

Cryptogenic Ischemic Stroke Recovery at 24 - Anita Hsieh

Aged only 24 Anita Hsieh experienced a cryptogenic stroke and 5 years on she is on the path to recovery and continues to make progress.

A Stroke Of Life

Instagram

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Bill 0:28

Where everyone was in a similar situation as you.

Intro 0:34

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

Bill 0:47

Hello, and welcome to episode 223 of the recovery after stroke podcast. 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.

Bill 1:05

If you would like to support this podcast, the best way to do that is to leave the show a five-star review and a few words about what the show means to you on iTunes, and Spotify. And if you're watching on YouTube, comment below the video, like this episode, and to get notifications of future episodes, subscribe to the show and hit the notifications bell.

Bill 1:24

Now sharing the show with family and friends on social media will make it possible for people who may need this type of content to find it easier. And that might make a massive difference to someone that is on the road to recovery after their own experience with stroke so please do share.

Introduction - Cryptogenic Ischemic Stroke



Bill 1:40

Now my guest today is Anita Hsieh who was only 24 when she experienced a cryptogenic ischemic stroke that she is still recovering from five years on and continues to make positive progress. Anita Hsieh, welcome to the podcast.

Anita Hsieh 1:57

Thank you for having me.

Bill 1:59

My pleasure. Thank you for being here and making the time to reach out and become involved and be my guest. Tell me a little bit about what happened to you.

Anita Hsieh 2:12

I had my stroke five years ago when I was 24. So it was totally unexpected. I didn't even know what a stroke was. To be honest, I didn't really think about my health that much. I don't even know the strokes science or anything like it never crossed my mind as a 24 year old girl.

Anita Hsieh 2:39

Like I was just doing my own thing, finishing off University getting into, you know, just applying for jobs and like going into the adult world. I didn't expect myself to be hospitalized with a stroke.

Bill 2:57

I can imagine, what was life like? What were you up to? What were you doing? How are you keeping yourself busy at that age?

Anita Hsieh 3:07

I didn't really think about it, like I was just busy. I was busy with school, I studied and accounting. So I was starting to do my CPA, so my certified public accounting designation. So I was pretty much very busy with studying and just being a 24-year-old going out having fun, just doing that thing.

Anita Hsieh 3:35

I didn't really think about my health, I go to my annual physicals and everything is fine. And I didn't show any physical signs of being in distress or I was sick. I look normal, I felt normal, And I just do my own thing and it just happened.

Bill 3:57

And you had an ischemic stroke. Do you know what the cause of it was? Did they work that out?

Anita Hsieh 4:03

To be honest, to this day they don't really know. In the beginning, I was very frustrated to not know what the reason was, if I knew I could at least prevented or

work on trying to, you know, be better than that part of my health.

Anita Hsieh 4:23

But they said that they still can't figure it out. It just could be a spontaneous occurrence. It just happened that I got a blood clot. And yeah, I had a stroke at 24 they were trying out a lot of things and told us they still don't know. And it's been five years.

Bill 4:49

I've heard for a lot of women that I've also interviewed who have had a stroke. Often they are taking the prescription birth control pill.

Anita Hsieh 5:05

No, they even asked me that too. And I wasn't at that time either. So I don't know. Maybe it's just my own hormones. I have no idea.

Bill 5:19

So there wasn't a hole in the heart, they checked all of that stuff, they ruled everything out. And now you're in hospital. How did you end up in hospital? What did you notice was happening to you before you actually had to go to hospital?

Not Knowing The Symptoms

Anita Hsieh 5:34

I was thankfully at home. To be honest even though I was feeling the symptoms, I didn't know I was having a stroke. I just thought like, what is happening to my body? So actually, the morning of my stroke, I had this pain, like on the side of my neck shoulder.

Anita Hsieh 5:59

And I was like, okay, maybe I just pulled a muscle or something. I didn't think about it I just thought, yeah, it's just a little pain. Because I did go to the dance class that day actually, and then at night, it just started happening, like my ears started ringing.

Anita Hsieh 6:26

And everything, just my head was spinning and I just couldn't speak anymore. I just felt like my whole world was changed. And at that time, my ex-boyfriend was actually there in the house, so I was very lucky.

Anita Hsieh 6:47

Because no one else was in the house. And then I just said, there's something wrong with me, please call my mom. I didn't think to call the ambulance or the hospital. I said, please call my mom.

Anita Hsieh 7:00

That's my initial thought then he called the hospital and the ambulance came, and they did the whole check while I was still semi-unconscious. And then they took me to the hospital and at that point I thought, in the ambulance, I was gonna die at 24 I was very scared.

Anita Hsieh 7:24

I was like, what is happening to me, this is my first time being in an ambulance. Nothing ever has happened to me. It's not like I broke a leg or anything. Just something weird is happening to my body. And I was like, I can't die right now I'm only 24 I just finished schooling, I still have a lot to do in my life.

Anita Hsieh 7:43

And I was really scared. And I was really scared to close my eyes thinking that if I do close my eyes, like I won't wake up. So that happened all the way to the hospital. And then, at that time, once I was in the hospital, the doctors did what they had to do but I was unconscious at that time.

Bill 8:10

Wow, pretty dramatic. And when you work from being unconscious, and you came around, what deficits were you left with that you had to deal with and overcome?

The Initial Deficits

Anita Hsieh 8:23

So I actually couldn't walk. And it was interesting, because it affected my cerebellum. So I had deficits on both sides, but were very different. Like I couldn't feel my left side. And my right side was the one where I had like spasms.

Anita Hsieh 8:45

And that like, I couldn't walk, and had double vision. And I had like short-term memory. I couldn't really speak I had a little bit of aphasia, and all those things like I just didn't expect to happen.

Anita Hsieh 9:02

I was like, what happened to me? I couldn't even get out of the bed, I couldn't even go into the bathroom to the toilet. And I was just like, what happened? And I didn't even know when I woke up that I had a stroke until my mom eventually told me I was still in quite a shock.

Bill 9:26

It's dramatic for anybody. And then when you're completely oblivious to being unhealthy as in, when you're young, and you're fresh, and you feel like, you're healthy and everything's going okay, and then all of a sudden, you're not, it's definitely going to be a big shock to the system, and it's going to challenge every thought, every idea that you've ever had about yourself.

Bill 9:51

Up until that point in time, it just changes everything. I mean, it did that for me. 37 I can't say I was feeling the healthiest but I certainly wasn't feeling unwell or like I wasn't capable of operating efficiently or being, you know, physically capable of doing all the tasks that I needed to do.

Bill 10:16

When you couldn't feel that stuff, are you thinking about the future at all? Are you just taking it day by day? How do you manage that time in your head? How do you kind come to terms with your thoughts?

Anita Hsieh 10:34

I wasn't even thinking, I thought that it was like a regular cold. I was just gonna get back right into it. And next day, I'll just be discharged and go do my own thing again. That didn't happen I was just leaning to my optimism.

Anita Hsieh 10:54

But yeah, that was not the case. And, for me, for the first part of things, I didn't really think that much, I felt like, my sole focus was to walk again, like I just really focused on my physical aspect.

Anita Hsieh 11:11

But once I think because the doctors are saying, because I'm young, I have a young brain, not saying that other people like it will be faster in recovery because of being young, but still, they don't really see young stroke patients like I was so young compared to all the stroke patients in the hospital.

Anita Hsieh 11:37

It was hard to relate in general, I was just in my room, I didn't talk to anyone, I was just like, on myself, because I don't know what to expect. But once I started, like just even being in a walker like walking, assisted, that's when it took me a while, like a few months to really wrap everything around my head.

Anita Hsieh 12:02

I didn't want to tell anyone. And I wasn't ready to tell everyone. So basically, I just was in denial, I guess. And for a bit until I sat down, I'm very thankful I had a whole team working with me in the rehab center.

Anita Hsieh 12:23

And that included like a therapist, and they really worked through that mental part of me, because I just couldn't wrap it around my head. This whole time. I felt like I was just stuck in this, dream world that this did not occur, but it did. And every day it was going by.

Bill 12:47

You know the part where you didn't tell anybody? Is there any shame linked into that? Is that perhaps some cultural shame, etc. Because I know that some of my relatives we wouldn't know if they were well or unwell. Whereas I talk about everything, and everybody knows everything about me.

Bill 13:03

But some people keep all that stuff to themselves, but then it's a real shock when you find out, you know, three, four, whatever months later, and it's like, why didn't you tell me? You know, I could have helped, or I would have loved to have been able to help or ease your burden a little bit. Did you guys have that in your family a little?

Too Young To Have A Stroke



Anita Hsieh 13:22

Yeah, culturally, I definitely felt ashamed and embarrassed being my age and cultural background like, you wouldn't expect a 20-something-year-old to be in this situation and not healthy, like what did I do? Like I must be really unhealthy to have a stroke happened to me?

Anita Hsieh 13:48

And yeah, I didn't want to tell any of my family members, like only my immediate family knows. So my parents and my sister to be honest, and I couldn't even tell my friends because even my friends think that oh, okay, like it can be better soon kind of thing.

Anita Hsieh 14:07

No one really knew stroke recovery and how the processes or anything, we're just in our 20s just having fun and doing our own thing right at that time is not the time where we think about our health.

Anita Hsieh 14:25

which we definitely took for granted. But at that time, I don't think I wouldn't like to think about my health either. I just wanted to do my own thing. So culturally, for sure. It took me about half a year to be able to really open up and talk about my stroke actually.

Bill 14:53

In hindsight, and maybe this you've never thought about it before but would it have been nice to have some fun friends come to visit you while you're spending

all this time in hospital in your rehab.

Anita Hsieh 15:05

Yeah, actually, I did tell like a few friends. And then they didn't come visit. But I still felt embarrassed, I felt embarrassed that they had to push me in a wheelchair, I felt ashamed that they had to do these things. For me, I just felt like everyone was staring at me if I left my room, even though I was at the rehab, or at the hospital.

Bill 15:36

Where everyone was in a similar situation as you. Looking back now, and knowing what you know, now, and having had five years of personal development and growth and wisdom, you see that time as perhaps a time whether you wouldn't repeat some of those things that you did or didn't do? Would you perhaps feel better about sharing about a difficult time in your life, rather than feeling embarrassed about a difficult time in your life?

Anita Hsieh 16:10

Yeah, I would definitely. Five years ago, I hated my life. I was just so frustrated. I'm like, why is this and now I'm like, that was a bus that in disguise. To be honest, I've learned a lot about myself over the five years that I wouldn't have, like, it definitely did suck, having a stroke.

Anita Hsieh 16:40

And to be that young, and to learn a lot. That was great. I got to work on myself. And I wish I shared it earlier, because it was actually very recent, one of my co-workers, she was 21. And she just recently had a stroke too.

Anita Hsieh 17:03

And I realized that she was going through the same thing as me. And she felt alone and I realized that if I could share that even before that, too, like she said, it helped a lot. So yeah, definitely, that's what I would have changed, like I would have been more open about my stroke.

Bill 17:26

And possibly help some other people going through similar difficult time.

Anita Hsieh 17:33

Yeah.

Bill 17:33

Yeah, makes sense. So it sounds like you've had a shift in your mindset in the way that you go about thinking about things. And sounds like you've let go some of your old beliefs, which were not serving you.

Bill 17:49

As a 24-year-old stroke survivor, maybe they were serving you up until that point in time, but as a stroke survivor, it sounds like you needed to dramatically change your perspective and the way you thought about things.

Anita Hsieh 18:01

Yeah, like I said, that it was a blessing in disguise so culturally, there's I come from an Asian background, where school is very important, studies, everything, in general, was just very, like, you gotta be like a straight A student, you had to do this and that.

Anita Hsieh 18:25

Like, it's just the expectations, I had a lot of expectations on myself too like, hold myself to that level and I don't know what to think about it. I just thought this is what my life is supposed to be, you know, do school, get a really good job, have a family, like the typical whatever society is.

Anita Hsieh 18:48

And then with my stroke. Like it was just so different than, like you said, like, my perspective, like my mindset changed so much. I just kind of opened up, I found myself learning more on how different I was, how I want to be different, like, I no longer want to conform into that.

Anita Hsieh 19:10

Like, it doesn't matter. In that sense. Like, I don't have to be a straight A student or, you know, go for the top of whatever career I needed to find, like, yeah, like, I could just do things the way I want to, because I guess, I did think that I was gonna of die so I felt like a lot of regrets came too like, I felt like, I thought of a lot of regrets.

Anita Hsieh 19:40

If I don't do it now I'm not gonna be 80 and think about it again and be like, I have another chance. So I might as well just start now at 24 where I have plenty of years to really do what I kind of want to do.

Bill 19:59

That's profound shift in mindset. I love that. So you know, your parents, perhaps they did have some expectations of you. And they were letting you know that you need to perform well academically and all that kind of stuff.

Bill 20:04

But I imagine when you became unwell, they know, they would have known people that have had a stroke before, because they're older, and they've been around on the planet more. And they would have definitely come across somebody that had a stroke. So when their daughter has a stroke, how did they respond? Like, did they surprise you with how they responded? Did you feel like you saw a different side of them?

Anita Hsieh 20:38

Definitely like, the four stages of grief. Like, my mom was definitely like my parents were definitely in denial at first, and then they were angry. Because like, why this happened, no one detected and then like the acceptance, but they took care of me, my mom was my primary caregiver.

Anita Hsieh 21:00

She had to do everything for my shade didn't work. And she was at home, like bathe me that feed me, did everything for me, and I really appreciate that part she just stopped everything and it just reminded me how when I felt on that day, I wanted to call my mom, like, even though they had these expectations.

Anita Hsieh 21:24

I still wanted my mom because I knew my mom was going to protect me take care of me and yes, definitely. They also learned and grew with me in that sense of that cultural expectations. And we live in Canada.

Anita Hsieh 21:47

So that's one good thing as there is a bit of both Western and Eastern mindsets. So it was a bit easier. And then they were with me to a lot of things, the rehab and being with me, so they saw a lot too.

Anita Hsieh 22:04

So it was the first time seeing me the character I am, and it also must be difficult for them to take care of me too. Because like, they thought they were done taking care of their kids, but now they're back at it again. Taking care of me feeding me

and doing everything.

Family Support After A Cryptogenic Ischemic Stroke

Bill 22:27

That's definitely a blessing when you've got somebody that can step in. I was 37 and my mum did exactly the same thing they were all over us like a rash. And we were completely and totally supported.

Bill 22:43

And we were lucky like that. I'm very thankful for that time. And my dad drove me around because I wasn't allowed to drive. And even though I didn't like the way he drives, and it was annoying. It was still good to have a taxi driver on speed dial.

Anita Hsieh 23:03

Yeah, for sure. They drove me around even though I got really nauseous when they drive because of my double visions. But I'm thankful for like, my parents, even my sister. For her to go through something like that. I have a younger sister and to see me like that too. It probably impacted them a lot too. But I'm very grateful I had them to take care of me and be there for me during that time too.

Bill 23:35

Yeah. So five years on are you still dealing with double vision and some of your deficits? What have you overcome?

Anita Hsieh 23:44

Yeah, so definitely my double vision went away I had my eyes check with the optometrist, everything was fine. I could drive again and all that stuff so yes I was very lucky, I could walk, I could do most of my mundane things. The only thing is my right hand is my dominant hand I still have a bit of spasm so it's hard for me to write and really just like mentally too like think faster and all those things especially when I am low on energy my deficits will show like my leg will start giving up I'll start limping more and my right leg will fail me but I could feel everything now except for a little bit of the feelings a bit different, but other than that, I'm very grateful that most of my deficits are pretty much like recovered. So I'm thankful for that.

Bill 24:56

That's fabulous. So you were in hospital for what about was it six months in rehabilitation and all that? How long?

Anita Hsieh 25:04

Around like that, I don't remember. I just felt like it was a very long time. Probably. Yeah, six months time. And then I was outpatient, so I just had to continue my rehab outside so it can be at home. Just go to the appointments.

Bill 25:22

And how long before you ended up becoming mobile again, where you gain some of your independence back and you're able to, you know, drive again and leave the house without supervision. How long did it take to get to that?

Anita Hsieh 25:37

I would say, around the one year mark, I was able to, I could walk, it's just had a cane that was and then I just got assisted walking. So like I needed someone to hold like, I could still walk slowly. And driving wise, that took the longest they took away my driver's license until I could pass my optometrist test. I guess they have a test for these things.

Anita Hsieh 26:11

And they want to ensure that I'm 100% like ready to do it. So that took a while and first few times I drove it was not fun. It was an interesting feeling I had a lot of panic attacks. It was overwhelming, I guess mentally. I had a lot of trouble with multitasking.

Anita Hsieh 26:38

So like a lot of stimulation just makes me go like, yeah, I cannot function with so many stimulation. I still feel like that a little bit. It's still hard for me to multitask. I need to focus on one thing, which is fine. Like, definitely know how to focus and use my brain as it's supposed to be right now. Just work for the best for me.

Bill 27:06

Yeah so we're crowds also difficult? Going into crowded locations where there's a lot of people and noise.

Anita Hsieh 27:14

Definitely, I remember the first time I went to restaurant for a family dinner with

like, my extended family like my cousins, aunts, uncles, and even just people moving their chair getting cutlery like, oh my gosh, like it was just so overwhelming like I felt sick to my stomach that was just so bad.

Bill 27:37

It is something that I can relate to. That's why I asked and I know a lot of survivors can, even now and I have been on this journey for about 10 years. Even now when I go to a crowded cafe or restaurant, and the certain pitches of certain people's voices, predominantly female, higher pitched voices are really, really difficult for me to handle to the point where I have been known to sit in a restaurant with my hands over my ears while we're there, because I just can't deal with the noise and I can go to those people and say to them stop talking or leave.

Intro 28:21

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like how long will it take to recover? Will I actually recover? What things should I avoid in case I make matters worse?

Intro 28:38

Doctors will explain things but obviously, you've never had a stroke before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you.

Intro 29:01

It's called seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery. Head to the website now, recoveryafterstroke.com and download the guide. It's free.

Bill 29:21

And I don't want to leave the restaurant that I'm at I want to be there because that's why we went but I have been known to shorten my stay at a particular venue or restaurant because I can't manage the noise and it's excruciatingly

painful to be there. So I have to excuse myself and not be there.

Anita Hsieh 29:50

Yeah, I definitely feel that sometimes. Well, since the pandemic happened, and there's not as many people so I actually feel a bit better. But yeah, the noise levels even to this day it's up to a certain amount of level I could get. I don't know. But yeah, totally it's really frustrating.

Bill 30:15

And before the pandemic, did you find yourself canceling on people and not going to events where you were invited to because of that reason?

Anita Hsieh 30:23

Yeah, like well before that, like, I just shut because I didn't tell anyone where I've been and I just like shut down like I didn't go anywhere and to be honest, my mom was pretty strict on what I ate. Afterwards, she was like everything, like, really healthy and I just ate a lot of home-cooked meals, because she wasn't sure what was happening to me. So they just want to be sure, like health-wise, whatever I put in my body. Like, it's not fat and greasy and whatever.

Bill 31:05

She just want to take a little bit of control back and support you the best way that she could and for her it was through nutrition and making sure that you are A, eating and B, probably eating healthy and all the things that moms want to make sure you're doing.

Anita Hsieh 31:21

Yeah. So that limit me a lot but my friends that have actually come to the house and visit me. And in the beginning, my mom had to tell them to leave, like I couldn't even do it. Because at that point, like, it was just too much. My mom was like, Are you tired? And I'm like, yeah, and she's telling my friends she has to take a breather like, it's too much.

Anita Hsieh 31:52

But eventually, they just kind of get it and then they come for a short period of time when they visit me just to talk. And then I eventually kind of went out. I went to one of my friend's wedding, she was moving to the States. So I didn't want to say no to that. And that was very interesting it was a lot. It was definitely a lot. I would say I don't think it was ready for that at that time. But I'm so happy I went

because she moved.

Sensory Overload Caused By Cryptogenic Ischemic Stroke



Bill 32:26

I remember being at events like weddings, or, you know, full-on parties or something like that. And then needing literally the whole next day to recover and rest. Is that your experience? Does it take a long time to recharge the batteries?

Anita Hsieh 32:44

Yes, definitely a lot. Even before my stroke. I was more of an introvert. So I needed to recharge from just being social and going out. And then when my stroke Yeah, it was like, double the time. And one thing that I feel like it's hard for people to comprehend because I look normal, I look fine.

Anita Hsieh 33:09

They don't think that. But sometimes I just want to know that even though I love normal, I'm still dealing with some of even like the tiredness and stuff and I actually have to work twice as hard just to write or to type or do my job. And that's one thing that sometimes could get frustrating in that sense.

Anita Hsieh 33:38

And even now like I got COVID I feel like I have no energy. But I'm like barely there. But like it's been once a week and I still feel a little bit and I just sometimes I feel bad for taking so much time to rest. That's one thing I still need to really

work on. I feel guilty for taking rests even though I know that I need it.

Bill 34:14

I recently posted about this on Instagram, I had the same issue, I'm 10 years post-stroke. But still some days are really difficult and I can't do anything. And the best thing that I need to do is lie down and just be there the entire day. If I'm doing that, I do feel the same thing.

Bill 34:33

I feel like I'm being unproductive and I could be doing more. I should be doing better and all those crazy things into my head. But the other part of 100% knows that the correct thing to do is the part where you're lying down for an entire day and you're recharging your batteries. And my head is what does that other stuff to me like it just messes with me.

Bill 34:57

And I try to switch it off but it's definitely got something to do with, you know, your upbringing and you have to work and you have to do all these things. So I can't always just shake it and switch it off. I feel good, especially if, let's say, I was in the middle of doing things or the day that I was unwell, I had some stuff that I needed to do, because they were on the agenda. And I didn't get them done and then I'm wondering about my God the next day, and what I'm going to have to do the next day to catch up. And it's like, just get over it and stop and rest five minutes.

Anita Hsieh 35:33

Definitely, I definitely still, to this day, I just feel like I'm just having an internal battle with myself a lot. Yeah, it's pretty hard to shut that. I still try to, but I'm just going back and forth. Like this is the right thing to do. This is not.

Bill 35:59

Because I can I'm gonna give you permission to rest whenever you need to. And you can remember that I said that. So next time you feel that way. Just remember that I said it, and whoever's listening and watching, you have permission to rest, permission granted. Just keep that in the back of your mind, then let that be the thing that you remember during those moments where you're doubting yourself. So how did your career end up going? Did you end up working in the field that you were studying?

Anita Hsieh 36:34

Yeah. So I actually, I am working right now. I just didn't pursue my destination. I was like, No, I can't do this right now. And like, even now today, like, recently, I have been thinking about it. And I'm like, I don't think I could put myself into that much energy. It's just a lot.

Anita Hsieh 36:56

But I'm thankful I have a job like I don't have to reach for the top as long as I'm earning some income to support myself and I'm actually still living with my parents, I'm thankful for that, culturally, it's pretty like a norm for like me and like my sister to live with my parents.

Anita Hsieh 37:23

So I'm grateful for that. I still live with my parents at this time, so I can really just work on myself. And yeah, and I was very thankful with my job, I didn't start off full time, like I did a gradual, like, it was an ease to go back, I worked like two days for like, five hours. And then I gradually increased it while I was working with my therapist.

Anita Hsieh 37:57

So that was really good. I'm very thankful for that. And even when I started working, I was scared to tell people, my coworkers, colleagues, that I had a stroke too that was also interesting. And that was like, a year, I already told my family and friends.

Anita Hsieh 38:21

But I still felt that same way. When I had to tell new people. And it was interesting, but eventually, I did I may have the courage to just talk about I think there was an event about health and like, heart and stroke. And I was like, you know, I'm just gonna raise my hand and tell my experience and I did a lot of them actually had questions, which I'm really glad I did share my experience with them because everyone was just really shocked.

Sharing Your Story - Anita Hsieh



Bill 38:59

Yeah, is it good to share it from an emotional perspective? Does it help lift some kind of burden? Do you feel lighter for sharing your story is it better get it out than keep it in?

Anita Hsieh 39:15

Yeah, I feel free. It's like, you want to be a butterfly and or birds like you feel like you just spread your wings. Because even if they don't have a stroke, I'm pretty sure at least someone knows about someone who had a stroke and just even just telling one person you could spread that stroke can happen anywhere like anytime no matter what age.

Anita Hsieh 39:51

Like, oh, it's something for elderlies and if they're high risk, no, like it happened to me. So I just wanted that to be out there, that it could happen to anyone. Not that I wish it did, but I mean, yeah, just to be aware that raising the awareness, it felt good. I felt like oh, wow. Now people can see me I don't have to hide. And they know my situation and I gave them a little bit of information about stroke.

Bill 40:28

And, and you've got a legitimate reason. If you're having a bad day, we've got a legitimate reason if your deficits are playing up because you're tired, and you don't have to worry about people wondering what is going on with her. You can basically tell them I'm feeling exhausted today.

Bill 40:50

And now you know, the reason why, and this is what happens sometimes. But I'll

be better with a little rest. Does that make it better? Because I imagined at the beginning, they would have been seeing some things, some of your behavior and thinking what's going on with her?

Anita Hsieh 41:10

Yeah, for sure. I cried at work, because it was just too much one day and other time my manager saw, and he completely was in shock. And he's like, you know, just go home. And I was like, Okay, I'm gonna go home. Like, I think it wasn't enough, especially in the beginning, I was just, everything is so new, I'm learning so much information.

Anita Hsieh 41:37

And yeah, it was just a lot. And sometimes it gets frustrating, because I just couldn't be as fast as I used to be. And I had to take my time. But now I'm in a good place where everyone understands that I know, my own limits. And yeah, so that is good. But in the beginning, it was just trial and error, a lot of emotions, were coming out at work that I did not want to show at work, but it did happen.

Bill 42:13

I remember working for three years between 2016, and 2019, in an office. Again, for the same reasons I couldn't participate in life as normal, because I was so unwell. And friend of mine gave me a job in an organization where he was the manager that I would be reporting to. So it was very useful, because he completely knew my situation. But the people around us didn't know my situation.

Bill 42:44

They often questioned my level of contribution and my output because it wasn't as high as other people. And I wasn't contributing to the workload the way that they were. And it was quite interesting to be seen as somebody who's not pulling his weight, because I always thought that I did. And the reason I wasn't pulling my weight is because I was not capable of doing more than I was doing.

Bill 43:12

For example, we had two monitors at our desk and those monitors, would just fry my brain, getting within a couple of hours of being at work, I wouldn't be able to operate anymore, I'd have to get up and go for a walk for half an hour, and then come back and try and somehow get through the rest of the day.

Bill 43:30

And a lot of the stuff that we worked on was spreadsheets all day, every day, a whole bunch of spreadsheets that just used to make life really difficult because I had to think a lot and use my brain way more because of the fact that it was injured, and the effort was greater.

Bill 43:52

And numbers and spreadsheets are not my favorite thing anyway. And now they were twice as hard. And it was extremely difficult. And I remember I finally resigned after putting up with it for three years, when my friend who's my boss came to me and said, you know, this is your level of expertise with a spreadsheet, we're going to take it to the next level now because we're going to change a few things around and we need to increase everybody's skills around the spreadsheets, etc.

Bill 44:26

And that meeting ended, the whole team was in there, that meeting ended, there was probably about 15 people in it. And when they left, I waited for everyone to leave the room. And I immediately resigned on the spot. And he said to relax what just happened? What was so bad? I said to him nothing. I just am not going to be able to fulfill the requirements that you have of your team members.

Bill 44:52

And I don't want to make it look bad and I don't want to be bringing the team down or anything like that. There's no way I can do this role. And that's how I ended up leaving, I couldn't do it to him and I couldn't do it for myself. And I was just going to be filling space there and actually not being productive enough.

Bill 45:19

And maybe I was going to be causing him a problem because I know that he wouldn't have wanted to get rid of me and sack me because he knew my situation. And he was very lenient, and he was very caring. But I couldn't do that to him. That's how challenging it was for me.

Anita Hsieh 45:38

Definitely, I feel a lot like that. Like, I'm always thinking about my job. And like what I'm supposed to do, like, even to this day, I'm still trying to find myself. But it's a growing part of me like, I'm still trying to figure out what I could do what I do best, what doesn't overtake my energy. I'm still struggling with that to this

day, too. But I'm not to the point where like, I'm just going to resign. But yeah, like I could do my job. But I'm still taking the time to figure out myself.

Taking The Time To Recover



Bill 46:27

You need time. Absolutely. I mean, at 2016, I was only two years out of brain surgery. So it hadn't been a lot of time, things were still healing and recovering. And by 2019, I was still healing and recovering. I wasn't anywhere near maybe my old self, I don't know, if I wasn't feeling like my old self still. And I think things started to work for me started to feel better for me, sort of from about 2020 onwards.

Bill 47:03

And then from there, I still have noticed, you know, gradual improvements in everything that I do in my memory, my ability to look at monitors my ability to focus for longer periods of time, it has gradually got better and better and better.

Bill 47:23

But there was always those little backward steps, those drops, where I needed to reassess and stop and settle down and do lesson and recover. So it might seem weird for somebody if they've just started their stroke journey or their recovery. If I say that five years down the road, it's just still way early on in your recovery. But I think you're testament to that and saw my and now I'm another five years ahead of you. And it's like, it gets better even after that.

Anita Hsieh 48:00

That's good. Like, I don't know about you, I felt like even though physically, like, well a lot better. Mentally, it's a lot harder to work hard, like to recover than physical like for myself, like the physical I had so many to work on and exercises. And I feel like I'm still being challenged each day with different things that I don't know about. What, like some days I do, I don't know. Like, okay, this is challenging for me. Oh, this is okay for me. Like just stuff that. I don't know, my brain does that.

Bill 48:42

Yeah. And what's interesting is there isn't a lot you can do to rehabilitate your mind. When you're feeling like this. This is a weapon other than rest and sleep. There's not that much more that you can do for the body. We can go to all sorts of physical therapy, we can go to the gym, we can run we can bike ride, you can do all these things. We can play sports, whether you're able-bodied or not.

Bill 49:09

You can still participate in sports, but for the brain, there's not that many people coming to you and going do this let's go exercise like this or there's not that many people got ideas about that I don't have any and there certainly not a lot of experts that come that there is some ideas about supporting the brain through nutrition and meditation and sleeping more and even exercise does help. But yeah, it seems like we're lacking some tools and resources to heal a brain. That's all I can come up with.

Anita Hsieh 49:55

Yeah, totally agree.

Bill 49:59

So you rest more therefore do you sleep more? Have you improved or changed your sleeping habits? Or have they altered on their own as a result of the stroke?

Anita Hsieh 50:16

I definitely. Well, before I was like, sleep is not important. I could pull, like all-nighters go out and stuff, and I definitely take it more seriously. I had definitely have a routine. But after my stroke, I could sleep for days and days, like it just needed it.

Anita Hsieh 50:32

But now, I have a very structured like, seven to eight hours of sleep, and it's like

eight hours is like really good. But some days, like, most majority of days, I get between seven to eight hours. When I'm really tired, I used to be so against naps. I don't know why it's just like, I feel like I wasted my day. But no, like I do enjoy like, if I'm really tired I will take a nap.

Bill 51:17

You know, in a lot of European countries. Napping is part of almost their religion. In the middle of the day.

Anita Hsieh 51:23

Yeah. And I was like, Okay, well, other parts of the country. Yeah, they do that. But yeah, in my mind, I was like, Oh my gosh, I'm wasting half my day, like taking a nap and I just didn't want that or like, if I nap now I'm not going to sleep at night. But I've been okay. Yeah, I've been okay. I just really am trying to even to say, be aware of my body, like learn to listen to my body.

Anita Hsieh 51:54

Because I tend to just go over that a lot. Like I just I burn out really quickly. And I realized I needed to stop that or else I'm just going backwards a lot. I'm taking more breaks than I need to if I know ahead of time like if it's just rest day or taking breaks. So that's one thing I'm still working on to acknowledge, my body if I'm really tired or even just a little tired. Maybe it's time for me to rest.

Bill 52:25

Yeah. When I think about the location you live in in Canada, I always shadow with the thought that you guys have a really cold, snowy winter and I can't deal with I enjoy it. And the cold even where I live in Melbourne, Australia, we have a cold winter. We don't have a lot of snow in the city where I live, but I don't like it at all. I don't enjoy it at all. So I'm wondering about your experience with weather? And how much if any change that you've experienced with the cold or the heat? Is it different for you these days?

Anita Hsieh 53:14

It's more like I'm very scared to walk outside. Like I'm scared of falling. Now i'm better, because I have more confidence. After my stroke once it goes really cold and snowy there's also like hail and ice like you can't see it. Wintertime sometimes it gets very dangerous, even just for normal people to walk like not just me.

Anita Hsieh 53:44

That's scary and the cold and the heat doesn't really affect me because I've lived in Canada all my life. I was born here so I'm used to half a year being really cold and more than half the year I feel like majority of the year it's really cold and like three months of summer.

Anita Hsieh 54:05

And because I'm home we have heat. So like we have to have heat or else it'll just freeze everything. But I feel safe at home. One thing I did was more of a transition as I used to like doing a lot of activities. Like skating, skiing and all that stuff. And he couldn't do those things anymore.

Anita Hsieh 54:33

Like last year I did try and it was really tough. It was scary to bounce on just to play this or it was just different and learning to cope with that. Just learning that there's a lot of stuff that is hard for me to do. So that's one thing but yeah, temperature-wise. I feel okay. I'm always just warming up to be outside, and in the summer, I want as hot as fire and I also like the heat, but I like both.

Dealing With Temperature Issues

Bill 55:07

I never liked the cold, I can't still deal with the cold, and it doesn't matter how much clothes you put on, I never feel warm. And even now, with my left side, my left side is colder than my right side as a result of my stroke and the deficits that I deal with. So when I didn't enjoy the cold to begin with, now half of my body experiences the cold even more dramatically, and it's kind of like that's the worst thing.

Bill 55:38

Like I don't need to move 1000 kilometers north and go closer to go to warmer, you know, and stay there and be there all the time because it gets less cold in the north of Australia than it does where we live. But it's great that you can still deal with it. And it's not an issue. I know a lot of people get impacted by the heat predominantly because it seems to drain their energy more. And perhaps they can't regulate their body temperature. I'm not sure why but stroke seems to cause that challenge.

Bill 55:38

Yeah, I guess heat wise it's not that hot compared to other countries where I live like in Canada like, well, sometimes we get like, high 30s but that's like the max, I think. Yeah, like it doesn't get too unbearable. So and because like maybe because I'm always inside. Like I don't really go out that much so I don't feel that.

Anita Hsieh 56:44

But then it just reminded me that I actually took a trip with my family to Asia, we went to Thailand, and that kind of heat yeah, I definitely felt draining. I was just completely exhausted. And on top of the heat. It was just a lot of people like it was just everything all at once. For me it was a lot like I just wanted to stay in my hotel sometimes. But yeah, I still managed to do things. But yeah, I didn't realize that part.

Bill 57:26

It's hot and humid in Thailand, isn't it?

Anita Hsieh 57:29

Very, very hot. And it's just a lot of people because in Canada, everything is so spread out we have so much space like I'm just used to that kind and then when you go to Thailand where it's super hot and humid. And then there's so much people. I was just like, oh, this is all pot a lot. But it was fun. It was interesting to see how I managed traveling since it was like my first big big trip after my stroke with my family.

Bill 58:04

We did a really big trip to the United States after my stroke it takes 26, 27 hours. It's intense and then by the time you get there, you haven't slept properly in the rest of it. And for me, we got to New York and my wife wanted to see all of New York immediately and I want to sleep immediately I don't want to go anywhere.

Bill 58:35

That was the difference in the way that we felt. And I was afraid of that trip because I didn't know whether I was going to have another stroke or I didn't know anything about the hospital system out there. I took the most expensive travel insurance policy, were you nervous about doing the trip and are you glad you did it anyway?

Anita Hsieh 59:00

Yeah, I was so nervous. I was like what if I had a stroke like you said, I bought like the most expensive everything covered because a lot don't cover pre-existing conditions and the stroke was the pre existing condition. And like you hear stories that long flights and blood clots and I was like, Oh no, like I had a blood clot and that's how the stroke happened.

Anita Hsieh 59:22

Like, I bought compression socks I was very nervous and even though mine was not 20 something hours of flight to Asia it was like 13 ish because I went to Taiwan first. And it was still long. I remember getting up a lot just to walk around because I was so nervous about my legs. It was just it was interesting. I'm glad I did it, but I also felt really different.

Anita Hsieh 59:52

And then beginning when I got there I was super tired. My body felt different like I felt tingly and that freaked me out like I don't know, it's just the air like or the heat because I'm not used to that much heat compared to Canada since we went in November like it's cold here like not that cold yet, but so cold compared to like, it was just a big drastic change within 30 hours maybe.

Anita Hsieh 1:00:21

And my body just felt very tingly. And I was really worried that I'm gonna be numb or I'm gonna have a stroke. And I'm in a country where like, I don't. Yeah, like you said, I don't know the healthcare system in Asia, I was very nervous, but now that I think about it. I'm back here I'm very happy.

Bill 1:00:49

Did you have to get permission from your medical team to fly or to travel? Did you do that or not?

Anita Hsieh 1:00:57

No because I waited a while in the beginning. I couldn't fly, but I didn't fly anywhere anyways. So after that, I did speak to my family practitioner about it and she just ensured that I have everything ready like medication, and stuff and how to prepare for it because I was really worried.

Anita Hsieh 1:01:23

And that's about it. You know, just compression socks because I am still on blood thinners. So I had to take that every day. And I just continue to do that. And just

to make sure that you get a lot. I just registered my name to the Government of Canada just to make sure and like I just said all the things I have to say.

Bill 1:01:58

All the precautions. It sounds like you well planned for it. And that's the thing we did as well. We just planned everything as much as we could to control some of those things that previously maybe I never would have considered or I never would have thought about.

Bill 1:02:13

We did a little bit of overthinking about it and a bit of time to plan. And in the end, it was worth it. But I was really unsure if I should go. I really didn't engage with my wife at the beginning about the trip. And I wasn't excited. She was wondering why I wasn't excited. But when we got there, I really enjoyed myself it was New York in winter, so it wasn't fun, because it was cold.

Bill 1:02:42

But I went anyway. But it was just after they had a hurricane back then Hurricane Sandy. And the weather was very settled after that had happened. And although it was cold, the sun was out safe, we were walking in the sun, with a few layers on, it was quite comfortable, you could really easily get around. So So while I was there, I really enjoyed myself, but trying to imagine myself there was really, really difficult.

Bill 1:03:17

And I think what I'm trying to say to people listening and watching is definitely if you're thinking about traveling, if you get the go ahead from your medical team, and you put a little bit of time into the planning of it, and you don't over think too far into the future and you get there. You might actually have a great experience. And that's really what I'm doing to encourage people to do that.

Anita Hsieh 1:03:39

Yeah. I love to travel. I like to see different cultures, visit different countries. So I was somewhat devastated when they didn't let me travel in the beginning. But that's totally understandable. And like you said, overhiking did get to me. I was like, excited for a day then overthinking and I just kept going back and forth because I really wanted to travel but yeah, definitely speak to have medical professionals first but yeah, it's really worth it.

Sooner Rather Than Later

Bill 1:04:20

Yeah. And I also did the whole thing that you were talking about earlier, which was I might not be around next year. Why don't I just go this year and enjoy myself? Because I don't know what's gonna happen next year. I definitely did that. That was kind of what got me over the line that I better do it now if I don't do it now I'm never going to do it.

Bill 1:04:41

We shouldn't wait any longer. You know, we waited until we were married for a good 10 or 15 years before we traveled anywhere with our family because it wasn't easy. Finances and the rest of it and then my wife was like what if we don't go now when are we going to go? We might not be healthy and well, in the future, let's go now while we can enjoy it.

Anita Hsieh 1:05:06

Definitely, I think of it a lot of I still somewhat have that energy I should go now, because later on, I probably won't have as much energy as I could. So that's one thing. I have a lot of things that I was scared to do. Like I really want to do, I always had to remind myself like, if I don't do it now, I don't know when I could do it.

Anita Hsieh 1:05:33

So that's one good thing about this stroke set up, like, it really challenged me to overcome a lot of my fears, which is really good, because or else I'll just be, you know, hiding and be living in a bubble and not experiencing everything the world has to offer.

Bill 1:05:54

Yeah, I couldn't agree more. While we've kind of come in to the end of the interview, I want to ask you one last question. And it's about the fact that you rescheduled a couple of times to get to this particular time, which is pretty cool, people do that all the time and it's no problem.

Bill 1:06:14

But when you wrote me a note as to why you were rescheduling, you said, that you're really looking forward to this interview. And I'm curious to know, about

what was it about being on this podcast or any podcast that you look forward to? What is it about? What did you want to achieve, like coming on here?

Anita Hsieh 1:06:40

So there's a lot of things like talking to you, also a stroke survivor, I felt like in the beginning of my stroke journey, I didn't have anyone to talk to I didn't feel like it was relatable. Like I felt like I didn't belong to anything, I felt so alone. And being able to talk to someone who also been through a stroke, even though there's so many different kinds of stroke.

Anita Hsieh 1:07:11

But still being part of something and just talking like, I really wanted to do that, and it also challenged me, because speaking to someone from across the world, like Australia from Canada, is like for me, even before I'm shy, soft spoken that I like to challenge myself to do this.

Anita Hsieh 1:07:40

And I want to do this for myself and for everybody and share my experience too. And the whole time of like, coming out, like spreading my wings, like talking about my stroke to you and everyone who's listening. Like, it feels great. Yeah, that's why I was really looking forward to it and I had seen your Instagram and everything. And it just felt like yeah, I really wanted to be, I guest.

Bill 1:08:11

Beautiful, that is the perfect reason and any other reason that somebody might have, why they want to be on my podcast, that's a perfect reason as well. That's exactly why I do the podcast I do for exactly that reason. I didn't know any stroke survivors, I didn't feel like I belonged, I didn't feel like anyone understood me, and I still feel that now, because the majority of people I know, thank God haven't had a stroke.

Bill 1:08:38

And that's perfectly fine. But that means that I need to talk about it often I need to talk about it with people who understand me who get me, and I need to do something positive with this terrible situation that I've found myself in. So you're actually doing me a very big service by coming on here.

Bill 1:09:00

I really truly appreciate the fact that you did that. And I hope that you'll feel good

about the fact that there is people that are watching and listening now who are going to contact me and let me know that they really enjoyed listening to your episode, they'll say to me, that I related a lot to the stuff that Anita shared, and that they feel less alone and they feel more understood as a result of the fact that you decided to come on the podcast. So thank you very much for being on here.

Anita Hsieh 1:09:34

Thank you for having me, too. This was really great.

Bill 1:09:38

Thanks for joining us on today's episode. If you're a stroke survivor with a story to share about your experience, come and 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 or care for someone who is a stroke survivor or you are also one of the fabulous people that help other people who are stroke survivors.

Bill 1:10:00

Go to recoveryafterstroke.com/contact fill out the contact form and as soon as I receive your request I will respond with more details on how you can choose a time that works for you and me to meet over zoom. Thanks again for being here and listening. I really appreciate you see you on the next episode.

Intro 1:10:19

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Intro 1:10:36

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Intro 1:10:52

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Intro 1:11:13

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Intro 1:11:27

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Intro 1:11:50

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