

# Living With Nystagmus After Stroke - Sammy Taylor

**Living with Nystagmus after a stroke has seen Sammy Taylor go on a deep journey of acceptance and rediscovery that has enhanced her life with unexpected blessings once thought to be unattainable.**

Instagram

Highlights:

03:00 Introduction  
04:39 Diagnosed With Brain Tumor At 18  
12:43 Discovering Suppressed Emotions  
21:53 Always The Sick Person  
30:36 Living With Nystagmus  
42:32 Sammy Taylor's Book  
50:32 Living Life After Stroke  
1:03:49 Being Independent After A Stroke  
1:20:16 Acceptance

Transcription:

Sammy Taylor 0:00

I had a lady reach out to me on Instagram last Tuesday, she was frantically wanting someone to speak to because her daughter, Kirsty who was the same sort of age I was she's 24 now, she has all the same complications as me.

Sammy Taylor 0:16

And I think her mom was in sheer desperation and wanting, you know, some advice. And so I gave my WhatsApp number and had a conversation with her on Monday, and it's crazy seeing her daughter because she has every single complication that I had like two years ago.

Sammy Taylor 0:34

We were talking about our eyes, we've both got nystagmus. And there's currently nothing for nystagmus to treat it, every surgeon I've spoken to has said it's

permanent. And when you acquire it later on in life, you also get what's called Oscillopsia, which is the sensation that the world around you is moving.

Sammy Taylor 0:55

So I walk down the street and the trees and the people are everything around me is moving in front, which means that when you had like a cerebellar stroke, and you suffer with balance issues anyway, on the cerebellum like a tumor or anything, it makes the balance, like harder to comprehend and harder to deal with.

Sammy Taylor 1:15

And I just said to her, look the reason I live with it now is I can cope with it almost I was in a state of shit while I'm with it two years ago with that sensation. But the reason I'm not that in that case anymore, is not because it's changed it's no different than it was.

Sammy Taylor 1:31

However, I am just fully hopeful, and trusting the fact that in five or 10 years, there will be more, you know, studies that come out all the time, and in 10 years, I'm still only going to be you know, 37 and so, you know, even if it's 20 years, it's still a good age. If I lived that long to then, you know, have a cure then.

Intro 1:55

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

Bill Gasiamis 2:09

Hello, and welcome to another episode of the Recovery after Stroke podcast. Recently, Spotify released a new feature, that allows you to rate your favorite shows, in a similar way to how the Apple podcast app allows it.

Bill Gasiamis 2:23

If you think the show deserves a five-star review, I'd love it if you went across and left the show a five-star review right now. And then come back and listen to this episode. The reason for this is because it will help the show rank better on search engines and stroke survivors who are looking for information and stories about stroke recovery will be able to find the show easier and better.

Bill Gasiamis 2:49

And therefore will make a massive difference in their recovery. So go to your favorite podcast app and share what the podcast means to you. That really will make a huge difference.

## Introduction - Sammy Taylor



Bill Gasiamis 3:00

Now this is episode 186. And my guest today is Sammy Taylor, who experienced a cerebellar stroke that has impacted her eyes leaving her with nystagmus which according to the American Optometric Association is a vision condition in which the eyes make repetitive uncontrolled movements.

Bill Gasiamis 3:20

These movements often result in reduced vision and depth perception and can affect balance and coordination. This involuntary eye movement can occur from side to side, up and down, or in a circular pattern. Sammy Taylor, welcome to the podcast.

Sammy Taylor 3:37

Thanks so much for having me.

Bill Gasiamis 3:39

My pleasure. Thanks for being here. Tell me a little bit about what happened to you.

Sammy Taylor 3:46

So, in 2019, I had brain surgery. So I had a craniotomy to move polycystic

astrocytoma and during the surgery, part of my brain didn't get any blood supply. And so I woke up with a stroke the next day, which was classified as a cerebellar stroke.

Sammy Taylor 4:11

And well, it just affected I guess everything in the cerebellum area, which is where the tumors are anyway. So it's very hard to say whether I mean because I was struggling with coordination and balance issues on that it was kind of hard to say in the following months recovering whether things were getting better or things were the way they were because, you know, the position of the tumor and so on.

## **Sammy Taylor Was Diagnosed With Brain Tumor At 18**

Bill Gasiamis 4:39

When we hear about brain tumors, people usually don't have enough information to make a qualified response at the time when they're given the news that there's a brain tumor in there. And we have to go in, what's it like to be in a doctor's surgery to go through all the tests, and then get a result like that, especially when you're so young?

Sammy Taylor 5:06

It's really funny actually, because first diagnosed with a brain tumor when I was 18 years old. So I didn't have the surgery until five years later. And it's funny because I'm writing a book now.

Sammy Taylor 5:22

And I'm trying to do some of the emotional work because I realized that when I read it for the third time, it was kind of, you know, I just dumped almost the events as I could recall them. But it's because they happened so long ago, that now I get asked, Oh, so what was it like? Or when did you find out you had a tumor, then I have to kind of remember that.

Sammy Taylor 5:43

I lived with it for like, five, or six years, and I almost forgot that I had it because I was so naive and young at the time. And so now that I'm working with a therapist each week to kind of add some depth to that back. And she's really good in terms

of I mean, it's quite exhausting had a session this morning, where she puts me in, like, you know, a meditative state and takes me right back to that room.

Sammy Taylor 6:06

So I can feel every emotion. And on Monday, we went right back to the beginning, where I was like, 18 at a doctor's office, and I was like, wow, I had no idea that I even had this kind of reaction to it, that I've suppressed for so long. But I guess when I was so young, I remember thinking, I didn't tell anyone at the time.

Sammy Taylor 6:29

So with who my ex-boyfriend is now, the two of us just strolled into the doctor's office, I mean, I was having headaches, and my doctor at the time sent me for an MRI just to rule anything out. And so we walked into that surgery room and just thinking it was going to be, you know, a routine kind of "you're fine, you can go home" That's it.

Sammy Taylor 6:53

And so when they told us that we just weren't expecting at all. And I remember just being in such shock and disbelief. And I don't remember too much changing when I look back. And I was trying to say that to the therapist, you know, I was in shock and disbelief that it was almost a little bit of denial, I guess, because I carried on so normally like, as you can imagine.

Sammy Taylor 7:16

But then actually, when I was looking back on those five years between when I was first diagnosed, and then when I had the surgery, I did so many drastic things in that time, like I moved to a new city, I had a career change, I left my boyfriend of six years, I felt alone. And it was like I've done nothing for 18 years.

Sammy Taylor 7:35

And so actually, maybe subconsciously, I was just almost living as if I never accepted anything, you know, that convert that I guess in a way that I was living just in case, I was gonna find out one day that you know, the opposite can be true.

Bill Gasiamis 7:50

The one certain thing is death, every single day we're closer to it doesn't matter how old or young you are. The reality is that I asked the question on Instagram, just yesterday, I asked the guys what has stroke taught them, and some of them responded were stroke has taught them to live to not take things for granted, or

that they never know when your time is up, or how quickly life can change.

Bill Gasiamis 8:17

And it's given people this sense of gratitude, it's given this person this sense of, I only get one shot at this might as well make the most of it to live actively, every day, they talk about living actively, in the life, not just sort of getting by, and not just sort of getting by for me, it resonated that's kind of like you're going through the motions.

Bill Gasiamis 8:39

You wake up in the morning, you go to work, you punch a card, for example, you come home, you pick up something to eat, you make something to eat, you sit down, you watch Netflix, or trashy TV shows or whatever. And I sort of see myself when I do that dumber than I was the day before.

Bill Gasiamis 8:57

Because I haven't evolved or grown or developed anything new that I can take to the world and benefit from like, may benefit from and the world benefits from. And I'm kind of, you know, I'm 48 this year. So you think about the shortness of life more often. And my parents are in their late 70s. And we talk about let's make a date, for example, to go somewhere to do something.

Bill Gasiamis 9:35

And the first thing they start with is, you know, God willing, it's like if I'm alive and all these things, and it's like, Well, okay, so at some point you become aware that life is going to end for me it was when the strike happened, it became obvious to me that it might not be another day after this or two or three or whatever.

Bill Gasiamis 9:56

So I needed to make a few things good, it took me three years to get to brain surgery. So there was quite a delay for me as well. And I was really good about it. When I got to brain surgery, I was really good. I had done all that work about, you know, telling people, I loved them, and sorry, and behaving more appropriately and apologizing more often and all that type of thing. What were the main concerns that I had? You had about did you say five years before you got to brain surgery?

Sammy Taylor 10:34

Yeah, I did, but no one knew. So it was just my ex-boyfriend at the time. And I wasn't with him by the time I found out that I needed brain surgery. So it was just my mom, who was the only person that knew, and my older sister. And so then I just decided not to tell anyone that I needed surgery because it was almost like I couldn't bear the questions of like, they would be so shocked as I was.

Sammy Taylor 11:00

But almost, then I would have to always explain that I'd been living with it for six years before and not mentioned anything. So I was torn between that. And then I thought okay, well, I've come this far in my head, then I was thinking well, unknowingly, but I've come this far, I may as well go get the rest without telling anyone.

Sammy Taylor 11:20

I just didn't. And I just decided that I was so confident that it was going to be fine. I mean, I met with four surgeons before I had the surgery. I ended up getting to kind of semi-choose who I went with, which also weighed heavily on my mind when things went sour when I woke up because I thought this could be because I made the decision and whatnot.

Sammy Taylor 11:42

But essentially I was so confident that it's gonna be fine. And all the surgeons had confirmed that, that I just decided then I won't tell anyone, I will just you know, I won't tell my family, I won't worry, my friends or anyone, I won't kind of have that negative energy on this journey with me.

Sammy Taylor 11:59

And I will just show everyone afterward when it's like, well, then, of course afterward I looked fundamentally different. I couldn't walk I couldn't feed myself right for the longest time. And so then it was like a major shock, because then no one knew and it had the complete opposite reaction of what I wanted it to do wasn't settling at all. It was oh my god overnight like this, you know, you've changed?

Bill Gasiamis 12:25

Yeah. Is there trauma associated with that? It sounds like you did a really good job of avoiding dealing with any emotional challenges at the beginning, and then you got through travel to do all these things. I think it's great that you did that,

regardless of whether or not you had a brain tumor.

## **Sammy Taylor Discovering Suppressed Emotions**

Bill Gasiamis 12:43

But I think it's just great that you did those things. It's one thing that I didn't get to do when I was younger, and I regret not doing is going out and about and being with my friends and meeting new people overseas and all that kind of stuff. But was there any trauma associated with that, that you discovered when you went back into this hypnotic state with the therapist?

Sammy Taylor 13:04

Oh, there's so much I mean, so in my book, there's so many themes that I want to cover. And so each session I have with that we just have time to cover one. My book has all that lists all the major themes.

Sammy Taylor 13:18

So I pick one, you know, that I want to discuss and today was right after I had the stroke and it was taken back in that operating room when you know I woke up because even then I remember waking up after the surgery. And I couldn't see at all I've gotten a segment in my eyes like both sides.

Sammy Taylor 13:37

And so at the time, before it settled down just a little bit like now I have a very small central window of gaze that when I first had the stroke, and it was like all over my eyes, I couldn't see at all. So then I remember saying to the nurse, oh my god, I can't see I was just in such a state of panic. I was like, I can't see I can't see.

Sammy Taylor 14:00

But as I was saying that to her, I realized that my mouth was I couldn't speak either. And so I knew that my mouth was wrong, something had happened. And I remember her stroking my hair and going, no, Samantha don't worry, it's just the anesthetic it'll wear off soon.

Sammy Taylor 14:15

And I was like, No, you don't understand like I can't see at all. And so times like that where I go back in the room. And I think again, it comes with denial and almost maybe not telling anyone leading that because also I was you know, I was



studying hard at the time in a financial role.

Sammy Taylor 14:34

I was trying to get accredited with a SEMA qualification. And I was getting a promotion at work and so then it kind of switched overnight in this office and I thought why needs to keep it secret because I don't want A people to think I'm not capable of work.

Sammy Taylor 14:51

And I was just going through all these things in my mind thinking my friends won't see me the same then I've got to think I've just moved to London. So I was developing a new social circle, and so I was surrounded by people that weren't family or like close, close friends that I've known for years.

Sammy Taylor 15:06

And so I thought, What do I want to like establish this friendship ground now based on like, feeling like they would pity me because I'm now this like, ill person? So I just had loads of mixed emotions. And so obviously, like now when I get back in those rooms, it's all these, like, things that I didn't even know that was I felt until they come out now.

Sammy Taylor 15:29

And I'm like, well it's too late now, like, it doesn't affect my life. It's so different now, for example, so when I'm writing it's like it feels a little bit easier. So maybe add some of that emotional side because it does feel like a very different person. And I finished writing books last year that I think I needed the right that you had to almost go back now. And the emotional side is that I'm not so close to it like it's not my life now.

Bill Gasiamis 15:55

Awesome. So there's a separation from the trauma, now you're not going about it, and remembering it and getting re-traumatized. You're just recalling what happened in the past. And you're able to develop the story further and make a deeper so that there's an emotional aspect of it because you feel like there was an emotional aspect that was missing. After all, you had kind of like to shut it out.

Bill Gasiamis 16:20

Because you had to get through all these stages. And I don't know what the right or wrong thing is. But as you're describing it, to me, it feels like you've done the

right thing, because you've got to this stage, and look at you now and you're reflecting on it, and everything's kind of worked out. And you managed to get all those things done that you wanted to get done while you were getting to brain surgery. And it kind of has worked out, hasn't it don't you think?

Sammy Taylor 16:52

Yeah, I look back now. And I think, well, it's like it went well. Like I said, like keeping it secret and kind of shutting out this emotional trauma, it worked well for me. But then I've never really been one of these people. But I guess, like when I have a headache or a cold, I don't tell my mom or my sister or my family because they're worried.

Sammy Taylor 16:59

So in the nicest way possible. But then it might be you know, every day for like, two weeks. How are you feeling today? Or how are you feeling today, I don't feel like I don't feel that anymore. So I'm fine. But then I thought well, that's a common cold. So God what they're gonna be like when you know, I've got this huge like mass in my brain.

Sammy Taylor 17:34

And so the days that and the reason I kept it secret was because, you know, I guess the worst, sometimes, quite a lot of times actually would be so overwhelmed, but like work, and if I was having a really good day, I'd even crying because I'm like, I'm gonna have to take a break from this soon. And then equally, if I was having a really bad day, I was overwhelmed thinking, like, I wasn't feeling like capable.

Sammy Taylor 18:00

But at the same time, like, I'd go home and then like cry in my room or like journal things. But the next day, I could put on a brave face and carry on as normal. Whereas if too many people knew, it was like, almost, I imagine I wouldn't have had the opportunity to have moments where I'd be able to forget about it. Because there would always be someone messaging me or asking how I feel in the nicest, you know, with the right intentions you can, you can never shut off if that's the case. And so I thought, you know, I'm just gonna do it on my own.

Bill Gasiamis 18:34

I love it. I'm 10 years in this this week was kind of my 10th anniversary of the first

bleed. And I have relationships with people who are still once-a-year kind of people, you know they're really lovely people, but we just only see them once or twice a year. And we're still on the how are you? Kind of part of the relationship like how are you and I'm like, I'm good, but they're not asking me like the general how are you small talk kind of thing.

Bill Gasiamis 19:08

They're talking about the stroke still, you know, they're talking about how are you going? How are you doing? How have you been it's like, I don't know man, it's like 10 years and six years in surgery, everything is normal, whatever I've been left with and whatever I'm dealing with, it's all normal part of my life now it's all just normal.

Bill Gasiamis 19:27

So I can't move them from that "How are you?" kind of situation and I know what you mean and worriers having worriers around me worrying people. That makes it difficult for me as I can't cope with having people around who just want to know what the hell's wrong all the time, like what's wrong?

Bill Gasiamis 19:48

And they asking you what's wrong? It's not actually about you, it's about them. It's to either ease their anxiety they're asking you hoping to ease their anxiety. So if you say everything's fantastic. They don't give a shit if that's the truth or not, they just want to hear everything's fantastic. So they don't have to worry about you, because they're just habitual worriers.

Bill Gasiamis 20:09

So I know exactly what you mean. And I know, parents and family can be the worst, because, you know, they care about us more than most people, I suppose, or they can care about us the most. So if they've got bad habits around how they care, then it's really difficult on the other person, and that's part of the stroke recovery, it's like really important to make the circle of people that you interact with.

Bill Gasiamis 20:41

The best version of the people that you can get. Not that we don't love, the ones that are worrying, but to limit the interactions with them, and to try and steer the interactions in different directions so that it's not always about experiencing their

anxiety from the question that looks like they care. Because it's trying to relieve their anxiety. That's, my experience. Does that resonate with you?

Sammy Taylor 21:11

Everything you said, I mean, I've got people in my family who are ring now and they say, How's your health? Like, what do you mean? How's my health? How's your health? I asked you how your health is, it's like, you know, it's fine now it's good. But it's, it's that classic, where they just forever.

Sammy Taylor 21:32

That's what I worried about, actually, when I, the reason I didn't want to tell people was because I didn't want them to now see me, as you know, a sick person over. But it turns out that even if you recover, you're always going to be, the same way you're parent's like baby, you're always going to be someone now that had a stroke.

## Always The Sick Person



Bill Gasiamis 21:53

Yeah, "the sick person" and just because somebody appears, and this is the real difficulty with invisible symptoms of stroke, and all that kind of stuff, just because you appear normal like me, doesn't mean I'm well. But also, just because you, quote-unquote, don't appear normal doesn't mean you're sick.

Bill Gasiamis 22:14

And it's all these assumptions that people make, and nobody stops to have a real conversation with you at all. Because it's too much for them. They can't cope with

it. I don't know what it is. And they just don't lend an ear the way they need you.

Bill Gasiamis 22:27

They don't listen to your responses that's about you. They listen to the response that's about them. And we're getting nowhere in this conversation again, and it's like, oh, well, isn't the weather great today? And it's better to just change the subject.

Sammy Taylor 22:45

No, it's so true. I resonate as well, when you said, you know, that a lot of the times they will ask you how you're feeling they don't care about the answer. They want to alleviate their anxieties. And I noticed that so much, you know, with my family, they feel like maybe they need to worry.

Sammy Taylor 23:03

And so they just always check-in. And then as soon as I think I'm like, fine, or I say I'm fine, it's okay. And it's like, then they go off and live their normal days and stuff. And it's like, okay, well, what happened to like the general chitchat as well, sometimes, like, I remember, like going through I mean, you probably notice as well, but straight after my, my kind of stroke and my surgery my friendship groups changed massively as well because you do notice who's like they're around you or not.

Sammy Taylor 23:34

And even though everything is completely fine, not well, it's not completely fine. But I mean, things are like now. And it's like, my life is like back to normal. And I do get people from, like, you know, like school and things that messaged me now on Instagram. And I'm like, well hang on a minute, you didn't message me like two years when I needed people.

Sammy Taylor 23:54

And so like now I'm very, very cutthroat with that. And I just think that anyone who was not necessarily supportive or around during that time, I can't imagine that I'd ever need anything in the future. And I know that might sound negative to some people. But for me, it's just very much a case of, well, I can't imagine that I'm never going to go through anything quite as big as what I went through.

Sammy Taylor 24:17

So to go through that, like on my own pretty much. And with the small group of

people that I had around me, it's enough now I'm content with that. And it makes me realize that maybe I just don't need other additional people. And I think it's a good thing to maybe find out when you're young. So I don't see that as a negative. But I found that out. You know, when I was like, 25, I think that's positive actually.

Bill Gasiamis 24:42

Yeah, about four years ago, I ran into somebody who I hadn't seen during my illness, so it's good so maybe I hadn't seen them for six years. Or seven years before I was unwell, but they were in touch with people that I was in touch with, so we never crossed paths at mutual gatherings or events, but we were new people, the same people.

Bill Gasiamis 25:10

And I was at a pub. And this was about four years ago, I was at a pub, and he, I saw this guy, and he bumped into me. And he starts the conversation. Hey, going the usual stuff, you know, there's a bit of conversation there. And then he goes, sorry, I didn't come and see you when you were in the hospital. It's like, I haven't seen you for six years, at least.

Bill Gasiamis 25:37

And let's all right, like, doesn't matter that you didn't come in the hospital. And based on the person that I know you are, it's probably better that you didn't come to the hospital. I didn't say that to him. But I was immediately I was thinking, it's probably better that you didn't come to the hospital, because I wouldn't be able to deal with somebody like you in the hospital.

Bill Gasiamis 25:57

Because he always used to make the conversation about himself anyway. So I was feeling like, he would say something to me, like, oh, man, you know, you got your head cut open, and there's blood gushing out or whatever. And, you know, you're, you just had brain surgery, you can't walk anymore.

Bill Gasiamis 26:17

And I was feeling like he would go and throw in a. But you remember when my wife left me, right? And I was dreading people like that coming, into the room. Because for once in my life, no, it was actually about me, I was in the hospital, and I was unwell. And I'm not going to let it be about you.

Bill Gasiamis 26:40

If we're going to talk about small talk, that's fine. But if you want to talk about me, now's your time to step up and have an emotional conversation with your friend who's in the bed opposite you is unwell and needs an emotional conversation need to talk about something serious, not about you, and not about irrelevant stuff.

Bill Gasiamis 27:04

Because there's never been a better time to be serious, because right now, it's serious. And I'm not feeling well. And I need somebody to guide my spirit. And make it feel like everything's gonna be okay. On the other side of this, whatever that looks like. And you're not capable of doing that you're not the guy who's capable of doing that. So it's okay that you're not here, like, totally okay.

Bill Gasiamis 27:30

So the first thing to come out of his mouth is sorry, I didn't come to the hospital, you've had for years since the hospital to come and see me out of the hospital as well. You still didn't come. So I kind of feel like they know, instinctively inside somewhere that they are not useful to have around.

Bill Gasiamis 27:54

And they give us the best gift of not turning up. What they don't know is that they don't need to apologize for that. You know, they shouldn't feel guilty about it. They should just go Hey, listen. You were unwell for a while I heard about that. Well, I hope you're doing better. And that's it, leave it at that there's no need for an apology, or I'm not expecting one.

Sammy Taylor 28:17

Yeah, it's almost as if they assume maybe that you didn't have anyone around or, you know, their presence would have made a huge difference. But I just think now I just leave everything to kind of, I hate the saying things happen for a reason.

Sammy Taylor 28:33

Because some really bad things do happen. But I don't believe in that. I just believe that, you know, life is so unpredictable. We never know, from one day to the next what's going to happen. And when you make peace with the fact that you can just change like unexpectedly you just kind of, you know, it doesn't matter who's around you at what certain day, as long as they kind of add into your life, I

always think in some way.

Sammy Taylor 28:56

So, yeah, I mean, I guess you're saying as well, me and my friends. My best friend Heather, has been recently diagnosed with stage four. Well, they said it's like, you know, it's not terminal with say, it's a throat cancer and they class it as stage 123 normal cancers.

Sammy Taylor 29:15

And then when it's throat cancer, it's for A, B, and C, on the way that it, you know, grows and things. And so she had surgery a few weeks ago, and it's grown again, she had another surgery. And then she just found out that even though they removed the whole tumor, she found out two days ago, that she's got to have another surgery because it's already spread again.

Sammy Taylor 29:39

So they've got removed every single lymph node but for years, we've had this, you know, we've never really understood when some people can be so kind of in competition with like, whose day is the worst and things you have a headache and someone's like, well, I've got this and I've got that and so we make a joke of that now.

Sammy Taylor 29:59

So when I see her as he sees me and things were always like yeah but I had brain surgery she goes Yeah, but I've got stage four cancer and I'm like yeah but I had a stroke we've like fully make like a joke of it and just like pay off like you know whose situation is worse? And it's really funny that we do that, to be honest.

Bill Gasiamis 30:19

It is really funny. I love it because the two of you understand that you're taking a piss off the people that do that the guy with you know, with the splinter in his finger is the guy you're taking the piss out of there comes to the hospital, and says oh you've had an s, troke. Yeah, I've got a splinter in my finger.

## **Living With Nystagmus**





Bill Gasiamis 30:36

Wow like, wow, you must be suffering immense trauma, emotional, physical, mental. Keep it to yourself, and don't worry about the splinter you'll be fine. So how long has it been since your surgery now? How long has it been since all of that has been in the past?

Sammy Taylor 31:00

Well, two and a half years, but I have a hospital appointment tomorrow, for example at East Grinstead, they're are amazing hospital in the UK. They focus on reconstructive, reanimation, and facial surgery. So I had face surgery there in September 2020. But in October 2021. I'm always having these surgeries. Then I had platinum eye surgery.

Sammy Taylor 31:32

So tomorrow is like that's basically like a weight, they put in the lid to obviously close the eye and make it blink. And so tomorrow, I'm just having my checkup with my surgeon for that. But I've got like four different surgeons for different things. So it's crazy. But again, because I guess the stroke happened two and a half years ago.

Sammy Taylor 31:52

And so now when I say that, it seems long, but I'm still in hospital all the time, or I'm still having corrective surgeries, or this and the other and I for example today and my therapist and like this emotional state, I was like, wow, I just the reason I haven't processed any of these motions is because it's been ongoing one thing after the other.

Sammy Taylor 32:15

It's like, oh, great, you can now walk again. Yeah, we need to do your eye surgery, because first of all in March 2020 first UK lockdown. I had strabismus eye surgery for the vision. So it's like okay, great. You can walk and now we need to fix your eyes like, you know, stop using term thing.

Sammy Taylor 32:35

And then when I recovered from that, it was like Okay, great. Like now your face will never heal so we need to do you know a nerve graft from that. So then when I recover from that, it's like, okay, well, now we're gonna do another eye surgery and so you can blink again. So it's been constant. I've never really had a break still, even now, I haven't had necessarily a right to just be like, Okay, well, wow, that happened. That was weird.

Bill Gasiamis 33:00

I love it, you're busy. You're busy doing stuff and getting stuff done. I love it. I'm gonna, like I'm feeling really kind of pumped up and emotional about this in a good way. Like, is it fucking fantastic that there are so many surgeries that they can do to support people who've had a stroke? And 30 years ago, none of this stuff was available for anybody. Is that fucking brilliant? Or what?

Sammy Taylor 33:26

Oh my god, it's insane. It's so good. Like, last September, when I had my face surgery, I was the first in the UK to have that particular surgery. And fourth in the world. My surgeon like was amazing. And I fully trusted him from the get-go even though I listened to and recorded that session when I was in there. And I listened to it the other day.

Sammy Taylor 33:51

And those were so like laughing that we notice like the first time that we're going to be doing this and he's trying to reassure me like a laughy way because I'm nervously laughing I think saying it's not pioneering don't worry like I've done this before. Like I said, I've not done this particular surgery he was saying but I know how to do it.

Sammy Taylor 34:10

But then he was like I need to do on this state because then I need to like go on this course and pay for it. And I was like wait wait, You don't even know how to do

it. And he was referring to it as you know when you the analogy he gave me was when you embark on a long road trip you wouldn't go without a map you want to be prepared.

Sammy Taylor 34:31

I was like wait you are like the surgery it's like this laughing stuff. It's crazy. But then I have goals messaged me on Instagram still now which is which is one of the main reasons I share everything that I do. And it's made for that reason. And I have girls though in you know, all kinds of countries saying oh my god, I'm at a loose end like I'm desperate for something like we don't have this in our country.

Sammy Taylor 34:59

Please put me in touch with someone. And then when I suggest my surgeon I'm like, well, actually, they don't do like, you know, NHS don't do you know, overseas patients, but maybe contact them privately. And it's just like makes me realize how fortunate I am, for example, to have the NHS here, because I haven't I mean, you wait a long time, but I don't have to pay or think about it.

Sammy Taylor 35:24

So it's like you are given, for example, they do suggest as pioneer and surgery, they can do it for you. And it's not a case of it's just a no likes no pun intended, but it's like to them, they don't even see it as Yeah, okay, you can't like what made it lead to the platinum chain surgery is the best one at the moment. You don't have to ask almost for these massive breakthroughs. They just want to do it for you. And it makes your life so much better.

Bill Gasiamis 35:54

The NHS in the UK is the National Health Service. In Australia, we've got Medicare, it's the same kind of service. And through our taxes, our weekly daily work taxes, and the goods and services tax, which is a 10% tax on every purchase that you make. There's a fund that goes towards our hospital system, where if you don't have health coverage if you don't have insurance, you're fully covered.

Bill Gasiamis 36:25

So I am grateful for that as well because I went to Greece and had a conversation with some people about two years after my brain surgery, three years after my brain surgery, and when I got there, people were saying to me, man, my cousin, for example, fell over broke her leg. And at that time, she had to get it looked at

and repaired.

Bill Gasiamis 36:52

And because she couldn't walk and I was at the hospital with it, I would be told you guys need to go to that particular window, get the invoice when go to the next window pay the bill, and then bring the receipt to us. So we can do a scan of the leg to see if it's broken or not.

Bill Gasiamis 37:12

And I'm losing my mind, I mean, what the hell, like just scan the lady's leg, and then let's pay for the frickin bill, whatever it is, you know, make sure that you get this person help. So she has to wait to go through the windows with a broken leg in a queue. And then, once she's done that, she can get her scan. And I couldn't believe it, I was pushing her through these windows.

Bill Gasiamis 37:38

So in Australia, you go to the hospital, and they scan your leg. And that's the last time you hear from anybody. If it's broken, they sort it out if it's not you go home, and they tell you how to fix it and look after and go home. And then when we're talking about my brain surgery.

Bill Gasiamis 37:59

And the guys were going, Oh, that must have cost a bundle or that kind of thing. I'm like, oh, oh, no, no, it didn't cost me anything. What do you mean, it didn't cost you anything? And I was like, Well, that's one of the reasons why in Australia, we pay tax. In Greece, they try to avoid tax under any circumstance.

Bill Gasiamis 38:17

And the system there was faltering. And one of the main issues they had all those financial problems back in 2010 was that they never collected taxes. And all they did was spend, spend, spend. And I said to the guy, well, it cost me \$0 to go to the hospital, have all the appointments, all the tests, all the things that I'd done, and then go to brain surgery, and then get all the rehab for a month.

Bill Gasiamis 38:50

And then get all the aftercare for three, four, or five years, it cost me completely zero. And they were just looking at me like I was talking in some other language they were stunned. So, for me, I take it for granted, and it's normal. And then I hear people in the United States complain about Medicare, Obamacare, and all

that kind of stuff.

Bill Gasiamis 39:15

And I don't know the politics of it. But Obama was trying to implement something similar. If that service was available in the United States, that would be like becoming a socialist republic of some kind and converting the United States of America into something worse than what it already was like caring for people was going to become worse.

Bill Gasiamis 39:37

And I just can't compute the issues that they have in America with getting a bill like that over the line, like a law like that over luck, where every human participates in their health and well-being by putting a small amount of text towards it and it's like one or 2% for us like it's not massive.

Bill Gasiamis 40:01

And then in the United States, they didn't say that as a positive thing to do for A yourself and B for your fellow human beings and your fellow country people. It's just a bizarro world so and then all the surgeries that are available to us are our leading-edge cutting edge.

Bill Gasiamis 40:24

Even though there is this free supposed system or this system that we pay for through our Taxes, that has helped the doctors who come to Australia become established to learn the greatest amount of things that they need to learn.

Bill Gasiamis 40:38

And that's all we have some of the best hospitals in the world in our five cities in our five, six cities that are world-class and that you can get amazing surgeries in and all this type of stuff that has never been done before and is getting tested and proven here and changing the way that people are getting helped and supported.

Bill Gasiamis 41:00

So when I hear about people from overseas, it breaks my heart, it's really difficult to hear about people who can't access services just because they live in the wrong part of the world. But then I think about things like GoFundMe, which has changed the game for a lot of people who have been able to raise money to put towards such an amazing cause, like getting surgery or getting some additional support for a loved one or themselves.

Bill Gasiamis 41:32

And even though it has, it's been really hard for people overseas, and still is, for a lot of people, it's much better than what it was still like still, things are improving because of these amazing services like GoFundMe, and all that hundreds of other ones that are out there.

Bill Gasiamis 41:50

So I suppose things are getting better. But there's a long way to go. Things are getting better for the stroke community because there are communities like this that exist and Instagram is full of people who are talking about their stroke and sharing their stories. Every second stroke of respect is writing a book. And that wasn't the case. 10 years ago, when I started on this journey.

Bill Gasiamis 42:17

I'm writing a book I'm probably halfway through, it's been the hardest thing that I've ever had to do. Because I was never academic or, you know, literate in that way in kind of telling stories in a way that other people would consume them.

## **Sammy Taylor's Book**

Bill Gasiamis 42:32

So things are way different than they were 10 or 12 years ago, and I can't imagine how good or better and how improved they're going to be in another 10 or 12 years. Tell me about the idea behind your book. Why did you decide to write the book? And how far off is it from being finished and ready to print?

Intro 42:57

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

Intro 43:21

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](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.

Intro 43:40

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](https://recoveryafterstroke.com), and download the guide. It's free.

Sammy Taylor 44:00

I think the whole it just goes back to what you just said. I mean, I had a lady reach out to me on Instagram last Tuesday through my UK account. And she was frantically you know wanting someone to speak to because her daughter Kirsty was the same sort of age I was she's 24 now so she's around the same sort of age I was when I first had brain surgery.

Sammy Taylor 44:26

And she suffered all the same complications as me. And I think her mom's just in sheer desperation and wanting you know some advice. And so I gave her my WhatsApp number. I had a conversation with her on Monday and it's crazy seeing her daughter actually because she has every single complication that I had, like two years ago.

Sammy Taylor 44:49

So I know is very like almost not comforting to them to know. It does get better and us almost saying that no, everyone's journey is completely different as well. And I don't know unnecessarily the ins and outs of her surgery. But for example, we were talking about our eyes, we've both got nystagmus.

Sammy Taylor 45:07

And there's currently nothing for nystagmus to treat it. Every surgeon I've spoken to said it is permanent. And when you require it later on in life, you also get what's called Oscillopsia, which is the sensation that the world around you is moving. So I walk down the street and the trees and the people and everything around me are moving in front.

Sammy Taylor 45:31

This means that when you have a cerebellar stroke, and you suffer from balance issues anyway, like a tumor or anything, it makes the balance harder to comprehend and harder to deal with. And I just said to her look the reason I live with it now is that I can cope with it I was in a state of sheer overwhelm with it

two years ago with that sensation.

Sammy Taylor 45:55

But the reason I'm not in that case anymore is not because it's changed, it's no different than it was. However, I am just fully hopeful, and trusting the fact that in five or 10 years, there will be more, you know, studies that come out all the time, and in 10 years, I'm still only going to be you know, 37.

Sammy Taylor 46:14

And so, you know, even if it's 20 years, it's still a good age, if I lived that long to then, you know, have a cure that and then. So I think the main reason for that book, The reason I'm writing a book, right is the relatability of it. So when I mean, it's not even that long ago, two years ago that when I first you know, had got the news that I was having brain surgery, and I went on Instagram, and I couldn't find anyone, really of my age or similarities who was going through it.

Sammy Taylor 46:47

And then when I had a stroke, it was even worse, because I was like hashtagging stroke recovery. And it's a lot more, you know, as in like a lot more of an Instagram community now and people who are like coming forward and sharing their stories, but there wasn't even that two years ago.

Sammy Taylor 47:03

And so I felt alone with it. And the comparisons with just hostile sites on Instagram that we're sharing, you know, stroke survivors that not to stereotype, but they were just so unrelatable to me, and, you know, much, much older, for example, a different kind of stroke.

Sammy Taylor 47:19

And I think, you know, I've gone through pretty much not like to my like surgery at home, but I've gone through everything really that, you know, you go through kind of my age in terms of having brain surgery or a stroke.

Sammy Taylor 47:35

So then to have like the first you know, face surgery in the UK, and it also comes down to those online dating in the mix where you then you go from being I mean, when I was like 24, I was in the height of my career, I was in like prime and I had loads of, you know, I wasn't short of like dating in the city.



Sammy Taylor 47:40

And it was like a classic when you're 24. And like single and like having fun and like loads of male attention things. And then almost overnight that changed. So it's not even just a book that kind of shares my brain tumor journey. It's everything, like my relationships and friendship groups that changed at the time.

Sammy Taylor 48:15

I have a strange relationship, with my dad who, when he found out the news of my brain surgery didn't want anything to do with me or my sister suffering from mental health issues. And whilst this was all going on. And there was, you know, illnesses and other illnesses and family that were to contend with.

Sammy Taylor 48:34

And so, you know, there's all these different themes. And then obviously, two of my surgeries, or three of them now actually were in the pandemic. So when COVID-19 hit and so there's so many themes in the book, but I realized could you know, even just, I guess, going through any kind of challenge, and I set out to business about that.

Sammy Taylor 48:55

And I really kind of like use my mindset and like, you know, focus on like, positivity and really kind of I knew that I couldn't heal my body that I could, like, heal my brain. And so, you know, I just kind of like heal my mind in a way. So I guess there are those assets started here, when they come to me, like, you know, I've got some friends who come to me and they want to know about how to start business and it's so different, like, it could be anything.

Sammy Taylor 49:20

So it's not necessarily just the straight virus, but I think that's why I wanted to write it because there was a lot of substance that I realized was, you know, relatability was the key. And you know, it's why I wanted two years ago to go on Instagram, and it's why now girls and their parents and messaged me now and they want to know all these different, you know, different kinds of questions they have, and they want answers to it desperate, like desperately seeking answers like I was.

Bill Gasiamis 49:49

Yeah, I love what you do because you're showing that before there was a lot of

shit after there's life, a lot of life. A lot of stuff going on normal stuff that people go through normally.

Sammy Taylor 50:05

There's still some shit. Right? So, then it was like it was all on up for me. And then that's when my best friend got diagnosed with cancer. And so I was like, wow, you know, I said to my sister and I have this mantra, something good is about to happen, and I was like, You know what, something good did happen. Just shit just all over again. It's like a constant, it's a wave. It's okay. When you when you make peace with it, you have no fear, really, and anxiety about life.

## Living Life After Stroke



**Brain tumour patient, 25, is left with one side of her face PARALYSED after surgery to remove the growth 'caused her to have a stroke'**

By Connor Boyd Health Reporter For Mailonline  
11:10 22 Nov 2019, updated 20:41 24 Nov 2019



Bill Gasiamis 50:32

It's normal life. That's all it is. It's not always pleasant. My mother-in-law died two weeks before my brain surgery. You know, we had to go into brain surgery with my wife mourning her mom, I wasn't allowed to be a pallbearer because I wasn't allowed to hold anything heavy or strain myself or get too upset or emotional because the bleed was still bleeding three years after the first time.

Bill Gasiamis 50:56

And then, and then I had to go into brain surgery and my wife had to Well imagine that I was going to survive, and that was only going to be the only outcome. But of course, her mum's death was fresh on her mind and still in trauma. She's doing the whole, you know, maybe he's not gonna make it. Maybe I won't see him again, maybe who knows?

Bill Gasiamis 51:20

So that's what do you do? Like, that's kind of that's what life does. It's just doing its thing. And we've just got to do our thing and continue through it. And, you know, I've met some guys, and I've coached some people around stroke recovery. And they've said to me, like, what have I done, that's been so bad, that I deserve all of this?

Bill Gasiamis 51:40

It's like, get your head out of your ass, you haven't done anything, all you've done is woken up and be alive, and you're living a life and everybody else is doing the same thing. You're not immune to the rest of life, just because you're going through something bad. Health-wise, you're fully involved in life, that is what you're doing.

Bill Gasiamis 52:03

It makes it it's like a weird way to flip it, but you're fully involved in life when you're unwell and trying to survive and stay alive. That's exactly what we're meant to be doing. That's the most amazing part of life is, we don't appreciate it until we have to fight to keep it.

Bill Gasiamis 52:24

And every one goes through there, you've got like 10 books in you, like, you're such a veteran, at your age at 27, you have a wealth of knowledge, a wealth of experience, a wealth of maturity, you have a really good sense of how to mentally approach things, you've been able to go back and understand what your emotional state was like.

Bill Gasiamis 52:50

So you can relate to people from an emotional level, and you're a female who has had your face impacted. Therefore, you kind of understand that girly, long hair, facial feature type of issues that people go through. And they can't imagine being any different from what they were when they were born or how they woke up for the last 20 or 30 years.

Bill Gasiamis 53:15

And I interviewed a lady just a couple of episodes ago, who's going to be an interview that goes live just before you. So for people who listen to the series, maybe it's one or two before this interview. She talks about how, after her stroke,

she wasn't sure whether she'd be able to have a relationship again, and how would somebody be able to love me. And you know, what's that going to be like in the future?

Bill Gasiamis 53:41

And of course, that was just a crappy story. She was telling herself and it was coming from fear and the rest of it and sharing the time that as well. Somebody she is lovable, doesn't matter whether she has an I problem or a smile problem or whatever. Like she's a perfectly lovable human being and she found love in it.

Bill Gasiamis 54:00

She's in a relationship now. So I think that's what's beautiful about what you're doing. It's and what a lot of stroke survivors do is they, they start with, I'm going to make it about me, and then they do the recovery. And somewhere even though they're still on the About Me part of the recovery, they think about other people, and it's like, let me help other people well I'm going through this, maybe it'll make that part is that's what I did.

Bill Gasiamis 54:28

And I kind of found myself in that state and went how did I make it about other people? Like what's that about? You're nicer than I thought Bill, like, what's all this stuff? And do you know what I mean? There's that weird thing that when we must make an effort to support other people. I just don't get it. I understand because I'm doing it and I love doing it.

Bill Gasiamis 54:52

But I don't kind of like I just can't compute how we turn it into something about other people. That makes us better and our recovery improves because of that. And then we start to hold ourselves to a higher standard. And I don't know we become a voice, for our fellow survivors, I suppose.

Bill Gasiamis 55:19

Do you find it weird that you're in this helping space where you think about when you were 18? Like, as if you were ever going to be somebody who helps other people overcome something so serious as a stroke? Isn't that weird?

Sammy Taylor 55:35

It's, it's crazy to think I just can't even Yeah, I still can't get my head around it. I don't know about you. But for me, it was just, it wasn't even a conscious decision

that this is what I was gonna do. Like, I realize now that when I'm like writing the book, I'm on this particular chapter, how I first started my business.

Sammy Taylor 55:57

And then it was a case of I couldn't sleep, I was like, suffering insomnia for like, nights, you know, months on end, I didn't tell anyone. So I had no one to confide in. And so setting up using the brain, like my business became such a welcome distraction.

Sammy Taylor 56:13

Because when I couldn't sleep, then I mean, I've known as well you say, to take yourself out of your room, so you don't start associating your room as a place you can't sleep. And so I went downstairs in the kitchen, but I wasn't, you know, simulated by the TV or anything like that.

Sammy Taylor 56:29

So I just, I took, you know, I journal every single day, and I started, like, just writing and writing pages and pages. And then that's when I thought, you know I might just start a blog and like writing, I'll do that. And then when I had the stroke, and I was recovering from that, and I, Ben was doing bracelets, and that's how I kind of beads in the brain started.

Sammy Taylor 56:54

And it was very much I was handwriting, the labels, I was walking to the post office, it was all such, I didn't want to do it at first, because I couldn't physically do it, that then I pushed through it. And I was like, No, you know, what, and my writing improved, because I was writing labels every day, my walking, because I was forcing myself to go to the post office.

Sammy Taylor 57:15

And, there's all these different things. And I guess, as well as I mean, I was off work, and I was off long-term set for quite a long time. And so I could have maybe just, you know, watch Netflix and watch all these TV series and look back on the year and, you know, deep down, I worried that my, you know, brain wasn't going to be like stimulated by that.

Sammy Taylor 57:36

Or it was going to, you know, I was going to like almost lose brain cells by like not doing anything you know creative or the thought-provoking. So it helped my

writing as well also helped my cooking visibility. And it just ended like I just helped him so many things and how so many, you know, all the things that I was hindered by, recovering.

Bill Gasiamis 58:00

Yeah, it's neuroplasticity in action. And it's for a good cause. So it's positive neuroplasticity. And it's rewiring your brain's ability to think to write to express yourself, you know, to rewiring your hand to write it's rewiring your legs to walk, you're going and interacting with people in public, you know, you're starting to do all those things that you "normally" do.

Bill Gasiamis 58:26

And therefore life has this common theme of normality, and you're involved in it and you're taking an active part. And you don't realize that at the beginning, but now you can reflect on it and go wow, that was such an amazing thing that I did was to go out and participate in this thing in this way because I got the added benefits of doing stuff that I wasn't planning to get benefits from like improve my writing.

Bill Gasiamis 58:56

What a stroke of genius that was to go down that path and right handwritten labels for people who had bought stuff. And your writing you were using that to raise money for was it the brain tumor research?

Sammy Taylor 59:16

No, it's very interesting. So when I was first diagnosed, I mean not when I was first diagnosed because I forget that I was diagnosed when I was you know, 18. So I go like 2019 When I was first diagnosed but when I first found out about the surgery, I had two very conflicting views from different surgeons who said the complete opposite.

Sammy Taylor 59:39

And so the reason I got in contact with brain stress was because I just desperately needed their advice on what to do. They were the ones that put me in contact with a third private brain surgeon and paid for the consultation and everything so I did a sponsored walk they wanted to raise money. There was always that part of me that was just so so so grateful even now.

Sammy Taylor 1:00:04

Because of what they did, because it wasn't even the monetary aspect it was so small in comparison to the way that it made me feel and the impact that it had. And I just felt like I could never repay that. And so I'll never feel like I've done to like repay that. And so it was very much that reason, the reason I wanted to do these bracelets was to continue donating to them somehow for the rest of my life.

Sammy Taylor 1:00:29

But also, I knew I was going to be on long-term sick for quite a long time, potentially. And so I needed a way of supplementing my income. And so that's kind of like what I did. And again, it was, you know, I said this to the girl the other day on the phone, whether or not it was the right thing to do, I moved back initially straight after my brain surgery, my stroke, I couldn't do anything myself.

Sammy Taylor 1:00:53

So I moved back home with my mom to recover. And you know, she'd love for me, but we clashed personalities because I'm such an independent person that I was making me almost like it was getting me in, like a worse mental state. Because I was like, all that, you know, everything that I can't do as a reminder of what I couldn't do consistently, or daily basis.

Sammy Taylor 1:01:19

So, five weeks after I still couldn't feed myself walk down the street unaided, or walk that far up the stairs carrying something, for example, I decided to move back into my house in London. So I lived like for, you know, people between the ages of like 25 and 32 at the time, and there's me, you know, overnight, they didn't care that overnight, I walked into this house share then that was like this party house before I left, and all of a sudden now I can't walk up stairs on my own.

Sammy Taylor 1:01:51

But I knew that no one left when I did it, everyone was fearful of my family, and everything was like you can do it. You can't pay for anything. But I'm saying to the physio I was having daily physio at the time. And I just said get me to the place where I can just walk down the street if I need to. Even if I held something, I had to hold an umbrella like a stick at the time.

Sammy Taylor 1:02:13

And I couldn't do any more shopping or anything or washing or anything. But I

had no choice but to move back to London and the House share meant that yes, I did struggle for like quite a few weeks and months and I had no choice but to do things myself because no one else was going to do them for me. And so in a way that massively helped my recovery.

Sammy Taylor 1:02:36

And I do think it's a bit cutthroat now, like, if that happened to any of my friends, I would 100% like, No, you can't do that on your own, like you need someone there. But, I do think that my recovery was perhaps that quicker than it maybe would have been had I stayed, you know, wrapped and got a wall, never done anything myself at home in that recovery.

Sammy Taylor 1:02:58

So again, I could think maybe, again, been back in London, that I had nothing to do my housemates were often like the office and passing and rooftop bars. And so very much I didn't even have my family then to look after me. So it was just me in my house day on you know, it's quite lonely.

Sammy Taylor 1:03:19

And so beat in the rain really, that's at the point where, you know, that took off because I just put everything into it. After all, it became like, my kind of safety net and my companion in a way like I know that sounds sad, but and I sat in my room like not having anyone else it was you know, it was just there at the time. So yeah, it was almost wasn't intentional, that's just the way that it kind of transpired then because I was on my own for so long.

## **Being Independent After A Stroke**

Bill Gasiamis 1:03:49

I love the fact that you went back and lived in London on your own. It's a masterstroke. I mean, it sounds counterintuitive, but it is the best thing that you could have possibly done. That level of ability that you had was enough, obviously to get you through and to get you better.

Bill Gasiamis 1:04:09

And it teaches so much about yourself. It teaches you so much about yourself how resilient you are, how tough you are, how willing you are to succeed how much you're going to fight to overcome. You know, you're putting yourself first mentally



as well, which is a real masterstroke because there's nothing worse than relying on the one person that you want to rely on which is your mum, for example, but she's not up to the task.

Bill Gasiamis 1:04:36

And through no fault of her own. She just doesn't have the skills to support you because she doesn't know how to support somebody who is like you. And that's the thing about parents, his parent's responsibility to adapt, to grow to become better versions of themselves to to live with their kids who are different than them.

Bill Gasiamis 1:04:58

But a lot of people don't realize that it's our job to grow and become better versions of ourselves, more evolved versions of ourselves. So we can deal with these widow things that came out of your mom's belly, you know? And it's like, how do I bring them into the world?

Bill Gasiamis 1:05:14

And how do I relate to them, even though they're so different? How do I not make them be like me, and then not be able to rely on that person? Some people would have taken that seriously, the wrong way, and negatively, and felt let down and disappointed. But it sounds like you love your mom. But it's like, it's good for her to be over there. I can love her from a distance.

Bill Gasiamis 1:05:39

And I can go back to being myself and finding a way to overcome all these obstacles, because let's face it, some obstacles, you need to do them on your own and work out yourself how to get around them. Because that person that you went to your mum, she's never gone through what you've gone through how the hell is she supposed to know how to get through the other side?

Bill Gasiamis 1:06:00

What can she share, to support you to do that? Nothing. And that's the same as my parents, they had no idea my brother didn't, but my wife did. And nobody does, and they still don't, I never want them to know what it's like to go through a stroke, and overcome it. So I'll let them do their thing, the way they need to do their thing.

Bill Gasiamis 1:06:21

And I'll find my unique ways to overcome my challenges because every stroke is unique. Even what you did and how I did my recovery, might not help each other. But at least we kind of get each other. And that's far different from our other family members.

Sammy Taylor 1:06:44

I guess, like it comes back to you just didn't stand on the notion. So like you said, our experiences are different. But we've already gone through some of the same emotions. And you know, for me, for example, growing up overnight, it was always like grief miles south. But that didn't come out until a few years later.

Sammy Taylor 1:07:04

And so there were all these different notions. And so when I was having outbursts like that, it was very easy. My mom won't mind me saying this, because we've always kind of, we're so independent. And so she's raised amazingly on her own to be independent, though, which means to do clash heads, because I'm so strong-willed as she is, and I have like, three other sisters.

Sammy Taylor 1:07:28

And so that was a house of five women, and we were all strong-willed, which was an absolute nightmare growing up. So I was always busting heads with my mom, because then when I was coming down that, you know, I remember in the early days of recovering that house, and she was having to, for example, like wash me in the shower, or tie my hair out when I couldn't do it.

Sammy Taylor 1:07:48

And all these things and then like, cut my food for me like I was like a child again, and so it was demoralizing for me. But it was when I would come downstairs frustrated. She would tell my physio, oh, she's depressed today or she's negative today. And I'll be like, Well, Mom, I'm just having like, one little outburst. I'm sorry, that yes, like let me this one day just have my little outburst because it's not even a whole day.

Sammy Taylor 1:08:20

But if I come downstairs, frustrated, because you've had my hair, and I'm 26 years old, then you've done it horrible because I hated it. It was like in a tight clap or something like I've gone to school the day that she used to do, it was just wrong. But so I was like, Yeah, I am frustrated this day. But it doesn't mean that

I'm a negative person. Or, you know, I'm symbolic of someone who's like pessimistic.

Sammy Taylor 1:08:44

I'm positive 95% of the time, but I'm only human. I'm not like a robot. I do have feelings as well. So all they want, you know, I'm this amazing. This Ray, this inspirational person. So I you know, I'm not losing sometimes, like I just saved my room, like crying sometimes thinking, Oh, my God, like what has happened.

Sammy Taylor 1:09:03

But you live in your land, it's part of life. And I think it's so normal to be like, you know, have these notions that that's what she couldn't handle. I was supposed to be like, you know, we've been taught to be strong all the time. When we were younger, sometimes it was something like this happened in a massive challenge.

Sammy Taylor 1:09:20

You just have mood swings, for example, mood changes, or especially something like overnight. That's like a fundamental change. And so it's not that that person is now like broken forever. But you have to always allow them to just express it in their own way. And yeah, that's about it. Headmaster release, I just thought I'm just gonna take myself off to London. It just doesn't mean that I'm doing it for a week. But God does it. At least I can cry. At least like these. So that's kind of what I did.

Bill Gasiamis 1:09:50

Yeah. And Mum doesn't have to worry about seeing you cry and knowing how to respond and trying to stop you from crying and all that kind of stuff. She just has to, she just has to get over the fact that you're not near her. And that's probably better for her to time, I feel like that would have been.

Bill Gasiamis 1:10:08

Because distance does make it a little better, I think, especially when somebody is going through a tough time, like not being in their face or all over them the whole time, I think, really is important giving people space to be themselves, and in stroke be their ugly self, their angry self, their shitty self, whatever it is, you know, to lead people to go through the gamut of emotions.

Bill Gasiamis 1:10:33

And then also, because that kind of releases them, doesn't it? That allows them to

go away, and not remain trapped inside their body. That's kind of how I see it. Now I love your I love your attitude, I'm going to go back briefly to when you mentioned nystagmus, which is the involuntary eye movement, that causes the eye to rapidly move from side to side, up and down, or in a circle, and might blur your vision, right?

Bill Gasiamis 1:11:07

So I love that you're finding a way to even kind of shift that thing that's happening to you now as in like 10 or 20 or 30 years from now, there might be a solution for that as well. So you've got this long view of recovery as well. And faith in that it'll be okay. In the end, something will be okay and work itself out. In the end. I love that mindset.

Bill Gasiamis 1:11:42

And it's a really good way to round off this episode and remind people that that's what stroke recovery is there's this terrible time at the beginning. And then there's this weird middle stage where things are resettling leveling out the new way that things work or the way that your body works, or the way that your mind works in your emotions work, that's all kind of working itself out in this other stage.

Bill Gasiamis 1:12:14

and then there is the immediate, long-term part of that, say 2 3 4 5 years down the track, when you're sort of starting to get a better understanding of how you now operate in the world and how the world operates around you now that you're beyond, and then there's the very distant future, which is 10 or 20 years away, which I've interviewed stroke survivors that are that far out.

Bill Gasiamis 1:12:42

And then stroke becomes something they talk about, but it's not how they live their life anymore. It's just become something that happened to them ages and ages ago. And their life is quote, unquote, normal.

Bill Gasiamis 1:12:57

And they just go about doing things the way they do things, however, that looks or whatever the body appears to operate like, or they just find a way to continue living and experiencing an awesome life and solving problems even into the future.

Bill Gasiamis 1:13:14

So I love how you've got this really busy short-term version of your recovery, which is happening now in the last two and a half years. And, you know, since your brain surgery, and then you've got this, and we'll park that stuff for the future. That's just brilliant. I love it.

Sammy Taylor 1:13:33

I feel like you have to do that to get through it. And so, yeah, it's kind of always a coping mechanism, maybe. But I think when I had my first real holidays, it all happened last September, we weren't big enough.

Sammy Taylor 1:13:48

And it was the first I hated the thought of it for because there was, it was a hen party, there were loads of bells, concept pictures out I've never been in a social situation like that. And I thought I was still very, very self-conscious with my face and things.

Sammy Taylor 1:14:05

And then something clicked on that, you know, on that holiday and I listened to a podcast episode. And with Jay Shetty, before I went, and one of his guests said that you'll never get to be with this version of yourself again. And it's changed my mindset toward them.

Sammy Taylor 1:14:25

I got just almost overnight like I was just, I could deal with my situation and accept it because I knew that it wasn't permanent. I knew wouldn't live with it forever. And, you know, I'd look back at photos and a holiday and be like, well, you know, the same way I do now look back at photos and like my younger self and things and almost think well I'll never get to be with that person again.

Sammy Taylor 1:14:47

Or who I am on this holiday or who I was back then at certain times and so you just go through these different ways in life and I almost think it's quite good to hold on to that little bit of hope that you know, you're not you I'm waiting for that. But I'm not waiting for a cure for nystagmus.

Sammy Taylor 1:15:04

I'm just very much, you know, every surgeon in the UK has pretty much told me that it's permanent, that it's almost a bonus. Now you learn to accept it and live

with it. And then it's a bonus if you suddenly, you know, there's a trial that comes out in 10 years, or 10 20 30 years, and you just kind of accept that.

Sammy Taylor 1:15:23

It's not overnight, that these things happen, but you kind of live and you make the best of the situation that you've been dealt, and you can still have a really good and really happy life and make peace, you know, move forward with it.

Bill Gasiamis 1:15:36

Yeah, I'm looking at the photos right now. From your trip to Mykonos. I mean, they are next level, amazing photos, that footage. And, yeah, it's like, that's what it's about now, isn't it? It's about actually going, you know, what, under no circumstances am I going to miss out on living life, and having life and experiencing life.

Bill Gasiamis 1:16:00

And then remembering all the good times, and dealing with and overcoming the bad times, because maybe we don't want to remember the bad times the same way we want to remember the good times.

Bill Gasiamis 1:16:13

But that's okay, we're gonna probably go through more bad times, let's get some skills under our belt as to how to overcome them, deal with them, and move on from them. And let's learn how to live life and have great experiences. And I love that you went to Mykonos during a pandemic.

Sammy Taylor 1:16:32

Oh my gosh. And it's so funny because I can resonate when you said you, spoke to that lady who, though should never have another relationship again. And so I had all these emotions. So if my raised surgery, and, you know, there are so many things that went on with a girl my age and single and city and thing, and I never date again, and I went on some like, you know, some dates on a hinge and it was almost a bit of a milestone for me.

Sammy Taylor 1:17:02

But I couldn't find out because I was so oh my gosh, what they think like they're looking at my face or my mouth, all these things. And I would go and like that. And you know, we will meet in a cafe, I would give that at first and be like, Where can I sit on which side? Can I sit on it? And then I thought, well, actually, that's

silly, because if it goes any further, they're gonna see my other side.

Sammy Taylor 1:17:22

And so how long can you hide it? And so I just really, I know, this sounds kind of sad that I made a peaceful holiday, that I wouldn't be in the relationship, but I was okay with it. And so I had all these things going. And then, like I said, I listened to that thing on the plane, that quote, and you know, you never get to be this version of yourself again.

Sammy Taylor 1:17:46

And because of that, I had the most amazing holiday. And then three days before the end, I met my boyfriend, who I'm with now. And it was crazy how it happened. It was not even I don't even know how it happened. But he just fully accepted. He wanted to know everything he read in every single blog post that night that we'd met, he wanted to know everything, it was a bit of a holiday romance.

Sammy Taylor 1:18:08

So we had like three days together still on the island. So we were like meeting and he was seeing my friends groups. And I felt like I hoped to him and he didn't look to me more in those three days than I had with anyone in the two and a half years. And I think that really comes with you know, I just really made peace with the situation of how it was.

Sammy Taylor 1:18:29

I wasn't you know, even looking at first I was clinging on to I'm not God, this is wrong, like my face is not how it should be, like my age. And it was like I was grieving for this person. And when I let that go and just kind of thought, you know what you can live them.

Sammy Taylor 1:18:44

You can live an amazing lifestyle with all these complications. And it's not the end of the world and you know, you can you've proven that you still go now you still haven't you still making memories, and you're going to amazing places. So when I let go and just accepted all that everything seemed to, like fell into place.

Sammy Taylor 1:19:03

So I met Leo and then I got like I had a career change last September and again, that was because when I was working in finance, I physically couldn't even see the screen now. So there was like a physical barrier to that and I lived my career

thought and so that in itself was almost a bit of an emotional kind of breathing call, I guess. But I love it now so I write for a mental health company called Mindre. I work full-time for them.

Sammy Taylor 1:19:34

And it's nowhere near what I would have envisioned. So if you'd asked me two years ago if I love it more probably yes. Because it's way more thrilling than it would have been. So now I'm just so you know, so comfortable with the path that I'm gonna end up on and I just know that whatever happens it's the right thing at the right time and not to fear it.

Sammy Taylor 1:19:55

Because, you know, if you stumble across some dips in the road All the way. Or as I like to call it, this is like an absolute road accident. And then you know, it's gonna level out and it's gonna be, you know what.

## Acceptance



Bill Gasiamis 1:20:16

I love how you came to acceptance and then you fell into relationship acceptance that I'll never have one. And now you're in one life. That's such a spin-out. Like, that's bizarre, right? But I tell you what it is, from my perspective as a man, and you know, what's sexy about a woman is not just the outside.

Bill Gasiamis 1:20:42

It's also the inside the ability to be strong, but not much strong for the sake of strong where you pretend nothing's wrong, strong where you're prepared to accept that when shit's wrong, you're going to find a way through and going to



overcome it and grow and that kind of strength.

Bill Gasiamis 1:21:00

I dislike it in my wife when she, I dislike it because I can't help her right. After all, I don't know how to help when she goes into a difficult emotional stage. And she doesn't have the tools to overcome them. Because she's never been to that particular one before.

Bill Gasiamis 1:21:20

I hate seeing her like that, and it doesn't get me excited. It just makes me feel like I'm not good enough for her. Or we're not good enough for each other or something like that. Because I don't know how to help her support her and bring her out. And that's my lesson, that's my lesson is okay, let her go with that and let her overcome it.

Bill Gasiamis 1:21:42

If she stays there for too long, I get too shitty about it. And when she finds the path forward, and the solution, and she starts and you see the strength in her comeback, it's like, wow, like I love this person again, like I love what she's, how she's overcome it, what she's gone through.

Bill Gasiamis 1:22:02

And I wish I had the words to describe it. Like, it's, I'm gonna use the word sex, it's not the right word, right? But it's like, it's sexy when you can see somebody that's just capable of just going, you know what, fuck it, I'm gonna find a way through, like, I'm going to fight through this, I'm going to grow, I'm going to overcome.

Bill Gasiamis 1:22:27

And he would have been just in awe of you, obviously, for your story, but also because he would have seen in you that that acceptance, that huge acceptance. And that is maybe what we need, as well. Like, what I need from her is her my wife's acceptance of a situation and whatever, rather than fighting it and worrying about that situation, kind of helps me accept it and come to it as well.

Bill Gasiamis 1:22:57

And that unites me, that's how I get united with my wife, I find myself becoming not that I'm ever disconnected from her, but like united when both of us can't bring ourselves to accept something and get through it. And especially since the

stroke, like I used to go to counseling, and my counselor would say to me, you know, like, what do you think of your missus, you know, like, far out, she's stuck around, she's awesome.

Bill Gasiamis 1:23:29

She's gone through all this shit, her mom passed away, like all this stuff. And somehow, as this person who I didn't think had that level of resilience in her has done, they've she's found that she's grown from it, she's used the turf, to like to drive her going forward. And as a result of that, she went back to school, she's studying psychology, she got a degree, she did all these things.

Bill Gasiamis 1:23:58

And now she's going into her master's and it's like, wow, like, that's somebody that I can follow, support, grow with, feel inspired by. That's kind of what happens when you make the decision that I'm going to be okay, I'm going to live an amazing life, etc. And what the outside looks like, doesn't matter.

Bill Gasiamis 1:24:24

You know, you kind of do all these things, and then, and even if I don't find a relationship and even if I don't end up with another guy or I'll be fine, life's gonna still be amazing. That is probably what made Leo go, man. This is a well-rounded not just an outside view of a person. This is a well-rounded, amazing person that I can get behind and be part of her life. And we can both grow together and have great experiences within. And he's going I hit the jackpot, you know?

Sammy Taylor 1:25:05

Yeah. I remember like, when he asked me when I first met him and you know, it's classic, you know, what's your Instagram and I thought, oh god here we go like I often wonder like give it to this like person that we've met in quite a dark place and so I thought like, oh okay yeah really we chat here maybe because like it's dark things and thought of GOD YES on it so I gave my Instagram and then he just read every single blog post and he just couldn't get enough he just text me like I want to know everything.

Sammy Taylor 1:25:35

Like want to order no let's meet up the next day like we spoke about everything and he was genuinely interested in knowing the whole story and then a first date practice proper date was he came to the UK to see me in London about a week

later.

Sammy Taylor 1:25:38

But a week and a half later, I just had the eye surgery and so oh my god, I lit my I was like we think it was a breeze. It was still sick together. I thought, oh my god, like I wasn't like in my prime Nicanor. So I was still turned and blonde. And I had said, I thought oh my god.

Sammy Taylor 1:26:09

And now like a first date is like, I mean that face-to-face first photo together, I've got like these sunglasses on because I was so black. I couldn't subject anyone else in the world to it. But he didn't even care. And so we talked about it now. And I did say something the other day, like what was it? Like, you know, did you not notice my face?

Sammy Taylor 1:26:31

And so he was like, Yeah, of course it is. But I just saw your Instagram and was so amazed by like, the thought and like, the whole journey is on there. And like reading your blogs, he was exactly what you just said he was I was so amazed with how you just handled the whole thing and how, what happened to you like, you could make what you have done out of it all.

Sammy Taylor 1:26:53

And he was like, you just fascinated me. And I just wanted to know, like everything about you. And it just goes like what you say I guess where it's like, because I guess like. After all, I've made peace with it. And I wasn't, like scared anymore.

Bill Gasiamis 1:27:13

You know, they said behind every great man is a great woman. You're 27 and you've lived the life of somebody who might be in their 90s Like, you've been through so much you've had to learn to overcome the resilience. And there's something about like, it's magnetic, you know, to find somebody who has that depth of life experience at 27. And to be around them.

Bill Gasiamis 1:27:43

And if you're the right kind of person, because you want to grow with them. And because of them and learn from them. Because I want to learn and grow from my wife, I don't want to be the I don't want to know everything and tell her how to

live life and whatever. I want to know what's unique about the way that she goes about life. There's something magnetically unbelievably attractive about that.

Bill Gasiamis 1:28:06

Like it's hard to separate and it's not it's not the is your inspiration and all that. It's not that like it's something else. It's just attractive. It's really attractive. So good on Leo, like he's hit the jackpot, like I said, Good on you, mate. Well done. Yeah. So I appreciate our conversation.

Bill Gasiamis 1:28:36

Thank you so much for getting on the podcast well done, for doing all the amazing things that you're doing good luck with all your procedures and your recovery to come. I wish you all the best tell me about what the book is called. And also where people can find you if they want to connect with you.

Sammy Taylor 1:28:58

So the book will be called Inside My Heads. And it's very, very nearly out there. So I can be found on my Instagram handle is TC Brain UK. My personal is sammybitb and as well my website is tcbrainuk.com. So all the you know details on there. And so if anyone wants to kind of reach out say hello, then. Yeah, that's where you should find me.

Bill Gasiamis 1:29:27

Thanks for being on the podcast.

Sammy Taylor 1:29:28

No worries. Thank you so much for having me. It's great chatting to you.

Bill Gasiamis 1:29:31

Well, thanks again for joining us on today's episode. I hope you enjoyed the conversation and got something positive from it. Please do LIKE SHARE, COMMENT, and post thumbs up. Please do interact with the show. In whichever way you can. It would just make a massive difference to the way the search engines rank the show and the way that other people who are searching for this type of content will be able to find the show.

Bill Gasiamis 1:29:56

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please do leave a comment because I love responding to comments and, and having an interaction with people who are listening.

Bill Gasiamis 1:30:16

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Intro 1:31:36

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