

Emotional Changes After Stroke - Sam Hanes

Sam Hanes Experienced a bleed in the brain due to an AVM, he is also dealing with 4 aneurysms, has had a craniotomy and gamma knife treatment and 5 years since this saga started he is now raising awareness about stroke

Socials:

www.instagram.com/brokenbrainsurvivors/

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Transcription:

Sam 0:00

I used to be able to block all this from seeing so much death in my career, people would say I was cold because like if I went to a funeral, I wouldn't shed a tear. Now if I think of something, I get a little emotional.

Sam 0:19

And eight months after my stroke and everything. I would always call my dad whenever I would go to the doctor's office, and he would call me vice-versa. He just lived right down the street from me.

Sam 0:38

So we were always working on cars or stuff like that. We had old classic cars and everything and I was in the shower about to go to my doctor's appointment that morning.

Sam 0:48

My phone rang and I opened the curtain seeing it was him. I said, I'll call him back in the second and something said pick it up, I picked it up and I heard, somebody say my dad was on the floor.

Intro 1:00

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

Bill 1:13

Hello, and welcome to recovery after stroke, a podcast full of answers, advice and practical tools for stroke survivors to help you take back your life after a stroke and build a stronger future. I'm your host three times a stroke survivor Bill Gasiamis.

Bill 1:29

After my life was turned upside down and I went from being an active father to being stuck in hospital, I knew if I wanted to get back to the life I loved before the recovery was up to me.

Bill 1:40

After years of researching and discovering I'll learn how to heal my brain and rebuild a healthier and happier life than I ever dreamed possible. And now I've made it my mission to empower other stroke survivors like you to recover faster, achieve your goals and take back the freedom you deserve.

Bill 1:56

If you enjoy this episode and want more resources, accessible training, and hands on support, check out my recovery after stroke membership community created especially for stroke survivors and caregivers.

Bill 2:09

This is your clear pathway to transform your symptoms, reduce your anxiety and navigate your journey to recovery with confidence, head to

recoveryafterstroke.com to find out more after this podcast. But for now let's dive right into today's episode.

Introduction



Bill 2:24

This is Episode 154 and my guest today is medical professional Sam Hanes. Sam has spent 20 years plus as a medical professional helping in hospitals. He has five years ago experienced a hemorrhagic stroke from an AVM, he has had four aneurysms, and part of his treatment required a craniotomy and gamma knife was also used to manage the inoperable AVM.

Bill 2:52

Sam Hanes, welcome to the podcast.

Sam 2:55

Hey, how you doing, Bill?

Bill 2:57

I'm doing really well. Thanks so much for reaching out. I'm glad to have you on here. You know, we don't get a lot of men on the podcast. And I'm not sure why that is. Men don't seem to want to talk about this stuff too much.

Sam 3:12

Well, I've kind of found out 20 years of working in the medical field, I always tell patients where our work, you know, men wait five days before coming in when they knew they should have come in the first day.

Sam 3:25

And women will go for help. So that's probably part of the reasoning behind. You don't want to show weakness and stuff like that. But with the brain injury, it doesn't matter how big you are, who you are. It's debilitating in so many levels, you know. So that's probably the reason why you don't have that many men come on here.

Bill 3:49

It's tough. Tell me a little bit about the work that you do.

Sam 3:51

So I've been a respiratory therapist for 20 years, I've worked in the ICUs, I actually worked the last pandemic, or I don't think was classified as a pandemic, it was the swine flu.

Sam 4:06

I was working at Vanderbilt in 2009. And so I've seen a lot of deaths from that, you know, and so this virus is kind of hit in the same way dealing with the lungs, but it's just a different beast in this virus, you know.

Sam 4:23

And I know we're in the whole world in the middle of this political divide, and then you throw a virus in there with a pandemic and then make people go broke. And so it is just, there's so many levels to this virus.

Sam 4:43

And because the hospital is on lockdown. The people are not actually seeing people die, you know. And so, as a respiratory therapist, unfortunately, my job I mean, we save many lives in my career. I've seen so many miraculous recoveries.

Sam 5:01

But unfortunately, this one right here is just this year, I'll say 2020 was the most deaths I've seen. From a respiratory point of view. I mean, unfortunately, the end of life, people don't think about, you know, the doctor writes the thing, take the patient off the vent, because that's their wishes.

Sam 5:24

But there has to be a person go take that person off the vent, and watch them take their last breath. And that actually comes back into my first few months of recovering Oh, like I told you in the email. Are you ready to peel back the onion?

Because there are so many levels?

Bill 5:45

Yeah, tell me about what happened to you first, let's do that. And yeah, we'll dive into it. That's what it's about.

The Begining Of Emotional Challenges After Stroke



Sam 5:51

So I was in the gym, August the 14th 2015. Like I said, I've worked respiratory for 20 years now. But at that time was about 15. And I had a routine, my routine actually saved my life. Because I had this AVM that I did not know about, it had gave me signs and symptoms before this, but nobody picked up on them.

Sam 6:17

And so they just said it was you're just probably lifting heavy weight, you got some nerve damage under that right arm because it didn't affect nothing, on my right side except my arm. And it would only affect it like three times a year for about a minute.

Sam 6:33

And so unfortunately, our great medical system here in the United States, an MRI of your brain, or CT, if you ever looked at your bill, other than the insurance, picking up a big portion of it, if you have insurance, it's \$5,000. And the reason I know that number is because I've had so many scans after my Gamma Knife every

three months, every six months, and I do it every year now.

Sam 7:02

And so I see those bills. So the average person is not going to spend that much and the average ER doctor has somebody over them saying, Do not order anything that is not need. So if you don't go in there with a massive headache, you're throwing up, they're not going to scan you if they would've scanned me.

Sam 7:23

I would have been a controlled surgery, another life flighted surgery, you know, and all the other ordeals I had to go through. But fortunately, I had that routine. Like I said, I would get up, I will always work night shift. So I would go get up at 2:30 go to the gym workout for an hour, hour and a half go home to shower and go to work.

Sam 7:44

I'd done that religiously whatever city I worked in because I was a traveling respiratory therapist. So I got to work in a lot of major medical centers, Vanderbilt University, Cincinnati, Georgetown University that kind of traveled around, I'd done that actual routine, every city I was in.

Sam 8:03

And so this particular day, I was two days into my seven days in a row that I would work. I work seven on seven off at the time. And I remember I went to just warm up on some overhead presses. And next thing I know I dropped down and I started projectile vomiting.

Sam 8:26

Now I don't I don't really remember this I got a little bit I say I got 15 seconds a memory several months after my injury because I actually lost two weeks before my injury and four weeks after my injury.

Sam 8:40

I'm pretty much memory lost. And so there's a lot of key factors at play in that it is kind of comical some of it but like I said, ruptured the little bit of memory I got back I was hanging on, luckily this gym was a private gym and my one of my good friends owned the gym.

Sam 9:04

And so my thought was when I'm throwing up, I gotta get the hell off here and clean this up or Joey's gonna be pissed. And then I realized I'm holding on now, I had earphones in and there was one this day there was one person across from me, but he was doing hack squats and he had his back towards me.

Sam 9:25

They say that's the guy that actually started the chain reaction to get me help. He came over I kind of vaguely remember him asking me Do you need help? And I don't remember anything else but I know they said he took me to the garbage can I threw up there and then he took me in the bathroom and laid me down.

Sam 9:44

And ran next door to get the process of 911 called and get some help to me go get the owner that has other business. And in that short little time I actually called my mother and I call my girlfriend. Now I accidentally FaceTime them only reason I know I'd done this because there's a blurred kind of eerie picture of me.

Sam 10:08

I accidentally took a picture of myself. And there was a light behind me. So my face is kind of blurred. But it gave me the exact time and date that I basically passed away because I actually called them and because I butt-dialed them every day in the gym.

Sam 10:27

I didn't answer them. So they hung up on me. And so, ofcourse, probably about 15 minutes later, they got an emergency call saying he's in the back of an ambulance going to the hospital.

Sam 10:40

And so they took me to the local hospital. It was like, the perfect storm to hospitals in the major cities around me were tied up the neurosurgeons in New Orleans and in Alabama. And so this ER doc that I was in this local hospital, said we got to get him north, this major medical center in Jackson, Mississippi.

Sam 11:04

So they airlifted me up there. But I don't have no memory of that place. I went back and talk to him. But that kind of started a chain reaction of, well, he's got this AVM for aneurysms, and we don't think he's going to survive.

Bill 11:25

How old were you at the time when they discovered it?

Sam 11:28

I was 44.

Bill 11:30

Yeah, so the four aneurisms were separately located to the AVM?

Sam 11:39

They were kind of in the cluster. I know they went in and so this is kind of where I got paralyzed on my right side temporarily. When they airlifted me up there, the only reason I know this, and I went back.

Sam 11:51

And so when I was able to read again, I read every one of my medical notes, I read the surgery notes but I didn't know a word. I looked it up, you know, so. But I mean, I've been in the medical field for now 20 years at that time 15.

Sam 12:12

That was my blessing in disguise, is that I understood what the doctors were saying. When my family didn't, you know, my family was just like any other family, oh, my God, he's got this mass, you know, or he's got these vessels what he's gonna die?

Sam 12:29

They you know, I mean, I see it all the time and the hospitals. And the anxiety from the families causes a lot of turmoil and the critical first parts of a saving a life, you know. And so that I know, in my notes, it said that they went and glued me.

Sam 12:50

So they stopped my bleed. They tried to do me with the two-glue, Black Onyx, and the second glue and they done. My mother said that I came out. And I couldn't move my right arm.

Sam 13:05

And unfortunately, I've talked to several neurosurgeons they said, believe it or not, that happens more often than you would think. Because you got glue, and if

they don't backfill those vessels and clear the catheter, before they come out, now you got a glue clot, a clot to clot, they don't matter for blood cholesterol or glue.

Sam 13:28

So I was a hemorrhagic stroke, and I'm still weak in my right arm. I seem to go to the gym they're like, Oh, you got muscles. I said, Yeah, I had a stroke. And I'm weak in my right. You know, I just have that lingering effect and I'm right handed. So I've had to learn to do things with my left more than I do with my right.

Bill 13:51

You know, the aneurisms, they've been clipped? Did they go in through the skull? Or did it all get done through your groin?

Sam 14:00

So I've actually got a scar from my ear. All the way to my forehead. And you can kind of see that screw right there. You see that bulge in my forehead? I actually got 18 little screws.

Bill 14:17

Put your head a bit lower.

Sam 14:18

I'm sorry. There's my screw. The scar goes here. Unfortunately, you know, I told my surgeon I said, you know, you could have grind the screw off or something. You know, I'm bald.

Bill 14:38

Do you make people touch it?

Back To Work After A Stroke

Sam 14:39

Yes actually taken care of patients. So I was fortunate enough to go back to work eight months later, and actually use it as a tool. You know, I've had so many patients say you don't know what pain is, oh, let me just turn a little bit. And when I show them this, then they're like oh, man, I don't have it so bad or, you know, it kind of just breaks the ice.

Bill 15:05

Yeah, nothing better than a medical professional completely and totally understanding you not that we want them to, we would rather they were oblivious to our issues. But I do the same thing when people talk to me about stuff and you know, I want to mess with them a little bit.

Bill 15:23

Usually my hair is a lot shorter. It's usually a number one so you can see my scar. I do that I say to them, give me your hand, to touch, touch this, feel my screw. And that messes with them.

Sam 15:36

If I shake my head, I can feel it, you know, I can feel my forehead kind of rub cross that screw up. You know, I always wear hats. Most people didn't know I was bald. And that's what I told the surgeon I was like, you could have at least but screw a little bit lower. Because I can't wear a hat. Except if I tilt it. You know? That's actually tender, you know? I mean, it's a piece of metal under there. I've learned to embrace it.

Bill 16:04

Are you constantly afraid that you're going to get hit on the head? This is my biggest fear. Now my biggest fear is that I'm going to have an impact on the side of my skull where the plate is and where the screws are. If somebody comes near my head, they get the whole, you know, don't touch my head get away from my head.

Sam 16:26

I'm not scared. I don't know. I mean, I just got a this is I used to see it as a curse, because like I said, mines and layers. So at first, when I was brain injured. I had the medical experience. I couldn't read the written word. I know you just had somebody on there talking about the parietal lobe.

Sam 16:49

So my AVM is actually in the middle of my primary motor cortex. It branches from my parietal to my frontal lobe. So I had lots of side effects. You know, so I remember the surgeons, they saved my life, they stabilize me, and they said, You know what, we're gonna send him to a rehab.

Sam 17:09

So I stayed up there for 12 days, and then they sent me to a rehab for 15 days.

And due to insurance purposes, we figured we would save my rehab stay for after my craniotomy.

Sam 17:22

But that's where I kind of have some memories sitting at that rehab. I knew everything the nurses were saying, but I couldn't read the written word. So my parietal lobe had me I can kind of picture them now. Words like cat, dog hat, stuff like that, and I couldn't read them.

Sam 17:44

And it was so frustrating. And then I had the I call it a skip in the record. I talk like this and the frustration was, I knew everything I wanted to say, but I couldn't get my brain to tell my mouth to say those words.

Sam 18:03

They just would not come out. And so I remember sitting there with a speech therapist, and they had a one in training. And I told her, I said, I know all the medical field. I have been in this. I know what's in front of me. I just can't read it. And it would make me so frustrated. You know?

Emotional Changes After Stroke

Bill 18:24

Are you frustrated that you can't read it? Are you frustrated because you you're a medical professional, and therefore you should know better or be doing better? What's going on in your brain? Because I wasn't frustrated? I had no idea what the hell was going on. And I just went with it you know? So what's going on with your brain?

Intro 18:44

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

Intro 19:09

If this is you, you may be missing out on doing things that could help speed up

your recovery. If you're finding yourself in that situation. Stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called the seven questions to ask your doctor about your stroke.

Intro 19:28

These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke. They'll not only help you better understand your condition, and they'll help you take a more active role in your recovery. head to the website. Now, recovery after stroke, calm and download the guide, It's free.

Sam 19:49

So all these people in medical uniforms. I've been around medical uniforms, you know for 15 years at the time. And so these are like co workers to me even though I didn't work at this particular rehab, this was the frustration, I'll do everything the doctors were saying, and, but I couldn't speak real well.

Sam 20:10

And, you know, here I am sitting in a wheelchair, so I can't walk at this time. So I always say it's like, I had two computers. When one was on, I knew everything, medical heard everything, I know what the doctor is saying.

Sam 20:30

And then I was to this other side, at other times, that I can't read plain words, I can't get up and walk. And see, I didn't know that they'd glued me and kind of paralyzed me on my right side. So I remember them pushing me up to a table, putting breakfast in front of me, and I can't reach for the spoon.

Sam 20:51

And so I tell patients, and I tell family members that I'm around the hospital all the time. I said, Go brush your teeth with your non-dominant hand, go feed yourself with your non-dominant hand, let's see if you can put that spoon straight to your mouth.

Sam 21:05

See now I can do it perfect. But back then I remember I was chasing the spoon to try to get a bite of grits or whatever I was eating. And I just couldn't imagine why this was, like I said, I was kind of online sometimes. And I was offline the other time. And it was a bar to me.

Sam 21:28

And I mean, I remember some of it. I can remember like, and my family can't understand this. Most people can't understand that. Unfortunately, my dad has passed away now but at that time, he was on oxygen COPD or stuff like that. I remember being that rehab, and a notary public coming in sitting in the chair in front of me, I'm sitting in the wheelchair, my dad came down the hall, he's huffing and puffing sitting in the chair next to me.

Sam 21:57

But there's three other people in the room with me, my mother, my stepmom, and my girlfriend, because they were on my right side. I had no clue those people were even there. So I have memories of my father. And this guy that was doing the notary public. I have no memory of my mother being there. And believe it or not, people get their feelings hurt.

Bill 22:23

I know that they make it about them.

Sam 22:25

They get their feelings hurt from a stroke survivor, because like I can remember a few people coming to see me. And those people are like, Oh, he remembers me. Unfortunately, the girlfriend I was with at the time used to get mad at me, because she said I was right there in the room with you. And I'm like, she thought I was making it up saying I don't remember her being there.

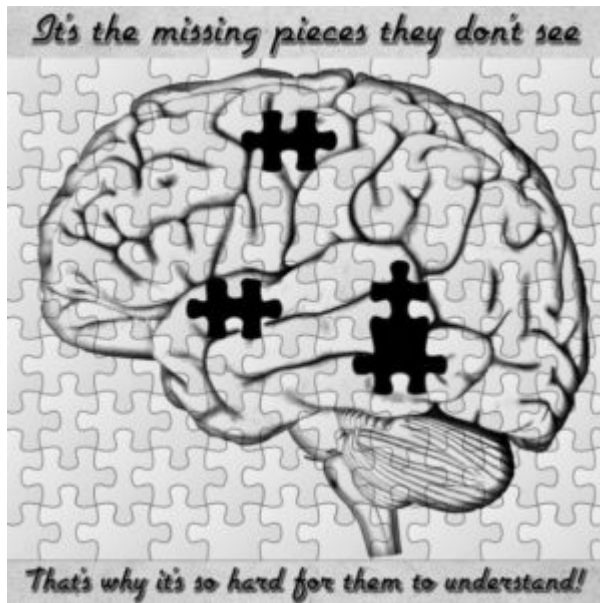
Bill 22:48

This is more about them than it does you and that's an interesting situation. It really frustrates me when I hear about people visiting stroke survivors making it about them, you know, you hear about, oh you had a stroke or yeah you'll be right, yeah, you know what happened to me.

Bill 23:04

You know, I had my little pinky got stuck in a jar or some stupid, silly thing. And they try and minimize your experience. And they also tried to somehow relate to you, and they just go about it in a terrible way. And they have no idea how to really do it and what an impact it makes.

Memory Challenges



Bill 23:24

I was forgetting people all the time as well. I was forgetting who came to visit me and I did the opposite. I was complaining to my wife that his sister didn't come to visit me. Why hasn't my sister in law come to visit me? And she said, but she did. She was one of the first people that were there.

Bill 23:42

But that was one of the most acute phases of my of my recovery. After the second time my AVM bled. I mean, I had no idea that people came from interstate to come and visit me. And a year or so later, they were telling me about the visit that they made.

Bill 24:01

And I'm like, you came to visit me you traveled 1000 kilometres and you came to visit me? I don't remember a thing. So if they're going to get their feelings hurt. There's something wrong with them.

Sam 24:19

Well, that's like when I initially got flown airlifted to that hospital. I had a co worker that came he's not from the coast down here. He was from another state and he didn't have nothing to do that weekend. So he drove up there to see me and he said my whole goal was to go see if you were brain damaged, and if you forgot your profession.

Sam 24:42

So he said he came up there and gave me some bits sentence and a scenario of a patient and gave me a blood gas and I answered how to correct that blood gas. The blood work through the ventilator you know, and so he came back down here told my other co-worker he remembers all of his respiratory and that's what is the crazy part.

Sam 25:06

So I remember him, but I don't remember any of my family being next to me or my girlfriend at the time. I had like five best friends that came and took a picture next to me in the bed. I remember the only friend that came to see me. I have a friend that's paralyzed from the waist down. I remember him sitting at the end of my bed in his wheelchair.

Sam 25:30

I had no clue the other ones were there. And now they said I had a talk with him and everything. But that's what people don't get with a hemorrhagic stroke. You know, we talk, you know, and that that's my biggest advocacy thing, when I go to speak to people, is a majority.

Sam 25:49

So they teach you about extreme IQ strokes, facial droop, paralysis, hate speak. My family said I was actually time traveling back to places I worked. They said they actually my younger brother would ask, each day I was in Jackson for the first 12 days. Where are you at?

Sam 26:11

And they said, I would say clear as a bell. Where else I'm in Nashville with a new, okay, he's in 2009 to 2010. I was living with a bandmate. In three doors down. I was up there working at Vanderbilt. And so they gave me my phone. And I was actually texting that bandmate like I was still living with him. But the very next day, he would ask me where I was at.

Sam 26:36

And I was in Cincinnati. Well, they knew Okay, I worked in Cincinnati in 2007, and the first part of 2009. And so somehow, I was starting over Facebook, in the ICU or my phone. And I went back months later and looked on my Facebook that I had at the time. And I wrote downtown Cincinnati trying to break in hospitals to work as a therapist.

Sam 27:01

And a lot of people came in and asked questions underneath me and said, I thought you are in the ICU yourself. Of course, I never answered them. But I was I say this part of my brain was damaged. This part was functioning and I was just doing stuff. But they said I would be laying in bed and at the hospital, they would call Code Blue.

Sam 27:22

Well, I'm a respiratory therapist, I go to every code blue in the hospital. They said I would raise my hands. I'll be there in a minute. So I was and I tell people I had bells and whistles around me I was used to the monitors. I was used to the pulse ox. I used to blood pressure cuffs, how we used to all these bells and whistles. So yeah, part of my brain was injured. But there was a part that had clarity of the place I was in or the environment I was in. So I would react to the environment.

Bill 27:56

I had a really good friend of mine. He also lives in Melbourne, Australia where I live. And in the early 1990s we had a underworld gang war and there was a brand 30 murders over a period of a few years related or related to this particular gang war or whatever it was.

Bill 28:23

And it was in the news and then the front of the newspapers all day, every day. That's all we ever heard. And then my friend had a stroke. He had a aneurysm that person the back of his head, I think it was the the vertebral artery I'm not sure which one of his burst, but one of them burst or one of his carotid arteries, I'm not sure.

Bill 28:48

And when he was coming around and started to talk to people, he was telling them stories of how he was involved with the leader of the gang that was responsible for a lot of these deaths and how he was dealing drugs, and he and how he was best mates with him.

Bill 29:09

And it was an amazing man and all this kind of stuff. And he was telling the story. And people didn't know whether he was making it up, or really truly believing it. But he was not making it up. He was truly believing that it was the most bizarre

story that he could come up with.

Bill 29:28

And he was telling it like, it was his life. And this is a person has never done a cricket thing in his entire life, you know? And it was so strange to hear him talk about that and his family were just forever bewildered by hearing their stories and they were trying to gently tell him that that's not the case you're in hospital. You had brain surgery, your head's half mangled, and it's got nothing to do with what's happening in the drug war so bizarre.

Sam 29:59

But to him it was real.

Bill 30:01

Real, properly real. Yeah, he wasn't making it up.

Sam 30:06

That's like me so there was a, so I had a rupture. And then they let me rest for a month and a week. So I remember they sent me to that rehab stayed there, like set for about 15 days. Which that was so bizarre, because, like, I don't remember why I got up out of the bed.

Sam 30:30

If it was to get my phone on the bedside table or what, but I ended up falling fallen in about hitting my head. I didn't know I couldn't walk, and it was nighttime. And so when the nurse came in, I told him immediately he said, what are you doing? I said, I don't know but you better not trust me, you better put me in that bed and lock me down, or I'll get you in trouble.

Sam 30:55

By the way, you're gonna have to fill out a lot of paperwork for this, because every time a patient falls, the nurses have to fill it. So there's the part, okay, there's the medical experience coming in. But then I don't even know why I got up out of the bed. I didn't know I couldn't walk, you know.

Sam 31:11

But when he put me back in that bed, again, I was back. I call it time travel now because I was actually when I live with that bandmate I was actually texting him while I was in this hospital, just like I was living with him back in 2000 to 2010.

And so I would write him long paragraphs, and I remembered I accidentally deleted that thing.

Sam 31:37

And that upset me. And so then I started, the nurse was sitting there, it was a male nurse, he was sitting at the door watching me. And I was telling him, all the trips I ever went out. So three or down started, like back here in 2000, our 1999 or something like that.

Sam 31:55

So every year as a little time off, I would go out with my best friend at the time and go on tour with him for like 10 or 12 days, and then come back to my normal job. I was telling him stories that were supposed to stay on the road, you know. And I remember telling him after he said I would talk and then I would fall asleep. And then I would wake up and pick right back up where I started the store left off.

Sam 32:23

And I told him that morning I said whatever I told you, you should have wrote it down because those stories have never been told anybody you know, he said, Man, you would pass out. And you would, it's almost like you pick right back up on the next word like you were reading the sentence, you know.

Sam 32:39

And so I remember leaving there as us. That's where I kind of come up with this. The first part of what I call the three phases, three phases of stroke recovery. And so I was in that first phase where I repeated myself every five minutes. I had that five minute repeat all the time, and then I would realize I'm repeating myself, but I couldn't stop it, you know.

Sam 33:07

And so I got more clarity when they went up there and cracked my skull. When they took me back up here and they cracked my skull. Then I recognized everybody around me, even my son. And they told me that's when they after the surgery. I say that I told him that my surgeon I said he talked to me a lot because I was in the medical field and his nurses even said he talks to you well, a lot more than any other patient. He said. He said, he said It must be because you understand what he's saying.

Sam 33:42

Well, when he woke me up from the craniotomy, he said, I got some good news and bad news. And I said, what you cracked my store gave me the scar. And then you got some bad news because he told me I said I was able to get one of your aneurisms. But I couldn't get to the other three.

Sam 34:01

And we're going to send you in six weeks to get Gamma Knife 90 minutes a gamma knife. We're going to try that option. He said, If I would have took your AVM out, you would have lost your walk your talk and a combination of both. So we're going to roll the dice with the radiation now and so six weeks later, I had to go get screwed into Halo, which Hello, I had a screw I had just been freshly cracked.

Pseudobulbar Affect

Sam 34:27

So they actually had to shift the halo over and put it a little bit off. Oh man, I was just I was lucky that the three doctors could not agree to go to 90 minutes. They but I remember they stopped at 55 minutes. And at this time I was I didn't know I was having pseudobulbar affect. I don't know. Do you know what that is?

Bill 34:52

No. What is it?

Sam 34:54

Like I had the part where it was. I just cried. I just cried if the wind blew wrong, I cried.

Bill 35:04

I know what that is. I didn't know what it was called. But I know what that is.

Sam 35:08

Well, luckily, I actually was, I was sitting on my after my craniotomy and it might have been before, but yeah, it was before my Gamma Knife. I remember sitting on my couch, and I had the flat effect. So, you know, I didn't smile, the flat effect it, you can have it for long periods of time. I had it maybe for a couple months.

Sam 35:32

So my family would come over and thought I was depressed because I didn't

smile. I was flat. And I recognize patients that I take care of that have flat effect. I'm at because these patients before they had their craniotomy, they smiled. And also now they're a bit straight, no facial expression.

Sam 35:53

You could go joke with them. And they, hahaha, just be flat. I mean, just no facial expressions, you know. And so luckily, there was a here in the States, there was a Danny Glover actor, he had a commercial, it was about a medication. But he said, I'm an actor, and I can laugh, and I can cry.

Sam 36:17

But if you have pseudobulbar affect, and it had a box up there, and the first one was brain injury, it was several listings in there that could call pseudobulbar affect. The first one was brain injury I recorded that took it to my local doctor.

Sam 36:32

And of course, I had that broken speech at the time. I was like, this is what's happening to me, you know. And so he put me on, not the medication the commercial was for, but he put me on a medication that kind of tone my emotions down. And it did help, even though I had that crying for a long time.

Bill 36:52

Yeah. It was that bad that you needed it dealt with?

Sam 36:58

Yes not a tear. I'm talking about sob. and I'll tell you a funny story.

Bill 37:06

All the time? Any time? Every time?

Sam 37:09

Yes it even happened when I went back to work. And we had a running joke with the nurses. Because I I was educating them on what I was going through. And so I said, If I say it's about to rain, that means I need to walk off. I need to exit immediately.

Bill 37:27

It's about to rain. I love that.

Sam 37:32

Every so often, a new nurse will be like, it's sunny outside. I said, Nope. The other nurse was like, No, that's his code word. He's got to leave right now. Because I'd get in there with somebody that was passing away.

Sam 37:42

And I was emotionally all over the place, you know? And I can relate to these patients, you know, being on a deathbed. And so I would have some great conversations, but then they would trigger the rain.

Bill 38:00

So what's it like for you now that was sounds like a really tumultuous time. You don't really have a succinct way of explaining it. You're all over the place. It sounds exactly like you were back there. That's kind of the feeling that I'm getting from listening to it. What do you like now? have things settle down a fair bit? Have they changed? Are you the same as you were before stroke? Or are you a different little version of yourself?

Sam 38:35

Oh, I'm definitely a different version of myself. You know, we all all survivors, their old life back but I say you can never get 100% you might get 80% but is it really? 80% because man is so has so many layers, man. It's eat totally different things now, things are actually hated for 44 years.

Sam 39:00

Coconut my mom used to always try to slip down into cookies or cake. I can bite it. It wasn't so much the taste. It was the texture. Nope, it's got coconut in it. I can eat a bag of coconut right now. You broke it open, man. I mean, I eat coconut all time. That don't freak my family out. But they're like, Whoa, this is kind of strange. You know?

Sam 39:22

You never had coconut in your cabinets. Coconut water. You didn't ever have anything coconut. I used to love coffee, which most medical people do. I keep standard coffee. It don't matter how much sugar I put in. It's bitter. I try once a month and I can't stand it.

Bill 39:42

It's affected your flavor and your taste sensation and bitter is way more bitter than it has been.

Sam 39:50

It's extremely bitter. I mean, that's the best way the only way I know to explain coffee and it don't matter what flavor it is when I drink it. It's bittersweet be, you know, yeah, it is what it could have been from the Gamma Knife I meant my Gamma Knife experience. Whenever I would talk to other survivors, you know, they were either AVM unruptured, they were AVM that ruptured or a stroke.

Sam 40:17

But most of them didn't have the layers that I had the stroke, the craniotomy, that clip in the glue and the Gamma Knife. And when I say I had some, I was lucky to have these three doctors, all three doctors had to agree to keep giving me radiation. I question that at first, when they stopped at 55 minutes, I was like, you got to think part of my brain is medical.

Sam 40:43

And so I'm thinking how many open hearts have ever taken care of that went in for a five hour surgery and came out for never? They come out on time or later? Most surgeries don't come out early. Why is my radiation stopping at 55? And I'm not giving them 90 minutes, you know, am I gonna have to go through this again? And it was a blessing in disguise.

Bill 41:07

Why were they doing it? What were they trying to avoid? Were they're trying to avoid something?

Sam 41:12

So where I'm at, you know, when AVM ruptures, they say, you know, you have like a 30% chance of re rupture within the first year. Every year it goes up, I have these multiple aneurisms. So yeah, I beat one odds of actually pulling through this. Am I going to be another one.

Sam 41:32

So the Gamma Knife was to close that AVM off. And they told me it would be two to three years. But when they backed off at 55 minutes, I just, again, my part of my brain that's medically saying, and why didn't you give me the whole 90 minutes, you know?

Sam 41:49

And because I remember I can remember early on like, the first month after

gamma knife, they say, Oh, it don't kill one hair follicle. Look, it was like I drank the biggest gallon of hot coffee and it burnt my mouth. Everything I couldn't taste nothing. It felt like my mouth was scalded. Couldn't smell nothing. It just it wiped out all my senses, you know?

Bill 42:19

So it sounds like they tried to minimize the harm of the radiation. Is that what they were trying to do?

Possible Effects of Gamma Knife

Sam 42:25

Yes. And so jumping, kind of forward? Just to answer your question. I have to wear one of these now. AFO two and a half years later after my stroke. So I used to go not too far from where I am right now and run this two and a half mile bridge. But two and a half years later, I was in the hospital one night walk in and thought I had gum on the bottom of my shoe. It wouldn't go.

Bill 42:59

Was it dog doo doo?

Sam 43:01

No, it was nothing. Oh, it was the radiation killing the neurons from my foot. And I was losing. I was starting to have drop foot. Yes, due to the location on my AVM. And now I get it. My neurosurgeon told me this, he said, Look, you're going to lose something from this gamma knife.

Sam 43:27

What's in those sales around the AVM? We don't know, you could lose a function. You could lose taste speech, you could lose anything. It was the control of my right leg. So for two and a half years, I can run I mean, I worked out I'd done everything I could I just couldn't speak real well. And my emotions were flipped upside down, you know. And I started having foot drop, and I didn't know I had foot drop for about a month or so. I just kept falling. I've completely fallen and fallen hard.

Bill 44:01

You didn't notice your leg moving differently or didn't notice it. You weren't aware of it? Or you were just what was it? How did you not notice it? And

especially when you're falling heaps?

Sam 44:16

Well, I was like, it'd be I'd fall when I'd get groceries out of the back of the car. And I'd fall completely backwards. Boom. Like what in the world? Where'd this come from? And so I actually walked into a new doctor that took over my case, just a local doctor that does my meds and stuff.

Sam 44:36

And when I turned the corner seen him I said hey man, I need a knee brace. I've just unstable for some reason. He said no. When you turn the corner I noticed you have foot drop. And so I tell people, you know you unconsciously walk heel to toe. You don't think about it.

Sam 44:52

From the day you start walking you just walk but you make one of your feet. If you tied a five pound weight to the toes, One foot and tried to walk that would give you foot drop. And that would throw you off. It would just it throws you off completely.

Sam 45:06

I mean, if I don't wear my AFO I'm gonna fall you know, I mean, I fall all the time. When I'm around the house, I don't wear it. So I'm blessed. Man, I can talk giving if you gave me the option to run or talk. Forget running. I'm gonna talk.

Bill 45:28

Yeah I understand. And I, I kind of feel the same way I've got left side numbness, the entire left side feels numb, and it's colder, and tenses up and it gets all messed up and naughty, and all that kind of stuff. And I need, you know, multiple massages, and all sorts of things.

Bill 45:46

So I can talk and I can get along with my life. And it's really, really good. I don't actually pay attention to any of my deficits, unless they're causing me pain on the day, which is often but I don't really care about them. Like, I'm not interested in giving them the time of day. Do you know what I mean? I'm not keen on dwelling on them and giving them any energy, it's just, I'm gonna get on with it.

Bill 46:18

And if my balance is off, while my balance is off, if I stumble, which I do, often I stumble, no big deal. Of course, it'll be a big deal if I stumble, and then fall and hurt myself. And I don't want to be in that situation. But until that happens, I'm not putting any thoughts in my mind about what my future may be like, right now. It's good.

Bill 46:41

And I'm going to do everything I can to put myself in the best situation so that I don't end up tripping over later on in life, when it's really important. And a hip fracture, can mean you know, can mean the end. Oh, God, you don't even want to bring in the heel. I know, I know. But it's a real issue. Because I've met a lot of stroke survivors have fallen, after they've been released from hospital to recover from the stroke, they're doing well.

Bill 47:12

And then the fall makes it a massive setback, and really impacts their mental health. And it impacts their ability to have a cognitive recovery. And I didn't understand how the two could be connected. But I've seen it a number of times now. And it's definitely connected.

Bill 47:29

And that's the thing. So I try not to give these things that I'm left with the time of day. I try not to give him any energy. It's my way of going. Screw you. I'm getting on with it. And I'm gonna do the best I can. But but it but they, they don't want to let me get away with it.

Bill 47:49

You know, they they remind me every once in a while, you know? You're not as you were, you're not normal. You're different now. So it's interesting to hear your perspective on the AFO and the foot drop and the way that you go about it. And that you're blessed because we are blessed. And let's face it, a lot of people are doing it worse. I hate saying that.

Bill 48:13

But everyone can say that about somebody else. So if you feel like you're doing worse than me, and you've heard this, there's somebody doing worse than you and it's not a competition who's doing better. It the company, that the comment is about focusing on what the blessings are. And I know stroke is shit. So hopefully I

haven't offended anybody. Right now in this last few minutes.

Sam 48:41

Well, that's like so I jokingly say this, but I've been on many trips to try to bring awareness to stroke. So I went and met Kyle from share your stroke of genius up in New York.

Bill 48:56

Kyle Mengelkamp. Yeah, he's a cool dude. I had him on the podcast.

Sam 49:01

Early in my recovery. So I'm talking about like, the first year so kind of speed past the Gamma Knife. I was stuck in a disability system that here that said, that we're basing my disability off of my gamma knife and not my stroke and my craniotomy. Yeah they just looked at my last procedure, which was gamma knife and you can have gamma knife and go back to work the next day, you know.

Sam 49:31

But if they read deep enough, they would see like six weeks before, he was having a craniotomy and six weeks before that, he had the stroke. And so I was stuck in a disability system that would not help me I was gonna lose my house, my car and everything.

Losing A Loved One In Relation To Pseudobulbar Affect

Sam 49:47

And unfortunately, this is where my brain injury will kick in. That I used to be able to block all this from seeing so much death in my career. People would say I was cold because like if I went to a funeral, I wouldn't shed a tear. Now, if I think of something, get a little emotional.

Sam 50:13

And eight months after my stroke and everything. I would always call my dad whenever I would go to the doctor's office, and he would call me vice versa. He just lived right down the street from me. So we were always working on cars or stuff like that. We had old classic cars and everything.

Sam 50:39

And I was in the shower about to go to my doctor's appointment that morning that my phone rang and I opened the curtain I'm seeing it was him. I said, I'll call him back in a second and something said, pick it up, picked it up, and I heard somebody saying my dad was on the floor.

Sam 50:55

And so jeans over a wet body out the door, I was hauling ass up there. And needless to say the one person I know I tell people, I put my hands on 1000 people and a 15 year career at that time. I mean, sometimes I go to code like, at Vanderbilt, I might go six times a night, you know, you might go to and you might save can lose five, save five, it's just a you're doing a job to save a life.

Sam 51:25

This is the one life I should have been able to save. And me and that fireman, we tried our hardest, but the therapist in me said, we're going to save him and the son of me said come back Dad, you know, needless to say he passed away. And I've pushed against my family.

Sam 51:46

Because now I'm a brain injury survivor in my world has been rocked. And I need some normalcy in my life. And so I went to the doctor that has known me since I was a kid and I went to him and said, I promised you the rarest case at the end of your career. I need you to write two sentences for me.

Sam 52:09

Can return to work cannot do chest compressions. He wrote it. I went to the hospital where I work. I said I want to come back to work. They said whoa, we got to we got to test you. This was my way of trying. I said forget the disability. I don't care what back money they would pay me. Money is not object come take my house. I don't care. I want some normalcy.

Sam 52:33

And my normal life was the hospital. I knew these people would understand what I was going through. Yeah. And so they let me come back to work. But then they drilled me and this was the crazy part of my injury. I could look at a blood from a blood gas and tell you what to do. I was intubated patient, but then I couldn't get my own locker. Yeah, or I would forget my password every day and have to call it it's me again. I need a new password.

Bill 53:01

How long did it take for you to get back to work?

Sam 53:06

I went back to work a week after my dad passed away. I'm determined.

Bill 53:11

How long since that Gamma Knife though?

Sam 53:15

So my dad passed away. March the 30th I believe it was of 2016 I had the Gamma Knife on October the 30th. So my rupture was August the 14th. My craniotomy was September the 21st. My Gamma Knife was October the 30th.

Bill 53:37

All in 2016?

Sam 53:39

That's 2015.

Bill 53:41

Oh, wow. Okay, so you we're back to work about a year later?

Sam 53:46

It was less than a year I went back to work. I want to say maybe April the 15th of that year.

Bill 53:54

Okay. Did you feel I know that you got back? I know you were in the Did you feel confident? Were there times where you said I don't know what the hell I'm doing?

Sam 54:06

I was confident about my ability. So that's the crazy thing. I could look at a blood gas. I knew what the workload I need to do the breathing treatments. If I was intubating patients two weeks after I got back, you know, I was having to prove myself again.

Sam 54:22

And I had no problem with that. But then I had to ask help to get in my locker are calling it all the time or what's the passcode to this simple little things that I

should have been able to remember, were just and they'd say well put in your phone. I said oh behind the password. That makes sense.

Bill 54:43

I was at home recovering on my own because I was good enough to be at home alone after the brain surgery. Probably maybe two or three months after it was still quite warm and because it was quite warm in Melbourne, it was summer, I didn't want to go for a walk outside, because the heat was really affecting me.

Bill 55:08

So I was allowed to drive at that time, and I would drive to the local shopping mall, park the car, and then walk in the shopping mall was my way of getting exercise. And I did it because it was air conditioned. Try, getting back to the car. Oh my gosh, I often spent many, you know, half an hour or more, walking through the car parks just trying to remember which car park I had parked in, and having no idea and then just walking around in circles trying to find the car. It was like a Seinfeld episode.

Bill 55:45

I mean, it was terrible. But I could do all the things that I needed to do to get there. I could drive I could, you know, walk, I could do some browsing, I could do all those things. And it just as soon as I had to turn my attention to getting back into the car, and no idea where it was not that single inkling of where it was. In fact, if it felt as it felt like it had been stolen.

Bill 56:11

Like that's how bad it felt it was just terrible. And no matter what I did, It wasn't getting better quickly. It got better, but it wasn't getting better quickly. So I know what you mean about being able to do really complex tasks. And then the one thing that's meant to be well, that appears to be simple, becomes really difficult.

Bill 56:41

I have another friend who was in Melbourne and also had a stroke. And she couldn't find in her car, the volume button on her radio. So she could do everything else, but had no idea where the volume button was. Even if she was staring at it.

Sam 57:03

Wow, whenever I go speak to like groups or families often asked them, because

because of my frontal lobe injury, I was real blunt at first. So I was like, so what would you do if you couldn't wipe your ass or brush your own teeth? I mean, that's a blunt statement, you know, but it pull somebody into the conversation.

Sam 57:25

Uh, whoa, I've never thought about that. I said, that's two things you do behind closed doors, that's private. But if you have a stroke, because I've talked to a lot of diabetes or CHF a lot of patients and I try to tell them, there's so many things that can cause a stroke.

Sam 57:44

I said, there is no reset button on a stroke. There's no Mulligan, you know, we're not playing golf, and you get to let me pull the ball back here and hit it again. Your life changes from that moment that happens. And you know, I mean, but I would also ask them stuff like, so if I asked you this question.

Sensory Overstimulation



Sam 58:07

If you had a choice of one sensory, what would you pick? Sight? Hearing? Taste? Smell? the feeling of air conditioner. He hit me on top of your head, you know? I said because any too will overstimulate you.

Sam 58:22

So I would get overstimulated. I'm so bad. I had to go to listen to I would drive down the interstate or to work. Listen to meditation music. Because what I listened to all the time and used to go take pictures of rock bands with I could

hear things in the music I've never heard before. You know? I never heard that high hat.

Bill 58:48

Did you ever get over stimulated while you're at work and had to take time out and rest? Because that's a pretty full on environment. There's noises, there's really bright lights, there's a lot of information on the paperwork that you're reading.

Sam 59:02

Yeah, so I would get overstimulated and then the pseudo bulb effect would kick in. And oh, it would just I'd be I'd have to go hide in a room and catch my composure. It's embarrassing. I got to where when I go to talk to a stroke group.

Sam 59:19

Because there's always that one stroke person sitting in a wheelchair that has a frontal lobe that lashes out at you because I've, I've experienced that and I've had to tell him, yeah, I used to be like, you or this person over here that's sitting in the wheelchair that can't speak.

Sam 59:35

And I said, you'll are going to see what my brain injury brings to me, because I'm gonna cry right along with you, as I bring my memories that I can pull back up. I remember myself sitting in that wheelchair. I remember a lot of that stuff. You know, the there's a big gap of my recovery that didn't it still don't come to me to this day.

Sam 59:58

Here's a funny little tid bit. So I was in a relationship. So I lost two weeks before my stroke. And me and my girlfriend split up. But first person I asked for was her. So my family didn't know if we got back together or not. So who did they bring them up beside her.

Sam 1:00:25

And she tried to call the shots, which calls a bunch of family drama, you know, but yeah. I lost that spanned the time of us actually breaking up. And how I knew it was true was my dad, he loved this girl, or, you know, he really liked her. And he said, Yeah, you brought your convertible Mustang to my shop and said, I'm done. He said, your car sits at my shop. And so I knew my dad wasn't gonna lie about it.

And that's the only reason I would have took my car back. So I had to go through a new relationship.

Bill 1:01:08

And a breakup again.

Sam 1:01:10

Yeah, it eventually ended because I had to tell my family, I don't remember breaking up with her. And if she goes back to doing whatever she done, the causes break up. Then it'll play out, you know, eventually. But I learned so much from her. And I actually taught her a lot of stuff.

Sam 1:01:31

I was dealing with a brain injury patient. She just never talked about her, she had a VP shunt in her head. And I had to teach her. So when I got back to where I could read the written word, I was like diving into my medical field, my medical records. And then I'll have a dive into heart VP shot. And I told her, I said, You've had your VP shot for 12 years.

Sam 1:01:54

Do you know those things only last, they have a warranty of six months to 10 years, you're going to have to have another brain surgery in your lifetime. And she would she was one of those ones that denied her injury. You know, it, if I don't speak about it, it don't exist. But it gave so much clarity to me, of our up and down relationship. You know, when she didn't hydrate well, when she didn't eat the right amount of food.

Sam 1:02:24

People don't realize you don't hydrate guess what? You still had the same amount of blood cells and fluid in your body. If you have a VP shunt, it's because you have overproduction of cerebral spinal fluid. And I would try to educate her. But again, that was just a little tidbit that my two weeks of lost memory actually lost a breakup. So I had to go back and relive all that stuff. Like I said, this onion has many layers, man.

Bill 1:02:56

It certainly does. I mean, that's what strikes survivors often find that's one of the hardest things to convey is that stroke recovery is not, you can put a timeline on, it's not like a broken ankle, or broken foot or broken arm, it doesn't have six

weeks, and then you take the cast off, and then it's better.

Bill 1:03:13

And then you go through a little bit of rehab, and you go back to your normal life. It's not like that. And that's one of the hardest things. And I've got people who I coach through their own recovery. And it's, but but it's been nine months. Why am I not better? It's been around.

Bill 1:03:29

And so how do you get the message across to somebody that it's, I've been 10 years nearly, and I'm still recovering. And the recovery has changed a lot. It's different, but I'm still recovering, I might be in my emotional phase of my recovery, or my psychological phase of my recovery, whatever it is, it's still ongoing, it hasn't stopped.

Bill 1:03:55

So I hate doing that to people who are so early on. And potentially giving them the the news that sorry, this is going to continue for far longer. And I'm going to have to disappoint you and tell you that in 12 months, you're not going to miraculously get better. It would be great, but it's very, very rare.

Sam 1:04:15

Well, I found out, I said can I get exposed to so I mean, I seek out every brain injury and every stroke survivor that comes into my hospital. And I found out that I mean, we as humans. We don't realize it took us a year to learn how to walk. But when we get it taken away from us, we want it back tomorrow.

Sam 1:04:40

And it just don't work that way. You know, but we want it now. Now now and it's hard. It's hard for a stroke survivor. Like I said, the first two years, I was so focused on bringing light to the world about stroke, you know, so I traveled across 10 different states and went back to every hospital that I worked in.

Sam 1:05:03

Walked in with street clothes and tattoos, always say, because you get judged by the your first sight. And I would go in there and say, Can I speak to a stroke advocate? And you wouldn't believe how many hospitals fail at that one question. Most of them, small hospitals don't have a stroke advocate.

Sam 1:05:26

But so I went back to Vanderbilt, and they were spot on. I mean, I went and talked to two stroke advocates, I actually, so when I worked at Vanderbilt, they didn't have a neuro residency there. But I'd done my research and they had started when in 2013. So as I was talking to the head stroke advocate, she requested, they just hired a new person, I went up there to talk to him, she got called to income and stroke into the ER at that moment.

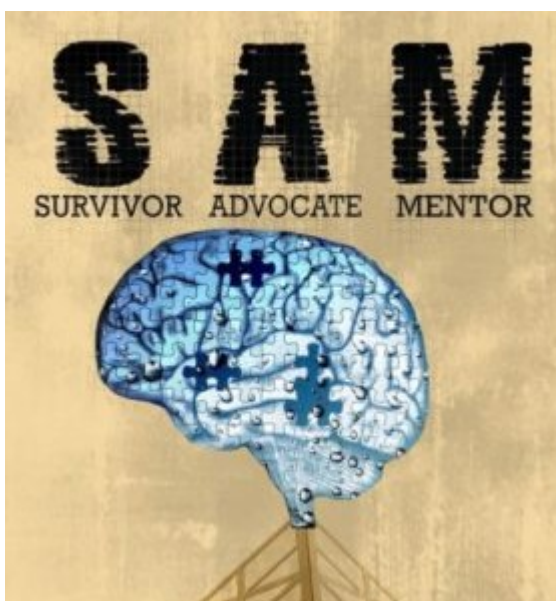
Sam 1:05:56

And so I went and talked to him for a while. And then I said, Hey, let me go, where's these residents at and crazy how I used to work there, when I walked in, there was a totally different place. But as I walked the halls, I started getting memory back. And so I went and found those residents.

Sam 1:06:13

And I mean, to me, residents in the hospital, always say, like a cobia, quail. There's one dominant one and the rest, follow wherever they go, you know, so I wouldn't seek them out. And I showed him my scans and everything. But they got called to that stroke that was coming into the ER, but I was glad to see that they had an advocate they had, because the one question I asked is, okay, you save the stroke survivor.

The Stroke Advocacy



Sam 1:06:40

When you send them home what do you tell their family, because if you don't

educate that family, you're sending them home with a, what they think is a little Chihuahua on a leash, but they really got a rock wall or a bulldog on that leash. And eventually, after about the 10th time of them, tell him their strokes of average, you're so blessed, they're going to get bit because that stroke survivors go lash out.

Sam 1:07:08

It's just that's and so my early on thing was, if I go talk to stroke survivors, they're going to forget me. If I talk to the families, yeah, that's the best way for me to help the stroke survivor, I can get them to understand that they might repeat themselves every five minutes, they might cry, they might lash out, but they might not remember it five minutes later.

Sam 1:07:33

It's a tough pill for the family to get cussed out. And they're taking care of this person, and then they leave out and come back in and the survivor act like nothing happened, that still staying that family member, it can be hard for them to cook food at night for that person, you know.

Bill 1:07:52

And make a tasty, yeah, they're not gonna make it, they're gonna make a terrible.

Sam 1:07:57

And so when I went to these hospitals, I went back to some major medical centers, I'm not going to call their name out, but I walk in there. And I let one I love working at the hospital. And I let them pass me around for two hours. That's Oh, go here and see this person, go over here and talk to this person.

Sam 1:08:16

And finally, this lady came to me instead. Who are you looking for? I thought I had a stroke. She said, Oh, we have a great stroke team. I said okay, I survived. I'm going home, who talks to my family? And they had no clue. And that's where the break in the link is.

Sam 1:08:35

If you don't teach a family, look, they have a frontal lobe injury, they're gonna cuss you out. They're gonna do all kinds of stuff. They don't have a filter, that's a set up for failure. Or, hey, they got memory problems, you know, or like me, I couldn't read the written word for a good amount of time, you know. And so that

was frustrating for me. And you come in, tell me I'm blessed. I can't read.

Bill 1:09:04

Yeah, and it's fresh. It's just happened. You're in the hardest part of the recovery, the very early phase and you're navigating it you don't know what's going on. It's all new. Well, you perhaps more better equipped than most people but you're right. The rest of the families and the survivors with no idea. I didn't know what I had to deal with when I was going to come home and my wife had to cop the brunt of that. She really copped it.

Sam 1:09:34

If you go on the support groups anywhere on Facebook, and you type in this question, how many people are still with their partner that they were with? When they had their stroke? Yeah. 80 to 90% of those people will say they're not willing. They walked away.

Bill 1:09:52

That's a great question. I'm gonna ask that on my Instagram one day.

Sam 1:09:56

There's there's some up there that you know, they they stuck in there. with them, but they are the few, you know. And so I get on there and try to help people, man. I try to answer questions, but there's also low, there's people on their height, say there's people in some of those support groups that are pissed at the world and try to start fires.

Sam 1:10:18

And you know, no matter what your belief is, when you go on there like this one guy, he goes on there every year, and he has this one question and man, it makes the fire flame. Yes, this simple question. Is there any atheist stroke survivors only? Oh, my God, everybody believes in any religion comes on there.

Sam 1:10:44

And I thought I believed in God, but what God would do this to me and just Oh, they. And that's what this guy's wanting to do. He's wanting to start the fire. I'm pissed at the world. This happened to me. I want a bunch of people to be pissed.

Bill 1:10:58

That's fair enough that people are pissed at God or whoever. It's fair enough.

Like, I totally get it. And I had this exact same thing happened on my Facebook Recovery After Stroke. Where I asked the question, the question was, was stroke the worst thing that happened to you?

Bill 1:11:19

And some people said, they found God. And God helped them through, which is an amazing thing, whether they found them or whatever, I don't mind. Yeah, whatever helped you through. And then this other person said, What God? You know, God does terrible things to people and blah blah.

Bill 1:11:37

So what he was trying to do was school them on their experience of finding God. And that's not nice. If he said, if the question was, did you find or lose God during your stroke experience, then his comment was relevant, and I'm happy to hear it.

Bill 1:11:54

But in this instance, he was trying to minimize somebody else's experience. And he did not want to listen to me, or read my comments. When I said to him, it's just not appropriate. Like this is not a religious page. This is a stroke page. A religion is another page.

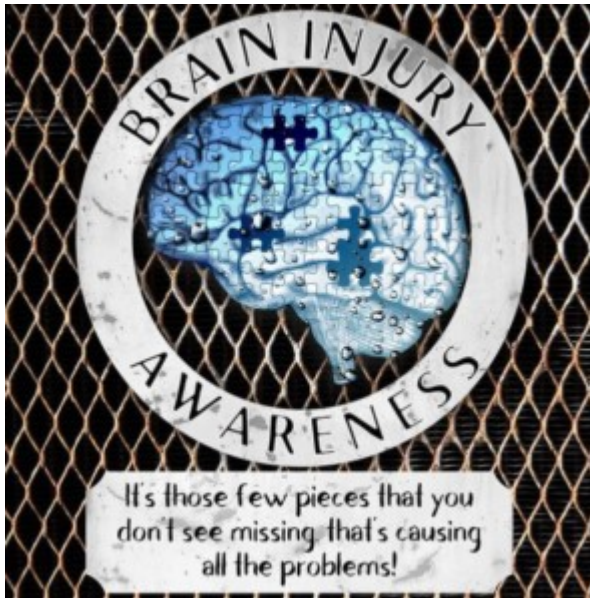
Sam 1:12:12

On that note, I had to actually, it took a long time for me to not take it personal when people would do that, because I hadn't realized, Hey, I'm talking to people with a brain injury. What do I expect? Is though, yes, I mean, myself, I have a brain injury, I have to convince people. Look, I am a stroke survivor. I have, I don't tell people my challenges outside of the hospital. I know I struggle here and there a little bit.

Sam 1:12:42

And I told him, I said, when I can't do my job, I went and told my boss when I can't do my job, I'll personally turn in my resignation. I will not put anybody at harm's way. Yeah, you know, and I told her that early on, I tell her every year but yeah, it's I tell them, these people have a brain injury.

Breaking Barriers



Sam 1:13:00

You go in there. And because we have so many patients come in and they don't. Some nurses will come and tell me there's a brain injury patient in this room. Go see if you can give them some insight, you know. And man it's like, I tell people that a brain injury crosses all race, religion, all that stuff.

Sam 1:13:23

You can walk into a room with a total stranger. If they see your scar, or you see their scar is like instant connection. This person knows where I've been knows what I've been through. So it's a community that like, there is no barriers to it. Except we have brain injuries, and sometimes we lash out.

Bill 1:13:45

Yeah. And we speak inappropriately, but that's okay. That's why we're good at forgiving as well. We'll forgive. Sam, thank you so much for being on the podcast. Thank you so much for reaching out. Thank you for sharing your story. I'm always saddened to hear when life continues to happen during stroke recovery, and we lose loved ones, and people pass away.

Bill 1:14:08

It's the nature of it, like things don't stop because you had a stroke. And it complicates recovering. It makes things harder, and it makes people feel a little bit more overwhelmed. I'm glad that you cried on my podcast because that's the clip I'm going to use to show everybody that men can cry, and that it's okay.

Sam 1:14:32

Hey, I have no problem with it. The people that are around me know that it can

come at any time now. It's not as bad now but if I go talk to people or if I'm there's a patient pass away or I'm talking to the family members. And I have to say, you have to excuse me, I have a brain injury. I can't control this. You know.

Bill 1:14:55

But isn't it accepted that medical professionals I will cry every once in a while, especially around patients. Isn't that a good thing?

Sam 1:15:05

So your new nurses usually do. But as you've been in it 10 plus years? It hardens you. Well, you have to be able to do the job, you know, this patient passes away, but you got four or five other patients you got to take care of. So, you know, my family didn't know what I'd done for a living.

Sam 1:15:30

I mean, they knew but they didn't really know, you go ask the average person about a respiratory therapist. And they did give breathing treatments, their treatment jockey, they call us, you know, yeah, they don't realize we go to every code, we, when the doctor writes this on the piece of paper, or send it across on a computer, pull the patient off, we have to do that.

Sam 1:15:50

And that was part of my, when I had Gamma Knife. My family thought I was seeing spirits. Because I was talking about these people. And they said, Oh, he's I mean, he's way out there, something's going wrong with him. And it wasn't. So a lot of times you go to a code, if you're in a big hospital, you don't know this patient, it's on another floor, you've never seen this patient, you go in there and do the job and either save them or you don't.

Sam 1:16:23

And then you got to go right back to work. And so I've seen little babies pass away, I've seen just, I'm godly amounts of people. But when after my gamma knife, when I would try to go to sleep, the best way to describe it, and I'm describing like this before to a group.

Sam 1:16:43

When I close my eyes, it looked like an old nine millimeter film reel going. And it was every code that I've ever been to. I've talked about vivid, like it was a movie, back to back to back to back. So of course, I didn't want to sleep. And so I went

for like three days without sleep.

Sam 1:17:03

And then I was really hallucinate and thought people was trying to break in my house and stuff, you know, but finally, I gathered across to my family, what I'd done and what it has seen, so this part of my brain being injured, those little Flashpoint memories of not even memories, not something that you can actually pull back up into memory, Oh, I remember that code.

Sam 1:17:26

When you do 200 or 300 codes in a year, you're not going to remember every one of them. And so I was seeing these people like I was in the room doing the actual event. And I did not want to close my eyes. I've wrote about that before. It just, it was a memory that I I would have never thought I could pull those people back up. I mean, remember six year old kid passed away from undiagnosed diabetes, you know, I'm it just so much clarity, I could hear his mother cry.

Bill 1:18:02

And if you have to have that with you every day at work, you're not going to be able to work really are you so you do have to separate yourself. You do have to switch that off, and you've got to put it behind you otherwise you're going to be unable to help anybody else. It's going to be terrible.

Sam 1:18:18

Yes. And it is not that we're cold. We have to do a job and to be able to do that job. You have to go clear your mind and do the job. Hoping the best outcome but bring a brain injury into it. It turns the movie reels on, you know.

Bill 1:18:35

And what did you call it? It turns the rain on from time to time.

Sam 1:18:39

Oh, yeah. It's about to rain.

Bill 1:18:44

Sam, thank you so much for being on the podcast. I really enjoyed our chat. Thanks so much for joining me on today's recovery after stroke podcast. Do you ever wish there was just one place to go for resources, advice and support in your stroke recovery? Whether you've been navigating your journey for weeks, months

or years now I know firsthand how difficult it can be to get the answers you need.

Bill 1:19:06

This road is both physically and mentally challenging from reclaiming your independence to getting back to work to rebuilding your confidence and more. Your symptoms don't follow a rulebook and as soon as you leave the hospital you no longer have medical professionals on tap.

Bill 1:19:22

I know for me It felt as if I was teaching myself a new language from scratch with no native speaker insight. If this sounds like you, I'm here to tell you that you're not alone. And there is a better way to navigate your recovery and build a fulfilling life that you love.

Bill 1:19:38

I've created an inclusive, supportive and accessible membership community called recovery after stroke. This only one support and resource program is designed to help you take your health into your own hands.

Bill 1:19:51

This is your guidebook through every step in your journey from reducing fatigue, to strengthening your brain health to overcoming anxiety and more To find out more and to join the community head to recoveryafterstroke.com see you next time

Intro 1:20:06

importantly we present many podcast designed to give you an insight and understanding into the experiences of other individuals opinions and treatments, protocols disgusting any podcast or the individual's own experience and we do not necessarily share the same opinion nor do we recommend any treatment protocol discussed.

Intro 1:20:23

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Intro 1:20:40

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Intro 1:21:01

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Intro 1:21:25

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