, their recovery, how they're fighting back, how they're overcoming what they're learning along the way, because they all help me. And every episode I get something out of, every person I interview I get something out of, and I am glad that there's more people talking about it, because I can't be the only voice. Like there's just not, it's not, it's not diverse enough for me to be the only guy talking about strike.

The Role of Podcasts and Personal Stories In

Stroke Recovery and Fatigue

Bill Gasiamis 1:39:06

I can't represent women. I can't represent people from different socio economic backgrounds. I can only represent me the way that I experienced it, and that's what I love. I've I'm even having meetings with people now online for half an hour who have reached out and said, Oh, how do I start a podcast? Or what can I do? I try to fit in. If somebody asks me, you know, how do I do it? Because I want to know. I want to make sure that none of us, former stroke survivors, and unfortunately, stroke survivors to come are without information.

Bill Gasiamis 1:39:42

And I don't want them to go through all the tough stuff that we all went through, that we can avoid. If we can avoid some of the tough stuff on their journey, if we can help with that, then I think that's a great thing. The rest we can make space for them to discover and overcome on their own. You know? So. Um, yeah, thanks again. I really appreciate it. This has been an amazing chat. We've been going for more than an hour and a half, just gone like that, but brilliant.

Alyssa Van Steen 1:40:11

Sorry, but thank you very much. This is it's been I was so looking forward to this. I was so looking forward to this. So thank you. I'm I'm so grateful for you.

Bill Gasiamis 1:40:25

Well, that's it for another episode of the recovery after stroke podcast, some stories don't resolve neatly. They keep unfolding, and Elisa's is one of them. She's back at work, she's driving, she's walking with support, but she's also still exhausted, still navigating deficits, still waking up some days needing more time to function than the world expects, and yet she's showing up for herself, for others and now for this community. If you're in a season where progress feels invisible, let Alyssa story be proof that healing isn't about going back.

Bill Gasiamis 1:41:01

It's about becoming someone new, someone stronger, softer, more aware of what really matters. Thanks again to bionics for supporting this episode. For anyone listening who might be dealing with foot drop, there's actually a way to try the bionics device in a free one hour trial, just to see if it's the right fit for you, bionics offers trial days at different locations across the United States. Just call to

schedule a time we'll catch you in the next episode.

Intro 1:41:33

Importantly, we present many podcasts designed to give you an insight and understanding into the experiences of other individuals, 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 all content on this website and any linked blog, podcast or video material controlled this website or content is created and produced for informational purposes only and is largely based on the personal experience of Bill Gasiamis.

Intro 1:42:02

The content is intended to complement your medical treatment and support healing. It is not intended to be a substitute for professional medical advice and should not be relied on as health advice. The information is general and may not be suitable for your personal injuries, circumstances or health objectives. Do not use our content as a standalone resource to diagnose, treat, cure or prevent any disease for therapeutic purposes or as a substitute for the advice of a health professional.

Intro 1:42:27

Never delay seeking advice or disregard the advice of a medical professional, your doctor or your rehabilitation program based on our content, if you have any questions or concerns about your health or medical condition, please seek guidance from a doctor or other medical professional if you are experiencing a health emergency or think you might be call triple zero if in Australia or your local emergency number immediately for emergency assistance or go to the nearest hospital emergency department. Medical information changes constantly.

Final Thoughts and Gratitude

Intro 1:42:54

While we aim to provide current quality information in our content, we do not provide any guarantees and assume no legal liability or responsibility for the accuracy, currency or completeness of the content. If you choose to rely on any information within our content, you do so solely at your own risk. We are careful with links we provide. However, third party links from our website are followed at

your own risk, and we are not responsible for any information you find there.