

# Cavernoma - Ginger Burden

Ginger Burden had a Cavernoma in her brainstem three years ago that caused her to have double vision in her right eye that eventually required surgery about a year and a half later.

Instagram: [www.instagram.com/ginburd/](https://www.instagram.com/ginburd/)

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Ginger 0:00

I think learning how to adapt to the outside world with whatever physical limitation I'm experiencing at the moment, the vision or balance or whatever, figuring out how to not get overwhelmed and stressed out when I go out in public and go into new situations. Because I want I mean, I very much am a person who likes to be out doing things and I don't want these things to stop me.

Ginger 0:28

I want to figure out a way to be comfortable, kind of no matter what. So I know that sounds kind of vague, but I'm trying to kind of approach it from like you know, broad, bigger picture kind of Outlook so that I can be adaptable because you know, in my situation, you know, yeah, good days, your bad days, bad weeks, good weeks, you know, I want to be able to enjoy life kind of no matter what.

Intro 0:57

This is recovery after a stroke with Bill Gasiamis. Helping you go from where you

are to where you'd rather be

## Introduction



Bill 1:03

Bill from [recoveryafterstroke.com](http://recoveryafterstroke.com). This is Episode 97 and my guest today is Ginger Burden. Ginger experienced the brainstem stroke and is recovering from the physical impact surgery had on her body and vision. Some time ago now I launched the recovery after stroke coaching people who are being coached by me are getting the support they need to find solutions to their challenges including fatigue, anger, and isolation, amongst other things, especially in this time of Coronavirus, isolation, getting to support and staying on track with your recovery has never been more important.

Bill 1:39

If you're a stroke survivor who wants to know how to heal your brain overcome fatigue and reduce anxiety. recovery after stroke coaching might be for you. If you have fallen in the cracks between hospital and home care, and desire to gain momentum in your recovery but do not know where to start. This is where I can help.

Bill 1:57

I'll coach you and help you gain clarity on where you are currently. In your recovery journey, I'll 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 overcome what's stopping you from getting to your goal. Right now, everyone is interested in

learning what recovery after stroke coaching is all about.

Bill 2:18

You get a seven-day free trial to decide if it's the right fit for you. 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](https://recoveryafterstroke.com/coaching), if you are listening online, and now it's on with the show. Ginger Burden, welcome to the podcast.

Ginger 2:39

Thank you so much. I'm happy to be here.

Bill 2:41

Thanks for being here this is a bit of a big thing for you because it wasn't that long ago that you decided to start being a little bit more active and a little bit more public about what's going on for you. What happened to you?

## Brainstem Surgery



Ginger 2:59

Oh, gosh. Hopefully, I can kind of keep this sort of brief enough. But, it kind of started about three years ago, I woke up one morning and had double vision in my right eye. And it turned out that I had a cavernous malformation in my brainstem. And they didn't want to operate right away. They tend to kind of watch and wait. So we did, but it turned out I had to have an operation anyway, About a year and a half later.

Ginger 3:25

So I had my first surgery to remove the cavernous malformation from my brainstem. And the surgery went, Okay, as far as these things go, I did come out of it with the facial weakness, and also some damage to my left eye, which they were not expecting. It doesn't have a full range of movement, it kind of bounces a little bit like it's on a trampoline kind of.

Ginger 3:52

And then so that's what happened with the first surgery and then about two months later we discovered that they had not gotten all of the cavernous malformations out and it bled and created a significant hemorrhage that they told me that if it had happened to anybody else it would have killed him. But since I had had the surgery, it created kind of like a cavity for the blood to collect in.

Ginger 4:22

So instead of killing me, it just did lots of damage. So I had a lot of damage to the left side of my body. And I had very limited mobility in my left leg and left arm. For a long time, I was completely numb from the top of my head down to my toes. And this event, this hemorrhage is what I later learned was, it was a stroke.

Ginger 4:49

But they didn't tell me that right away. They were just focusing on the hemorrhage and getting the hemorrhage fixed. So I went in and got a second emergency surgery and from what we know what we think they were able to remove the hemorrhage and the cavernous malformation, hopefully, and the surgery went well, and I went into inpatient rehab to learn how to walk and kind of take care of myself again, and I was inpatient rehab for that 10 days. And then I went home, and I've been doing outpatient rehab and kind of home recovery ever since.

Bill 5:28

Wow, what a journey. And isn't it interesting that doctors will treat a hemorrhage, but they won't necessarily talk about a stroke? And I went about two and a half years before somebody finally said to me, the hemorrhage that you had was kind of like a stroke, but we don't call it that because it didn't begin like that. It created a stroke.

Bill 5:52

But that's not what it was. Exactly. And you didn't get dealt with by the stroke team. You got dealt with by this other time and I'm like, but all that you issues that I'm having is stroke issues. That would have been great to know two and a half years earlier so I can connect with people who are going to help me out early on.

Ginger 6:09

Absolutely. I understand. I remember when they sent me to the inpatient rehab, they put me in the stroke ward. And I was like, wait a stroke ward. I didn't have a stroke. They're like, Yes, you did what you had, essentially was a stroke. And then they treated me luckily, and I guess I'm lucky for that. They've kind of treated my symptoms and my recovery from a stroke point of view. So in that way, I think I'm probably pretty fortunate.

Bill 6:35

Yeah, you had double vision in you said one I was one of the symptoms, how did you get double vision in one eye or what did that mean?

Ginger 6:45

The bleeding from the cavernous malformation caused six-nerve palsy, so one of the nerves that connect from your brainstem is damaged and the eyes start to drift inward and it doesn't have full mobility. In fact, before my first surgery, it kind of had started to heal and started to get a little bit more movement. But then once the surgery happened, it damaged the nerve pretty badly. So it's worse off than ever now. So basically, you know, just the I just doesn't move properly, they don't move together. So I have to read the patch to help me see essentially

Bill 7:26

Yeah, because the other eye's perfectly fine and healthy and

Ginger 7:31

Well like I said they they did do some damage in the first surgery. Yeah. At first, it also could not move fully from left to right. that's gotten better. But now it constantly bounces like this like a trampoline so they think that that was all but they don't know I'm doing eye therapy to try to help that out. But we will see.

Bill 7:58

I had an interview with a lady called Maggie Whittum, she was Episode 47. And the episode was called The Great Now What? Maggie talked about double vision

and this bouncing of the eye that constantly happens that makes it challenging for people. So what aren't you able to do with regards to now the way that the vision is with that eye?

Ginger 8:25

Well, before this, I was a graphic designer. So a lot of visual work I was not able to do that. Unfortunately, since then, driving, I haven't been able to get back to driving and that's a combination of vision and mobility I have very little use out of my left arm and hand. So I could probably maybe manage it, you know, on a straight, quiet road, but I haven't tried it. It might be a while before I do that. For the safety of myself and others.

Bill 8:56

Yeah, that's a bit of a scary thought. I thought the same thing. When I first got back into the car, I thought, like, What if something happens again? And what am I going to do if I black out and hurt somebody I was motivated not to drive. But then as I started to get better and start to feel confident about it, I didn't go for a drive on my own the first time I went for a drive with a family member, and then later on, I went on my own but yeah, that means that you would have a lot less ability to get out and about and therefore you're in the house more often.

Bill 9:32

And is that kind of how it started? To for you to turn into this kind of person who was not prepared to put herself out there and talk about what was going on? Is that how that started? Or did it come about another way?

## **Facing the new reality**



Ginger 9:48

Yeah, I never expected like, honestly, the hardest part of all this was coming home and starting to kind of like face would happen to me. Now all of a sudden, I can't imagine being in a wheelchair for a few months after getting out of the hospital, I couldn't get around, I had to have help doing everything going to the bathroom getting dressed, I couldn't get off the couch on my own at first and you know, I, I struggled with that I just didn't feel like me anymore.

Ginger 10:18

So I didn't, you know, it was just hard for me to kind of connect with other people. And then when I did start to try to get out and about, it was just really hard, it's just overwhelming, you know, physically overwhelming, the vision issue was kind of like keeping me from wanting to go places and it would be it would just kind of throw me off and all of my balance issues and body issues would sort of get worse with like the stress around that.

Ginger 10:46

So I just kind of stopped going places. It was just it just became too much. And then you know, over time, I worked a lot on my mental and physical health in strings and so over time started to kind of connect that a bit and was wanting to connect and talk to people and share. This kind of knew me, I guess. And then all this, the COVID-19 stuff happened and we all went back and had to stay in our homes.

Ginger 11:17

So it was kind of like odd timing for me. But honestly that sort of prior isolation,

in some ways might have helped me be able to cope with this situation a little bit more, maybe that's kind of like the positive I'm sort of trying to bring to the situation.

Bill 11:39

Yeah, I agree with that. I speak to stroke survivors every day. And one of my coaching clients is going through some challenges with COVID-19 isolation in that she's reasonably early on in her recovery and as a result of that, it's making it a lot harder for her because she's focused on recovering. And she's a real trooper and a fighter and she just wants to get out there and make things happen and she can't.

Bill 12:05

And although she's not the type of person who is going to be out and about all the time, she missed the opportunity to go to a physio to rehab all that kind of thing. And it made, does it, it made her focus on what she can't do more than what she can do. Because she's other circumstances are restricting her from what she can do.

Bill 12:31

I was nearly eight years out of that first stroke, and my surgery was in November 2014. When we went into lockdown, it was kind of like, well, I've been here before, like I get it, I get not being able to get out and about and not doing things and whatever and it didn't bother me so much.

Bill 12:52

And it's been a good opportunity to not do too much to not exert myself and to not overdo things. That being said, I'll be glad when I can get out and about and catch up with people. But it was familiar, the whole the whole lockdown type of existence was familiar and not disconcerting. Like, there was no issue for me.

Ginger 13:24

Yeah, I can relate to that, too. Sometimes I kind of wonder if you know, I'm gonna get too comfortable, you know, with the notion of staying home, and then you know what I am kind of confronted with the opportunity to get out, you know, am I going to be kind of once again, more wanting to isolate a little bit more and I don't want to kind of put myself in that space, you know, so I'm working hard to prepare myself and stay as connected to people as I can in any way that I can you



know, in the situation.

Bill 14:02

Yeah, you don't seem like you're going to go down that path, you contacted me, you're keen to get on the podcast, and your posts on Instagram started to reflect somebody willing to get out there and start talking. And I know that when you start talking, it starts to heal you and it starts to get that stuff off your chest, and it starts to make you feel better.

Bill 14:22

And the more you do that, the more you want to do that. And if you're connecting with the right people, then it's much more. There's much more of a reason to go out and connect and share when I was connecting with the wrong people, people who don't understand stroke. And fair enough, they don't understand stroke, it used to frustrate me that they would do the whole well look right.

Bill 14:33

And therefore, based on how you look, everything must be amazing. And that was challenging because I didn't want to go into a real long-winded conversation about how I was feeling and how that has changed my life. After all, they weren't A. equipped to handle that kind of information. And B. I don't know that it would have made a difference to their perception of stroke because they've never been through it.

Bill 15:11

So just kind of go along with it. But then when I connected with stroke survivors through Zoom or in person, it felt better. And I kind of found a group of people who, what's the word group of people who just got me they got me and we got to this weird place in the shittiest away but now that we're here, we get each other.

Ginger 15:39

Yeah, that's amazing. And I haven't you know, I'm kind of searching for that a little bit. I know that there are groups here and groups online. But I haven't really up to this point been very active in like searching for it, but I feel like even just like a little bit that I've done in this, you know, your podcast and your Instagram account.

Ginger 16:04

And doing this right now is like a huge help and makes me it kind of validates my

experience and kind of makes me feel normal because everybody else in my life, you know, no one has experienced something like this. So I feel just kind of different than everybody most of the time, but so I can understand what you're saying like finding people that can relate to you in some way, is a huge part of like just feeling better about yourself and your situation and your experience and everything else. So I want to thank you for having a podcast like this and for giving people a chance to connect in this way.

## **The Recovery After Stroke Podcast**

Bill 16:46

Yeah, my pleasure. I mean, it started as a selfish thing. It was all about me really, at the beginning. And then I realized, hey, this is strangely not about me at all the amount of people contacting me saying it was the right episode. They needed to hear that story or thank you for sharing that. I realized quickly. Oh, okay, it's not really about me nobody gives a crap about me.

Bill 17:08

And I'm not saying it that way they care about my story. But I want to hear from other people, right? And I'm like, all right, well, let's run with it. And the more people who contact me and tell me, the more I can't do it, so we're nearly at 100 episodes, and I'm so stoked that I'm there. And every single one of those people who has contacted me to be on a podcast or who I've contacted, I mean, we're talking about every one of them has had a stroke, or is caring for somebody that had a stroke.

Bill 17:43

And no matter if we're at 100 episodes, not one of those stories is the same story, and not one of those people has the same problems. They have similar challenges to overcome, but everyone is unique. So when you put out a new episode, it sounds like the same but people come out of nowhere and go wow, like I can relate to that episode.

Bill 18:06

It's not that different from the one before, but they related to the one that got them thinking or changing their mindset, or feeling like there's hope and, more importantly, feeling like they're not alone. It's not just about them. So thanks for saying that. And I appreciate it and it's just brought so much joy to me to be able

to do this. I was gonna ask you how old were you when you had the first bleed.

Ginger 18:38

I guess it was three years ago. I was 36 or 37. I think I don't know. Something like that. 36 or 37?

Bill 18:55

So 36 or 37. Excuse me were there any signs that a stroke or a bleed or something was coming on? Did you notice anything different in the days leading up to it?

Ginger 19:10

No, not at all. I mean, I woke up and then double vision and am going downstairs and be like, I can't, I can't see I don't know what's going on. , my family in the doctor I first went to thought it was just a sinus infection symptom, said a sinus infection at the time, they thought I just had blurred vision or whatever.

Ginger 19:33

I went to an eye doctor and she said, I think you need to have an MRI so I won't get one. And they found this shadow of what they said at first and then I eventually went to a neurologist and that's when they kind of consulted with other people and other neurologists and they determined that it was a cavernous malformation. Of course, I didn't know for sure until they got in there and looked at it. But you know, also signs kind of pointed to that being the case and it looks like they're right about it,

Bill 20:05

They can't see it because the blood is still in there obstructing the view. So, an MRI is not conclusive, and I got a similar diagnosis, there's a shadow on your brain and we don't know what caused it. And then they went down the path of you know, it could be tumor, it could be cancerous. It could be this, it could be that.

Bill 20:25

And they didn't know in my head, they didn't know for about two years, because I opted not to have surgery. And then slowly the blood was small in size, and then it got really big, the second blade, and then it got really small as it started to get absorbed and sorted out by my head. And, then they were able to see what caused it but it took about two years.

Bill 20:52

And finally, after the third bleed, they figured that they needed to go in and resolve that and get rid of it. And that's when all the major challenges sort of happened to me as well. So other than the blurred vision how long did it take before you went from blurred vision to the hospital to do that MRI? Was it a lot of time that elapsed?

Ginger 21:21

I think it was about two or three weeks, maybe two weeks.

Ginger 21:28

Because I just wasn't talking to the right people, honestly. And they just thought it was they just didn't think anything about it is, you know, again, I thought it was a sinus infection or something. And I kind of saw various people before I saw, you know, some qualified neurologists that I'm still seeing To this day, and they didn't want to do surgery at first, you know, they're like, we don't want to go into your brainstem it's dangerous to do that.

Ginger 21:56

Let's just watch and wait and see what happens. And at first, you know, look like it was resolving, or at least absorbing, or at least not being active in bleeding. So after about eight months of checking on it, we decided to wait a year for the next scan. And fortunately, in that year time, it grew in blood. And we're in I think I had, you know, a few different episodes, mini-strokes, you know, in that time that I just didn't even know about. So by the time I got the MRI, they're like, oops, it's too big. We got to go in there and get that out.

Bill 22:36

How long were you in hospital?

Ginger 22:39

The first time I was like three or four days, and I didn't even need any kind of rehab afterward. I just went straight home. Then the second time after the hemorrhage and the stroke, I was in hospital and rehab all together about three weeks. Cuz I was in the hospital, they're kind of like waiting to stabilize me before the second surgery, waiting for my surgeon to like, kind of get prepared. So I was in the hospital for about a week before the surgery and then a few days after, and then rehab for about 10 or so. days after that.

Bill 23:19

Yeah. And then you're at home and who was with you at home were you around family?

Ginger 23:26

My husband was here so he stayed with me the entire time in the hospital, like in the room, he stayed with me in rehab, and then obviously here and he had to do everything for me, and as I said, I couldn't go to the bathroom on my own. I couldn't get dressed, I couldn't get my food or anything like that for a long time.

Ginger 23:50

And so he had to do everything and work, and take me to appointments and do, you know, errands and cooking and all that kind of stuff. So caregivers are amazing. We just never would have imagined everything that would go into something like this. But now I got much more independent, you know, much, much, much more independent. But those early days were rough.

## **When partners become stroke carers**

Bill 24:15

Yeah, I remember what my wife went through, she was the same for me. She was the person who did everything and she was navigating the whole thing on her own I was spaced out in my head and didn't know what was going on. I was my emotions were all over the place. I was cranky and abusive at times and all sorts of things.

Bill 24:36

And she was just running with it kind of like in some kind of like an automatic kind of mode. And she had to be there for nearly three years. By the time everything was sorted. She had to be there for nearly three years, you know, and just can't imagine what that was like. She put her whole life on hold for me.

Bill 25:01

And she had been doing that for my kids already. You know, she was a mom of two teenagers at the time. So I can't imagine what was going through her head and I'm grateful for her. She made a massive difference to my being able to heal and recover. So then things started to get better did your husband How was he about leave you at home alone? How did he start to come around with all of that?

Because I imagine there would have been some anxiety about that.

Ginger 25:33

Well, I really couldn't be alone for a while. So he had to go somewhere. I'd have somebody here with me for a few months and then eventually, you know, as I started getting more independent and capable, and strong you know, he can leave me now as an issue but you know, it took a while and didn't like you know, if I wanted to go somewhere, very occasionally I would go somewhere with a friend.

Ginger 25:56

He would have a hard time with it because you know, it just kind of no what I was going through and like how kind of like fragile I was, you know, just kind of made him nervous to like, you don't think of me kind of being without him to like, catch me if I fell or whatever, got sick or something so that was an adjustment you know, but we finally got into a good routine with that.

Bill 26:23

Yeah, he had finally started to let you go.

Ginger 26:28

Yeah, I mean yeah, like I said, I couldn't even shower or go to the bathroom or get dressed or anything on my own for a long time. So you know, even though that's not something that we enjoyed it it kind of creates like a was a dependency but like a bond. Like once you like I started becoming more independent. It was a good thing, but also I think it made him just nervous to kind of like, let me start doing those things on my own.

Bill 26:59

Yeah. Ginger, are you comfortable with me talking about intimacy?

Ginger 27:03

Sure.

Intro 27:05

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like, how long will it take to recover? Will I recover? What things should I avoid in case I make matters worse? Doctors will explain things. But, because you've never had a stroke before, you probably don't know what

questions to ask.

Intro 27:30

If this is you, you may miss 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](http://recoveryafterstroke.com) where you can download a guide that will help you it's called Seven Questions to Ask Your Doctor about your Stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke. They'll not only help you better understand your condition. They'll help you take a more active role in your recovery. head to the website now, [recoveryafterstroke.com](http://recoveryafterstroke.com) and download the guide. It's free.

Bill 28:17

So, like me when a stroke happened, there was no intimacy. And then I had a little bit of anxiety about going back there because it was a blade for me my scenario playing in my mind was a high blood pressure episode was another blade, and I didn't want to do that to my wife in an intimate moment, but let's get back to that.

Ginger 28:43

I asked my doctor about that so I can understand your concern. Um, and she said, Oh, it's fine. Um, but you know, for me also because I have suddenly disabled and like, I don't have the use of half of my body. That creates kind of a whole new set of obstacles. So, you know, it's been just, you know, it's been challenging, but, you know, that's everything requires a lot of open communication and patience and time, and trust. And, you know, it's a it's a process. It's a journey, you know, nothing's perfect, but, you know, we've been able to kind of like, work through that a little bit. Yeah, not easy, but, you know, put in the time and effort and it's getting easier.

Bill 29:33

Yeah, that's such a good thing to put time and effort into, isn't it?

Ginger 29:37

Yeah, I would say.

Bill 29:40

The reward is well.

Ginger 29:43

Right.

Bill 29:45

Well, I'm glad that you guys are getting there. Hey, your name is Ginger. From the photos that I see and from the image in front of me you have ginger hair.

Ginger 29:56

A little bit. Yeah. And it's kind of purple on the ends I don't know if you could tell or not.

Bill 30:02

And you've got two cats that appear to be ginger.

Ginger 30:04

They are yes they are. I'm surprised they're not running all over me right now.

Bill 30:08

There's a bit of a ginger theme in your family.

Ginger 30:11

There is there is yes,

Bill 30:13

The cat seems to get harassed and one of them's wearing your eyepatch.

Ginger 30:18

He loves it. I guarantee. He loves to wear hats eyepatches and wigs.

Bill 30:24

Yeah, I've seen the one. That's hilarious.

Ginger 30:29

I'm sure he's thrilled by it. Yeah.

Bill 30:32

And then there's the photo with both of you. next to each other. You've cropped the photo and you've got him and you with the eyepatch on.

Ginger 30:41

With the matching eyepatch yes.



Bill 30:42

That's hilarious and then there is and then there's another one with a toy cuddly lion that's on top of him.

Ginger 30:50

Mm hmm. They're two different cats like they're twins. They're twin brothers. So the pictures are yeah. Is it one or the other? Yeah. They're very relaxed, like, chill cats, they tolerate almost anything luckily.

Bill 31:08

One of them's got some kind of a jar, or a frame a hat anything on their head.

Ginger 31:14

Yes. Yep. very patient cats.

Bill 31:18

They are very patient cats. So tell me about what's it like to have an animal in your life because a lot of stroke survivors who end up being alone or end up being stuck in their home or whatever, may not realize that animals can be very therapeutic at times. Are you somebody who gets a lot from that?

Ginger 31:39

Yes, yes. I mean, they are very, I like to think that they're very intuitive. So especially at first when I was just laying in bed and the wheelchair, they were very confused, you know, because I couldn't pick them up. I couldn't bend down to pet them, but they would just stay on me all the time like laying I mean, I would be in bed and they would be one or both would be on me all the time.

Ginger 32:04

And then they always wanted me to play with them and I couldn't but now that I can, you know, it's so rewarding. I mean, I get, you know, a lot of the exercise I get is chasing them around and picking them up and doing things. So I mean, I can't imagine not having them here. And being away from them for three weeks was hard.

Ginger 32:24

I went into the hospital when I was having that hemorrhage and going into the hospital and saying goodbye to them was like, so difficult. Because I didn't know if I was going to see them again, what kind of condition that would be, and when I

came back, so it's just been like, I can't even find words for how rewarding it's been to have them here and now healing for sure.

Bill 32:49

They are fur babies and I

Ginger 32:51

They are

## **Caring for animals while recovering from a stroke**



Bill 32:52

I used to hear that and think oh, that's a bit cringy but it's not when I think about my experience with animals, we've had animals in our home. Since I was a baby, they have always had cats, so I have this unique relationship with cats and animals. And I never really considered how much they do. Just by being passive and being needy and whiny and whingey. You know, they stimulate conversation because I yell at her so to speak, I said, listen, you know, stop behaving that way, or don't go there or get out of there, or stop making a mess with your food and.

Ginger 33:32

And does she listen to you?

Bill 33:34

Never, she kind of does that. And then she just ignored me and kept doing whatever she wanted. But the beauty of it is, is that that's creating a conversation

and a stimulus somewhere. And then because cats are so needy with regards to when you get home, if they're hungry, you can't do anything other than feed them. I mean, they have to be fed.

Bill 33:57

And if you don't feed them, don't be quiet. So that whole relying on them relying on us is cool because it makes us do things for someone else or something else that perhaps we wouldn't have done in the past. And it's like you said, it's, it means that you're getting exercise, it means that you're bending, you're opening a can, or you're preparing some food or you're cleaning their litter out. Do you see that as something that other people might benefit from in our situation?

Ginger 34:31

Absolutely. I mean, I think obviously, there are the physical limitations to consider like if you, you've got to make sure you can care properly care for you're in the physical condition to care for an animal but if you are, I think it's amazingly rewarding to like you said kind of have someone or something depend on you. And you know, you kind of gives you something to do and like look at you like a routine. To get into something that looks after and the reward you get back the love and the fun is just it's so rewarding I guess it's a whole package of the reward honestly, there's no downside to it to me.

Bill 35:15

And with a cat, you wouldn't call it unconditional love, would you?

Ginger 35:20

My cats? I don't know if they are they are very constantly loving and always wanting to be affectionate. So no, no, no, no, all cats are like that. But for whatever reason these cats are

Bill 35:34

cats, not unconditional loving.

Ginger 35:37

I've heard I've heard it.

Bill 35:39

Yeah, when she wants to be loved. She'll let you know by coming and sitting on you. And if you want that in return from her you go up and try and get a hug from

her. She (inaudible) came

Ginger 35:53

It's gotta be on their terms.

Bill 35:55

Yeah, she might let you get away for a few minutes but not too long. One of our previous guests Clare Coffield on episode 92. She told me she's a lady who's approaching her 70th birthday. And she told me she only got a cat after her stroke in the last few years, and she'd never had an animal before in her life to care for.

Bill 36:16

And she could not believe what she's been missing out on. She just said, It is amazing. To think that she not once in her life considered that a pet might be something that would give her companionship make her feel better, love her that she could love and care for. She's just and she's a mom. She's had that relationship with somebody before but she just couldn't imagine herself doing that with an animal now that she has. She just can't understand how she didn't go down that path.

Ginger 36:49

Yeah, I didn't have pets growing up. So I didn't understand either. Like I when I got these cats I didn't know it could be so Just like how much love and fun and enjoyment you could get from having an animal I just didn't know I didn't have that context. So, I mean, I'm just grateful. So I'm just very grateful that we had them. And they were here for both of us, my husband and I both like, you know, they've provided lots of like, support I don't know this is the right word, but just, you know, just joy and fun and love through all this craziness.

Bill 37:27

Yeah, we have two children. They're not they're way beyond 18 years of age. Now, Christine and I, my wife and I, and now it's all about it's become about the cat. So before it was the kids did this or the kids didn't know it was about the cat. And now I do stuff like say, if you do that if you misbehave, I'm going to tell you're mom on you.

Ginger 37:47

We do that too.

Bill 37:48

Their mom will be there now. And Christine was going don't worry about it. Ignore it. Very interesting interaction that we all have all the three of us and the kids that we all have together now. She's a member of the family. She runs the show she owns one of the chairs that nobody else can go to. And yeah, it's just something that I think some people who are stroke survivors might consider going down that path with some kind of a real gentle, easy-to-care-for animal and cats tend to be mostly easy to care for because they sleep a lot.

Ginger 38:25

Yeah, they're pretty independent, and they can go, you know, you don't have to take them outside all the time, or walk them and things like that. And so yeah, I recommend cats for lots of reasons, but it's a good one, the low maintenance aspect of it, for sure.

Bill 38:41

Yeah, nothing like some good old animal therapy. So now that you're three years out of post-stroke, and

Ginger 38:52

Well, more like a year and a half, three years started the eyes stuff and then my stroke happened about a year and a half ago.

Bill 38:59

Yeah, other than their physical challenges of weakness on the left side and the things that you described already. What are some of the things that you hope to overcome so that you can start changing your focus I got to that point where I thought, I've got to start overcoming certain things so I can change my focus and find a new way to include myself in the world. What are some of the things that you're hoping to overcome?

## **Focus on things to overcome**



Ginger 39:33

I think that as time is going on, and I'm becoming more accustomed to the physical limitations that I had, and it's also in there also like, getting better, like I'm working hard to work on my walking as I can walk without, like, without a cane. Now I was on it. I was in a wheelchair for a while then a walker and a cane and now I'm walking without anything and that's, you know, really kind of focused a lot on my physical strength and getting kind of back into as much shape as I can.

Ginger 40:08

But then also, I think learning how to adapt to the outside world with whatever physical limitation I'm experiencing at the moment, the vision or balance or whatever, figuring out how to not get overwhelmed and stressed out when I go out in public and go into new situations. Because I want I mean, I very much am a person who likes to be out doing things and I don't want these things to stop me.

Ginger 40:39

I want to figure out a way to be comfortable, kind of no matter what. So I know that sounds kind of vague, but I'm trying to kind of approach it from like a broad, bigger picture kind of outlook, so that I can be adaptable because you know, in my situation, you know, you have good days. bad days, bad weeks, good weeks, you know, I want to be able to enjoy life kind of no matter what.

Bill 41:06

So, I like that being broad is good early on in stroke recovery, because if you want to play basketball, from the moment that you got out of surgery, and you can't do

that yet, that's gonna be frustrating. After all, that's a really big skill to be able to achieve. For some people, it's going to be hard and perhaps very frustrating. But if you want to just do something broad, like I want to be able to just stand that's more doable than running at the beginning.

Bill 41:36

And I remember going through rehab and my therapist asking me, what did I want to do? And I said to him, Well, I want to be able to just go into a swimming pool, so that when I'm walking in the swimming pool and re-training myself to walk, I don't have to be afraid of falling over that's it. And they put me into a swimming pool and then that started this maybe from the walking in the swimming pool, I'll work outside on my own, and so on.

Bill 42:04

And then that started to change as I went through therapy. And then about six months after I was home after surgery, my outpatient therapist said to me, what do you want to achieve? And I said, I'd like to run and he said, what does that mean? And I said, not a marathon or anything just across the road so that I can get out of the way of a car if it's coming. And it was such a, it started to become more fine-tuned, why I needed to run and why I needed to walk and it had a purpose behind it, and I got there. And I don't enjoy running, but now I can run on a treadmill if I want to.

Ginger 42:41

That's amazing,

Bill 42:42

You know, for about five minutes or so. And that's five minutes more than I care to really.

Ginger 42:50

I don't enjoy running either. But yeah, I understand.

Bill 42:54

Yeah, you know what I mean so being broad. I think is great so that you can narrow it down later. It's like having, it's like trying to work out what career you want to do when you know you leave school. Well, I don't know. I'll just try something and I'll see how it goes. And if it goes, Well, I'll continue that down the path if I don't like it, I'll try something new.

Ginger 43:16

Yeah, I think flexibility has been like, one of the biggest, learning to be flexible. and adaptability has been one of the biggest challenges for me, you know? Because you don't know like, I didn't know early on, I still don't know what my abilities are going to be a year from now, a month a week. And I first you know, I remember going into rehab and then asking them what my goal was, and my goal was to walk out of rehab on my own.

Ginger 43:52

Well, I learned very quickly that that wasn't gonna happen. So my next goal was to transfer from the bed to the wheelchair safely. That was the goal and that's what I accomplished before I left. And over time, I've kind of learned to set smaller kind of more general goals. Yeah. And in just recently, you know, after I've kind of been used to kind of walking around the house on my own without the cane.

Ginger 44:21

I wanted to work on my stamina because I can only kind of walk a little bit at a time before I get very tired and worn out. So I started on the treadmill, like, I could only do about 30 seconds. At first, it was very painful and hard. And now I'm at almost seven minutes of solid walking, which I thought I would never do.

Ginger 44:42

Like it's it's, it seems impossible. So that's kind of showing me too, that I can accomplish things that I didn't think I could do before. And now these kind of like more generic like exactly what you said like these sort of broader goals. I can make it more specific and kind of like, actually get more targeted with what I'm trying to do. And it feels really good to be able to do that.

Bill 45:09

Yeah. And it's okay to have a big goal. Yeah, though, I'm going to walk out of the hospital again. Because if you don't get there, what that means is now you've got some feedback, and you can look back and go, Okay, what am I lacking to be able to do that? Now I can focus on those things that I'm missing, which if I did, might help me perhaps, I don't have enough time to walk out of the hospital, but I have enough time to walk out of, you know, whatever, whenever.

Bill 45:45



Let's not get that big goal and be upset that we didn't reach it. Let's just use it as the Okay, the benchmark of oh, okay, so that big goal is made up of a whole bunch of little goals. And if I achieved one of those, and then the next one in the next one, then before you know it, if I look back and reflect maybe in 12 months, maybe I'm further along than I expected, and that's okay.

Bill 46:07

That means you don't feel overwhelmed. And that means you don't feel like a failure or that means that you don't get concerned too much about not having achieved that yet. And I didn't have any goals or ideas or thoughts about what I was going to do. I just knew that I was going to walk when I was asked when I kind of contemplated the possibilities of what might happen to me after surgery, I expected the worst in that I expected that I wasn't going to be able to do anything with my left side after surgery.

Bill 46:45

And that kind of almost was the situation and then I just made the goal of now I'm going to walk so I didn't think about anything else a timeline or when or how or what because I started to get these lessons about time, at the beginning three years almost before that, because every time I thought I was going to get my memory back or every time I thought I was going to be able to do a calculation or drive or write, all those timelines got stretched out by things that were out of my control so that by the time I got to surgery, I was like, okay, I don't know how long this is gonna take. But I'm just going to go on the path to achieving that outcome. And whenever I get there, I get there.

## **A stroke recovery mindset**

Ginger 47:26

I had to kind of learn to approach it that way, too. You know what I think and also that there was kind of like a not fully understanding my situation, not fully understanding kind of what it happened to me. It all happened very quickly. I don't think that's the case for a lot of people. Sometimes these things just happen in the blink of an eye, and then it takes a while to kind of catch up to, oh, this really happened and this did this thing to me and it's going to take this amount of work or, you know, a general sort of like idea of this kind of work that I had to do to like, kind of get past it.

Ginger 48:05

And it's a lot for people to like, understand, and wrap their minds around, you know, you're processing the trauma that would happen to you and figuring out what your body is doing. And so it's a real process-heavy one. I mean, the rewarding one, you know? Maybe doesn't always feel that way but it's a process.

Bill 48:27

And it's shitty as well, the whole shitty like, you're going through this shitty time. And before that, you don't have any skills. You don't have any way of knowing how to navigate a stroke. I mean, it's right. You don't learn these things until you're in it. It's like having kids. You just have no idea what the hell you're doing until you have one.

Bill 48:50

And then you're trying to sort of work it out and if you don't upgrade the kind of level that you're at, and I'm not talking about learning more things or reading more books I'm talking about upgrading yourself and your identity that I, I am a learner or I'm now somebody that doesn't give up or I'm now somebody who is always going to strive for improvement, whether it takes one day, one hour, one week, one year doesn't matter, I'm going to always you've got to upgrade yourself to get through that process and mindset plays a massive role. What was your mindset like before stroke and is it similar and or different now?

Ginger 49:31

It's very different, you know, I can't even you know, I it's hard for me to even kind of identify what my mindset, you know, would be I mean, you know, I've kind of always been a positive person, but, you know, sort of like a day by day kind of take it, take it day by day sort of thing. And I guess in some ways, I am still like that, you know, I had to be that now because every day is different.

Bill 50:02

So what I'm saying what I'm asking is how much mindset plays in your recovery because you're gonna have the bad days. Let's face it, we're both sitting here being quite energetic and talkative, and the rest of it, but we're gonna have our crappy days. So how much does mindset play a role in getting you through those darker days? Or those more difficult days? Or those days where you're doing shit self-talk?

Ginger 50:31

Oh, gosh, it's huge. And I you know, I struggle with that too. At first, you know, I just didn't know how to, like, you know, to have the bad day isn't a bad week, you know, and feel like it's just this is just permanent this way. It's going to always be I don't know how to get out of this and over time, you know, and honestly, therapy has been a huge like mental health therapy has been a huge help for me.

Ginger 50:55

Learning how to kind of break out those patterns and sort of like being able to pull back and say just be kind to myself, like kindness and compassion towards yourself is key, being gentle being loving because you just never know what you're gonna get. And on the dark days, just kind of like the understanding that it will pass and you know, everything is temporary in your energy kind of moves in a flow.

Ginger 51:22

And the dark days will be over and then you'll have, you have days again, and it's just always a wave. So, I think I kind of said earlier that the flexibility and the ability to adapt are huge. And then also just having as much kindness and compassion towards yourself, even on the dark days when you're telling yourself all these negative things. Learning how to maybe step out of that and kind of like figure out how to talk to yourself nicely, even through the darkness.

Bill 51:56

Yeah, I remember having some days where I would be Feeling a certain way, you know, really negative kind of experience and my wife would be trying to work out what's going on. And I think I finally got to that point where I said, I'm having a shit day, and I want to have a shit day and I want to be shitty. And I don't want to be happy and I don't want to be.

Bill 52:15

I just want to be the way I'm being. And I'm sorry if it's affecting you negatively or bothering you. I'll be okay in a day or tomorrow in an hour. Or right now, I just need to be like, this can't change. I don't know what to do to change it. So I just want to be it. And then just being able to.

Ginger 52:32

Yeah, I was gonna say, being able to, like express that and identify this what's

going on? is huge.

Bill 52:38

Yeah. And that's the most I could do. I couldn't say any more than that. I just feel shit. I want to feel shit I want to stay here. I don't want to change and I want to bitch and moan and complain. And, hopefully, I'll stop at some point. But it's not about you. I don't want you to get upset annoyed and offended at me or any of that stuff.

Bill 52:58

I just want you to know it's something that I'm going through that it took a long time for me to get to that. And then you know what's cool about that is that gives her permission to say that back to me, because she had the same terrible days that I had, because of me. And because of what I was going through, she was going through the same thing. feeling stuck, isolated, you know, her identity is coming into question, am I going to become a carrier for this guy now for the rest of his life?

Bill 53:22

You know, I don't know what she was thinking. So that gave her permission to be like that. I recently also did an episode, Episode 82, which was about how to have a growth mindset. And that is an important thing. You know, there's, if you can have a growth mindset, and you can have just small amounts of growth, and that for me was growth, being able to just sit in my state and accept that I was this way.

Bill 53:52

Allowing me to have this growth mindset allowed me to start talking about things that I'd never spoken about before because it wasn't okay to be shitty in our house before that, you know that's not what you do. You don't act that way you don't be that way. Snap out of it was the kind of usual approach. And the usual approach doesn't work in these situations.

Ginger 54:17

Yeah, I mean, that's me that sounds very, very familiar. But you know, it takes a long time to kind of be able to recognize those patterns and you know, the feeling shitty and feeling like you're being shitty. Just feel shitty and you can't see much more beyond that. So when you get to the point when you can kind of see, okay,

I'm going to feel this way for a bit deal with myself, just ride it out. And then it'll, it'll pass. And, you know, it takes a long time to get there to get that kind of understanding. But, you know, then once you kind of accept that it's going to happen from time to time, you can manage it better.

## Identifying the signals

Bill 54:55

You can just stay there and know that it's going to end that feeling that way, it's kind of for me it was embodied It started in my body and then it ended up in my state of mind. You know, it kind of was a loop. And if my body felt unwell then my mind followed. And then as my body started to rest and relax, I started to get better then my mind came back.

Bill 55:21

I was just allowed allowed myself to go through that cycle. And, and then learned that when I felt this way. It was the sign it was okay, sit down, rest, recover, do nothing, go nowhere. And just heal and just relax and just get better. And that's what I have. Now. We all have this massive signal of now's the time to rest.

Ginger 55:51

Yeah, and again, I can relate. I can relate to that. It's like you know, being able to kind of be more in tune with your body and You know, what, how it's gonna affect everything else around you. It's a gift to be able to sort of like being able to pay attention to that and react or not react accordingly.

Bill 56:13

Yeah. And if people listening out there, you don't get there, you'll get it. It's just a matter of time. You're a year and a half, almost or kind of out of your surgery, and nearly three years into the whole journey. Somebody who listens to this might be earlier on in their journey and their experience. What would you say to them? Now reflect on what would you say actually to yourself, reflecting on what you already know.

Ginger 56:45

Oh, gosh, um, just to be patient, and again, just try to be as patient and kind and loving through the process because it's brand new and there are going to be some dark days you may not understand what's going on, you know, at any given point,

but you know this even though it might feel like this kind of bad stuff negative feeling emotions mood is gonna last forever. It's not going to, you know, time moves on and also just learning to accept whatever kind of state you're in at the moment, accept it and just try to be patient and kind to yourself.

Ginger 57:42

I think that was the biggest thing that I had to learn early on for me, because it was just I didn't know how to do that very well. was very hard for me. Oh, I can't do this thing. I can't do that thing. I can't do this anymore. Why can't I do it? You know, I should be walking by now. I should be doing it by now you get buried and shoulds. Yeah, so just just to kind of step back and just try to accept the process and love yourself through it.

Bill 58:12

Yeah. You strike me as somebody who will find a new way to do your life to be yourself and to express yourself and being somebody who is a graphic artist. You'll get a lot actually from checking out The Great Now What? Maggie is visually creative as well and she created to try and explain to people what it was that she was feeling she created some figurines from, I think they were Barbie dolls. On one of them, she added clay on the left side, to show the difference in how she felt in her body and to express that somebody who couldn't see what, she was experiencing.

Bill 59:04

And then on another one, because she has hypersensitivity issues on her skin, she wrapped one in barbed wire. And then she has a couple of different versions of that. And she's somebody who, those figurines they painted such a powerful picture instantly when you look at them, you can just go yep, exactly that's me that's how I feel.

Bill 59:34

So when we're done with the podcast, I'll send you will link to that episode. And then you can just look out for The Great Now What and Maggie is somebody who is going to and I think she already has participated in a play that's done by an organization that supports actors that come from all walks of life that are dealing with some kind of a disability and it's a really powerful organization because it enables so many people to express themselves into, you know, go back into the arts.

Bill 1:00:14

So it's amazing. Yeah, you'll love it. I have a feeling that you'll get there as well. I also looked at your Insta and I see there's a different colored eyepatch and a different texture eyepatch. Is that every day?

Ginger 1:00:29

Oh, I wish I wish I had that many. But you know, it just kind of depends on my mood or my outfit, or my hair. Yeah, I've got a purple one and a blue one, the red one is black glitter. All kinds of different ones. I love it.

Bill 1:00:45

I love it. Good on you. Well, thank you so much for being on the podcast. And more importantly, thank you for being brave and finding the courage to put yourself out there. Because from that, I think you'll grow and you'll become the kind of person who's once again despite what's happened to you able to be comfortable in your skin feeling positive about life and you know making a difference to people and this is so selfless doing what you did is so selfless and I appreciate that because that makes a massive difference to all the other people listening

Ginger 1:01:25

Thank you yeah and kind of want to add to that a little bit I know that you know facial weakness for others uses for example, facial weakness and eye damage are probably pretty typical with strokes, many strokes. And I don't see a lot of other people with facial weakness or facial paralysis out there. So I kind of wanted to I was very nervous to do this. You know, on the video part anyway, not very nervous, a little bit nervous. However, I want to kind of show that it's okay to have a facial weakness and to wear iPads. It's cool. It's great, you know. And so I appreciate that you allow me to share my story with you and with your listeners and followers and I just really appreciate that.

Bill 1:02:18

My pleasure. Thank you so much for being on the podcast.

Ginger 1:02:19

Thank you so much for having me.

Intro 1:02:22

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