Pontine Stroke Recovery - Ginn Thompson

Ginn Thompson is on the road to Pontine Stroke Recovery which occurred in March 2022 when she was age 38.

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Ginn Thompson 0:00

From when I had my stroke on a Thursday, to even when I was in the hospital, I was either breastfeeding or pumping, which isn't an easy thing to do when you're okay. And that can be really draining, and I don't know how I did that. I think when I look back on it was a really incredible thing. And I am proud of myself for doing that.

Intro 0:35

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

Bill 0:49

Hello, and welcome to episode 212 of the recovery after stroke podcast. If you are a stroke survivor with a story to share about your experience with stroke, and you have been thinking about reaching out to be a guest on the show but we're waiting for the right time to reach out, this is it.

Bill 1:04

If you go to recoveryafterstroke.com/contact, you will find a form that you can fill out to apply to be a guest on the show. As soon as I receive it I will respond with more details on how you can choose a time that works for you and me to meet over zoom.

Introduction



Bill 1:20

My guest today is Ginn Thompson, who was breastfeeding her newest baby boy and recovering from a stroke at the same time. Ginn Thompson welcome to the podcast.

Ginn Thompson 1:29 Thank you for having me.

Bill 1:31

My pleasure. Thank you for being here and reaching out and agreeing to be interviewed. Tell me a little bit about what happened to you.

Pontine Stroke

Ginn Thompson 1:39

Well, back in February of 2022, I had a baby, my third son every single week, pretty well as expected. And then about six weeks later, I went to follow up with my doctor. I think it was a Tuesday I got cleared, all was good and two days later, I had a pontine stroke.

Bill 2:04

Did they know the cause of the stroke?

Ginn Thompson 2:10

They have not figured out the cause. I have no underlying heart issues, I'm not on birth control, I just had a baby obviously. The ultrasounds of all my arteries everything have been fine. So no history of it in my family. Nothing that would indicate that I could potentially have one.

Bill 2:36

And you are only 38 years old.

Ginn Thompson 2:39

Yeah, it was the day before my 39th birthday.

Bill 2:43

Wow. That's a heck of a way to be spending your 39th birthday.

Ginn Thompson 2:48

It was I was sitting on the couch feeding my son. And I stood up and all of a sudden, my eye was very hot. Like I had touched a jalapeno and then touched it and all of a sudden I got very dizzy. And I don't remember a lot of my birthday this year. But somehow we made it through and I continued to feed him until I went into the hospital on a Monday afterwards.

Bill 3:25

Okay, so how many days lapsed between that incident and then when you went to hospital?

Ginn Thompson 3:33

So my father is a physician he lives in Ohio. My mom was actually here visiting us

on that Thursday night when it happened. It happened about 7:30 Central time I believe. When it happened she immediately FaceTimed him to look at me and make sure he thought we shouldn't go straight to the hospital because I could not stand up.

Ginn Thompson 4:00

He said, let's sit down and I did not have a lot of the symptoms that you normally see on a stroke survivor I had no drooping, I could raise my arms fine. So we stayed until about 24 hours later. And by the middle of the day she FaceTimed him again and he looked at me and said you need to go to the hospital.

Another Case of Misdiagnosis

Ginn Thompson 4:33

We went to the hospital and they sent me home. They thought it was a migraine. Because I just had a baby they thought it was something related to that they did a CT, showed nothing. By Sunday when I still couldn't talk I sounded like my four year old little boy, just slurring my words.

Ginn Thompson 4:59

We decided we needed to get someone to order us an MRI pretty quick. Monday morning, we tried my family doctor here where I live, we tried my OB, and we did not feel like we should go back to the hospital that sent me home. So we went to a hospital in the nearest big city, which is about an hour away. And they didn't believe me either. That that's what I thought I'd had. Triage took about an hour to even take me back to a room. It was quite frustrating the whole process.

Bill 5:42

That whole thing, it's the one thing that irritates me so much when I hear people saying the doctor didn't believe me. I mean, if somebody comes in and says, I think I'm having a stroke, wouldn't it be better to rule it out, rather than assume it's not there. I know, they're human so I'm gonna give them a break, and because of them, we're here and all that kind of stuff.

Bill 6:10

But the assumption that you know what it is just because that person has walked into your hospital, and you already know what it isn't, or what it is. He's just insane that they do that without any information without any proof. One way or

the other. I can't get over it. I hear it's so often, I would have thought it was a thing of the past, you know, I've been going on this journey for 10 years myself, I would have thought by now it was a thing of the past, but it's not, it's so common to hear that people get turned away from the one place that they go to for help.

Ginn Thompson 6:51

Well, it's very frustrating, because that's what was going on. I told them, that's what I thought was going on. And it's almost like they didn't even listen to the symptoms that I was presenting. I felt very alone. The medical community wanted nothing to do with me, because I had no warning signs, I had nothing that could put me in the category of having a stroke.

Ginn Thompson 7:29

I was young and healthy, I'm not overweight. It's just it was very, very frustrating. Because I feel like I'm pretty literate in the medical community because my father is a doctor, and we've been around the medical world. And just to be kind of pushed aside like that is very frustrating. And it wasn't until they diagnosed it that things started moving a little bit quicker. And even then I don't think what was done was done fast enough, if that makes sense.

Bill 8:10

Yeah, it completely does. So you're a mum of two, then soon after you've become a mom of three. And in a very small amount of time between the birth of your third child and you being at home. With that third child, you experience a pontine stroke.

Bill 8:33

And then you're in hospital. And I imagine at that time, you have to leave the kids at home, and you're being treated for a stroke. What's that? Like? What does it feel like to be taken away from your children, and as a result of that situation at the same time being treated for something life-threatening? How did you navigate that?

Ginn Thompson 9:07

Well, I my family was here to help on with the kids fortunately. So I knew they were in good hands while my husband and I were at the hospital. But you feel very helpless on every end because I knew I could not, there was almost no way shape or form that I could take care of the kids.

Ginn Thompson 9:34

I was still in the days leading up to me going to the hospital was still breastfeeding with after having a stroke and I'm not quite sure how I did that. But then being at the hospital, you I couldn't throw a ball. I couldn't use my right hand. So how am I supposed to make them a peanut butter jelly sandwich? It was a main point of focus for me. And my recovery was getting back because I knew that I had to be able to take care of them. And that wasn't going to be an easy thing to do by myself anymore.

Bill 10:24

Yeah. How long did it take for you to leave hospital?

Ginn Thompson 10:28

I was only in the hospital about 36 hours, maybe not even that, and they sent me home. I was told to follow up with a neurologist. But the neurologist didn't have an appointment until the end of July, which was another extremely frustrating thing, because you think they're going to give you answers. I was able to start therapy the next week.

Ginn Thompson 11:07

But I was told from the beginning, though, the doctor is only going to be with you a couple of minutes in your appointment, and your therapist is only going to be with you an hour, maybe once a couple times a week at most. So most of the time, you're going to be by yourself or with your family. And no one is going to care about your recovery as much as you are. And I think that really helped me stay focused on the fact that I had to get better and most of it, I was gonna have to figure it out by myself.

Bill 11:48

And that's so sad, but it's so true. It is so true. It's the reality, most of us end up getting patched up and sent home and then then you're left on your own to work out the mental health issues, the physical issues, the emotional issues, and then all the economic issues, and the feeding issues, and just being normal human issues. It's just such a dramatic shift in your life experience that you can't happen to manage all those things at once.

Bill 12:25

You don't have the skills to because you've never been taught how to you all you

knew was what, what it was like before that. And you're a mum, before the strike, and you're a mum after the strike, and you're dealing with little children. How much harder was motherhood or parenting? After the stroke compared to before?

Ginn Thompson 12:47

I think the hardest thing was to come home and have my seven-year-old say, I know you had a stroke. And you go do you know what that means for Mommy? I need you to help me. Can you help me walk up the stairs and to have to rely on them for some of the things and you try to be positive about what's going on and get them to help in your recovery.

Ginn Thompson 13:22

My dad was drafted into the NFL, out of college. And I remember calling him in the hospital. And the first thing I said to him was, I can't throw a football anymore. Because we used to do that a lot. And so getting the football out when we were at home or the baseball and having my son throw it to me and practice catching or practice throwing to him and making my recovery part of being a mom really, really helped me.

Ginn Thompson 13:55

Like I said, I'm going to practice getting you a peanut butter and jelly today or pouring the milk into your cup and it going all over the place and then say okay, I'm going to try it again and get it right this time. Them helping me do that made it a lot easier because I'm teaching them those things already. My four-year-old can't do a lot on his own sometimes, so you have to help them and I think keeping in mind that I met that same level now. I have to practice just like he does really helped me get better quicker.

Bill 14:43

That's amazing, isn't it that you're at the same stage at 38 that your son is that for with pouring the milk into the glass for example. You both are not completely capable of doing it without spilling some milk.

Ginn Thompson 14:57

Yeah, he thought it was funny.

Bill 15:00

So from his perspective, it would be, I'm not the only one in this situation.

Ginn Thompson 15:06

Yeah. And I found it extremely frustrating. And I remember going in another room and crying just because I couldn't get all of it in the glass and just not wanting him to see that I felt that emotion even though it was really real in the moment, obviously.

Bill 15:27

Yeah, it's fairly new for you. Because this only happened in March of 2022, which is just a few months ago, we're in August 2022 now. So has this been the hardest few months of your life so far?

Ginn Thompson 15:48

Oh, by far, it's sort of frustrating, I do marketing and communication for school district for a living. It's hard to be a good communicator of your message in the school district if you can't communicate. So I've had to work really hard to be able to try to work.

Ginn Thompson 16:19

Fortunately, I always say the way the pontine stroke hits your router and not your CPU it's very global. But fortunately, you know, everything I've learned about marketing, I still know about marketing, it's just harder for me to execute the things I need to do. But there's things that people will say to me at work, I haven't seen a teacher for a while, and she'll come in and say, Wow, you look great, you're doing great.

Ginn Thompson 16:54

I look the same. If you just look at me, My smile is different. You know, there's things that I know will never be 100%, again, that are very frustrating to me. So you kind of put on that brave face for people to say, thanks, thanks for asking how I'm doing.

Post Stroke Deficits

Ginn Thompson 17:19

But it's actually a very frustrating thing to go through when you're in the moment. I'm still finding things that I didn't know, were wrong. There's been such big kind of milestones in the recovery along the way. And like, for example, I just realized the other day that my right eye doesn't close all the away. It sort of

flutters. I hadn't noticed that yet. But you kind of gotta get some of the other stuff off the docket before you get to it.

Bill 18:00

Let me shed some light on something that I just realized. So in the episode before this one, episode 211, I interviewed Will paring wood and Will's in the UK. And he's had some challenges after his stroke, one of them being that he's highly emotional, etc.

Bill 18:16

And he was talking to me about all the things that he's experienced, or the deficits etc. And I've spoken about my deficits for 200. And something episodes, as well, to almost everybody that I speak to what I what occurred to me literally this week, was that when I'm facing the sun, and I put my sunglasses on in certain lights, my eye does this weird spasm contraction thing that you can't see, it's kind of happening in turtle.

Bill 18:47

And it's been doing that for years. And I just realized today that it's also on my left side where the majority of my deficits are, and therefore, it's probably got something to do with the stroke and the deficits that I had on the left side. It only occurred to me last week when I was driving, and it was like a big aha moment.

Bill 19:07

It's like, ah, no wonder that thing does that on that eye, and it doesn't do it on the other eye. So my vision is okay, but it has this real weird response to sunglasses and certain positions of the sun when I put my sunglasses on. So don't feel so bad that you're still discovering what it is that you're lacking.

Bill 19:07

Well, that makes me feel better about discovering things this week, but also makes me wonder what I'll discover years down the road.

Bill 19:39

Yeah, you might discover some things that are definitely explainable by what it is that you've been through and you just weren't aware of it or you didn't pay enough attention to it or like you said, there was so many other things in front of mind that you just are not as aware of those little things as you are of the other things.

Bill 20:01

So for me, my biggest issue is balanced, when I'm tired and the way my left side feels and the hypersensitivity and also. And then the muscle stiffness and pain that I feel in the imbalance in the way that my left side feels a lot tighter than my right side. So they're the ones that are kind of playing on my mind on a daily basis, that's what I noticed.

Bill 20:31

And only is in this very small window, when I'm sitting down driving the car, in this direction facing the sun and putting my sunglasses on that I get this spasm in my eye, so I have to really be conscious of it. And when you're driving, I'm really I'm focusing on the road and the traffic and the pedestrians. So it was just a big Well, Oh, okay. I was bit shocked by that noticing.

Ginn Thompson 21:05

That's so interesting. I also just noticed that on my right side, which is the side that was affected, I only get patches of goosebumps on my skin when I get cold. I knew I did not feel temperature really on this side. I just felt like air or whatever. But I didn't realize that my skin was that kind of disconnected still, so that kind of makes me laugh a little bit. I think it's sort of freaky.

Bill 21:41

It is freaky. In summer I will perspire on my left side, and not my right side.

Ginn Thompson 21:48

Me too well, opposite. But yeah, it's, so interesting. I've had a lot of trouble with my vision, and stimuli. I work in an office with big windows and I have fluorescent lights, and then the computer screen in front of me. And I almost have to wear my sunglasses the whole time I'm at my desk. It's really affected my my left eye, oddly enough the right side of both of my eyes, but the right side of my left eye quite a bit.

Ginn Thompson 22:32

So that seems to be the main challenge I'm overcoming at the moment. But you know, stress, I just feel stressed so much more. And it doesn't even have to be real stress, it can just be walking in my house and hearing the TV on and the kids yelling. But I immediately kind of get tired and cramp up. And I just have to keep you know, there's so much more energy that goes into telling yourself reminding

yourself to walk right or to use your hand correctly, you're to relax your shoulders and keep your shoulder blades back and it can be exhausting.

Light Sensitivity After A Pons Stroke

Bill 23:18

Yeah, and to breathe. Now. I was working in an office for a little while as well before. So probably that finished in 2019, from 2016 to 2019. And we had fluorescent lights and a big window. And I would often wear my sunglasses in the office. And one of the things that happened by chance is the light globe on top of me blue.

Bill 23:51

And they were going to get it replaced. And just as they were going around counting all the light globes, I just asked Is it possible not to replace that light globe. So the rest of the room had the light bulbs replaced. And but I didn't have my one replaced. And that made a massive difference to the way that I experienced that sensitivity to light, especially fluorescent light.

Bill 24:15

And it eased my fatigue levels and it decreased the levels of my fatigue. So perhaps it's a suggestion that you can make about just removing any fluorescent light that's directly above you or very close to being directly above you. Just so that it can ease the amount of I'm not sure like, what the word is, but the intensity perhaps of the light that's hitting you from above. It really will help. fluorescent light is one of the worst lights for anybody especially for people who have got a brain injury that they're so early on in the recovery.

Ginn Thompson 24:58

Yeah, it's funny the maintenance guy came in today. And I said, Is there any way you could take out just like one bulb, so I could try it, I just have power the one over my desk. And see if that makes a difference. Immediately I could tell a difference. You know, so hopefully that will continue to make me feel better. Because by about one or two o'clock in the afternoon, I would be so fatigued, I couldn't even look at my computer anymore, I was just worthless.

Bill 25:31

Yeah, that's the same experience that I had. Also, what I do at home, is all my

overhead lights don't go on especially, well, we might have them on for dinner. And then as soon as dinner is over, if it's in winter, when we're still on a very short day, we'll switch on the lamp.

Bill 25:52

And then the only overhead lights that are on, we have our kitchen, our meals and our dining and then our little sitting area nook area where we watch TV or whatever we do. So the only lights that are on are the ones at the far end where the kitchen is, so that it illuminates the room, but it's nowhere near me and nowhere near above my head.

Bill 26:16

And then the lamps that are switched on have got those really warm LED globes that make it feel like it's an old day globe. And then that just allows my brain to just unwind as well. At the same time, rather than being constantly bombarded by this sensation above my head.

Bill 26:44

And from time to time, we'll have people come over and then we'll switch all the lights on because people are over. It's really uncomfortable to sit in my underwear in my house with overhead light projecting, especially at night, it's just really difficult.

Bill 27:00

The sun no longer impacts me negatively, like that, where it used to. But definitely, the overhead lights do. And what I also noticed is that on cloudy days, where it's got, you know, the weird, hazy kind of sunlight where you don't really get the sun but you get a lot of brightness that glare that really impacts me. So on a really hazy day, or cloudy day I'll wear my sunglasses as well.

Ginn Thompson 27:38

Yeah, that's so interesting. Because in my living room, here, where we spend most of the time, I don't have any overhead lights, we just have a couple on the wall that you can see. And shutters on our window. When we moved in. It's just been here ever since. And this room is just dark enough that I didn't even realize I had anything wrong in my eyes until I started back to work, which was probably about six weeks after my stroke. So I've had the same experience so far.

Bill 28:14

Yeah, what does your employer understand transitioning people back to work after a stroke? Do they have any concept of that? I know that you didn't beforehand, neither did I. But do your employer have any concept of that?

Ginn Thompson 28:31

Yeah, they're awesome. If I need to go home, if I need to work from home, they're very, very understanding. And I can't thank them enough for being such a big part of my recovery because they've allowed me to do what I need to do. I always feel terrible because I also had a baby right before that.

Ginn Thompson 29:04

And I had a pretty sensitive pregnancy. So I would go home about two every day, I would only stay half days because being pregnant was really a strain on my body. So I would work from home in the afternoons do different things. And I always am so afraid that because I look the same even though I'm not the same, but they'll mistake that for like me taking advantage of the situation.

Ginn Thompson 29:43

And I think they completely trust me at this point that I'm just doing what's best for me. And I'm trying to kind of redefine self-care for myself. Because it's not always like let's go get your nails done, or these things that I used to think were self-care.

Ginn Thompson 30:06

Now it's like putting an ice pack on my neck or my eyes for just five minutes. So I can calm everything down. It's taking a walk to get away from my computer screen, just 10 minutes around the block. It's so different than it used to be. And that's something I still am having a lot of anxiety about and working through.

Bill 30:32

Wow Ginn, you're so needy. Really, you know, I mean, come on. So tell me about that anxiety part of it, though, because that's interesting. Clearly, you're self conscious. Clearly you're you care about what other people's perception of you are. But if people are responding in a negative way to that, and I'm speaking by example, okay.

Bill 31:01

Because I was a complete idiot. Before then I didn't understand anything about anything. So I had all the answers in my head conclusions that I would come to

about people and the way that they went about their life and why they were doing certain things. But if they're doing that, that says more about them, and their ignorance than it does about you. But does that still affect you? Does that still bother you and make you feel bad?

Ginn Thompson 31:33

Well, I want to say I don't care what people think about me. Because I don't, but I also worry about them comparing the old me to the me now, even though I feel like I'm actually a more well-rounded person, because I had my stroke. I know that people don't understand that and won't understand that.

Educating People About Pontine Stroke Recovery



Ginn Thompson 32:03

I had a guy come into my office. Gosh, this must have been two months ago. And he was just a painter. That was painting one of the schools in our district. And he came in and dealt with some people and on his way out, I of course, had my sunglasses on.

Ginn Thompson 32:24

And he's like, "Why do you have your sunglasses on?" In this just rude tone. And I said, because he was so rude. I was kind of like, because I had a stroke is that okay? He said, Yeah, and just went on his way. And I'm sure he didn't think twice about it.

Ginn Thompson 32:44

But I replayed that conversation in my head every single day. Because it's very frustrating for people I know, people notice that, that they come in and I have my sunglasses on or that the light's out over my head. But I don't want it to affect

anybody else, if that makes sense. So I don't want someone to feel uncomfortable, because I'm talking to them with my sunglasses on instead of just, you know, normal like I normally would have before my stroke.

Intro 33:19

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, and doctors will explain things that obviously, you've never had a stroke before, you probably don't know what questions to ask.

Intro 33:43

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 the seven questions to ask your doctor about your stroke.

Intro 34:02

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, and 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 34:22

Screw them! You know I'm seeing you getting emotional over this and, you know, shedding a few tears about this. And it's like, honestly, I mean, I took it as an opportunity to educate people because I was such an idiot and so uneducated beforehand. And I say that in a loving way to myself. It's not that I feel bad about who I was.

Bill 34:53

I just was who I was but I think what it is it's an opportunity for you to do lovingly if the situation allows for it, to save you, because of my brain injury, my eyes really hurt when there's too much sun, or too much light. And that's why I need sunglasses. And what that's done is tied in your sunglasses to your brain injury, and your needs all in the one little sentence, you know, and then it'll make that person think twice, perhaps it'll make them less judgmental.

Bill 35:32

And if it does, fantastic, and if it doesn't, who cares? Like really, it's a person, you're never going to come across again, they're never going to really get to know you, they don't really care about you, they just feel the need to run their mouth. And then somehow, impress upon you, their noticing of your weirdness or your strangeness.

Bill 36:03

But the reality is, none of us are all the same, none of us are all able to conform or comply to the same rules and requirements as everybody else. We're all individuals, we all have individual needs, etc. Imagine if we were all arrogant and rude and abrupt as that guy.

Bill 36:24

I mean, it would be so boring and terrible, some of us need to be nice and polite, and he feels the need to be rude and arrogant and abrupt. So, because I don't know you, well enough to understand deeply how this comment from this person has impacted you. All I can say is they don't know any better.

Ginn Thompson 36:52

Yeah, those types of interactions are still something I am working on in regular therapy as one of my steps. And it's something that I think I'm aware of, and I just have to fix it in me. I do struggle with recall. So I'm very conscious of my interactions with others.

Ginn Thompson 37:33

And even in that situation, well, with all situations, if I have to deal with someone I always play it back in my head to think about, okay, did you say that the right way? I remember, this was soon after my stroke, my boss and his wife came to see us and I said, Oh, your hair looks nice, or something to that effect. And I met, she looks very pretty that day.

Ginn Thompson 38:04

And that still bothers me because I just didn't say the words the right way. And those are the kinds of things that I'm like, you've got bigger fish to fry, you need to get over that. But for some reason, they sort of hang on. So you know, it's not just like the physical therapy and the speech therapy and everything. I'm still working through a lot of it with my therapist every week, my regular therapist,

just trying to get my mind wrapped around all the anxiety and everything that comes with it, there's so much to unpack.

Bill 38:48

Yeah, absolutely. And it's early days. So let me give you a little bit of an ability to sort of breathe a sigh of relief a little bit, it's early days, it will improve, you'll absolutely get better. And a lot of these things will settle down. So keep that in the front of your mind that it's early days.

Bill 39:09

It sounds to me maybe I'm wrong, so you'll correct me if I'm wrong. It sounds to me that you're a bit of a perfectionist before the stroke. And you're trying to apply the same methodology to yourself after stroke, except you're actually not the same as you were before stroke you're completely different after stroke.

Bill 39:29

So you're going to find that having new ways of processing thoughts in your head about what something means applying a new meaning to these things might be more helpful than keeping the old meaning and trying to superimpose it onto this new experience that you're having.

Ginn Thompson 39:54

Yeah, I am type A, like the deck finition of it. And it's interesting, this whole process, you know, I'm trying to apply the same thing to like, being a mom. Like, you don't have to be a perfect mom, because you can't be you couldn't be before. But you definitely can't be now, that you've had a stroke.

Ginn Thompson 40:28

And it really motivated me a lot to try to get as much of my house in order as possible for them, in case something ever happens again, because I know, that is common with pontine strokes. You know, they can't tell me why the first one happend.

Ginn Thompson 40:52

So who's to say there's not another one down the line. So I feel like my perfectionist mentality may come into handy with all these other pieces of my life, but it's certainly something that I mentally have to work on. And that it's gonna take me a while.

Bill 41:23

They're just new skills to learn and apply and new awarenesses that you need to have, a new aha moment that you need to experience so that you can start this new transition this new approach to life, which as a type A personality that you are, let me tell you you'll work it out, you will apply it you'll find a way.

The Art of Imperfection



Bill 41:44

So there's a there's a beautiful word or I want to call it a word for lack of a better explanation. There's a beautiful word in Japanese called Wabi-sabi. And Wabi-sabi is the art of imperfection. So what they'll do is they'll make a perfect item, piece of furniture, whatever, and they'll intentionally create an imperfect place somewhere on that piece, whether it's visible or not, I'm not sure that it matters.

Bill 42:29

And that is specifically put there to give the person that's building it and the person that's experiencing this probably closer to truth, thing where the fact there is no such thing as perfection, there is no perfect thing, there is always imperfection, somewhere and that if we're good at experiencing imperfection and having imperfection in our life, in some way, shape, or form.

Bill 43:02

And embodying that you have a better experience or a better not sure if it's life overall, but a better experience in life in that, you know, you have an acceptance of things that they are as good as they are. And then they're also imperfect in

some way, shape, or form.

Bill 43:23

And that's how we all are, doesn't matter how much we strive to be well, or to be perfect, we're always going muck up. And we're always going to do things wrong. And we're always going to upset people that we didn't know that were gonna get upset, et cetera.

Bill 43:39

And, together with that word wabi-sabi comes the art of Kintsugi, which is, again, in Japanese pottery, they'll repair a pot that might get damaged or broken, and they'll glue it together and then they'll align all the cracks with gold leaf to take the crack, that should make that vase or that pot useless or render it not useful anymore.

Bill 44:14

And they will make it not only useful but they'll enhance it and they'll make it look more fantastical fabulous than it used to be just because it has gone through this life experience of getting broken and then repaired. So many maybe there's some little things that you can reflect on about how some cultures approach, supposed imperfection and then how they also approach what's considered damaged by some people is considered enhanced by others.

Ginn Thompson 44:52

That's so interesting. I will tell other people this I don't know if I believe it myself yet, but I will always say I was super human before and now I'm just human. I had to be like the rest of you someday, so it's just happened now. Yeah, I love that. Thanks for sharing that.

Bill 45:22

Yeah, when you get an opportunity later, as perhaps if you've got time when we finished the podcast, just Google wabi-sabi, and then Kintsugi and we'll chat about that after the episode briefly. So I can give you those that information. But for the people that are listening, it's a proper art form this wabi-sabi to accept imperfection and to incorporate it in the creation of something.

Bill 45:57

It's kind of this is as good as it's going to be. And let's just move on with the next project. And whatever that is. And even in that, this is as good as it's going to be,

is so good. That is so amazing. That is so fantastic. You know, you've achieved so much. You delivered such an amazing pace or whatever you want to call it even then, but you know, it has a little flaw. Big deal.

Ginn Thompson 45:57

I like that a lot.

Bill 46:12

That could be a big deal you have a little flaw.

Ginn Thompson 46:37

Right. I have to think about that. And I'll have to talk to my therapist about that.

Bill 46:47

And this is the other thing I'd love to ask you about is would you like it if your children were as perfectionist, as you were before your stroke? Would you be comfortable with seeing them be like that?

Ginn Thompson 47:05

I think I have one that's like that. My oldest son is very much like that, I think what I've tried to do with them is not be so hard on themselves. They can be a perfectionist, but just getting so upset with yourself is something that I know he struggles with. And I really try to, you know, it's okay, if you got a 98 and not an 100 on your school paper or something.

Ginn Thompson 47:44

And, you know, just teach them kindness and understanding, especially for people that are different, because that's something we have experience with now. And I think, I think we're getting there. I don't think he is going to be take ultimately not take himself as seriously as I feel like I did before my stroke. I've had to learn to accept help, and ask for help.

Ginn Thompson 48:26

For example, carrying the baby in the baby carrier is almost impossible for me. He's a big baby. He's like 20 pounds already at six months. And so trying to lift him up into the car and different things is impossible. So I've had to tell my husband, I need you to do this for me.

Ginn Thompson 48:50

Where I think before part of my perfectionist personality was not asking for help when I needed it and just powering through and making sure I could do it all myself because that made me feel better or tougher about who I was. And that's how I ended it totally is and I think with my son tub, I'm trying to teach him that it's okay to ask for help. It's okay to accept help. And that's something you're allowed to and you're going to need to do throughout life.

Bill 49:31

Yeah. So your husband, their dad, is here the polar opposite to you, what's his personality like?

Ginn Thompson 49:39

Oh, I'm such an introvert and he is such an extrovert. He's a college wrestling coach or was a college wrestling coach and now is during the pandemic we left the college sports world and he's now teaching physical education for the school district that I work in as well and coaching wrestling there.

Being An Introvert



Ginn Thompson 50:04

He's so good with the kids, he's so hands-on, and just is happy all the time and, just a joy of a person to be around. And I feel like I'm the complete opposite of that. I don't like to see people I would just stay in bed all day and watch TV, he has to be out among the crowd.

Bill 50:30

So is it easy for an introvert to get onto a podcast then?

Ginn Thompson 50:40

I'm part of a couple of stroke support groups online on Facebook specifically. And I found your podcast and have listened to it quite a bit. And one thing that I noticed, in all these communities that I've tried to become a part of, is there was no one like me.

Ginn Thompson 51:09

And so I wanted to put myself out there a little bit to make sure that someone didn't feel like me. And there was someone that knew what they were going through as a young mom I'm 39 I don't know if that's young, but having a new baby, being a mom of a couple of kids, just trying to get back to a normal life after a life altering event.

Bill 51:38

Yeah, good on you, truth is that a lot of people will relate to you that are listening, perhaps a lot of them won't reach out to be on the podcast. And that's the beauty of it. I I love that almost every person who I've interviewed wants to help out other stroke survivors.

Bill 51:56

And they can spend an hour doing that, and they get so much reward for that, because this episode will go to YouTube, it'll go to all the the other platforms for streaming podcasts, and it can be really listened to by person after person after person. And so many times one hour goes a really long way to supporting a heap of other people, that's just fantastic.

Bill 52:20

And we have had a few mums that unfortunately also experienced a stroke either just before, just after or during their pregnancy. And that is, you know, you're sharing similar concerns that they did about how they went around, being stroke survivors, managing all of that stuff, and then the best month that they could possibly be in, you know, experiencing guilt, and all these things simply just because they were unwell and they had to take care of themselves.

Bill 52:59

And, have to be the first priority when they really want to be the priority, the first priority what they want, their child or their children or their family, you know, so it goes towards the lesson that we all have to learn is that we have to be priority

number one, if we're well and healthy, and we can manage all the things we need to manage then, and only then can we be the best we can possibly be for the other people that need us like our family and our children.

Bill 53:37

So that's what I've got out of listening to a lot of mums that went through that as a dad, who had teenagers. When I had my stroke, they were all boy, they were 16 and 12. They were at the worst time in their lives as far as humans go when they're just terrible teenagers.

Bill 54:02

And I didn't know the language of teenagers before my stroke. So I was really struggling with trying to bring them in line or, you know, make them better humans or listen to what we said or obey our rules or all of that stuff. I was struggling with all of that. And then I was struggling with all of that plus, trying to explain to them how I'm feeling and what I'm experiencing because of the stroke and how they need to help out more.

Bill 54:32

And still, they refuse to help out because I appeared normal that I looked normal, and they couldn't understand it. So I struggled as a parent going through stroke recovery. And I'm just a dad, you know, I'm a little bit more removed from what a mom is from a child and I'm not downplaying my role or dad's role, but still, I was not the person who gave birth to their child and I don't have that level of emotional connection that mums do with their kids.

Bill 55:13

It's just a little bit more special, intense, or it's a greater bond. I'm not sure what the word is and that's why I love having mums on on the podcast, because many of them need to feel better about all of the challenges that they're experiencing and how harsh they are on themselves for being unwell. While they have kids, God forbid, you know. So it's interesting.

Ginn Thompson 55:49

From when I had my stroke on a Thursday, to even when I was in the hospital, I was either breastfeeding or pumping, which isn't an easy thing to do when you're okay. And that can be really draining. And I don't know how I did that. I think when I look back on it was a really incredible thing.

Ginn Thompson 56:16

And I am proud of myself for doing that. I couldn't get the contact out of my eye, but somehow I could breastfeed my son. And you know, that's just the way it goes. But I never want him to feel like things were not given to him. Or he was slighted because of my health. At least not when he's young. Maybe when he's older, but you know.

Bill 56:47

He wouldn't know anyway, if you were less than perfect.

Bill 56:52

That's true.

Bill 56:54

He would think oh, well, she's pretty perfect. I get fed when I need to get my nappy change when I need to. Things are pretty good.

Ginn Thompson 57:02

He's the perfect baby, he's been a joy to deal with. Even through all of this.

Bill 57:11

They say that about the third.

Bill 57:15

Must be true.

Bill 57:17

Because they tune into the world differently, you know, they're not first, they're not needy, they don't need all of the attention. They're not second and always competing with their sibling, their older sibling to be bigger, better, stronger, or whatever. And mums and dads usually have less time for the third one, because there's another two that they've got to care about.

Bill 57:37

So you fuss less over them. So I feel like the third one has the opportunity to become a little less needy and more self reliant is kind of how I feel about them. I know a few third child's I'm a second child. And there's only two of us, my older brother and me. And the second child seems to have that issue, you know, middle child syndrome if there's a third. So I'm wondering whether you're noticing that

with your middle child has he stepped into the middle child syndrome routine?

Ginn Thompson 58:14

Oh, yeah, he's like, as needy as they come. He needs a lot. And he wants to do a lot by himself. So you're trying to give him that freedom. But yet, you know, the perfectionist in me, I don't want you to try on 40 pairs of pants, because you want to I want you to put on the pants I've pulled out for you today.

Ginn Thompson 58:43

So he has definitely fit that role. And yeah, with the third one, you know, I hate to say it, but you kind of don't care as much anymore as you did about the small thing. So, he's either going in the middle one for mess, and the first one is my perfectionist.

Pontine Stroke Recovery

Bill 59:06

Yeah. Wow. That's interesting. So what are you hoping for in the months and weeks to come? What are your aspirations about this whole situation that you find yourself in?

Ginn Thompson 59:24

Well, I kept telling myself, you can't get back to normal or back to 100%. But you can get close. So I think I thought there for a while I was closer than I was. So my goal is just to try to gain a little bit every day and it may just be walking around the park that's by my house and not having to think about my foot going the right direction sometimes.

Ginn Thompson 59:59

But that's a small win. Not feeling like I have recall issues when I'm more tired or more stressed. Or even being able to handle situations with some of my colleagues, and not feel nervous about the situation or feel like they're looking at me different because I've had a stroke now.

Ginn Thompson 1:00:28

So I think it'll all take a while. But if my doctor had said, what you gained back in the first year is really going to be the most significant progress. And after that, a lot of it will be compensatory. And I set my goal immediately that I was going to try to work as hard as I can in that first year, to gain as much back as possible.

Ginn Thompson 1:00:59

Just so I felt normal, even if I'm not. And then, you know, work to tweak things along the way that still needed work. And just keep working hard. It may be something so simple to someone on the outside, but it's really significant to a stroke survivor. And I think that's really important to notice all those small things.

Bill 1:01:24

Yeah, you know, you have to notice the small wins, and you have to celebrate them. And the thing about doctors and deadlines, 12 months, six months, whatever is such a terrible thing to tell the survivor in my opinion, forget, Forget him. Forget deadlines, forget that the first 12 months and all that stuff. It is true and scientifically true that there is a part of the brain that is impacted. That is not part of the actual spot where the injury occurred.

Bill 1:01:26

So it's called the penumbra. It's the part after the damage, and the Penumbra is kind of been taken offline. But it's not damaged. It's not injured. And it's been taken offline because of inflammation and other reasons. And then what happens is, the penumbra comes back online the quickest.

Bill 1:02:12

And you notice the penumbra coming back online because things kind of accelerate in their improvement to a certain extent. And it's obviously different for a lot of different people. And then once the Penumbra is done, doing its healing the part around the damage, then there's a slower recovery to getting back and rewiring parts of the brain that are that have been taken offline because of the injury.

Bill 1:02:39

So the rewiring is what seems to take a bit longer and the reskilling of your brain in memory recall, for example, or in being able to deal with light or being able to deal with noises and sound and lots of people and all those things. That takes a little bit of time to readjust to for some people, they adjust to it more than others. When you're neurologically tired, you'll you'll be impacted by more than other times.

Bill 1:03:09

For example, I never went to concerts, football matches loud gatherings for many

years after the stroke, but I can go to them every so often now 10 years out, and not be as significantly anxious or impacted by it. So the thing that the doctors are talking about is that Penumbra coming back online. And that's why you why you notice a lot of improvements early on.

Bill 1:03:34

That being said, I speak to stroke survivors every single day who say to me that they've had an improvement, 5, 6, 7, 8, 9, 10 years down and even beyond, so you never stop getting better. And if you're doing other things like looking after your nutrition, and you're not drinking, and you're not smoking, and you are doing self care, and you're working less and you're sleeping better.

Bill 1:04:03

All of those things come together to create the perfect storm of recovery. And that's when you start getting these little bits and pieces of wins that perhaps eluded you early on or appear to take longer to get so don't do deadlines, don't to by 12 months this is that.

Bill 1:04:26

And if I haven't achieved that, that's terrible. And also don't do by 12 months, that's the most I can expect and if that doesn't come well then nothing else will come. That's it's not true. So it's a bit of a lack of clear, explaining by doctors as to what one should expect.

Bill 1:04:51

And my job here is to sometimes try and dissolve those myths of times and deadlines so that people listening and yourself can just be okay with constant and never-ending improvement like you were before you had a stroke, if that's the kind of personality that you sound like you had.

Ginn Thompson 1:05:15

Yeah, I will, I think that goes back to how the whole process was sort of managed. I mean, you know, they didn't believe me from the start. So why should I believe them type of thing. You had to have your own experience. And I have read that just the other day, someone six years down the road from their stroke, had some sort of breakthrough.

Ginn Thompson 1:05:46

And I thought, wow, that's interesting. But, I guess in my head, it's like, a

deadline or not a deadline. But it's like a point where I can check in and see, okay, what have you done this year, and in a year, when you feel like things are falling apart, I think that's a really good point in your head to just stop and look around and say, Okay, I have accomplished a ton. And I think I should celebrate that. So even again, just the little things, being able to walk the stroller down the street or something. It's a big deal.

Bill 1:06:30

Congratulations. On that mindset, I love it. Now, one of the other things that happens, why and why people might recover use of an arm or start to get better with their hand movements or their leg movements. There's, this thing called learned non-use, it's when the person's had a stroke, and that part of their body has gone offline.

Bill 1:06:54

And legitimately because of the stroke, so the arm might not be working. And then what they do is they use neuroplasticity, but in a negative way, so that it unlearned how to use the arm because it's currently injured and currently not working.

Bill 1:07:12

And then it becomes a habit to not use it because you're compensating with the other arm and the other hand. So sometimes what happens is the learned non-use is as much of an impact to the person's arm as the brain injury is. So the significance of both of them can be serious or can be consequential.

Bill 1:07:33

And so then what happens is, for some people, they overcome the learned non use 567 years down the track, because the recovery in the brain has occurred. So now it's rehabilitation to teach the arm, just how to work again, perhaps not exactly the same way or with as much mobility as before, but in a way that is meaningful and useful and helpful.

Bill 1:08:03

So there's also that aspect which doctors don't talk too much about where they assume that the reason why a limb isn't working is because of the injury to the brain, which is partly true. But for some people, it could be this other part where it's learned. It's the if you don't use it, you lose it kind of scenario.

Bill 1:08:25

And then they start for some reason focusing on it or using it, and it comes back online. So that's also that. That's one other thing that other people listening and watching and yourself can consider about what the future might hold. And that might not be the case for everybody. But it might be for some.

Ginn Thompson 1:08:45

Yeah, I was a I was a multi sports athlete growing up. And during basketball, I remember my dad just harping on me to use my left hand to dribble I'm mainly right handed. So when this all happened, and I couldn't use my right hand, I just started using my left hand for everything and credit to my therapist, they were very strong to say no, you need to use your right hand, use the fork and use all the things.

Ginn Thompson 1:09:17

And I've been able to gain the most of that movement back. Not a ton of the fine motor I'm still working on that, but that's that's so interesting that that can be such an issue because I can see someone having the same problem as me and not even knowing if it's a problem.

Bill 1:09:43

Yeah, it is. It's multifaceted. This stroke recovery thing. It's really that part of stroke where you need to educate yourself. Like you said at the beginning, you are on your own to an extent and you have to educate yourself, learn from other people that are going through what you're going through.

Bill 1:10:01

And just see what's the question everything? I suppose that's the best way to think about it in that, is this really what's happening? Or is it possible that something else is happening, you know? And whatever the answer is, or whatever the solution you get to his, well, that's okay. As long as you've worked it out and ruled that out, you could potentially move on from that.

Bill 1:10:26

And you might also learn something that you didn't know, that was the case, I really want to thank you for reaching out, and going out of your comfort zone as a person who prefers to be an introvert to get on the podcast and share your story and make it so that other people going through what you're going through, feel

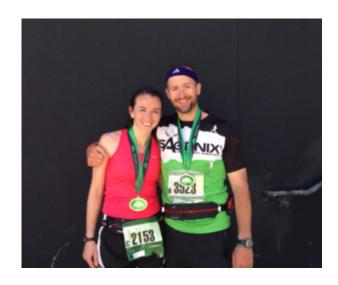
like they can relate to somebody and that they're not going about it alone. I really, really want to thank you for that.

Ginn Thompson 1:10:57 My pleasure.

Bill 1:10:59

And I hope your recovery continues to go well. And, I know that you'll see a lot of improvements, because you are just very early on in your recovery, there's a lot of recovery to go.

Pontine Stroke Recovery Is A Marathon



Ginn Thompson 1:11:13

Yeah, I think it's important. And I have to remind myself this all the time that it's a marathon and not a sprint through this, and it'll be probably for the rest of my life. So you just, you got to take it one day at a time and win the day and move on to the next one and see what it brings.

Bill 1:11:36

I feel like you've got a real good foundation to have a great recovery, whatever that means or looks like because you know about wins and losses as an athlete, you know about what it means to get back up and try again and improve your form and to keep going and to never give up.

Bill 1:12:01

And they're really amazing traits that you could apply to stroke recovery. They are, you know, the mindset of an athlete is such a useful mindset to overcoming

your own obstacles, the things that we put in our own way, so that we can continue on with our recovery. So I think you've got a good foundation for a really successful outcome.

Ginn Thompson 1:12:31

I appreciate that I'm in the mindset that practice definitely makes perfect. They tell you that all the time as an athlete, but I think it's true in stroke recovery, I think it's true in motherhood. And, you know, I'll never be the athlete that I once was, just because I am a different person.

Ginn Thompson 1:12:58

But I think learning to be a different athlete and a different mom and a different person overall it's kind of fun to challenge yourself and see what you're capable of becoming. So it's I don't want to say stroke recovery is fun, because it's not but it's hard work. And it's so fun to see what you're capable of.

Bill 1:13:30

Yeah, sounds like you're up for the challenge.

Ginn Thompson 1:13:34

We'll try, I don't really have a choice.

Bill 1:13:39

And on that note, thank you so much for being on the podcast.

Ginn Thompson 1:13:42

Thank you so much for having me.

Bill 1:13:44

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Bill 1:14:08

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social media will make it possible for people who may need this type of concept to find it easier. And that may make a massive difference to someone that is on the road to recovery after their own experience with stroke. Thanks again for being here and listening. I really appreciate you see you on the next episode.

Intro 1:14:40

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Intro 1:14:57

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Intro 1:15:19

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Intro 1:15:34

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Intro 1:15:59

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