

Overcoming Multiple Hemorrhagic Strokes & Brain Surgery - Kyle Johnson

A hemorrhagic stroke at age 33 and 3 additional bleeds in the brain at 34 seriously challenged Kyle Johnson. Listen to his story of recovery.

Instagram

Highlights:

- 01:44 Introduction
- 02:47 Pontine Cavernous Malformation
- 09:24 Getting Into Surgery
- 15:19 Dealing With Self-Esteem After A Stroke
- 23:10 Being Able To Walk Again
- 30:22 Exposure Therapy
- 34:45 It's Okay To Offend People
- 43:24 Self-Awareness
- 50:16 Stroke Humor
- 57:31 Life Before The Stroke
- 1:03:22 The Perpetual Pirate
- 1:11:19 Falling Out?
- 1:25:18 The Recovery After Stroke Podcast

Transcription:

Kyle Johnson 0:00

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Kyle Johnson 0:19

And I developed these tics that you would notice I'd rub my hand my thumb across my forehead because right down the center, I could feel a difference. Or I

would raise my hands up above my head all the time to make sure I still could, because that was one of my symptoms was I couldn't raise my hands above my eyeline. So I developed the nervous habit of constantly raising my hands above.

Intro 0:51

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

Bill Gasiamis 1:04

Hello, and welcome to episode 228 of the recovery after stroke podcast. To learn more about my guests, including links to their social media and other pages and to download a free transcript of the entire interview, please go to recoveryafterstroke.com/episodes.

Bill Gasiamis 1:21

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Introduction - Multiple Hemorrhagic Stroke

Bill Gasiamis 1:44

My guest today is Kyle Johnson who experienced a brain hemorrhage at age 33. Three brain hemorrhages at age 34. And then brain surgery, Carl has overcome a lot and is still dealing with some of the things that stroke has left with him. Kyle Johnson, welcome to the podcast.

Kyle Johnson 2:04

Thank you for having me Bill. I appreciate it.

Bill Gasiamis 2:06

My pleasure. Thank you for reaching out and being on the podcast. You are somebody who I can relate to a lot because one of the questions that I asked people about before they jump onto the podcast just to determine that there's some kind of a stroke survivor is what kind of stroke did you have? And when did

you have it? And how old were you at the time? And you've got here you were 34 times three? And then surgery at 34? And they're all hemorrhagic strokes. Tell me a little bit about what happened to you?

Kyle Johnson Pontine Cavernous Malformation

Kyle Johnson 2:48

I didn't know any of this, obviously, until I was 33. But I was born with what's called the pontine cavernous malformation of the brainstem. I don't think they could have made it any harder to say or pronounce remember, but they did.

Kyle Johnson 3:03

So when I was 33, pretty much what happens. What I understand, I'm sure someone out there is going to correct me if I'm wrong, is the blood vessels I like to call it they get really close and they hug really tight and then they explode.

Kyle Johnson 3:17

So inside my brainstem, I had one of these malformations, and it just started bleeding one day. And so that was in, I think it was July of 2016 was my first one. And then I had three more in 2017. I was 10 months, 13 days later was my first one.

Kyle Johnson 3:40

And then a couple of weeks later, or sorry, two months later was my third one. And then I'm not sure that between my third and my fourth one ever really healed. And then fourth one is when he got really bad where, I couldn't move and I was just constantly throwing up blood.

Kyle Johnson 4:00

So I got rushed to the ER for that one. And of course, you know, all the nurses and everybody, they already had my bed made up and they knew me and their ICU at that point because I'd pretty much lived there. And then they put me in pretty much a chemical-induced coma for about a week while they figure out what they're going to do.

Kyle Johnson 4:18

And what they ended up doing was a week later, they cut me down the back of my

neck and took out a piece of my skull, put a tube in there, cleaned everything up on the inside, pulled it out, put a piece of titanium in there and sewed it back up and sent me on my way. So yeah, those 18 months were give or take 18 months are pretty wild to say the least.

Bill Gasiamis 4:44

Yeah, you bring back so many memories, not pleasant ones. Oh my god. I had a bleed in Feb. 2012 in March 2012 in November 2014 And then Brain surgery in November 2014. And it's kind of the same thing they sort of said to me, it may have never really healed and that's why it continue to bleed out.

Bill Gasiamis 5:11

And mine wasn't a cavernous malformation. Mine was an arteriovenous malformation, which is just in a different location, but it's a similar kind of thing. And I didn't find myself particularly doing the anxious thing of worrying what about the next one?

Bill Gasiamis 5:29

Or if I have a next one, but what I did do was I did do the whole is this another one for many years? Because I was having weird sensations, feelings, etc. Did you have the whole is this another one? And then you were well, surprised or whatever to find out that in fact, it was. How did that happen?

Kyle Johnson 5:56

It's actually a question I get a lot was, you know, knowing what the first one felt like because the first one I got the nickname in the hospital of really bad word idiot, because I actually drove myself to the ER, because I was home with my son alone. Yeah, exactly. I like I went home, I fed the dogs, I drove myself to the ER with an eyepatch on like I do these days, and it was just a bad thing.

Kyle Johnson 6:22

And I developed these tics that you would notice I'd rub my hand, my thumb across my forehead, because right down the center, I could feel a difference. Or I would raise my hands up above my head all the time to make sure I still could, because that was one of my symptoms was I couldn't raise my hands above my eyeline.

Kyle Johnson 6:46

So I developed the nervous habit of constantly raising my hands above my head,

because I was always scared that it was going to have it again. And so much so that one of my buddies and I got together. And he's a back end programmer.

Kyle Johnson 7:03

And we built an app this is not a plug or anything, because it's not available anymore. But it was for me, where it was an application where it could go in there and make it sit on the phone to say, hey, every duration of time, like two hours or an hour, you have to push something on your phone, like a medical alert to say, yep, I'm still alive, right.

Kyle Johnson 7:27

And if you didn't push the button or acknowledge it, it would give you a countdown. And then if you didn't do it, still, it would then reach out through text message through people you set as your contacts and show them like, Hey, Kyle needs help this is there's last known location from GPS on the phone.

Kyle Johnson 7:46

That's how nervous I was. Because I was, you know, I think you've been through it, you know, it's a scary situation. When it actually happened again, it was of course, a bunch of denial, where I was downstairs doing something and I was sort of feeling really weird.

Kyle Johnson 8:07

And I was like, I'm just really hungry, right? It's like, ran upstairs and started eating. And the best way I could describe it was that I was the balloon and the water. So I was a water balloon. And somebody took a needle and just popped the balloon.

Kyle Johnson 8:24

And this felt like rushing water out of my body. And that was the strongest indication besides my eye because it did fix itself the first time and then it just stayed. But so that was a really strong indication for the second one. And then the third one was just, I was really dizzy and didn't feel good.

Kyle Johnson 8:47

So I called up the doctor. She's like, yep, come in. And I was like, are you sure? And I remember her response was you're bleeding through your brain. You, might want to come in. I was like, Okay, because, as you know, it's kind of expensive.

Kyle Johnson 9:03

And then the last time was, I've been thrown off. I couldn't lay flat or sit up. So if I did any of those movements, I would automatically throw up and I just started throwing up blood a lot. And I called my buddies and he came and picked me up. And I'm glad to say I didn't vomit in his car the whole time.

Kyle Johnson Getting Into Surgery

Kyle Johnson 9:24

Huge win for me. And part of that was, well, we got to the hospital and they're just like, you're back. I was like, Hey, guys, I just missed you so much let's go. So yeah, it was trippy. And I know I'm sure you felt this too it was one of those where you want something to be done so bad about it because you have no life at a certain point.

Kyle Johnson 9:48

But at the same time, you want to be invited to the dance, which you don't want to go. So when they're like hey, we're going to do surgery. It was like a sigh of relief but at the same time like oh my God, what is actually happening type of situation?

Bill Gasiamis 10:05

That was scary. I remember exactly that third time I was avoiding the surgery, you know, we can probably get away, can we get away with it? Can we get away with it? And third time my surgeon came in and said, We have to go in now.

Bill Gasiamis 10:19

And she said, are you up for it? And that was a sigh of relief yes let's get it done and dusted. She came back and checked up on me the second day and said, Are you still on board with surgery? And I said, Well, yeah, I'm on board I am.

Bill Gasiamis 10:35

And I wasn't confident that I didn't respond confidently, but I was. And then we went through all the pre op procedures, and the pre op procedures included, you know, going into get assessed for surgery. So it's a different kind of assessment.

Bill Gasiamis 10:51

And then the day of that assessment, which was about less than a week before surgery, as we were leaving the hospital, and we're going through the emergency

area exit or whatever it's called the ER. I started to feel, all my left side just just go in my eyes, I couldn't see and I was freaking out, and I was really scared.

Bill Gasiamis 11:20

And I said to my wife, I'm experiencing all of this stuff right now. And we cannot leave, we've got to go back to the ER and get somebody to look at us. And I'll remember, we're heading to my parents house. And they were just waiting for us to go for dinner.

Bill Gasiamis 11:36

And we rang them and said, something's wrong, we have to stay here, we're not leaving. Anyway, I've got cleared after about another three or four hours and it was, you know, well into the late hours of the night. And then we got sent home. And then a week after was surgery now what made it even worse for us, and I've mentioned that on a couple of previous podcast episodes is that my mother in-law had passed away and been buried literally a week before that.

Bill Gasiamis 12:06

So we were just at our wits end, like we didn't know what the hell was going on. And my wife broke down on the way home in the car, crying and having just a panic attack about what the next few days are going to be like, and what's going to come of it, what's going to happen. So it's pretty safe to say that I was relieved one moment, and then I was shitting myself for the rest of it.

Kyle Johnson 12:32

100% Yeah, I mean, I don't remember a lot of the week in between that what you're saying is 100%, right. And it's just one of those situations where it is relief of like, alright, they're gonna attempt to at least do something. But at the same time, because I wasn't coherent to a certain point, right?

Kyle Johnson 12:57

It's all this stuff that they're talking at you and with your family and stuff, like, well, he could die, or this or this or this right. I don't remember a lot of that piece. But I do remember the emotions that came with it. And I do remember the feeling of I don't know if the word is dread or despair. But, you know, you're adults, your parents, your significant other, your caretaker at the time is there.

Kyle Johnson 13:30

And, you know, you it's a hard situation to kind of wrap your head around unless

you're in that situation, which I want to be very clear. I don't wish that upon anybody, because it is asstastic situation to be in. Just, it's not fun. So yeah, it's been, it's been a journey. And I think, it's taken me, I guess five years, almost six years, to be able to at least open up a little bit more about it in general.

Kyle Johnson 14:02

Just because I don't know about you, but like, I was mad for a long time, I was upset with my body. I was you know, the whole like, why me situation and genetics thank you so much for that one. But, you know, it's hard to kind of wrap your head around. And, you know, I have more respect for my wife than I probably ever could.

Kyle Johnson 14:25

She's done more for me than any other human. She's what I call my superhero without a cape, we've been together 23 years now. And she's, she's been there through all of my stuff and all the ups and downs and yeah, it's a weird situation. So I can see that 100% of just that feeling of what is going to happen?

Bill Gasiamis 14:59

Only one way to find out is get through and somehow see later, like, if you have the opportunity to just see what comes of it. I mean, that's not a shallow conversation. You can't just say, Oh, let's see what happens. Well, it's actually really deep.

Dealing With Self-Esteem After A Stroke

Bill Gasiamis 15:19

But that's kind of where it starts, it starts Oh, well, let's just see what happens tomorrow and the next day, and then in three months, and then six months, and then we'll see what continues to happen. Tell me a little bit. Let's go back to that section, where you said that you didn't like yourself. So what specifically about yourself, didn't you like? What were you angry at?

Kyle Johnson 15:43

I felt like my body betrayed me. In a way. You know, we've been working out a lot doing the healthy thing. And I always joked that I was probably in the best shape of my life. So now I joke where I'm like, I don't want to be, I'd rather be in the middle most shape of my life, just to deter some of these chances again, because

inadvertently, they found a second malformation when they were doing the surgery.

Kyle Johnson 16:09

So there is a second one in there. But I get MRIs and everything, nothing's going negative so far. So high five on that one. But from not liking myself, it was a piece of anger, that I couldn't believe that I had something like this or that something like this could happen to everybody always thinks that why me? How did this happen?

Kyle Johnson 16:33

And then it became, like a, I think it's people always talk about the 12 steps, right? Like anger, denial, whatever it is, and that I went through the dial, but I went through, you know, researching just tons and tons and tons and my specific piece, there's not a ton out there about it. And then just disbelief, and then the acceptance of just losing that part of me. And that's, I think that's the piece that, like, if I had any advice to anybody, it's just be nice to yourself.

Intro 17:08

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind, like, how long will it take to recover? Will I actually recover? What things should I avoid? In case I make matters worse, and doctors will explain things that obviously, you've never had a stroke before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery.

Intro 17:38

If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery. Head to the website. Now, recoveryafterstroke.com. And download the guide. It's free.

Kyle Johnson 18:11

Because you being mean to yourself and you hating or being angry is not going to

help at all. And I know it's hard to to listen to someone and be like, oh, yeah, that makes sense. I'm just going to wake up tomorrow and snap out of it. But that's the piece like I'm on a couple of groups. And you know, people ask for advice. And I'm always my response is, Well sleep, because you need it. And to be kind to yourself, because if you're not kind to yourself, no one else is going to be. So to me, it was just anger, just like how could I do this to myself?

Bill Gasiamis 18:50

Just going about trying to come to some kind of terms of acceptance. And then you have to ask those crazy questions, which are not really real, you didn't really do anything to yourself, it's just that that's the stage of the process, you got to ask yourself that question and then determine whether or not is it really wasn't really me. And if it was, well, then how do I feel about myself?

Bill Gasiamis 19:18

And then what am I going to do about it? And am I going to do something about it? Or am I just going to dive into the pits of depression? But in your case, it sounds like you went through the process of that they and they helped you get an answer whether you liked it or not. And the answer helps you move forward in to the next stage, you know, beyond denial and anger. You know, it's kind of like grieve the whole grieving process. Did you do the bargaining stage where you were? If I get through this, I'll do this. Did you do any of that?

Kyle Johnson 19:52

I can't even tell you how many times I did that. I think the first one was the worst by far because so our son Ryan I was he had just turned to like, right when my first stroke happened, and I lost my father when I was right around two. So of course, my mind is going absolutely insane. And I, there was a couple things I did in my mind that I think they're insane now, but they helped me at the time. So one was, in my mind, this is really strange. So I apologize to everybody out there.

Kyle Johnson 20:27

But like, I would imagine my brainstem, like a clothesline is real tight, I match my brainstem, and I would literally put stakes around it with caution tape. In my mind, it'd be like, nobody touched this unless you're going to help fix it. And then I would say to myself, three things, get better get home play with Ryan. And obviously, Melissa, my wife who's like, I've already said the best person ever.

Kyle Johnson 20:56

Besides that, you know, being with him. You know, it's understanding I hadn't realize my why really fast of what am I in here for? And what do I need to get out of here for, and that was probably something that I may have done inadvertently, but focusing on why I want to still be here and focusing on why I need to be out so I can be with my family and make sure that they're taken care of and you know, they don't see me with tubes and all the fun stuff inside me.

Bill Gasiamis 21:29

Yeah, you're a really cool, dude, I'll tell you why. Because the symbolism of what you said, about placing stakes around your brainstem and then putting caution tape around that, I'm not sure if you actually realize how much of a positive influence impact that makes, because it's creating neural pathways around protecting self-protection of that zone, and telling your body to be careful with it, that is actually something legitimate that's happening. So when I was waiting to learn how to walk again, I was imagining myself walk again.

Bill Gasiamis 22:09

Exactly the same reason creates a neural pathway, a neural process that is the same as if I was walking, even though I hadn't got back on my feet yet. So that when I got there and started walking, my body was familiar with walking, even though I hadn't physically done it, because it had already created the pathways.

Bill Gasiamis 22:30

So what you're doing is saying, with the rest of your body, you're going, you guys that are handling, you know this part of me my brain, you guys need to take caution there. And you need to not create a negative impact in that space. And I'm not sure if you realize, but that is actually doing a world of good in your space visualization, and having that kind of approach to it. And that kind of care that you're giving yourself in that space in your head is next-level amazing.

Being Able To Walk Again After Multiple Hemorrhagic Stroke

Kyle Johnson 23:10

I appreciate that. Thank you very much night. I didn't know that it was just, I thought it was something weird that I was doing to get through all the

shenanigans that I was going through at the time. If you don't mind me asking you a question. How long did it take you to regain your ability to walk and stuff like that?

Bill Gasiamis 23:28

Within four, four weeks, I was walking again, I wouldn't say I was walking confidently or well, or anything like that. But to anyone who knew me, I was upright, I was walking. As far as they were concerned, the job was done, you know. So but after that what came was the knee, my left knee would collapse on me every so often. And give them multiple times a day. So when I'd be standing still in one spot, it would collapse when I'd be walking or collapse.

Bill Gasiamis 24:01

And that would make me feel like falling over. It was always numb and it still is numb. So when I was getting used to being on that leg again, I wouldn't know where the leg was in the world like in space. And I'd put my foot down without thinking really like my old version. And then I'd be find myself on the ground because my leg hadn't woken up to being on the ground yet my right side had but my left leg didn't know that it was supposed to be in the same situation and it would just collapse.

Bill Gasiamis 24:41

So I didn't feel good about walking probably for many years, although nobody would have been able to tell and what I find myself doing is leaning. I find myself off balance and leaning to the left a fair bit. And as I do it, which is even stranger when people are new Next to me, I find myself walking into their path or pumping into them with a wife.

Bill Gasiamis 25:05

Continuously it gets annoyed at me because stop walking in front of me would ya. So, it took the best of a month for me to walk again. And away from the wheelchair where I said to them, I'm going to walk without the wheelchair today. But then, yeah, there's still rehab, and still outpatient rehab and still training to get it better.

Kyle Johnson 25:33

Yeah, I know I had the same thing. I wobble when I walk. So for you, it was your left side. For me, it was my right side. So during my surgery, my right side

stopped working completely. And they came out and told my wife, my mom and everything, they're like, Well, you know, his right sides not working. And his face is palsy on this side, you know, he's probably going to be in a wheelchair, and he's going to have a feeding tube and all that stuff. And that was like halfway through the surgery.

Kyle Johnson 26:02

And that's what my family got to hear. So coming out of it, like, I guess it was a half hour or an hour, before the end of the surgery, my arm just started doing this. And they're like we're done. So that's when they patched it back up and do exactly what you said, I had to, I think it was four or five different times was restarting with speech. I know I see double vision and my eyes bounce.

Kyle Johnson 26:31

So I haven't seen a static 3d image in like six or seven years. And that exactly like what you said was, so I had a walker, because I lived in the hospital pretty much with rehab speech, OT PT, all that super awesome, great stuff. And I left with the walker. And I remember one day just being like, I'm either gonna build confidence or reliance, there is no in between.

Kyle Johnson 26:54

And to be able to show my son, hey, adults are fallible, I have to correct myself to learn how to talk again, to understand language to understand sounds, and to walk in, it's my fault. Guess what, dude, let's get backed up. Let's go. And that was a really good, I hate to say it. But that was a really good takeaway for him to be able to see people struggle and to understand it's okay.

Kyle Johnson 27:18

And so to your point, it's, it's, people don't know, but But you know, you know that when you're a little wobbly, or, like, my wife knows that she needs to walk on my right side, because I'm gonna bump into her first of all, and then I can't hear out of my left ear anymore. So it's kind of like it, she just holds real tight, you know, and I just bumped into her and walk into a wall or something.

Kyle Johnson 27:41

She's like, You okay, I'm still here. We're good to go. So I fully understand that. And, you know, it goes back to the people that understand it a lot that you've been around, or that we've been around that I probably say thank you too much to

them. Just because what they've done and what they're able to do versus a stranger on the street that they don't know.

Kyle Johnson 28:03

You know, they look at you and they're just like, I'm sure you've heard this a million times. It looks fine. Right? Well, I can always pull the card and like half. So I got that going for me. But yeah, it's That's crazy to think of. And do you ever look back and just thinking in amazement, almost of where you come from, in a way? So my wife makes me do this, she like pulls out her phone.

Kyle Johnson 28:35

And she'll make me watch a video of like me trying to move my hand or something. Or talk skills, look how far you've come? And I'm like, I don't want I don't want to see this. Like, I just don't want you to watch it at the goodness. Do you ever get that sense of wanting to go back and watch or seeing stuff? And you're just like trying to process it again? How do you get through some of those things?

Bill Gasiamis 28:59

So at the at the beginning, it's traumatic. And yeah, I do think back and I don't have a lot of, you know, 10 years ago, there wasn't a lot of reason to. And I didn't know any better to record myself doing any of that stuff. And post it on social media and you know, share an inspiring story, like a lot of people do nowadays, which I think is amazing. So I don't have much to look back at.

Bill Gasiamis 29:24

But we do have a lot of memories, and my wife and my kids remind me sometimes when things come up, but yeah, that gratitude that whole, super grateful for the fact that we've come through an amount of it, and we somehow unskilled pretty much, you know, we were in our 30s But we were very childlike. You know, we had never really faced adversity. We were very naive to the world still.

Bill Gasiamis 29:52

And then we get to the point where we're dealing with this stuff and without having the skills from past experiences, we found the skills and, you know, we we found a way through, we made some good decisions, we made some bad decisions, majority of them were good. And we came out the other side. The thing about going back and reviewing the footage of you talking, or you're in hospital

and all that kind of stuff, it's traumatizing.

Exposure Therapy

Bill Gasiamis 30:22

And I know a lot of people would like to avoid reliving the trauma. But what that is, is there's a psychological process in counseling that people that a counselor will take you through, which is specifically to expose you it's called exposure therapy to expose you to the trauma that you have experienced more than once regularly. And what happens is, then it becomes a memory of the exposure, not of the trauma. So it kind of separates you from the trauma and leaves the trauma in the past.

Bill Gasiamis 30:22

And then you talk about it and remember it from the next stage of the trauma, which is the memory of it. And then every memory that you're going back and remembering is a memory, you're not remembering the trauma. So what it does, it's it's how you heal, and leave trauma behind. And that's why I say counseling, counseling, counseling is the most important thing. It's not the most important thing.

Bill Gasiamis 31:26

They're all the most important thing. But in this context, because what counselling does is expose, it allows you to talk about it regularly, to a point where you eventually I kind of got sick of talking about the bad part of it. And then I kind of made all these came up with all these conclusions and changed my opinion of what his conclusions were at the beginning. I'll never be able to have a good life. I'll never be able to do this all the I'll nevers.

Bill Gasiamis 31:56

And then it was like, what are you doing now with your stroke? I started a podcast oh you started a podcast? Ah, okay, that's it. Tell me about that. And then it's like, would you have ever done that before? And I said, No. Why did you start a podcast about stroke? I don't know, it was about this. And about that. And then you get to this stage where you're doing these things that are because of the experience that you had.

Bill Gasiamis 32:24

And you're trying to reconcile your new identities who the hell am I, you know, why am I doing this? And why did that have to happen for me to do this? And then I started reflecting back on that trauma positively. Because it led to all these other things. All this growth, that's like, shit, that was a really bad experience. But oh, my gosh, look, how much good has come of it?

Kyle Johnson 32:55

Yeah, that's something that my wife, like, I just keep going back to her. Because she's the one I kind of kept me in line, let's be real. And she's probably the most positive person I know. And is exactly right. I mean, you obviously said it way more eloquent than I ever could. But that's exactly right. It's how do we, how do we look at the experience?

Kyle Johnson 33:19

Because like I said earlier, I wouldn't wish this on anybody. But at the end of the day, what positives can we take away from this? What can we share with people so that, you know, I get a lot of questions inadvertently, about the stroke process, or what I went through or even, you know, some of the people I work with, they know that I've had things, and they're asking how they can ask, right?

Kyle Johnson 33:46

And which I think is really cool, that they're at least engaging, and they're trying to understand because, you know, being on this podcast is, I'm an open book, right? You asked me a question, I'm gonna answer it. And they know that about me. And we build those relationships. And it's really awesome for them, to be able to hear the experiences and the things we went through and the things I went through.

Kyle Johnson 34:05

And then be able to say, with somebody else that had something similar or something else that cancer, whatever it may be, how do you approach them without them feeling weird about it, and then trying to engage in how to address the very touchy subjects is really cool. Because then, you know, that makes them feel like they're part of a solution too. And, you know, one of the things that I've taken away is I mean I've always been the best person, let's be real.

It's Okay To Offend People

Kyle Johnson 34:37

So it's one of those things where now it's like, okay, I can help other people learn to have a basic conversation about a human. And that's really, really neat to see is people wanting to understand how to have those conversations without, you know, the word offending or whatever.

Bill Gasiamis 35:07

I think offense is necessary. I think it's okay to offend people. Because I'll tell you why. Because if your intention is not to offend, and you're offended, well, your intentions were really cool. So that's all right, I've got no problem with people coming to me being afraid that they might offend me saying the wrong thing, and me getting offended.

Bill Gasiamis 35:28

Because I know most people actually aren't attacking me specifically, because I've done something wrong to them, or they're coming after me, what they're doing is that they're trying to navigate this situation, and they're learning how to, and they have the unfortunate experience is that every survivor of something is always going to respond differently to every other survivor of something.

Bill Gasiamis 35:52

So they're never going to get it right. And what they have to start with is, just ask a couple of questions, like, is this something you'd like to talk about? And if it's not, that's it, end it there. And if it is, well, what is there something that you prefer we didn't discuss? And that, you know, and then that person might answer? Well, I'll let you know when we get there, if we get there.

Bill Gasiamis 36:14

But what I've found is, although some people are in the, in the denial phase, and they're still not ready to talk about it, really, they're looking for the opportunity to talk about it to the right person in the right context. And, and they are, and they just don't know who that's going to be or who they can open up to.

Bill Gasiamis 36:35

That's why I love counseling, because when you go to counseling, you're paying that person, but also they're creating a space where it's safe for you to be able to

talk about it and express it and perhaps start moving through the stages, so that you can start putting them behind you like, you know, the stages of grief, for example.

Bill Gasiamis 36:54

And denial, and, and anger and frustration and all that stuff. That's kind of what I see, I've had people on this podcast, who hadn't spoken to anyone heard about their stroke for 10 years, and thought that the first person on the planet that they should speak to about it was me.

Bill Gasiamis 37:40

Well, graduations for that.

Bill Gasiamis 37:17

Thank you. But like, I'm not sure why me but whatever, I'll go with it. And then also 10 years, I'm sorry that you had to wait 10 years. But I'm glad you got there. So that's cool. And what they did is they put on a perception to the rest of the world that there was nothing wrong, that everything was okay. And I'm like you I'm an open book, I can't do that. I can't pretend that something's okay.

Bill Gasiamis 37:43

Because you see it all over my face that it's not okay, my behavior, the way I speak and respond and talk. So what I'd rather do is when somebody says, Man, are you alright today, you're not acting yourself, or you're behaving inappropriately, or whatever, I'm like, I'm not alright, today, you know, and thanks for picking me up on it. And I'm sorry, I'm gonna have to apologize for my behavior. And, hopefully, I'll be better tomorrow, but I might not be I might just be the same shit tomorrow that I was today. And I'm not intending on being that way. It just might be that.

Kyle Johnson 38:16

100% I mean, I think it's, I don't know if it's harder to mask it now than it was like, when, you know, when I had a bad day before, it was like, Alright, I can put it behind and whatever it is. Now. The smallest thing can just make me irritated or whatever it may be. And I have these conversations all the time. Like, yeah, I just need a minute, I can't fix it. It's not something I can just snap out of.

Kyle Johnson 38:50

It's something that I have to just deal with. And you know that I appreciate you

bringing it to my attention and I will do my darndest to not continue to have that but because I don't notice it. You know what I mean? Like, that's just the way it is for me at this point. And those people that bring it up, it's like, oh, man, you got a booger in your nose. You got something in your teeth.

Kyle Johnson 39:13

Well, thank you for telling me so I can fix the situation. But for this one I don't know if it's gonna get fixed at its same timely manner as picking something out of my face. So that goes with that gratitude of getting to getting those people on your side that are willing to tell you hey, you're being kind of a jerk, or you're being kind of a deck let's let's fix this. And you're like, Well, I'm gonna do my best, bye. So yeah, those people are super helpful and in your life as well.

Bill Gasiamis 39:44

Yeah, it's a two way street. You know, you got to take responsibility for when you're being an idiot and not blame the stroke. Although it's caused by the stroke. I don't think you need to blame it forever in a day, it's impossible to continuously blame an outsource the responsibility of your behavior on the stroke? It's not it's us. So it's part of us now. And we've got to find the way through. And sometimes there doesn't have to be a way through there just has to be a really good apology.

Kyle Johnson 40:14

Yeah, I mean, I think it's just acknowledging that yeah, guess what? Your right. Perception is reality, and I've been a piece of crap today, I apologize, I will do my best to be better. But I own my actions. And, you know, I'm gonna try, that's all I can say is I'm going to try. And I apologize, I'm not Yoda. Like, it's got to be a try situation.

Bill Gasiamis 40:39

Yeah. And the thing about it is you're gonna you're living with a neurological condition, we do get irritated, a lot easier, light sound, too much sensory overload. And especially if you've got an eye condition like yourself, you've got nystagmus that is going to cause you know, a level of discomfort and irritation to your brain.

Bill Gasiamis 41:02

So you're kind of already irritated without having gone into the public domain yet. And what that's doing is, it seems like you're short fused, or whatever, and it's

getting you over a small kind of get you over the line quickly. But it's like, no, I've already had my irritations already today, like as many as I can handle.

Bill Gasiamis 41:25

And this was the straw that broke the camel's back, for example. And it's like, okay, I know you don't get that because there's no way you can get it. Because you have to be like me, and I don't want you to be like me. But what I'm saying to you is just, you know, this is it, we're different people, we appear the same, but we are very, very different people.

Kyle Johnson 41:47

I had a co-worker at one point that, you know, he broke his foot. And whenever anything happened, he's like, Ah, he'd get really frustrated really quick. And this is after my, everything happened. And he looked at me, and he's like, I never even thought about, like how all because like, I used to have really bad headaches all the time. And you know, just trying to push through some stuff.

Kyle Johnson 42:13

And you know, he would bump his toe on something he's really frustrated. And one day, he did it. And I was just looking at him. And he's like, I never even think about how you deal with stuff. I can't imagine having, what you all have, what you're dealing with all the time and then having an injury. I was like, well, it takes it up a lot. Like when you get hurt, or like you said anything, unfortunately, can become a trigger.

Kyle Johnson 42:41

It's just how do you identify that and then try to mitigate it the best you possibly can to where, you know, people around me know, like, Hey, I just need a minute, I just need to go away and lay down for a minute in a calm, dark place and just get myself back.

Kyle Johnson 43:01

And, it's that whole piece of like, I appreciate you people for understanding that this is going to happen, and it's not a might, it is going to happen at some point in time. And if it does, I apologize. And I'll apologize after too. So yeah, it's it's been a trip to say the least.

Self-Awareness After Multiple Hemorrhagic Strokes

Bill Gasiamis 43:24

Yeah, you know, but what's been good about it, it sounds like to me, it sounds like that what's good about it is you've become more self-aware. Your sounds like your self-awareness has just gone through the roof. And that can be positive. That's only a positive surely.

Kyle Johnson 43:42

Before, people that are gonna watch this and know me, you know, I was, I apologize to all you out there that do know me ahead of this. And would agree with me on this when I was probably I knew myself very well, I was very confident in who I was as a person. Let's be real, maybe a little overconfident and looking at everybody else out there.

Kyle Johnson 44:04

And what this has done is had to teach me to look inside more and really understand what I'm putting out is what I deserve back. And that's a weird way to put it. But to your point, you do become more self aware to a certain extent because I know when I'm walking down a hallway or a street or something with my wife or my son that if I am wobbling, where my gait my walk is off.

Kyle Johnson 44:33

I know people are gonna watch me, right. So you become that self aware of like, what am I doing? How am I acting? Are people gonna think I'm weird? You know, whatever it may be. Or, you know, a lot of myself comes from humor, because as we all know, that's the best way to deal with bad tragedies. So plenty of conversations with my wife and like, that wasn't quite where it needed to go with the conversation, with dark humor.

Kyle Johnson 45:04

So it's having to understand and get repeatedly corrected, to truly understand yourself a little bit more, that's what I found for me is that I'd say these things, and I'd be corrected. And that would become something I'd be more mindful of. And I've had to build my own filters instead of naturally having them. Which is probably bad for me in the long run. Let's be real. Because I'm not sure my filter

system was great to start with.

Bill Gasiamis 45:32

Yeah, it sounds like it's you by design this time instead of you by default?

Kyle Johnson 45:37

Absolutely. That's a really fantastic way to put it actually. Before it was, you know, like, everybody could blame it on whatever you could say, like, I grew up that way. I'm just blunt, or whatever it is. Now it's, it's understanding that I need to understand what's coming out my mouth, because I expect that to come back in a certain way. So it's been a lot of learnings.

Kyle Johnson 46:04

And you are absolutely correct, that you become decided, I think it sounds like you did to becoming more self aware of what you're saying what you're physically doing, you know, all that kind of stuff. So it's been a great learning experience.

Kyle Johnson 46:21

Probably getting on with it, at some point, let's be real at the end of the day. But still, you know, it's been interesting to have to relearn all those different types of things of who you are as well. And maybe things that you didn't want to acknowledge about yourself as well.

Bill Gasiamis 46:42

You got no choice now.

Kyle Johnson 46:44

Exactly.

Bill Gasiamis 46:46

One thing about humor that I like about humor is if it triggers you, it's worth exploring it, you know, that whole situation, dark humor, whatever. And I follow, obviously, a lot of stroke survivors. And one person commented about a show that they were at. And it was a comedy show, and the comedian made a joke about stroke.

Bill Gasiamis 47:11

And the response on that person's social media profile was, you know, I went and saw this comedian, and he made a joke about stroke, stroke is no joke, you know,

he's an absolute disgrace, and all that kind of stuff. And that person got really offended that there was somebody on the other side of it, who made a joke about stroke. Now, I would have loved to have heard the joke about stroke, I reckon I would have found it funny and laughed.

Bill Gasiamis 47:38

But some people aren't in that stage, where they're able to have a laugh at themselves, or about their stroke, or whatever, and, are focusing on the negatives instead of the positives more often than not, and it is really serious. There's no doubt about it. It's really serious.

Bill Gasiamis 47:56

And so what I mean, the fact that it's really serious, and it's really hard, and it's really terrible, and all that kind of shit. So what, like, and what are we going to do? Like, just get depressed because it is really serious? We may as well have a laugh about it, because it's serious. To kind of turn it on its head and say, as serious as you think you are stroke? No, I'm gonna have a laugh about it.

Kyle Johnson 48:22

You got to own it. And like, I've actually a lot of people I know, like I make on it, maybe inappropriately, but I make jokes, a lot of like, hey, the strip stuff, and I've had people come up to me and be like, Hey, man, you shouldn't talk like that. And I'm like, yo, I'm owning this one that I'm allowed to, to joke and laugh. Because if I don't, other things are gonna come out that are gonna be worse.

Kyle Johnson 48:49

So I'm all for, you know, people that are able to bring a humor aside to the situation because as you said, it's a shit situation. But to at least have something unique come out of it, even if it's a joke, or even a bad one, whatever. But I just don't want to understand the whole I like, okay, maybe when a third half that I'd be a little bit pissy, but I wouldn't, you know, raise about it. It's more of a, you know, now, I used to joke with my friends all the time.

Kyle Johnson 49:25

Like, oh, I remember when I was younger, this is actual saying I used to say was, you know, I hope I brought my helmet because my head my brain might explode. And then it did. And so, so now, it's not like the funniest joke anymore, because it was a reality thing, but I still say it. Or, you know, I don't know.

Kyle Johnson 49:45

It's just one of those things where if you can't laugh at yourself and the things that are going on around you, then I think you kind of needs to reevaluate, because one, you're still here. And that is huge. Right? You may have deficits you may have whatever it is, but at the end of the day, just, we gotta be happy with it. And some things might offend you, I get it. But at the same time, it's a joke. That's a whole other comedy conversation, I guess.

Stroke Humor

Bill Gasiamis 50:16

It's a huge conversation, but it's a really important one. I'm not particularly qualified to have it. But I know just from my perspective, the thing about it is, with my mates, I was kind of the clumsy kind of guy. And I end up finding myself falling over often. And, of course, they would laugh at me.

Bill Gasiamis 50:45

And just because I had a brain surgery, and had to learn how to walk again, if they were with me in my house, when I fell over, they would laugh at me. Just because it was as a result of the the stroke or my clumsiness. I would like to think that, even though it hurt, and I got injured, you know, bruised, battered, like not kind of broken or anything. I would like to think that they would still laugh at me.

Kyle Johnson 51:18

Yeah, it's not malicious.

Bill Gasiamis 51:21

It's their instincts. It's their response.

Kyle Johnson 51:24

People falling, it's funny. I'm sorry, it is. I mean so I have a pair of pants that I will never get rid of, that are like these. It's like a weird, almost like a jogger material. Not like a fleece or something like really slick almost. And I remember one day after PT, I was sleeping and my father in law was at the house. And I was wearing these pants, and I want to get up, and I swung my leg over the bed.

Kyle Johnson 51:54

And I slid off the bed, and straight into the nightstand and hit my head. It was the

first time I'd fallen since I got out of the hospital. And he here's a huge dud, because, you know, I'm an adult male, and I'm laying on the floor, and you might as well just paint a chalk outline around me. And he's like, Dude, are you okay? And I was like, I had no idea what just happened.

Kyle Johnson 52:19

And I was like, I seriously think my pants just slipped me out of bed. And we just started laughing, because what are you going to do? And then I told my PT, my physical therapist, that I fell in what happened? Because she was like, you know, as you know, they ask you all the time, like, and he falls in a whatever. And I was like, Yeah, I fell out of bed. And we kind of go over sort of laughing. She's like, How in the hell do you fall out of bed like that? I was like, I don't know.

Kyle Johnson 52:47

But I'm never wearing these pants again. I'm like, 1% sure they're haunted. And it was a joke. It just turned into something that became relatable to her too. And that's, that's the piece that I think a lot of these people don't understand is these jokes come from a place to where I know that unit makes me feel more normal.

Kyle Johnson 53:09

Because when they're making fun of everything else, but I'm the one left out group, like Yeah, no, I, I want to be brought into the fold. I made dumb decisions, and I did dumb stuff. Yeah. So I don't know, I think it's a way to, to relate to a person and in order to make people feel more comfortable and to be involved, you know, to acknowledge that that actually happened.

Kyle Johnson 53:40

And there's a comedian. He has cerebral palsy, I think it is. And he talks about how he's disabled. And my gosh, I think it was like America's Got Talent or something. He was talking to Simon he's like, we're the only minority group that you can join at any point in time. You're just one bad bicycle ride away from joining our side. And when I heard that, I just started laughing they know people that got mad at the joke and I'm like, one ah, nope, you cannot say that like, Are you kidding?

Kyle Johnson 54:15

I guess but like you can't be offended by something that literally has no impact on you at all. besides making you laugh on the inside because you know that was

funny. And that's the case it's you know, it's the people that want to protect you are protect others from that kind of stuff, but at the same time, like, I don't need protection. I know what salami I know what I find funny, I don't like it. I'm gonna turn off. And I maybe this is that dark humor, please.

Bill Gasiamis 54:45

I love it. I love it. Because you just reminded me of a comedian that we used to have here. He was popular in the 90s his an Australian guy his real name was Christopher Widows and his stage name is Steady Eddie. And he has cerebral palsy.

Bill Gasiamis 55:06

Okay, and the guy's not steady. It's, a sick aussie humor thing that we do when somebody is short we call them stretch or tall when somebody is tall we call them small. So Steady Eddie was on stage breaking down those types of barriers in the 90s. And he was just tape hanging it on himself the entire time, he was talking about things like dating about driving about public transport, you name it, he was talking about everything. And we, because we didn't, because I was a lot younger in the 90s.

Bill Gasiamis 55:42

And I didn't have a filter of how people might get hurt or offended or whatever. I just took this guy, at his word, whatever he told me coming from his perspective of the world. To me, it was absolutely hilarious. And I know, some people might have got upset with him or whatever. But I thought he was amazing. And he was the only disabled person, whether they were on TV or movies or wherever that I had ever seen.

Bill Gasiamis 56:11

Being himself on stage in front of sold-out crowd saw that shows. So it's like, how can we take that away from this guy? How can we decide what is or isn't funny? And how can we not allow him to express himself in a way that helps him get through all the stuff that he's got to get through? Every single day of his entire life from the day he was born.

Bill Gasiamis 56:38

He's had to break down so many barriers to overcome the condition his you know, his his upbringing sounds like it was amazing. But his physical abilities were not

even with the majority of the people. So he had to work harder, much, much harder to get to that point where he was actually being his authentic self and living his life.

Bill Gasiamis 57:04

So I'm not going to take away his dark, sick jokes about cerebral palsy, not in a million years. I love that. So that's kind of the way I see it, you know, I think everything is potentially open for a little bit of, like, everything's open for criticism. Everything's open for comedy, I think.

Kyle Johnson - Life Before The Stroke

Bill Gasiamis 57:31

It's lovely to have a conversation with you, and go so deeply into the conversation. I love it. So just to move along a little bit, because I want to get to know a bit about you. What were you doing before all of this stuff? And how are you going about life under "normal" conditions?

Kyle Johnson 57:51

It was, you know, I picturesque would be a good word for it. You know, my wife and I, we've been together since high school type of situation. And we had moved out to Minnesota for work. And we were there for a couple of years. And the company, we both worked for the same company. And they went through some layoffs. So I was part of it, went to another company, and just things were not going well with the company itself.

Kyle Johnson 58:27

So I voluntarily left I was doing my own thing. And we're working out we're doing the right stuff for our bodies, and we're just being 30 year olds, you know, we had a kid and we were trying to raise on the best serve ability. And, you know, to your point, we had a few things that had gone wrong in our lives that we both struggled with at one point.

Kyle Johnson 58:47

But, you know, it wasn't like anything absolutely insane, you know, that we'd had to deal with. And, you know, when all this started happening was really, I look back at it, I'm like, I also see that, like, my wife had to go to Portland or something for work.

Kyle Johnson 59:09

So I was home alone with our son. And we're working out a lot, like I said, and we are on our D load week where we lower weights just to do that kind of stuff. And I remember, you know, used to throw in the air like every dad loves to do is throw their kid and make their wife freak out. So I was doing that and I realized I couldn't get my hands up. And I just like, Well, I gotta tensioner my back. I don't know, whatever because nothing else is really wrong.

Kyle Johnson 59:37

And then she left and you know, just kind of perpetuated and then which just kind of continued on. And I remember waking up that Monday to take him to school. And I could only see like, you know, 20 feet in front of me without it being crossed and I was like us. It's weird. I must have just slept wrong. I don't know. So I took him to school came back and you know, or daycare or whatever it was that I picked up later.

Kyle Johnson 1:00:10

And the next day it was like I could only see like, two feet or three feet. I'm like, What is going on? And I thought I literally put an eyepatch on from his Halloween collection, and Joven School. And on the way back, I called my wife and I was like, Hey, I'm not feeling real good. You know, I feel like my face is numb. noises are freaking me out. Like, I can't hear bass. Like it just couldn't understand certain things.

Kyle Johnson 1:00:36

So she called, her company had a nurse line. And they're like, hey, the things you described haven't call us right now. So she called me back. And she's like, Hey, they want you to call her I was like, Come on, man. So I pulled into the gas station, still got my patch on. I'm pumping gas, and I'm talking to the lady, I'm starting to slur. And it was one of those things where she's like, get off the phone. Get to the hospital right now. And I was like, whatever, I'm home alone, who's gonna feed the dogs, right.

Kyle Johnson 1:01:09

So for this, let me guess, go home, feed the dogs. And at that point, I realized that like it couldn't really see very well. And my right side was doing not like it was just a lot of things just like something might be wrong. So luckily, there there was not that far from where we lived at the time. And I remember parking, stumbling

into the hospital. And then like falling in the admissions chair.

Kyle Johnson 1:01:41

And lady just looked at me and I couldn't understand her. I couldn't do anything. She was looking at me. She's like, we're going back when I got a wheelchair that didn't MRI. And by the time I came out of the MRI couldn't talk, couldn't see nothing. But my wife knew that I was going to hospital. So I just handed the doctor my phone. And she called my wife.

Kyle Johnson 1:02:05

My wife is expecting me on the other end. And so Doctor being like, well, he doesn't have anything, but he's having a stroke right now. And he's bleeding in his brain, and we don't know what's gonna happen and all this stuff. So that was interesting, you know, kind of knocked it out for a while. We were just kids. I know, this is weird to say but like going to concerts going to plays doing normal family stuff. And now it's been a challenge.

Kyle Johnson 1:02:39

You know, we used to love going to, like Minnesota future concerts for music and stuff like that. And we've tried to go to concerts all the time. And now like, I have to wear headphones. If it's too loud, like, you know, I'm an old person. I'm like, God, it's too loud. I can't do this. So it's the overload. You know, I don't like being around a ton of people around me all the time. It's just, you know, little things you learn. And now I work from home. So this is literally my office in my bedroom. So this works out perfect for me.

The Perpetual Pirate

Bill Gasiamis 1:03:17

Yeah, I hear you. Perpetual Pirate is your Instagram name. And can you tell us why you're the Perpetual Pirate? Because for people that are watching on YouTube, they're listening to this. Why are you the perpetual pirate?

Kyle Johnson 1:03:39

when I first started my Instagram account, it was no I like everyone. It was just like, whatever type of social media account and after my first stroke, I love cars. I mean, you probably seen some of them. I love cars. I love Chinese. I took a little hiatus this driving was a little bit challenging to get back to but I loved it. And

when my when my I refused to turn back to being normal.

Kyle Johnson 1:04:10

I wear an eyepatch everywhere I drive. And I was like, You know what, I'm gonna own this. This is me. I am the perpetual pirate. I'm never getting rid of this eyepatch. I'm in this forever as they would say on the Instagram taglines and reels and all that stuff. And it just is something I got to own right.

Kyle Johnson 1:04:31

You own what's happening around you. And that's one of those things where I'm taking it back. It's mine. I'm owning it and if somebody asks, absolutely, let's talk about it. So gives you Yeah, exactly. I'm not gonna let it on me. I'm voting on it. It may take me down at some point but the whole time I'm gonna fight. So yeah, that's just where it comes from. It's just more of a little poke at it.

Bill Gasiamis 1:05:00

A lot of people struggle when they look in the mirror and see the way that their face has changed. And I'm looking at the photo on your Instagram, the profile photo, it's you and your wife and your baby. Yep. And, you know, there's an obvious change between that photo and now. Yeah, how did you come to terms with that? Have you come to terms with it? What's it like when you look in the mirror?

Kyle Johnson 1:05:32

I hate it. So, I mean, just to boil it down to that I absolutely hate looking at the mirror, still, I mean, I've gotten past all the anger and all the jazz but at the same time. So like, even at work, right? Like, I have my reading glasses that are reflective. So that way, when I put them on, you can only see the screen through my eyes. So people don't really tell them eyes are weird, or differ, I should say.

Kyle Johnson 1:06:05

So I am not a superfan looking at myself in the mirror. Although, you know, I tell my wife that, you know, she's got a good blessing, because half my face is going to be wrinkle free when we're like 80. So I'm going to be looking like a new baby, right? The at the end of the day, I don't like looking at my face.

Kyle Johnson 1:06:24

And people are like, Oh, I don't understand why I'm like, Well, it's hard to explain. I know what I know what I want to look like, I know what I used to look like, but

it's never coming back. So, you know, as long as my teeth are clean, and my nose is clean, you know? And was once in a while I don't know. It's just not something I walk into the mirror I'm like, aroused you this type of situation.

Kyle Johnson 1:06:51

So I'd say that's probably one of the biggest lingering effects is, you know, I would say my eyeline tends to naturally just go down when I'm in front of the mirror versus looking straight at myself. That's a really good question, actually. Because you're absolutely right, there are certain things that I keep that photo, and actually it's right back here, right there.

Kyle Johnson 1:07:20

And that's one of my favorite photos. That was when we were working out a lot. We just had Ryan, things are going well. And then you know, 18 months later, whatever it was, just kind of took it out. So that's one of my favorite family photos of that is when I can look back at it and be like, I love that time period. Just sort of one, you know, you're in shape. You know, just happy memories from that point.

Bill Gasiamis 1:07:53

Oblivious to the real world, aren't you? You're still kind of really oblivious all the problems that you're living with, you probably created in your own head up until they actually occurred. And then it's like, okay, these are a completely different set of problems that I'm not prepared for.

Bill Gasiamis 1:08:09

And I didn't know, were part of my life. For sure. So do you feel like there will be a time where you'll have fond memories, just like the ones that you describe from that time? Do you feel like you've made some of those now, in this new stage?

Kyle Johnson 1:08:31

Oh, absolutely. I mean, you've probably experienced this and if you haven't, please tell me you haven't. But there has been muster with this part. And then it kind of leads into it, which there's been a shift in relationships, from friends, family, whatever it is to what it was, to what it is now. You know, the people that if somebody is watching this, you're going to watch it, I apologize if this hurts your feelings, but at the same time, it is what it is, right?

Kyle Johnson 1:09:03

Where it's, you know, the people that are like, Oh, I can be there, whatever you

need help with, just let me know. And then you ask them, and they're just like, Oh, I'm cleaning my eyebrows, that day, like, cool. So that piece is something to kind of think about as the relationship pieces that are moving forward to where those are the happy memories that are focused on right is meeting the new people that I become friendly with.

Kyle Johnson 1:09:29

And, you know, I can be myself at this stage, where it's not they remember me from what I was, and all the things I was able to do and I could do at that point in time. But these are people that know me now. These are people that understand what I'm capable of now and appreciate that. And those are the memories that I remember of joking around and having a great time and watching our kids play and all the little things that you would do normally.

Kyle Johnson 1:09:58

But they only know me as this sort of allows them to not have those biases, preconceived notions of like Kyle used to be able to do that, or he used to maybe say this instead. But now they know me as this. And that's how I'm accepted as this. And that. That is those that that's the building blocks of the memories for me is knowing that people that accept me for who I am, and will actually be there and have fun.

Kyle Johnson 1:10:29

Like you said earlier, I have plenty of people that we took around all the time, about my face not working or my eyes being silly, or whatever it may be, because it's funny. And a lot of young people I do guess wouldn't necessarily have those kind of jokes, or the people that knew me at this stage, fair game man.

Kyle Johnson 1:10:51

And it's okay. So lucky looking back, it's looking at those memories that mean more to me, than a lot of the older ones that people I don't talk to anymore, or relationships that may not be there anymore, either. So, like you said, it's almost like remembering the memories to overtake the old ones, in a way.

Falling Out?

Bill Gasiamis 1:11:19

So you know, the previous people who were kind of in your life, and now they're

out, for whatever reason, you think about it, like they've gone through a trauma too, they've gone through the trauma of seeing their friend, who was well looked like this, who was unwell, looks like that. And they're grappling with their own mortality because of your potential mortality.

Bill Gasiamis 1:11:41

And they're grappling with the identities change that they've had, just by seeing that how your identity has shifted, they used to relate to you in this way, and they don't know or they're not capable of expanding the way that they relate to people beyond say, going to the football or going to the pub, or whatever it was. And then it's like, what do I do now? And yeah, I want to help the guy because he's a great guy and he's worth helping.

Bill Gasiamis 1:12:09

But when he asks, I hope he never asks, because when he asks, that's going to be a really difficult time for me, because I'm not going to feel comfortable being there, because I'm not well enough, or I'm not strong enough, or I don't have the capacity to support him emotionally, or in these other ways. Yeah I can lift a box and move it and I can push it, you know, push a chair or, you know, pick up a bed and relocate it or whatever.

Bill Gasiamis 1:12:38

But I don't have the emotional capacity to be around that guy. Because he's evolved. And I'm not evolved to that extent yet. I'm still the guy who's appears like an adult, appears like, he has some life experience, but really is 35 36 37 and hasn't really had any life experience because everything's been picture perfect so far.

Bill Gasiamis 1:13:05

And they've only ever lived with the perception of problems that they created in their head, because they didn't have any problems. And they probably felt left out and they thought they should have some. So they went about creating some. Do you know what I mean?

Kyle Johnson 1:13:17

100% And I think that's the other piece that comes with all this learning is that one of the things I've had to do, and I did this a lot when all this stuff first happened. And it took me a little bit to realize I was being a total dick while doing

it, which is comparative, or be comparing.

Kyle Johnson 1:13:41

Because at the end of the day, the stuff I went through sucks. And you know, I think for you, me and people that have gone through this, it's easy to do that one up, or you're like, Well, you had what I had for, but I don't know what to tell you. I got to tell you, though, to where it's like I had to learn and understand that. That what people are going through that is their own stuff.

Kyle Johnson 1:14:06

And that may be the worst thing that's happened to them. And you know what, I'm happy that that is the worst thing that has happened to them. And that is what's thrown you through a loop is you stepped on a Lego, and you think you're dying, man, express yourself, do what you need to do. I'm not comparing anymore. I'm not. I mean, yes, do I get judgy let's be real, I'm human.

Kyle Johnson 1:14:32

But at the end of the day, it's your experiences and what you're going through on your own and I wish you the absolute best getting through it. And you know, being that I have gone through some of these things. If you need help, let me know I don't know what I can't lift boxes for you or move the bed.

Kyle Johnson 1:14:53

But I could help you do something else maybe. So, yeah, it's that honest In case of like, yeah, I may have gone through some shit. But whatever you're going through is most important to you. And I have to I don't have the words appreciate, but understand it, I guess be the the bit, the better word for it is at least understand that what you're going through means more to you than what might mean to somebody else.

Bill Gasiamis 1:15:24

Yeah, absolutely. That's a really wise way to say it. Because what that does is it doesn't make hopefully, the other person feel guilty. And you're not doing that what you're doing this guy, Hey, you do you all do me. And if if we come to cross paths, again, we cross paths again, and we'll work it out. Then I had a friend of mine who I was really tight with for many years.

Bill Gasiamis 1:15:48

And then when he got married, you know, and I was married, you know, we kind

of continued on and we did all that stuff. And then, and then he got divorced. And then we never heard from him again. And we didn't hear from him again for a long time.

Bill Gasiamis 1:16:03

And I hear that a lot because people don't know how to relate to you without their partner at a family gathering or a function or whatever. And it's like, okay, I appreciate that to an extent. And then he found out that I was unwell. But he still didn't make it contact, they still didn't reach out or anything like that. And then we ran into each other at a local venue one time.

Bill Gasiamis 1:16:30

And then he said to me, man, I'm sorry, I haven't called and all that kind of stuff. And I'm like, Whatever, man, you need to apologize for it, you know, I know you're really unwell and sick it's all good. Don't worry about it, you know, no big deal. And then, to me, it just felt like, even if we kind of rekindled our friendship or tried to do something for him, it still would have been uncomfortable and bad.

Bill Gasiamis 1:16:56

And I think it's nicer to just let him go. So that he's not perpetually feeling uncomfortable and bad about what he has or hasn't done or how he has or hasn't behaved. I forgive you, I don't really mind I'm not holding a grudge, but also don't have the desire to hang around and be with you while you're going through that phase.

Bill Gasiamis 1:17:18

Because I'm done with that phase. Like, I don't have that. So I'll just do may you could do to you. And I'll always say hello to you if I sit on the street and chat to you and find out how you're going and all that sort of stuff. But I just don't really feel like we're at the same place to hang out together and spend time. So it's all good.

Kyle Johnson 1:17:38

But you know what, that's okay. And the people that say it's not have never had a falling out, let's be real. I mean, you hear these things all the time, like, oh, we just grew apart or whatever it is, yeah, people grow apart, it just happens to be that you and I had something that snapped us apart. And it that's just the way the world works. And you're absolutely right, to the point where now, this is me being

selfish, and I'll admit this all day long. But I don't have or want to have the energy to put forth on something like that.

Kyle Johnson 1:18:21

Like my wife and I are the same. Like, it's something I don't want to see we make snap judgments. But we evaluate situation and we're like, you know what, I do not have the emotional capacity to deal with whatever you are going through, I apologize, I will be here on whatever you need. But at the same time, you know, I had to own my own shit. Like, let's step in. And if we need to get through it, let's get through it. But at the same time, like, I just don't have the emotional capacity I used to have to spend on that.

Kyle Johnson 1:18:59

And like, to me, it's, I deeply apologize, and I'll be there to help you. But at the same time, I want to go hang out with my son, I want to go take him somewhere do mini golf or play video games or something. And, you know, no offense, but I want to do that. I mean, I'd love to help you but at the same time, jog on. And that's harsh. And I get it. That's also me being so selfish, to protect my own self from getting wrapped up there involved in the next level, whatever.

Kyle Johnson 1:18:59

Yeah, and you're prioritizing your time, which is amazing, because we don't do that right? We often don't do that. And now you're going hang on a sec. Let me say what I value more I value that more, that's going to bring me more joy, more happiness, it's going to be better for my long term, well being it's going to do better for what I'm trying to put out in the world or how I'm trying to raise my son, all that kind of stuff.

Bill Gasiamis 1:19:54

And it's like, Well, okay, I know what my values are. That's where I need to put my energy because that's Ultimately, why I was put on the planet why I decided to have kids. The rest of it is up to you to your journey, you work that out. And you will, you'll get through, you'll find a way. There's no doubt about if you keep searching for answers, you'll get answers. If you keep looking for problems, you'll get problems. So it's so good.

Kyle Johnson 1:20:20

Yeah, I mean, I apologize. I don't remember his name. But one of the what are

your other podcasts, there's a guy that started with he loves the American saying, if you're an asshole, you're gonna keep finding problems, or something like that. And I love that line. Because it's so true. And you can extrapolate it to so many different types of scenarios, where, you know, it's cliché, like, oh, put the positive out in the world, and, you know, you can manifest that's it, well, I can't manifest a brainstem.

Kyle Johnson 1:20:55

I can want to do all these things, and put all these positives in the world. But at the end of the day, my actions have consequences and my actions that I get to send with my son, and I get to teach him to be the right person, or perceivably, the right person, or you know, all those different things is, you know, communication is key, as long as it leads to action, as far as I'm concerned, because we could talk about all this stuff all day long.

Kyle Johnson 1:21:20

But if you don't go out in the world, and make it a better place on your own, or if you don't do all these things on your own. Again, what are you doing man? Let's step it and let's do this, and you're doing a podcast where people can truly understand and express and you give them the platform to do these things.

Kyle Johnson 1:21:36

And have people listen, and maybe learn a little bit about what you've gone through from a caretaker perspective, or, you know, from an actual survivor, whatever it may be, I think that's an absolutely beautiful thing to do. And it sheds light on something where, you know, not every stroke survivor is 65 or 70. You know, it's, it can happen to anybody.

Bill Gasiamis 1:22:04

And 70-year-olds are going through the same thing we're going through and the 83-year-olds, they're all going through the same thing. The guy who you mentioned was Rodrigo Sanmar. He's a Mexican film maker. And he was episode 207. And he was such a cool dude to speak to. And if anyone is curious about that line, what it is, as soon as you go and listen to the podcast, it's literally the first minute I've clipped it and put it at the beginning.

Bill Gasiamis 1:22:36

Because it's such a good line. And yeah, it's true, that's kind of you get what you

focus on is basically what he's saying. But he has a beautiful way of expressing that I had a really good time chatting with Rodrigo. And he's like you, he's physically and spiritually, spiritually and emotionally altered from this, and he is making the best of it. And he's doing amazing things in Mexico, as well as filming, doing, you know, documentaries, and all the stuff that he used to do.

Bill Gasiamis 1:23:09

He's also building some amazing, sustainable home and all this kind of stuff in a really economical, very eco friendly, and it's like, wow, you go man. And all this sort of started after the stroke for him. And it's like, what an amazing thing. I'm not sure I didn't ask you if it would have been the case anyway. But it seems to be his new passion project. You know, he's going all out trying to get this thing off the ground.

Bill Gasiamis 1:23:37

And I think they're going to be building hundreds of homes for people with this different idea. So, yeah, that's Rodrigo. I've really enjoyed chatting with you, man. I like your philosophy. I love the way you're going about your recovery. And I really appreciate you reaching out and connecting with me and asking to be on the podcast. I love it when people contact me to be on the show. It makes me feel like it's better than dragging people along to the show. You know what I mean?

Kyle Johnson 1:24:09

No, absolutely. And that's why I said earlier, just like I really appreciate the platform to allow people to do this and allow people to express different facets that I think you said earlier, if you haven't gone through this, the thought process of the random things don't come into play with the normal person. The normie as you know, cool kids these days a Handi capable.

Kyle Johnson 1:24:37

But you know, I think that you doing this alone and allowing people to express themselves, which is hard. Let's be real. It's not easy to come out here and to share your story all the time. But it is wonderful for people to hear the emotion that comes out of it in my story is not the same as anybody else's. But I'm not saying it's worse. I'm not saying it's better. It's just an experience of the human collective that people need to hear, or if they want to totally up to them. So yeah, no, I appreciate you having me on. And I appreciate the time very much.

The Recovery After Stroke Podcast

Bill Gasiamis 1:25:18

You're welcome. And that thing about the podcast is I've done it for my family to hear. They don't listen. But I've done it. Because what I'm thinking is, if they choose to listen, instead of me telling them, which is something I used to do a lot. They can come themselves, instead of taking the merhaba to the mountain, or what is it moving mountain or something like that.

Bill Gasiamis 1:25:19

There's a saying there about, you know, like, not pushing it onto people. It's just about creating the space for it. And then if people want to come, they'll come when they're ready, you know, and I'm really good with that. Really good with that. I have no problem with that plenty of people are coming, you know, this month, we're on track to get 6000 downloads of the podcast.

Bill Gasiamis 1:26:07

Oh, wow. Yeah, that's never happened before. So I'm pretty excited that we're going to probably crack the 6000 downloads for the podcast, which means that, perhaps is not 6000 people listening simultaneously. But there's more than 210 episodes now. And then there's a whole bunch of content that I can go to. So wherever stroke survivors are in their journey, wherever they are on their journey, they'll be able to relate to different people throughout the podcast, I want to make it the biggest podcast for the number of stroke survivors that have been interviewed in one place ever.

Bill Gasiamis 1:26:51

That's kind of my goal now. So there is, unfortunately, too many of us, or one in four people are going to have a stroke in their lifetime. And if you think about the size of the population of the planet, where there's something like 7 billion of us, that's more than a billion people, at least, are going to have, you know, nearly 2 billion people are going to have a stroke in their lifetime.

Bill Gasiamis 1:27:17

So and when I was going through this, there was nothing, I couldn't go anywhere to get information, there was some amazing communities locally that were doing good things, but there wasn't enough the way that I like to consume. You know, this type of content about stroke, it was, this to me can be very passive. Because if

I'm, if I'm driving up on an episode on or if I'm in the train, I can put an episode on.

Bill Gasiamis 1:27:44

And I can just pull on on in the background, if nobody's home, and I'm not bothering anybody, I can just listen. So that's kind of the beauty of it, you know, it can be real passive. And how lucky am I to speak to 210 or more stroke survivors, and tell me their version of it just so I can become better about myself and feel better about myself at the same time? I mean, it's such a gift and a blessing and everything either way, you know, and I know it goes both ways, everyone thanks me.

Bill Gasiamis 1:28:16

And it's like, you're the same, like, I feel the same for you. This just may as well have been the first episode, it doesn't make a difference to me, it's so amazing. I don't know how much you have to talk about your stroke. But I haven't got enough about it yet. I'm turning 10 episodes in and I still haven't stopped speaking about it, I still feel the need to continue speaking about it.

Bill Gasiamis 1:28:39

So this is more of a gift because of the other people that are helping me. So that's not more of a gift. It's just as much of a gift to me, you know. So thank you, and be well and have an amazing recovery. And enjoy the rest of, you know, the next chapter of your life.

Kyle Johnson 1:29:04

I appreciate that. And anybody who's listening out there is more than welcome to reach out to the person around them and make sure that they're doing okay, I think that's one of the pieces we talked about earlier is just making sure that you know the person next to you. So if anything does come up, you can make that decision, that quick decision that could possibly save a life.

Kyle Johnson 1:29:27

Because that's where it all just starts is having those human contexts where you know each other well enough to understand something's right or wrong. So no, I appreciate it. Thank you very much. And, you know, have a wonderful night and obviously, I'll be listening to the next ones, the next one after that. So thank you very much.

Bill Gasiamis 1:29:47

Thanks for being on the podcast. That's a wrap. What a cool chat man oh my God.

Kyle Johnson 1:29:54

I appreciate it.

Bill Gasiamis 1:29:55

What a really cool deep chat. I really appreciate it too. Thanks for watching. Hang on, it's just a lot of fun being here all the way in Australia and having a chat to somebody from the other side of the planet who I felt like I've known for ages. Who I've just met and know nothing else about, you know, it's unreal.

Kyle Johnson 1:30:15

Yeah, no, I said before I said on that is like, I know, it's not just me, I know, you're getting stuff out of it, too. But at the same time, you know, I think that I've been able to talk about it. And maybe express on like, little micro doses here and there. And recently, at that the company I work at, I did like a whole presentation to like 60 or 70 people about, it wasn't necessarily directly about me, but it was about my experiences and how it can be translated to what we talked about the very end is knowing the people around you.

Kyle Johnson 1:31:03

And knowing if something is wrong, you can make that quick decision. And it's just awesome to be able to, like you said, have these conversations to people around the world at this point in time. And it's beautiful to have these shared experiences or shitty experiences. Don't get me wrong, but to have that network of shared experiences is a beautiful thing.

Kyle Johnson 1:31:29

And I agree with you. There is not a lot out there for us to research. There's not a lot out there to listen to. I mean, there's people on Instagram, there's, you know, things like that. But to your point that, like, I remember just researching and finding nothing. And asking doctors and they're like, I don't know, yeah, go to a PT. Okay, cool. Thanks. So no, this is wonderful. I appreciate it very much. And yeah, that's the easiest way I can put it.

Bill Gasiamis 1:32:05

Thanks for joining us on today's episode, sharing the show with family and friends on social media will make it possible for people like you who may need this type of

content to find it easier. And that may make a massive difference to someone that is on the road to recovery after their own experience with stroke. Also, if you are stroke survivor with a story to share about your experience, come and join me on the show.

Bill Gasiamis 1:32:28

The interviews are not scripted, you did not have to plan for them. All you need to do to qualify is be a stroke survivor. Care for somebody who is a stroke survivor or be one of the fabulous people that help out stroke survivors. Just go to recoveryafterstroke.com/contact fill out the contact form and as soon as I receive your request, I will respond with more details on how you can choose a time that works for you and me to meet over zoom. Thanks again for being here and listening. I really appreciate you and see you on the next episode.

Intro 1:33:04

Importantly, we present many podcasts designed to give you an insight and understanding into the experiences of other individuals their opinions and treatment protocols discussed during 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 1:33:21

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Intro 1:33:44

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Intro 1:34:06

If you have any questions or concerns about your health or medical condition, please seek guidance from a doctor or other medical professional if you are experiencing a health emergency or think you might be, call 000 if in Australia or your local emergency number immediately for emergency assistance or go to the nearest hospital emergency department medical information changes constantly.

Intro 1:34:25

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