

102. 10 Years of Stroke Recovery - Stephanie Ho

After experiencing a ruptured AVM in her early 20's Stephanie Ho has now been on the stroke recovery journey for more than 10 years. In that time she has had to overcome a lot of obstacles including readjusting with her new self and dealing with lost friendships and discovering new ways to be herself.

Socials: <https://www.instagram.com/stephho88/>

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Transcription:

Stephanie 0:00

I particularly love the word that you use, which is reinventing yourself. I think that's very true. And it could be the single difference between how well you recover. And I don't just mean physically I mean, mentally, being able to face yourself and look yourself in the mirror and realize that the person that you once was the one that everyone still identifies you with, because you still have the same face needs to be reinvented.

Stephanie 0:39

When you go through a life-altering event, you are shaken up to the core and it's only natural for you to kind of shift everything, your values, what you believe in, what you care about out the window and start rebuilding from scratch.

Intro 1:01

This is recovery after stroke with Bill Gasiamis, helping you go from where you are to where you'd rather be.

Introduction

Bill 1:07

Bill from recoveryafterstroke.com, this is Episode 102 and my guest today is 10-year stroke survivor Stephanie Ho. Stephanie was in her early 20s when an AVM in her brain bled out. Stephanie has a very lovely way of approaching stroke recovery that I am certain you'll get a lot from.

Bill 1:27

And I believe that you will love this episode. Now when you get to the end of the episode, whether you are watching on YouTube or listening on your favorite podcast app, please do me a favor and share the episode with other groups you hang out in.

Bill 1:41

This will help someone that is going through a tough time at the moment feel better about the journey that they are on, and perhaps give them a sense of that there's light at the end of the tunnel. Also, if you feel that this podcast is a five-star podcast because it is I would love it if you spent a little time giving it a thumbs up on YouTube.

Bill 2:01

Or a five-star review. on your favorite podcast app, you'll be making me smile from ear to ear. also recently, I've put everything that I learned about what is important in stroke recovery into a course called the 10 steps to brain health for stroke survivors, and module one is now available at recoveryafterstroke.com.

Bill 2:22

This is a course that is included as part of my recovery after stroke coaching program that you get automatically when you become a member of the recovery after stroke podcast. Now this course will help you overcome fatigue, reduce anxiety, and support your memory amongst other things.

Bill 2:42

This 10 step program has been created to complement any medical interventions and works in conjunction with other physical therapies that you are undergoing.

So if you are a stroke survivor that wants to know how to heal your brain, overcome fatigue and reduce anxiety.

Bill 2:57

This is the cause for you If you feel like there is not enough support after you leave the hospital and you are afraid that your recovery will go backward, then this is where I can help. While you are participating in this course, I will coach you and help you gain clarity on where you are currently in your recovery journey.

Bill 3:18

I will help you create a picture of where you would like to be in your recovery 12 months from now, and I will coach you to help you overcome what's stopping you from getting there. Now right now, for anyone who's interested in learning what recovery, after stroke coaching is about you, get a seven-day free trial to decide if it's the right fit for you.

Bill 3:37

The price though will be increasing on July one by more than double. So take advantage of the seven-day free trial now by clicking the link below if you're watching on YouTube, or by going to recoveryafterstroke.com/coaching if you are listening online, and now it's on with the show. Stephanie Ho, welcome to the podcast.

Stephanie 3:57

Thank you for having me.

Bill 3:59

Yeah, thanks for being here. I love that we connected a little while ago, we had a really amazing chat offline, probably about a month ago now. And some of the things that we spoke about, I felt like we should have had a podcast episode about and I'm glad we're getting together to do that. Now, just before we get started, can you tell me a little bit about what happened to you?

The waking stroke

Stephanie 4:22

Sure. And thank you for having me again, Bill. So when it all started, my stroke happened actually 10 years ago. I was very, very young. I was still 22 I had just finished uni started. work was like, feeling pretty, ready to take on the world. And

yeah, after a few months of full-time work, one day I just woke up feeling actually fine.

Stephanie 5:00

I remember hearing my phone ring, and I got up and I checked a message. And I remember thinking I must be so out of it. Or maybe I had too many drinks the night before because I couldn't decipher the words or the letters in that message. And yeah, I think what was happening is my hemorrhage my stroke was, at this time, already bleeding out.

Stephanie 5:32

So my stroke was the Broca's area in the language center of my brain. And then yeah, I remember going to the bathroom next. And luckily my mom was there. She asked me how was my night before and at this point, this is when I freaked out because what I came out to reply with just jumble like just blah blah of a no sound.

Stephanie 6:11

And I freaked out, I walked downstairs and my brother he likely was still at home and he opened the door. And I'm just trying to muster some words, which is not working out. And he actually thinks I'm still drunk. at this point I should definitely mention that my brother is a very, very intelligent guy, very, very smart and goes to show that you know, even he didn't really know what was going on.

Stephanie 6:44

Maybe lack of public awareness or educational strokes, I typed can't wait. So I knew what something was wrong. But because there's no pain receptors in the brain I couldn't feel the pain. So I typed can't wait. And he's like, can't wait for what. And that at this point, my right-hand side collapsed.

Stephanie 7:10

And then he got very worried. And he googled a few things and then stroke came up. And then yeah, hence began the long journey from someone in the hospital where I got, I guess assessed moved to Prince of Wales. I stayed there for three months. Oh, no, like a month before my surgery before then going into inpatient for rehab. My stroke was actually quite severe, which I learned much later.

Stephanie 7:50

It was kind of like a golf ball sized hole in my head and that rendered me unable

to speak at all I couldn't read, write or I could still understand so that was a huge blessing in disguise. I walk or talk or use my right arm I was partially blind for a while and luckily that came back.

Stephanie 8:21

But yeah, I often talk about this part and it's almost surreal it's almost like I'm giving a synopsis of a movie because I don't remember much of it. I certainly wasn't in a space that I could feel worried or concerned I was just so spaced out.

Stephanie 8:45

So I often bring back attention to the recovery, which I think is more important, at least for the person going through the stroke or the recovery process because that's when your mind kind of like comes back online. And that's when you really do need their support. Physically, you know, mentally, spiritually all that.

Bill 9:10

I love what you said there because I was the same, I was pretty spaced out. And I love the similarity. Well, I don't love the similarity. But the similarity that mine was a golf ball size clot in my head as well. And it was there for a long time because I didn't have surgery for quite a number of years.

Bill 9:28

And it started to decrease in size. And as it decrease in size, more and more of the things that I'd lost came back on. And I was able to talk again, write an email again, drive again, work again. It took some time, but I did the same thing reflecting back on it.

Bill 9:46

It was somebody else's story that I was telling. I wasn't really telling my own story because I was out of it. And I was spaced out and I didn't have a concern in the world. There was no worry. Everyone else around me was freaking out and losing their minds but I was kind of chill and now that you're 10 years down the track, do you find that is there any drama talking about it any sort of issue do you have any does it bring up anything?

Stephanie 10:18

Um, not really is maybe the short answer. I'm certainly still very passionate about what's happened you know, it's been 10 years but I don't think there's been one day but I don't think remotely about that. Not necessarily about the day itself, but

rather the whole saga you know, that one fateful day determined, you know, the rest of my life really it's changed me as a person.

Stephanie 10:56

It's changed how I work, what I prioritize, what I've plan for just everything. So it's not painful, it doesn't run, you know, bring up certain negative feelings but it's still a very big part of my life every day and I think also people, you know my loved ones around me as well.

Stephanie's Deficits

Bill 11:23

Yeah, and that's because you have some deficits Is that right?

Stephanie 11:26

Yeah that's right so I had a pretty good night's sleep so hopefully I'm able to speak fairly cute clearly today. But you know what, I'm tired I slur my words. Like just my brains not quite connecting as well. Which is frustrating. If I'm tired, I also can't spell so well. And never was very good at spelling and then I have like spasticity in certain areas of my right hand, and my legs as well, when I'm cold in particular, the circulation doesn't run as well.

Stephanie 12:10

And then, you know things kind of seize up. I often joke to my family about my right hand side, specially My hand is almost like a sea creature likes to just close up when it senses like danger or something that it doesn't quite like. So that's the I don't know, Primal side of evolution maybe.

Bill 12:37

So I like what you're saying there, my left side. And again, you wouldn't see me and people wouldn't know that I had a stroke unless they knew about my podcast and heard me speak. But my deficits are not visible.

Bill 12:51

But there is proprioception issues. There's numbness, there's temperature issues. And when I get tired, my left side gets wonky. And my balance is a little bit off. But I relate to what you're saying. And I reckon there'd be many people listening that relate to what you just said about how your hand kind of has a mind of its own. It does its own thing.

Bill 13:16

I really don't like my hand being touched by anybody. Especially when they do it gently.

Stephanie 13:23

Oh, is it overstimulating? Is that why you don't like it?

Bill 13:27

Yeah, when they do it rough and they don't take care. It's no problem. But when they try to be gentle. Like my wife tries to be gentle. That really drives my senses nuts.

Stephanie 13:39

Yeah, right.

Bill 13:40

I might act up and she's trying to be nice and friendly and loving. And I'm being a bit nasty, but it's not me. It's that hand. That hand makes me do that.

Stephanie 13:52

Yeah, actually, I know exactly. What do you mean, It's almost like this because it's so gentle you know, your brain has enough time to receive all the messages from the hair, the tiny hairs in your arm or , wherever it's almost more distressing. So, yeah, when I go to the dentist, for example, when he's drilling on my right hand side, it doesn't hurt at all. Whereas like, tickles that is torture to me.

Bill 14:29

Right? It's like that anticipation of being tickled. You know, when people are gonna get tickled you're gonna go tickle somebody, and then they get all this strange feeling. They start laughing and they start freaking out and they haven't ever been tickled yet and then you tickle them. And it gets worse.

Stephanie 14:46

Yeah, it's a really weird thing. It really is. I, you know, we don't really know how the brain truly work and you know, all the things you take for granted like pain and, and pressure, things like that it really does all go out the window and is all very unique to to everyone. So yeah, like another weird thing after the stroke when I sneeze every, like three times every time I sneeze it's like three times and something happens when I scratch my nose and my thumb comes out the way that

I've been trying to, you know, practice in ot exercises for years. So it's really weird.

Bill 15:45

Seems like there's been a bit of a muddled up reconnection somewhere and things are firing and triggering in different in different ways.

Stephanie 15:54

Yeah, definitely like to think that there's literally a void space in my brain the size of a golf ball. And you know the fact that I'm able to talk to you have this conversation is a miracle in itself because they tell me that there's no language center anymore. So whatever way that my brain managed to hodgepodge these, like, connections I I'm still very very thankful because it still works or maybe not perfectly but I'm okay with sneezing three times.

Bill 16:34

Of course, except when you sneeze during Corona does people freak out? Oh my god she's sneezing.

Stephanie 16:43

Oh, yes, Corona. Can you believe we've found ourselves in this time? I it's helpful that we're able to have this conversation across borders because I'm in Sydney. you're in Melbourne, right? But, you know, I was just, I was actually just contemplating certain things about this, you know wide-spread pandemic, which now has made it, you know, all these issues, a collective one, everyone's going through the same thing roughly.

Stephanie 17:23

And I can't help but draw the parallels between, you know, people talk about anxiety and depression and trying to deal with uncertainty. These are all things that, you know, stroke survivors have to go through and in isolation, there is no other poor people where you can just say, hey, I'm feeling or going through this.

Stephanie 17:50

And how about you and having that camaraderie or support. It's just really hard because, at least for me, and I know that this goes for a lot of other people. When you go through stroke, most people thinking about the more obvious physical science which is not able to walk or talk or to do usual activities, but really, it's the sense of self that you lose and that of course makes you feel very isolated.

Stephanie 18:31

So yeah, when you're literally stuck at home because you can't do anything else, because you has really, really severe chronic fatigue issues. Where you know, going up getting out of bed and and brushing your teeth and having a shower is not to you know, you're like spent for the whole day. I think it's just funny because I'm like, you know what, I know that there's a whole pool of people who, yes, it's hard but can really deal with this. I think we've all gone through that before.

Dealing with stroke recovery and isolation

Bill 19:11

I agree with you. I was asked very early on when isolation started, how I'm coping or what was happening for me. And I was like, well, I've been here before, I don't really have an issue with isolation, per se. I'm not working again. And I know what that's like. I'm not out and about again, I know what that's like a limited amount of times where I can do stuff and for short amounts of time.

Bill 19:37

And all that stuff was really familiar, but where I noticed a slight difference in some other stroke survivors, I'm coaching somebody who is going through stroke recovery now and they are very early on in their stroke recovery. They don't have that distance like you and I have where I have eight years post stroke. Reflecting on it is an interesting reflection and you have 10 years.

Bill 20:05

And you're seeing the similarities and it's kind of familiar, but she's going through isolation from both stroke, and Coronavirus. So it kind of made it worse because she was really keen to get out and about and get rehab and put an end to rehab. So when I was reflecting on my experience, that's kind of what I noticed.

Bill 20:30

That's the main difference is that some stroke survivors are going through isolation times too, so to speak. And we are going through that second phase of isolation at a distance reflecting back on it and it's saying that it's familiar and we're okay with it and we know that it will pass and things will get better. But people who are right in it now, they haven't experienced that yet and they can't reflect that it will pass.

Stephanie 20:55

What a what a traumatic point. To imagine because oh my goodness did I miss thinking about during this period, you know, during my initial period of recovery, it was all about just trying to like squeeze out every single bit of flick of movement or any recovery I could get and to think that she has another huge hurdle to, consider, like let alone stroke is bad enough in itself.

Stephanie 21:34

But not being able to access the appropriate services and it's all about, you know, they talk about the golden windows or like three months to a year to, etc. Not to say that I truly believe in that I think people will continue to recover as much as they, you know, put out but there is truth in that first initial window. Yeah, I wish the best of luck to her because that must be so hard.

Bill 22:06

Yeah, what's good about it is that she's getting better and things have started is so she's got back to rehabilitation, which was really exciting for her. And the other issue was that minimize the amount of carers that were coming to her home. She was somebody who was living on her own. So the carers that were coming in and helping her that had to minimize all of that sort of stuff.

Bill 22:30

So then she started to get back on board, she started to get into rehab again, it started to lift her spirits, so she started to feel better. But of course, you know, there's the roller coaster ride of emotions, all those things that stroke survivors go through that, we know about our community knows about the people outside of stroke don't know about and I think it just made matters worse for her and what was really good was that at that time, she was really smart to reach out and go help somewhere.

Bill 23:02

So, she reached out to me, we began a coaching conversation. And that really made a difference it got out of some of those really difficult times where she needed to express herself and get stuff off her chest, and vent and do all those things. And she was able to do that. And then we're able to have this conversation backwards and forwards, even through email, or just messenger or something like that.

Bill 23:25

Just to spark a conversation. That's about something other than focusing on what the problems are. So stroke survivors that are listening would benefit really well by reaching out to somebody, whoever it is, and just saying, hey, let's have a chat, or can we have a chat or whatever, you know.

Stephanie 23:46

I'm so glad that she did. But the thing is, I feel to her for many reasons, but one of which is she's not a part of this what happens you know, most people, when they are beginning the path of recovery, they go into the, the gym and they see other people, maybe similar, maybe dissimilar, but at least you have a bit of a gauge of what other people are going through. Now, as I mentioned before, it's isolating itself, but to do it, sure you have clinicians and allied health people come in, but you don't really know how you're going.

Bill 24:36

Yeah you're missing a lot of information and feedback from people. And continuity in your recovery is sort of all over the place. And I felt really good about knowing that I had continuity of my recovery. So I started a certain day. This is the plan. There's all the things that we're going to do and that's going to continue for a certain amount of time, and that began for her. Everything was going great and then it stopped. So it did interfere with the continuity and the way that she felt about knowing where she was going because like, alright, am I going to get worse? What do I do now?

Stephanie 25:08

Yeah, ofcourse and also just having a benchmark, you know, I had a lot of people around me we had, who had knee and hip replacements. And I'm the single, you know, stroke patient who's young. So that kind of puts me up out as an outlier, which is I don't think it's true. Yeah, it's, um, there's so much value in being able to befriend someone and being able to just ask questions and know that oh, wow, that's normal. So that kind of puts my heart at ease and I can move on to the next stage or? Yeah, I think me being able to help her through that. It's going to be invaluable.

Bill 25:57

It is invaluable. That's What I was seeking when I was going through that, and I didn't have enough people to connect with either because the things on the

internet once are happening yet, you know, there were stroke survivor communities that I was getting involved in. I was 37. And those people that I was getting involved with lovely people, there's no issues there.

Bill 26:16

But they were in their late 60s in that and it was just something that I couldn't really relate to, of course, we related to the stroke recovery side of it relate to anything else. So it didn't really create a great connection for me. But I did make one amazing friend who was another stroke survivor, who I bumped into because it was just before my surgery, and somehow I bumped into him and we got in touch.

Being a young stroke survivor

Bill 26:45

And I asked him if I could speak with him before my surgery just because he was 10 years post-stroke then. And he was what I needed to see going into surgery I needed to see an example of what's possible, you know, And then Andrew became one of my best mates and he became somebody that really made a massive difference to me and inspired me to want to do the most I could do to get better you know? And I was lucky like that but very early on that isolation that being at home on my own, not having anyone to relate to was a big issue. I was 37 like, what's that like for a 22-year-old?

Stephanie 27:29

Yeah, you talking about it just reminds me oh, how crazy it is to navigate every single part of your life. And I really mean every single part because, you know, people think about, you know, work on relationships and friendships I'm talking about, well, I can't get out of bed without help my parents. I need to mediate between what kind of clothes I want to Because I can't express myself because I quote, I can't talk anymore.

Stephanie 28:07

I don't. It's very unfair to compare because I think it's just everyone's too unique, their strokes, and their personalities. But as a young stroke survivor, there's the added layer of just misconception or just lack of knowledge. You know, I think for example, if I can draw parallels between cancer and stroke, there's a lot of public awareness of what cancer is, you know, cancer is a thing that affects a lot of

people. There are multiple types of cancer people know this, but you have heatstroke and you think, Okay, I know it's it's a bad thing.

Stephanie 28:53

I think it's like a grandma and grandpa, you know, old older disease but People don't even know what the science of his stroke is, let alone you know what the recovery process would be. So I think it's just crazy to think that once the doctors are so great at keeping us alive, and then they gave us some rehab for a few months, and they just bid you farewell and you know, best of luck to you.

Stephanie 29:27

And I'm not saying I am trivializing it a bit, but essentially I think it won one way or another, you one day find yourself at home sitting there and just thinking what next I'm just freaking out. And people, you know, they're very kind and very lovely to say things like well, you must be very, very brave or, you know, very inspirational to get through all this together.

Stephanie 30:00

To be completely honest, what is more, truthful is I was so desperate I was just so desperate to get as much as I could back. I remember telling myself one day to put my feelings aside like all my emotions one day aside because I just need that this is the golden period for me to just give everything I had and then I will I'll allow myself to wallow and cry at the end just in case like it doesn't work out but yeah, I was just like, almost staring at down the barrel of a gun and going for a quiz that was my time.

Stephanie 30:47

And then on top of that very so you had this like make or break mission of life. And then I have lovely friends. Of course. Trying to be as supportive as they could. And it was a whole mess of just me not caring about all this other stuff that we used to care about, you know, like fashion, or like going out to parties and things like that, like I had a job to do. And then yeah, on top of that was the the lack of communication expression.

Stephanie 31:29

Just physically not being able to go to parties knowing that I couldn't go to the beach because my balance was off balance. I couldn't trust myself. I remember like going and going away once and it's my fault, but I kind of went out into the

ocean and I everyone else was out there and I just thought, you know what, I'm gonna see how I go and of course, I stumbled I got, you know myself a bit cut with oysters and yeah, I, I just knew that I had a new benchmark of things that I could achieve. And that was okay because I am now in you know, new goals for myself.

Bill 32:19

Yeah, we remember you reminded me of a couple of things that happened to me going back into the page and into water. And again, I mean, I even had my own misconceptions about stroke recovery. Even when I was two or three or four years down the check. I thought everything just goes he's gonna go back to normal.

Bill 32:39

You know, and it's like, I've gone into the water I remember at the beach this one time and I couldn't stand up because there were some waves coming through and they were just knocking me over. And it was like, far out man. This is so difficult. Trying to walk into the sand is so difficult because the waves making me Visually I lose my balance as well as actually in physically lose my balance.

Bill 33:05

So that was really strange to experience that. And then the other thing that was happening is the sand and the little shells and all those things that normally don't bother my other leg. Oh, really hurting my leg. And I'm going, Wow, this is way too painful. I've got to really get in really quickly and stop floating.

Bill 33:25

Because it hurts and I don't have another way to get into the water. I'm gonna have to suck it up a little bit and get you know, experience some pain, right? Wow, that was interesting. And now when I go to the beach I wear you know, beach shoes or whatever they call them. Yeah, rubber soles. I can actually walk into the water with otherwise. It's no fun.

Stephanie 33:47

So that was the first time you went back to the beach?

Bill 33:51

First time back and it was just something that I never expected. And it reminds me of a time when I did when I was I danced again for the first time with my wife, you know, we went to this ball and we just did this little dance. And I was way out of my comfort zone. I couldn't talk about two lifts fit. Oh my gosh, like, it was

terrible

Stephanie 34:14

for dancing the first place

Bill 34:16

I tried and then I was like, Well, no, no, I can't do this. I'm not going to do this because I'm going to fall over. And I don't want to be embarrassed when I fall, but I don't want to hurt myself and hit my head and and that's what made it really concerning.

Stephanie 34:30

Well, you caught the dancer beforehand,

Bill 34:32

not really. I wouldn't call myself a dancer. But you know, just gonna have one of those things that men do that hold their wife and they just do this thing and they're like, yeah, just get one of these things, you know? But those two experiences now that you've reminded me were almost traumatic to go and do again, but fun.

Bill 34:55

Once I got past all the trauma, but there were a little bit scary and then I remember But we ran out to this amazing waterfall just near where we live a couple of hours drive away. And it's a waterfall. And of course at the bottom of the waterfall, there's a big lake. And people go there and they climb down all these stairs and they get to the bottom of this, of this waterfall, and then they just swim in the lagoon and it's amazing.

Bill 35:19

It's beautiful. But the difference is, it's. Freshwater, you don't float like you do by water. Of course, I didn't know that. So I decided it's nice and flat and perfect for swimming. And I was gonna swim from the shore to underneath the waterfall. I was about halfway in and I became extremely immediately and I couldn't swim.

Bill 35:48

And I was like, go under and I thought I was gonna drown. So I got I was with people and I grabbed on to the person who was next to me just to get my breath and I told them to help me get back out. But that whole misconception, my own

misconceptions about what recovery was. And imagine somebody who's never had a stroke, like, the misconceptions that just through the roof, they've got no idea.

Stephanie 36:18

Yeah, I actually think it's, um, I would actually be more surprised if a person had a conception for me to prove wrong. I actually think stroke is so ill. I understood that people wouldn't know where to start. And I often get really cranky. When I hear or see, like, even in TV shows, American TV shows, they'll often use stroke as the butt of the joke of like, you having a stroke or you know, are you talking something wrong or there though it doesn't add to, to the public awareness at all, but I think it's fairly high because once you get to a point where you recover well enough to essentially reinsert yourself into normal society and then there's no rulebook, there's literally everything you used to do.

Stephanie 37:31

And then you just have to kind of like I say, you know, don't think about a 200 and see how far you go make sure you have someone around you but it is incredible to, to kind of go through the same thing used to do day in day out, it's almost a muscle memory and then for you to experience it all again for the first time.

Stephanie 37:57

And I think it's it's really doing Wanting and really scary, but it can be very rewarding and immigrating. If you give yourself that that chance. I think there's a lot of people who have that this is a whole other topic but of self identity where, you know, most people as assume that there are a certain person where they derive value in what they do their friends, because they drive, you know, all these portfolios, external factors.

Stephanie 38:36

And then when you find yourself in a hospital bed, unable to talk a walk or even use your phone, you start you start becoming fairly, very keenly aware of the person you are. And I think it's, it's very daunting when you go back out into that world. And you have to rediscover you and that at that world and how that intermingles and whether that works still. And that can be very hard to swallow when you realize that you can't really quite do the same things you used to do.

Bill 39:20

And you're discovering that while you're recovering from stroke, so it's not an

easy thing to reinvent yourself, rediscover yourself and then have to recover from stroke, overcome fatigue, all that kind of jazz. And it's like, I'm going to talk about needing to really dig deep and understand yourself and discover who you are.

Bill 39:41

And I think that's a really great point that you made is it's also difficult for people who discover what they are after the show, because sometimes they might discover that and he is you know, and I'm speaking from experience, who they are is sad. Somebody who's just stupidly focusing on Work, Work Work many, many, many, many, many all this stuff.

Bill 40:07

And then when I don't have any of that stuff, it's like, alright, what the hell else do I have? Like, who am I? What do I do with my life? Other than work? Who do I connect with and talk to other than people who I go to work with? How boring is my life like, that's kind of how I was thinking. And then I just went on a journey to find people that were amazing people to be with had nothing to do with work, or all the other stuff that I used to do cars going out any of that stuff.

Bill 40:35

They only had to do with stuff that was related to actually helping me grow and have an example of how to be a work guy, but also layer in some other amazing things that I could be not just a work guy. I could be a caring person. I could be a volunteer, which I am. I could be a podcaster which I am And all these things started to come into my reality as in, you don't have to just be the guy that goes to work and does that and nothing else. And then when that's gone, you're nobody.

Stephanie 41:11

Yeah, that's right. That's right.

Intro 41:16

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? Doctors will explain things, but obviously, because you've never had a stroke before, you probably don't know what questions to ask.

Intro 41:41

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. 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.

Reinventing yourself after stroke

Stephanie 42:28

It's really interesting how you say that I particularly love the word that you use, which is reinventing yourself because. I think that's very true. And it could be the single difference between how well you recover and I don't just mean physically I mean, mentally, being able to face yourself and look yourself in the mirror and realize that the person that you once was the one that everyone still identifies you with, because you still have the same face needs to be reinvented.

Stephanie 43:12

And I think, not to be too corny but it is true. When you go through a life-altering event, you're shaken up to the core and it's only natural for you to kind of shift everything your values what you believe in what you care about out the window and start rebuilding from scratch. I think it's a blessing and could be a curse, depending on how much you're able to accept what's happened.

Stephanie 43:50

And I know that it's all very different from what other people because, for example, I had my stroke from AVM. So Arteriovenous Malformation which I was born with. So a, it wasn't a lifestyle driven. It wasn't my fault per se. It was no one fault either, it's a random tangle of veins, which one day ruptured. And from that point, I think I was able to draw a line in the sand and realize that's what that's happened. And I can progress past that. But even before you asked me, whether talking about this, you know, did conjures up maybe feelings are not. I think that helps, you know, going through that grieving process grieving the past self of the person you once were whereas some people yeah, it's not as easy and I think.

Bill 44:57

Yeah, and I think mindset comes into it. And I know people talk about mindset a lot. But there's, you know, the work from Carol Dweck, she talks about the fixed mindset and the growth mindset. And if you're going through stroke, and I'm talking to people who are listening and watching now, if you're going through stroke, and you don't like who you are after stroke, as in the thinking back, and you're going, I did this, and I did that. And that's all I ever did. And now I can't do that. So who the heck am I? if you're gonna try and get back to who you were, you're going back to the person you were before you had a stroke.

Stephanie 45:41

That's a good point and we know how that ended up.

Bill 45:43

Yeah, right. You maybe don't want to go there exactly you know. And if you remain fixed in that previous mindset, you're going to struggle and you're going to suffer. The pain that it takes to go back to something that you can't get back. Once you step in a river and then you step out of that river. If you step back in that river, again, that river has changed, it may be in the same place and look the same.

Bill 46:08

But you've done something and you disturb the rocks in that river, and they've gone elsewhere. And slowly the banks are eroding, and the river is widening or shortening in some places or becoming more narrow. That's how we are when things happen and we change, that change has occurred. And now we have to find a way to evolve with the changes that are occurring. And that's where the growth mindset comes into it and what does a growth mindset mean?

Bill 46:37

I'm not going to give you a definition, but from my perspective, it's just being able to accept that things are going to change, allow them to change, and see what I gained from that change. If I gained something, even if it's knowledge, that I'm shit at change, that's still good because I learned at the moment, I'm not good at change and soon If I allow more change to occur, I might get better at it.

Stephanie 47:03

Yeah, absolutely. I think it's, um, it's so real internal Invisible war against yourself. You know, I think our brains are, of course hardwired to be quite

effective in being lazy, you know, that's why we have motor muscle memory, but when you like completely just hide and nothing else is what you used to know or believe you kind of are forced to survive by going with the change otherwise.

Stephanie 47:49

To me, the the opposite is not even an option because I wanted to be happy I wanted to be fulfilled maybe in a different version of what I used to imagine myself to be living but you know as cheesy as it can be I am happier more content and at peace with myself but only through having gone through the hard work of you know grieving the whole five stages of grieving is a real thing like the denial the anger all that in a certain wasn't easy and i think i don't know why in the hospital we are not given that option to to talk to a counselor or psych.

Stephanie 48:49

I never got offered that chance until much later. You know, I just feel like I should maybe even just chat with someone to make sure that I'm dealing with things. I have not forgotten something. And then I think what really frightens me is, so far I've had a fairly good journey. But one day, I would hate to think that I had this, I would have this thought. And then I would break down, you know, in this puddle because I just had this huge blind side, which I'd never thought about. So yeah, I think it's just can be very difficult that way.

Bill 49:39

I love what you said there about counseling. I mean, I went to counseling seven days after the first bleed in my brain, just because I was already seeing a counselor. And she's a smart lady. So I thought, Oh my gosh, like I need to go and tell her about what's happened to me, so that we can talk about it and blah, blah, blah.

Bill 49:59

And that was really Really good. But you're right. Not one time. Not one person came and said to me, like, how are you dealing with what you've just woken up from? And not in the sense of like, what's your body doing because they focus on your body, It's like, what about your emotional well being and your mental well being? Stroke survivors are crying at the drop of a hat all the time. And not one person says, maybe part of the stroke recovery journey needs to include counseling.

Lack of emotional counseling

Stephanie 50:37

It's just baffling to me because yes, yes, we have between you and I, we have 18 years of experience, but I think it is baffling. Because it's so ironic. You know, we're talking about the brain. You know, where every decision every muscle movement, it all starts from one big mass of an organ. And I am I'm so passionate about this particular point.

Stephanie 51:08

And I kind of like hop on and on about this in different rehab and stroke boards because I think people forget that again. You might be very good at saving my life but what kind of life are you letting me live if I'm not fully okay to still own my life and I mean that by knowing your when you wake up, people would give you meals they tell you when to shower, they tell you when to exercise, and then you just get dropped back home thinking yeah, off you go and I don't think it's very fair.

Stephanie 52:00

Or reasonable to expect that a person will just pick up where you left off. And for me to be completely autonomous or feel empowered enough to have been educated, and that's a whole other thing to keep going, you know, neurological conditions are very like literally the hardest thing to really get better. It's often lifetime kind of maintenance thing.

Stephanie 52:30

And you just expect me to know what I'm doing whereas you know, when I do my sit to stand thirty times every day you not explained to me why I'm doing them all kind of muscles you're trying to ask a to activate it's a missed opportunity. And luckily between I guess when we had our strokes, you know, good 10 eight years ago, now It's a lot better, I'm so pleased and relieved to know that there is a now shift to a patient centered care and they are now beginning to realize that the patient can actually be an asset, let alone also the subject matter experts themselves, they just please do ask them. Ask them what goals they want, because you'd be surprised. Even though we might be strict about work attire. We have, you know, us behind us, we do have our own brains and knowledge, please use that asset as well.

Bill 53:45

Yeah, it's interesting. I, I did get asked by two people what I wanted to achieve in rehab. And imagine how many people I saw like we saw we always see heaps and heaps of people at the beginning. There was only two people that have asked me what I wanted to achieve a one on one in outpatient rehab, and that was when I wanted to get to the point of running and not running a marathon but just running off the road, for example.

Bill 54:09

Yeah, safety running. And that person asked me, What would you like to achieve? And I said that and that's what we worked on. So that was really amazing. And then another person asked me, What would I feel comfortable doing, what kind of exercises and because I was at a facility that had a swimming pool, when I was learning how to walk again, I asked them to let me use the swimming pool to walk.

Bill 54:33

And that was amazing, because I felt safe. It was warm. It wasn't heavy, you know, I was being you know, I was kind of floating. And I was just feeling I felt completely safe. And those two things made such a massive difference that A that I had a choice. And be that I will then actually they had the insight to ask me whereas before that the whole process where they evaluated me Included only.

Bill 55:02

This is what we're going to do, these are the exercises that we're going to do. And it came a lot later when they asked me what I wanted to do. So it meant so much to me to be able to give them my version of what I wanted to do. And, of course, then I was more motivated, I was happier to be there. I was gonna, by default, create more neuroplasticity and get better results just because I was motivated.

Stephanie 55:31

Of course, I just think that, you know, it's been so long ago, but those still spot that sparkle in your eye. Just like can you imagine if they did that throughout your recovery? You know, can you imagine how much better and how much less stress or heartache you could save. I'm always saying that you might be exercising your foot or an arm.

Stephanie 56:06

And that's a physical result. But what we're really exercising is the brain. And it's

not like a broken bone where if I just left it would just heal by itself. It is the most cruel and boring thing you will ever go through, you know, doing 50 100 mundane exercises, but that's the that's the what I call the nugget of gold, where you really need to kind of, I often use the example of rehab needs to be as as difficult as almost like a hard math problem.

Stephanie 56:52

If you're doing an exercise, that it's really challenging and it's just making your brains scrambled because it's so hard. You are literally shedding those synapse fires between the brain and the part of the brain of the body you're trying to move. And I hope, I wish I wish a therapist had told me this much, much earlier because until I realized the difference, it's not like I'm going to the gym to be like a, you know, a meathead gym junkie.

Stephanie 57:29

It's I'm actually trying to do a really hard math problem like with my body. So having that education, I think is key. Having that bringing that person along, the ride of their recovery, explaining why things are happening. They are, why they are and how we should be doing them brings up that you know, motivation that you mentioned, but also the the empower and autonomy that comes along with that.

Stephanie 58:03

So when you know, put them out to the real world they'll feel confident enough to continue on with that and then using those principles of goals and also what you were trying to achieve they'll you know Westmont so we'll be able to slightly fine-tune in different aspects or activities, you know, ultimately rehab is really about being able to function in day to day life and I try to do that with everything I do when I went back to work. That was the ultimate speech therapy really, you know, in every way. So, yeah, I wish we had more autonomy, you know, and less that's kind of wrapped up in Cornwall.

Bill 58:30

I remember you said some things that triggered my memory again. And I remember when I was playing soccer as a 27-year-old or something like that. You would get ready for the game, first game of the year, and you would do a whole bunch of training and then you would go and play the game and you would realize, no matter how much training I do, I'm not game fit. I am still not able to

sustain myself for a whole entire game.

Stephanie 59:30

I totally understand that.

Bill 59:31

Yeah right? And isn't that's what stroke recoveries like because I did, probably four years of rehab recovery, all those things. And after surgery, I was probably out of action, maybe for about another two years. So maybe five years, where I was doing a whole bunch of stuff that was related to me. Recovering and healing where I was focused on it a lot. And then I went to work in an office behind the computer for the first time after five years. My lord. Oh my god, no match fitness. I could not get through three minutes of sitting behind that screen, you know?

Stephanie 1:00:19

Yeah.

Bill 1:00:20

Slowly slowly. That ramped up over three years, it ramped up to where I was more capable, but still not fully comfortable with being behind the computer for many, many hours without breaks and all that kind of thing. I was always up and about. So that's what that reminds me of that match fitness doesn't come from just going to rehabilitation because it doesn't create real-world situations, does it?

Stephanie 1:00:45

Yeah, I love that analogy. Particularly maybe because I'm also a football supporter. Maybe I don't want to know, who you support we'll talk about that later. But I think I'm the brain it's so effective that you know the term or the saying use it or lose it is really, really well in effect. But the thing is when we do rehab exercises in the hospital or at home those are very controlled environments you know you are not distracted you're not you're not I get stressed because you know that you're not being watched by another person.

Stephanie 1:01:31

Once you're out there you there's only so much we can do before you know matchday but that's the point like put a date and then go out there and just see how it go. Make sure you have those safety nets of you know, a person you can call at any time or for me it's always like a bottle of water and bit of sugar because that oh, you know, brain loves the carbs.

Stephanie 1:02:00

So I had that, that fix, but I think I think when I went back to work, which was two years after I had, you know, I didn't really know what had happened to me, all I knew was it was really bad. And I couldn't wait one more moment to just not try and get better that I just work and work and work. And I literally use my rehab became my new nine to five job. I had seven doctors, you know, every day, I had seven hours or something.

Stephanie 1:02:40

Yeah, I had three boxes to take every day and that was PT, OT and speech and, you know, I just make sure that I was just, you know, covering all my ground. But then on the day that I go back to work which is, you know, two years on It was just so it's almost comical because I like geared myself out so much. And then at the time I still living with my parents and I they live in back in the Shire into the city on the train that's like 45 minutes at a time and no Express services at the time so that's two hours just traveling.

Stephanie 1:03:30

And then I think I started off with just two hours for the first day going back and I was just wrecked. I've never been so wrecked, because your brain A like first of all, first of all, you're in this unknown environment, you're completely bugged, you're fully engaged. You feel like everything is attacking you in a weird way because It's also very new. So your concentration is to, you know, maximum 100% just ready to fight and flight, just in case.

Stephanie 1:04:10

And then. And then of course, when you go back to work, I work for a financial services company. At the time I was in consulting and there's a lot of young new people, two years on of course, half hold on for I didn't really know and also meant people didn't know me or what's happened to me.

The more we do it the easier it gets

Stephanie 1:04:36

So everything was a challenge. Everything was really really hard. And I think I'm not until you kind of do much as you can. In terms of prepping and then you go out and just test it. Yeah, it's A it's gonna be very really exhausting. It's gonna be really daunting, but the good news is, the more we do it, the easier gets, it's just

any, like anything else practice does make it so much easier.

Stephanie 1:05:09

I went from working three days a week, two hours a day to increasing that to three hours, four hours, and then so on and so forth. And I'm so relieved to say that that's happened. Because fatigue is just another thing to, you know, you can either make it or break, whether you can or not increase those hours. But I, I hesitate to actually share this part, but I'll just say it anyway, but this has worked for me. So there's a caveat.

Stephanie 1:05:46

But I remember thinking, you know, if the brain is the muscle, which it is, I'm going to, you know, I'm going to test myself push myself a little more each day. So there's this moment where you feel completely just, you are a zombie. You are like less, you know, it's like you've had 10 beers kind of thing, and you're just really out of it.

Stephanie 1:06:14

And I just remember, you know what, I'm gonna work for an extra 10 minutes and see how long ago and I kind of apply that every day. And like, sometimes he had this like, buzzy headache where your body is telling you you're new. You need to shut down. I went through that. And then yeah, somehow it kind of just got better and easier. Shoal. Everything else was getting easier as well. So maybe I was refocusing that energy to those 10 minutes, who knows? But it all kind of worked. I think pushing yourself within reason. did help me at least for my fatigue.

Bill 1:07:02

Yeah, it's one of those lessons learned. You have to actually, it's like anything, you've got to overdo it to work out where your limit is. And then you know, okay, I actually over did it for only five minutes and I achieved something and it didn't bother me and it was okay. But overdoing it for half an hour wiped me out. that's not for me to do. I'll just take it easy. And I'll be gentle on myself and I want to give myself a hard time. If I don't succeed, you know, I'll just say easy.

Stephanie 1:07:32

That's it the fact that you would try and you would be brave enough to to risk, you know, humiliation or to ask for help. That in itself is something to be congratulated and to celebrate. So you should definitely be very kind to yourself,

you know, you know that saying of, you know, half of the battle is turning up. So people who have had strokes is even more so. Because we work so much to get to back to like, you know, like that I, I have to do all that stuff. You know, we should kind of um take the time to, to appreciate that because of all people we should be able to know just how much we've gone through.

Bill 1:08:30

Yeah, one of the lessons I learned was if I thought about something that was challenging or difficult, like being in a place where there was going to be a lot of people a party or family gathering or something. The simple response was, no, I don't want to go, I'm not going and then and then that was really easy to fall into that routine and then end up nowhere and then always be isolated.

Bill 1:08:54

So it became Alright, I'll go and then when I went It wasn't about interacting or hanging out or talking rubbish or drinking beers or anything like that. It was just about actually getting there the task was to get there. And then everything else that came was a bonus. So if it came to it that I got to stand up by the barbecue and turn me around like men do, but then that was a bonus. If I didn't have the energy to do that, I sat there with the chair.

Bill 1:09:25

I kind of allowed myself to do to not talk myself out of something. Because previously if I had gone there, I would have done all these things and participated in this way. And in that way, this was now just about turning up and that's it.

Stephanie 1:09:41

Absolutely, Oh, I love the way that you reframe that. Because it really is about taking you one thing at a time. But to me it's also a missed opportunity. You know, we talked about rehab ultimately being us going out back into the world. I the one thing that I really, really struggled with was not being able to communicate and therefore express myself, not just, I need this or I want that I want to express my humor, I want to connect with people.

Stephanie 1:10:23

That was very, very hard. So, as I said, I could have as a 22 year old, you know, it's all about being cool. And you know, which I'm still with no, but the thing is, I realized that if I, if I started saying, No, it was, oh, I would most likely start

having that habit. So I found a little hack actually, for anyone who is suffering from aphasia, which Probably one of three people in jail after having a stroke.

Stephanie 1:11:03

So you're not alone. I really enjoyed going to bars because I'm a people are pretty tipsy anyways, so you're forgiven if you're having to repeat yourself. It's very loud. So you're, also forgive them because you're talking slower because you need to enunciate. And I'm telling you, it's the most. It's almost counterintuitive, but it's a very safe space to do that because no one really cares about that.

Stephanie 1:11:42

Really, people don't care too much about what you say, or what you're not saying. Turns out people are fairly self-centered in general. So if you're really struggling, you'll be surprised how much people will quickly you know, step in and say you must be like, oh, they'll try and finish your sentence for you. So, yeah, for me, that was a really nice hack, but also kept my confidence up, you know, it allowed me to maintain my friendship circles. Sure. I was like, oh, applying an overlay of rehab lens of rehab, which helps.

Stephanie 1:12:33

But you know, it's so important to still go get out there and just not be too worried about how other people see you. Because ultimately, if they don't see the value or the beauty of the person that is still within you, then maybe they're not the right friend you need anyway. So yeah, having a strike is weirdly great as sifting good, and not so good friends.

Bill 1:13:04

There's definitely a lot of good things that came out of my stroke okay, that looks like it is an awesome way to end the episode. Thank you so much for coming on and sharing your insights into stroke. I think it's gonna make a world of difference. These types of episodes do make a difference. People listen to them. They don't feel alone. They don't feel like they're the only one thinking the stuff that we spoke about. And as a result of that, maybe some of the things that we said can trigger their mind and make them think about perhaps how they go about their own stroke recovery and what they could do differently. So thanks for doing that. I really appreciate it.

Stephanie 1:13:42

No my pleasure, Bill. It's been a pleasure and I really enjoyed it. Thank you so much.

Intro 1:13:48

Discover how to support your recovery after stroke go to recoveryafterstroke.com