

All The Signs Of Stroke - Jason DePetris

The last thing Jason DePetris expected when eating breakfast one morning before running a marathon was that the numbness he was experiencing on his left side was one of the signs of stroke.

Socials: www.instagram.com/thebeherenowcollective/

Podcast Episode 108 with Dr. Michael Merzenich:
<https://recoveryafterstroke.com/rewiring-the-brain-michael-merzenich/>

Books

Grain Brain

Eat Fat Get Thin

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Transcription:

Jason 0:00

That there was a period of time where I was afraid to do anything on my own, especially after the craniotomy. So I had a lot of family members sort of rotating babysitting duty. Because I was afraid to you know, I legitimately wasn't capable of doing certain things, but I also was afraid to be alone too.

Jason 0:19

And what quickly developed was a sense of frustration at I was frustrated at being treated like I was helpless, but I also felt like I was helpless. And so what quickly developed was I would get mad at myself for feeling like I was helpless and feeling like I needed the help. And then when family members would try and step in and help, I would be like, I don't need that. Leave me alone.

Intro 0:44

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

Introduction



Bill 0:55

Bill from recoveryafterstroke.com This is Episode 110. My guest today is Jason DePetris. Jason was preparing for a marathon. And one day before the event he started to feel the classic symptoms of stroke, including speech issues of facial droop, and numbness on his left side.

Bill 1:15

Now when you get to the end of this episode, whether you're watching on YouTube or listening on your favorite podcast app, please do me a favor and share this episode in other groups you hang out in. This will help someone that is doing a tough at the moment perhaps feel a little better about the journey they are on.

Bill 1:30

Also, if you feel this podcast makes a massive difference to the stroke community, please do me a favor and give the show a five star review on iTunes or wherever you download your podcasts from. Now it's on with the show.

Bill 1:43

Jason DePetris. Welcome to the podcast.

Jason 1:46

Thank you. Thanks for having me.

Bill 1:47

It's always lovely to hear from a person who wants to be on the podcast and reaches out to me it really makes a massive difference actually because I don't have to do all the work to find people, so thank you as well. Mate tell me a little bit about what happened to you.

The signs of stroke



Jason 2:06

So I'm relatively new to the recovery journey. In October of last year, so October of 2019, I was traveling in Chicago. I'm from Los Angeles. I was traveling in Chicago and I was actually there to compete in the Chicago Marathon. And the day before the marathon we were sitting in a restaurant having breakfast. And it started with my hand went numb, and I dropped my fork on the ground.

Jason 2:35

And I didn't immediately think that there was anything super unusual about that because I've had issues with a pinched nerve in my neck for years, had seen a chiropractor for years, and I had gotten numb hands before so it was kind of annoying, but I wasn't alarmed. So then the numbness started to spread up my arm.

Jason 2:55

And shortly after that my speech started to get slurred my face started to droop

and when I really started to get scared as I was traveling with my spouse and my mother. My mom looked at me and she said, she goes, your faces drooping, go look in the mirror. And when I got up to go to the bathroom, my leg wasn't working properly.

Jason 3:15

I was sort of half limping half dragging my leg, that's when I got scared. And then by the time the paramedics arrived, I was fully paralyzed on the left side and I was actually kind of sliding out of the chair, my head was walling back, I was kind of sliding out of the chair. And I never really completely lost consciousness, but I was definitely not all there.

Jason 3:39

So by kind of dumb luck, the restaurant we happen to be eating at was just a couple blocks from the hospital. Just by chance, so I arrived at the hospital very quickly. I was very fortunate that they were able to administer the TPA right away the part that my family sort of still teases me about it still kind of, it wasn't funny at the time, but it's kind of funny now.

Jason 4:05

With the lack of oxygen to my brain and you know, I was, not all there. I was so focused on the marathon and all the training I had done that in the ER when they're telling me you're having a stroke. I was actually arguing with my family saying, I gotta get out of here I have to run the race tomorrow. And they were like, Jason, you're having a stroke, you're not going anywhere. So yeah, so I just chalked that up to lack of oxygen but and then during the CAT scan, they also discovered a large fusiform aneurysm in my belief it's called my MCA. My right MCA?

Bill 4:41

So not only did you miss out on breakfast now they we're going to stop you from going to a marathon?

Jason 4:47

Exactly. I was not happy about that.

Bill 4:51

What were you having for breakfast?

Jason 4:53

I was having pancakes.

Bill 4:58

So you can have some energy for the marathon, I love it.

Bill 5:01

Some interesting thing, the thing that you said about trying to convince people to let you go to the marathon that is so common people having a stroke, oblivious to the seriousness of what is happening to them, and they think it's just business as usual.

Bill 5:17

And you're not the only person I did the same thing. I had a bleed in my brain three times. I had it once in February of 2012, once in six weeks later, and then once in November of 2014. And the first time that it happened, I went to work for seven days with the same sensations that you had that you experienced.

Bill 5:41

And walked with a numb foot got on ladders with a numb foot made no difference to me whatsoever. My wife even told me I was walking strange. I ignored her. I went to the chiropractor instead of the doctor, the chiropractor told me to go to the doctor to the hospital. I ignored him I argued with him as well, like it's so unbelievable how we minimize things that are happening to us just so that we can do work or I don't know what achieve running in a marathon.

Jason 6:14

This happens to other people not to us, right? I mean, that's the way we think. This doesn't happen to me.

Bill 6:21

Yeah, indeed exactly right. I was 37, how old were you?

Jason 6:26

I was 41 when it happened.

Bill 6:28

Other than that incident at the cafe while you were eating, was there any signs before that, that maybe something is going on? In hindsight.

Jason 6:40

In hindsight, possibly, so we think the doctors presumed that it was actually the brain aneurysm that caused the clot to dislodge or lodge or whatever you want to call it and cause the stroke. We think that I probably had the aneurysm for many, many years. Also because it's a very large brain aneurysm. I had never had any medical incidents before that looking back there were some kind of odd symptoms in the months leading up to it that I didn't pay attention to at the time that were not severe enough for me to go to the doctor, but I think maybe something was happening.

Bill 7:20

So, you know, the aneurysm that was found later, but your stroke seemed to be because of a clot. Do they know the underlying cause of that?

Jason 7:32

They believe although there's really no way to know for sure after the fact but they believe that a clot formed in sort of in the base of the aneurysm and something caused it to dislodge and get sort of stuck in the artery.

Bill 7:47

Wow so this clot that almost killed you has also quite possibly saved your life because now they found the aneurysm that maybe caused it right? So what did they do to the aneurysm to treat it?

Jason 8:03

So yeah, you're absolutely right. That's pretty much what the surgeons told me is that that's probably in a strange way, a good thing that this happened because the aneurysm had the aneurysm ruptured, I very likely would not have survived that. When I returned home from Chicago, I saw a team of neurosurgeons here in Southern California, and they ended up doing a craniotomy and an attempted cerebral bypass.

Jason 8:32

So they harvested an artery from my arm and they attempted a bypass around the aneurysm and they were going to clip the aneurysm, but that was unsuccessful. So basically what happened was, during the surgery, the blood vessels began to spasm. And so they were unable to get blood to flow into the bypass and I also had a seizure on the operating table as well.

Jason 8:57

So they were unable to complete the bypassing. Clip, they completed the bypass but nothing was falling into it. And they after many, many tries and about double the amount of time that I was planned for the operation, they finally just closed up all my incisions because it was safer not to proceed any further.

Jason 9:16

So, about for almost exactly four weeks after the craniotomy I underwent a stent and coiling at another hospital for the aneurysm and that ultimately did work. Although that was successful and the stent uncoiling did work. Although, ironically, on July 21, just a couple weeks ago, I did experience a TIA and I was hospitalized again, and they discovered during that hospitalization that the stent is almost entirely blocked with blood clot. So we're now at the stage where we're trying to figure out what the next steps are and why that happened.

Bill 9:56

Okay, so treating that blood clot with blood-thinning medication, I imagine at the moment?

Jason 10:05

Yes.

Bill 10:07

So how does it make you feel going through all of that, and then getting to this point and then having a small episode a little while ago, what did that experience make you feel?

Jason 10:20

It's been quite a ride for a long time, after the original stroke, the sort of elephant in the room for me for a long time was the aneurysm not the stroke. I was much more afraid of the aneurysm than I was having another stroke. And frankly, again, with the whole this happens, other people not to me kind of mentality, frankly, hadn't even occurred to me that oh, this could happen again.

Jason 10:47

I thought, well, it's been dealt with, it's been solved. I was much more afraid of the aneurysm. This was a reality check. A lot of the fear and the anxiety that I thought I had dealt with and that I thought I was sort of past has now come screaming back into the picture. So that's been fun.

Bill 11:07

That's interesting, isn't it? I went in, I was told somebody is so dramatic. There's a blood vessel in your head that is leaking. There's blood coming out into your brain. And for me, the initial experience wasn't dramatic enough to concern me about what the future might hold. It was, Oh, well, it's just something that happens, you know, they'll fix it up whatever they said, is unlikely to bleed a second time.

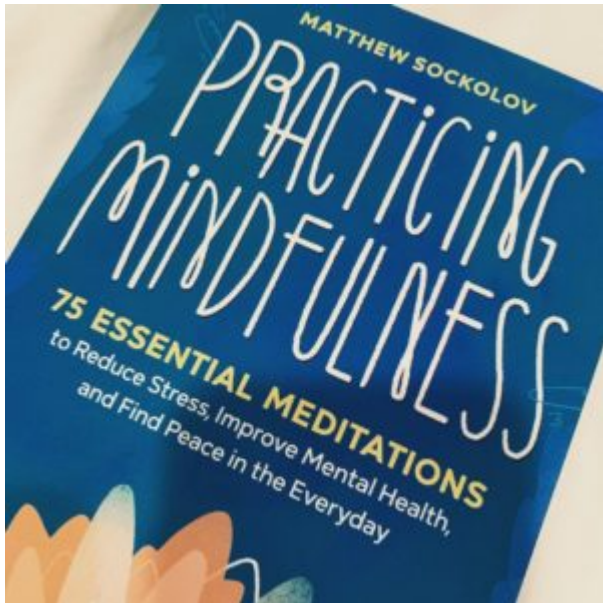
Bill 11:42

So I ran with that part of it. And six weeks later, when it happened again, it became so dramatic. I couldn't recognize my wife and then when I came out of hospital that time, I had to go through a whole process of learning how to type an email again, memorizing, driving, all those things that just went out the window immediately. That's how dramatic it had to get for me to start taking notice that this thing was serious, and that I might not be around in a few months time. Those things cross your mind. Did you have the mortal conversation with yourself?

Jason 12:24

Yeah, yeah, this, TIA really scared me because the for a few reasons. The first time this happened in Chicago, I didn't know what was happening as it was happening. The second time when I had the TIA it looked, felt, sounded, identical to the original stroke. So I knew exactly what was happening. And it was terrifying. Because my first thought was, I really kind of dodged a bullet the first time. I came away with relatively minor deficits compared to a lot of stroke patients.

Worried about the deficits



Jason 12:56

And my thought was, what deficits am I going to have this time? That's what I was thinking as I was waiting for the ambulance to arrive. And it did actually create some deficits. Luckily, again, I was very, very lucky. But the deficits are more severe than they were before. I'm starting physical therapy, I didn't have much in the way of physical deficits the first time. Now I'm much weaker on that side, my knee buckles underneath me. It's you know, so it is definitely more noticeable. It is more scary to me This time for sure.

Bill 13:32

Is that left side or right side?

Jason 13:35

Left side.

Bill 13:36

Yeah. So the knee-buckling, that's something that I had, and it continues, from time to time when I'm tired. It sort of gives way and you're so early on in the process, and uncertainty is normal, feelings that you have are quite normal. So what will happen is, as things start to progress, and you start to resolve some of the challenges the underlying challenges that are there, you'll start to feel better and better about it.

Bill 14:03

And then they'll become things that you just live with that don't really get in the way of the majority of the things that you do. But running might be something

that you don't get back to for us for some time right? Your need to run in marathons. What was behind that? What was the reason you decided to start running marathons?

Jason 14:27

That was sort of it was kind of my form of meditation. I've always been a very, very active person, I've always been a workaholic. I have always had trouble sitting still. And the marathon running was my form of meditation. That's how I would turn my brain off. And that's how I would process information and things like that.

Bill 14:55

So the big question is, how do you turn your brain off now?

Jason 15:03

That's something I'm still working with and learning about. I do a lot of mindfulness meditation. I do a lot of journaling. I enjoy writing. I'm writing a book right now. That's kind of my form of doing that now. It's definitely been a learning process. And I'm trying so hard. I mean don't get me wrong. I wish that none of this had ever happened. But if it was going to happen, I'm sort of glad it happened on the timeline it did.

Jason 15:37

I'm glad that the TIA was nine months after the stroke because I had some time to process and kind of learn how to deal with this stuff. I definitely have the fear and the anxiety and all of those things that I'm sure you know, I have, but I've had some time to learn how to manage those. So it is scary, but I'm much more prepared I think this time to accept it as you know what setbacks happen, they're inevitable. That's part of recovery. That's what recovery looks like. And that's not a reason to just quit.

Bill 16:10

So do you think that your previous process of preparing for marathons is serving you right now?

Jason 16:22

100,000,000% Yes absolutely. It's a very parallel or analogous kind of process, I think.

Bill 16:33

Yeah. And what kind of work were you doing? Before you had the stroke? What kind of work involved in?

Jason 16:41

I'm in the financial services industry?

Bill 16:45

Is there a lot of problem-solving in that space?

Jason 16:48

Yeah, definitely.

Bill 16:50

Yeah. And it seems to me that you brought problem-solving, you've brought, marathon running and all the things that are associated with getting to the finish line, you've brought that to your stroke recovery in that I've got these skills that I've used in the past to overcome challenges, issues, problems at work on the track, running, practicing.

Bill 17:17

And therefore, I can bring those into this stroke space and become curious about how to solve my problems in this space, how to occupy my mind, what else are you doing other than occupying your mind? I went into straightaway into nutrition like, okay, so I'm probably eating terrible food, I'm smoking, I'm drinking, I'll stop all of that.

Bill 17:38

Let me do what I can do with as little effort as possible to control something. And for me, I could easily control my food, and controlling my food wasn't about control. It was about doing what I could, with as little effort as possible, which meant that I ate less things that weren't good for me. And I just increased the things that were good for me. So do you relate to that type of method of solving problems?

Dealing with uncertainty

Jason 18:10

Yeah, I think so I think if I'm understanding what you mean, yeah, I mean, I, one

of the things that I've tried, I'm trying to be open, I don't know a clear way to say this I'm trying to be open to what this experience has to teach me. Clearly, it's not done. Clearly, I don't know everything. And I can't control everything. So I've really tried to be open to learning to worry about just the stuff that I can control.

Jason 18:38

I've always been sort of high strung and a warrior before and this really has been a lesson in there's a million things on my list now that I could worry about, that are legitimate things to worry about, but it's all wasted energy. So I like what you said. I try and just now worry about what I have control over. And not one of my best friends she calls it future tripping.

Jason 19:05

And so I tried to stop future tripping stop worrying about what might or might not happen. Stop worrying about what has happened. I mean, I told you I had a pinched nerve and for years I was going to the chiropractor, I can't tell you how many times I have second-guessed myself and thought, did that contribute to this event? Did all of that net cracking did that cause the stroke?

Jason 19:24

The truth is, I don't know. There's no way to know it may have it may not have at this point, it doesn't matter. I am where I am. I can't control that what I can control is what I do today. Like you said my diet what I eat, whether or not I follow the doctor's orders, whether or not I take time for self-care and to reflect and to slow down my life.

Jason 19:48

Another way that I do kind of what you were describing is I prioritize. Strokes are not uncommon and aneurysms are not uncommon but I've been told by several doctors my specific combination of facts in my case is very unusual. I have a literally have a team of doctors treating me I have so many doctors, I can't even remember all of them.

Jason 20:12

One of the things that I've done is prioritize. And I even reached out to a doctor today and said, Do I really need to see this other doctor? I already have three different neurologists, they're treating me already do I need 4 neurologist? You know what I mean? So I've tried to pare that down to and say, okay, what's

reasonable? What makes sense? I'm not going to ignore the doctor's orders. But if I follow everything, the doctor said, my medical file is 500 pages thick at this point. I need to figure out what actually is reasonable and makes sense and is, you know, can I handle?

Bill 20:45

Yeah, it sounds like it's time for focus. Rather than having everything going on at the same time. It's just narrow the focus and just go for a couple of things that you can do that are going to support A, your physical well being, B your mental well being. So that's really, really important for me. I did similar, I had doctors come into my hospital bed, the first hospital that I was taken to, and they would talk about me, and they wouldn't include me in the conversation.

Bill 21:20

It used to frustrate me. So I left that hospital and basically sacked that team and hired another team, so to speak, went to another hospital, found another group of doctors who worked the way that I needed them to work, which was very small amounts of information, but very focused and narrow communication style in that this is what happened, this is what we're exploring.

Bill 21:44

This is what we did. This is what didn't work, this is what we're going to try. None of the other stuff mattered. I just needed to know the details. I just needed to know the outcome or the goal that they had in mind. So then what I did is prepared myself so that I could support them, in them reaching that goal, which was to learn to remain still, I meditated, I changed my diet, I changed what I drank, I changed my relationships and how I behaved.

Bill 22:14

And what I did with the family and friends that perhaps loved me but I used to piss off all the time and yell and scream at and all of those things all that time that I had enabled me to step into this space that was calmer, therefore, my blood pressure would be lower, therefore, my stress hormone would be lower, therefore my heart rate would be better.

Bill 22:36

Therefore all these other things peripheral things would be impacted by me making this small changes. And that allowed me to be the best patient and I told

this to my surgeon, and her team on the bed that are preparing before for surgery. I said to them, I am going to be the best patient you've ever had. I've done all the preparation work for you so that you can have to just deal with the problem in there, not this whole problem with a guy who's losing his shit and is, you know, all over the place.

Bill 23:08

And whether they paid attention to that or not doesn't matter, but it made me actually turn up in a better place. And therefore, I wasn't getting in the way of any of the process. And it took me three years to get to that point. I had been at all the personal development courses that you could imagine up until that day.

Bill 23:38

But nothing really mattered until I took responsibility for me. And I started to change my life in very small ways that had massive, massive impacts. So it sounds like you're very similar in the way that you're approaching this. And I think that's going to serve you really, really well especially going forward. Because stroke doesn't go away the damn thing happens. And then for some reason, it never leaves people's lives.

Bill 24:09

You know, people talk about their stroke their head 30 years ago, and they talk about it like it just happened. Some people talk about it, like it was the best thing that ever happened to them. That's me I can get. I can say that now, but it wasn't at the beginning. Some people talk about it like, it's completely ruined their life still.

Bill 24:30

And it's 20 or 30 years down the track. So you may as well if you're going to be talking about your stroke, 20 years from now, you might as well be talking about it. From the space of this is what it taught me. This is how I change. This is how I evolved. This is how I adapted. This is how I became curious about new things I didn't before and the fact that only it seems what only 11 or so months or 10 months into your process. You're already on a stroke podcast who would have thought a year ago that you would have been talking about the topic of stroke on a stroke podcast.

Jason 25:06

Yeah, agreed, agreed. And I absolutely relate to what you're saying. And it doesn't mean that I'm like there yet. I mean, I have a lot to go through and a lot to learn, I'm sure Still.

Intro 25:16

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

Intro 25:40

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

Taking responsibility for stroke recovery



Jason 26:19

But I relate to what you're saying. And one of the things that you said that I connect with is the taking responsibility for myself. There was one particular moment and early on in my recovery that was sort of a turning point. Which was when I first came home from the hospital after the craniotomy, I mean I was not

in good shape. I was using a walker. I was literally so weak that I could not recline the recliner that we had bought.

Jason 26:46

So my husband and I bought a recliner because in anticipation of we knew I wasn't going to be able to sleep in the bed. And I was so weak I could not even pull the lever to raise the recliner and I was literally being waited on hand in foot because I physically was that weak, but I also had it in my head that I couldn't do anything.

Jason 27:11

And one of the early turning points for me was that there was a day where I realized my pill case was empty and it needed to be repopulated, and my spouse was working and was on a call. And I was gonna go get him to do it. And then I was like, no, I can do this. And so I got it. You know, I had visual issues from the stroke and whatever. So it's hard for me to read the labels and stuff, but I was like, no, I can figure this out.

Jason 27:37

And I sat down, I lined up all the pill bottles and I lined up the pill case and it took me a long time, but I repopulated all the pills. And he came into the room. He's like, do you need me to fill the pillowcase? And said no I did it. And he was like, oh, you did? And I was like, that was like an aha moment for me that like, Okay, this is what it's going to take is I need to step up and even if it's something that's simple, I need to step up and start taking care of that myself, I need to be the one to call the doctors. I need to be the one to send the emails, it might take me longer to do it. But that's part of the recovery.

Bill 28:12

It's the marathon analogy. I mean, you don't start the marathon thinking about the last step on the marathon that's gonna get you over the line, click, there's the time. That's not the how you start them out. You start it with the first step. And you've just got to make each next step. And you've just got to get to the end of the marathon. And in Episode 108, which is the one that I released a couple of days ago, I released it because I recorded it I think for Episode 27, which was a number of years ago.

Bill 28:47

I interviewed a gentleman called Dr. Michael Merzenich, who, he's the one of the founding fathers of the current research that studies that have gone into neuroplasticity. And we speak about neuroplasticity there's this positive thing that we can use neuroplasticity in our favor, we can use it to benefit us to learn to rewire the brain.

Bill 29:10

But neuroplasticity also works in the opposite way, we can rewire the brain to support negative thoughts and support negative processes and physical actions. So that thing that you did, it could have gone one way or another for you. If it went the other way. It meant that you were learning how not to do things. You were learning how difficult it was, you were learning how not to struggle through your learning how not to take responsibility.

Bill 29:40

So that is one of those things that people don't understand they are in a vulnerable state, their brain is changing rapidly trying to adjust and it's gonna take the path of least resistance and if the path of least resistance is the one that you chose to not do anything, it's going to go fine. We'll do that one. Then you were not being able to do things and then that stays with people and sometimes that gets in the way of recovery way more than the physical ailments.

Jason 30:12

That's fascinating. I never thought of neuroplasticity from that angle. I never thought about the fact that it can go both ways. That's fascinating.

Bill 30:19

Yeah, we can control neuroplasticity one way or another. What we choose determines the experience that we're going to have, you know, so 108 is the episode Michael Merzenich is an amazing guy. They invented the world's first cochlear implant, which was back in the 90s. And, and at some point, they had an aha moment where they realized that the cochlear implant is pretty much useless if the brain doesn't change, to adapt to listening through an electronic device.

Bill 30:52

And that was what made the cochlear implant successful it was that the fact that that it had the brain on its side and the brain used the electronic devices to listen. So it changed the game for what it meant about how to support people

overcoming conditions that were so, serious that hearing was gone, for example, and the guy that Michael worked in conjunction with or at a similar time with, that was also studying was a guy called Paul Bach-y-Rita and Paul Bach-y-Rita was trying to support people to overcome vision loss with mechanical devices strapped to the forehead.

Bill 31:31

And they were able to successfully get a blind person, somebody that's been blind from a few years after their birth to be able to see a garbage bin on the other side of a room and throw a basketball at that garbage bin and actually get it in and the way they did that was this device on the forehead created different responses depending on where the hand was. And where all the certain things were and somehow created a black and white image in that person's brain to be able to show them that, in fact, in the distance is this garbage bin, and you're holding the ball here.

Bill 32:23

And if you do that, you'll be able to get it towards the bin. And then the more they practice, the more that person was able to calibrate distance and the amount of time they needed and the effort they needed and so on to get the ball and push it in through the air into the brain. So neuroplasticity is amazing. But what people don't realize is they are activating neuroplasticity when they make a decision that's not serving them as well. And let's not wire that stuff in.

Jason 32:52

Yeah, there's already enough of that stuff in the world.

Touch base

Bill 32:55

Especially now we're going through the craziest time ever. You know, I have never had so much in common with every person on the planet as I do now, lockdowns, you know, the fear around COVID-19, and all that kind of stuff. And we can get ourselves all worked up and have all that stuff to worry about as well as how we're recovering from a stroke or we can just worry about recovering from a stroke and what the next solution to our problems are. I'm curious about your family, your husband, and the people that were with you at that cafe when this thing happened. Have you had a conversation with them about what they

went through?

Jason 33:43

Yes, we've had several conversations about that. I think that was not just a terrifying experience for me. I think it was a terrifying experience for them too. I'll never forget the look on my mom's face. When you know when Jeremy pulled out the phone and said I'm calling 911 I'll never forget the look on my mom's face. And you know, there's a lot I don't remember from that day, but I remember that.

Bill 34:13

Yeah. What are some of the things you mom has said about that time? Has she even spoken about it?

Jason 34:19

A little bit. On the humorous side of things, you know, trying to look at the bright side of things. One of the things that we've all kind of talked about since that incident, was that my mom has this sort of curious combination of in the actual crisis moment in the emergency. She's cool as a cucumber. She handles everything, she just gets it done. But she had several emotional breakdowns throughout the week.

Jason 34:47

Just weird odd times that you wouldn't expect. So like in the moment when we're calling the ambulance and I'm being loaded and I'm being taken in for surgery and all that. She was very, very on top of things. But then in just bizarre moments in the hospital room when we're sitting there, you know, eating lunch talking, she would break down and start crying or the nurse would come in and check on me and she would crying.

Jason 35:12

So yeah, I think it's I think there's a lot that went into that. And, I think, you know, it's hard to see anybody that you care about going through something scary like that. And then I think the combination of that and also trying to stay strong for them, I think is difficult. I have a younger brother who is 18 years younger than me. And, you know, we never lived together because by the time he was born, I was out of the house living on my own.

Jason 35:40

So we have sort of an uncle-nephew kind of relationship. And I had never seen him cry. I don't think he had ever seen me cry. And I was told by several family members that in the waiting room in the hospital when I was having a craniotomy that he broke down and had a pretty big moment because the surgery wasn't going well. They didn't know if I was going to make it out of the surgery. It's been interesting to see everybody's reaction along the way.

Bill 36:10

Yeah. Did you find yourself going into allaying everyone's concern mode? I'm from a big Greek family. everyone loses their shit. Yeah, they pretend that they're okay. They pretend that everything as well, but they can pull it off like they're terrible. So I spent most of my time because I was so comfortable in my own approach, my nearly three-year preparation for surgery because I was so comfortable. In my approach, I found myself constantly allaying the concerns of everybody else and saying, you know, it'll be right, I'm fine and all that kind of stuff. But I really believe that I wasn't just telling them for the sake of telling them. Were you playing that role as well?

Jason 36:59

Maybe a little bit. I think that what I found myself doing more than what you're describing is it was such a frightening experience for me, especially somebody who had never had I never had any health issues before that I'd never even spent the night in the hospital before this happened. It was so frightening that there was a period of time where I was afraid to do anything on my own, especially after the craniotomy.

Jason 37:29

So I had a lot of family members sort of rotating babysitting duty. Because I was afraid to you know, I legitimately wasn't capable of doing certain things, but I also was afraid to be alone too. And what quickly developed was a sense of frustration at being I was frustrated at being treated like I was helpless but I also felt like I was helpless.

Dealing with emotions

Jason 37:53

Yeah, and so what quickly develop those I would get mad at myself for feeling like I was helpless and feeling like I needed to help. And then when family members

would try and step in and help, I would be like, I don't need that leave me alone. And it was this weird sort of circle that it took me a while to get out of.

Bill 38:11

So you're helpless. You're happy to have the help, but at the same time you were angry for being helpless and having help.

Jason 38:21

Exactly, which of course, is completely fair to my family members that are trying to help.

Bill 38:29

So it's such a bizarre space to be in. I remember my dad, and I've said it before in other episodes, being my designated driver for everything. And he's such a shit driver, and I was just so frustrated to be in the car with him. Because, you know, I'm a typical backseat driver, you know, telling people what to do and where to go and all that type of thing.

Bill 38:50

And now I had my dad driving me around, he was doing me this amazing favor. He was just, he couldn't do anything else but he could drive so he said, you know what? I'll be his driver, and I just used to get so annoyed and frustrated with him. And I just think back at how terrible that was. But I get it. It's just loops. You create these loops and you sometimes can't get out of them.

Bill 39:12

You've just got to ride through them. And I remember even yelling and telling my wife, she did the worst thing in the world because she parked in the wrong car space. I mean, I couldn't drive, I couldn't do anything. And she parked in the wrong car space, and I told her off about it. I'm pretty sure I brought her close to tears.

Bill 39:32

It was such a terrible time, but it was part of the learning process and she's so mild-mannered that she put up with most of my junk and most of my stupidity. And then at least I had the ability to recognize later that I had been an idiot, and that an apology was required and sometimes more than one. Had Jeremy deal with all your crazy you know, behaviors?

Jason 40:06

Yeah, I've definitely had some of those apologies required moments to Jeremy to my parents to friends around me. Jeremy's very mild-mannered, very calm and relaxed personality. His most likely response in those moments is to just quietly get up and leave the room and come back when I'm calm. Which is the signal to me that I'm going off the rails.

Jason 40:37

I had one particular moment with one of my best friends who just being kind and wanting to be supportive, came over to spend some time with me and brought a big huge box with all these cupcakes. And I snapped at her and I said, I said something along the lines of like, what are you thinking like I just had a stroke because of a blood clot in my brain and like you're bringing me junk food, I can't eat this junk food. And it was like, you know, and it was just completely unreasonable like all I had to do was say thank you I'll eat it later and then not eat it. It was a completely unreasonable response so I've had those moments with my parents as well.

Bill 41:18

Yeah. They just bring food because food is such an emotional thing, isn't it. That's how people connect with people over a plate of food over a coffee. So they just do those things that make them feel emotionally a little better. And they don't realize, but nor should they realize they've never had a stroke. We don't want them to have a stroke. We don't want them to know what it's like.

Bill 41:39

So, it's kind of good when they are so oblivious to it, because that means they've never had our experience and that's what I got. That was the lesson one of the lessons I learned and how I was able to modulate my advice giving at that moment when they would just try to be nice. Tell me about what else you experienced. Do you have fatigue, cognitive fatigue and those types of things are you finding yourself hitting these little virtual walls during the day that you have to stop and rest for?

Jason 42:22

Yes, definitely more so after the TIA, I had it. I had it in the beginning after the original stroke. It was much, much worse after the craniotomy. A lot of the symptoms that I've experienced are actually from the craniotomy not from the

stroke. At least as far as I can figure. A lot of the symptoms that I experienced are more from that surgery than from anything else.

Jason 42:45

But I did have the fatigue from the stroke as well. It's much more pronounced after the TIA and I'm only two weeks post-TIA so it's very early. But yeah, I'm finding myself sleeping a full eight and a half, nine-hour night, and then still having to take a nap during the day and then still feeling tired. I'm still kind of in that stage. I had some damage to my retina from the stroke from the original stroke. I can see I can read I can work on the computer, but it definitely makes me more tired than it did before, staring at the screen, especially, type on the screen is very difficult.

Post-stroke diet

Bill 43:29

So I imagine you've already read up to get an understanding of the things that will stimulate the brain, like screens, like sounds like lighting. So if you minimize that, when you're feeling the way that you're feeling, it'll get better. And one of the things is that you need to look into and you need to research is the right kind of diet for decreasing inflammation.

Bill 43:56

And I'll give you the very basic version of that. It's very local carb diet, especially people recovering from a brain injury, the diet needs to be high fat. And what I'm talking about fat, not KFC, McDonald's type of fat, like just, you know, avocado, those types of amazing fats and fats that come from protein from animal fats, if you're that way inclined, and low carbs, because what carbs do is that they'll spike insulin, they'll spike cortisol, they'll increase blood pressure, they'll increase all these things in the body.

Bill 44:33

And those things as they spike and increase, they cause the energy high, you get that boost, and then you have that real quick energy drop off when they get used or sorted out. And then that puts people into a greater space of fatigue while the brain's already fatiguing. It creates this added level of fatigue. So if you want to minimize that, then that's a good way to go. You look at a book called Grain Brain by Dr. David Perlmutter.

Bill 45:05

And you look at a book called Eat Fat Get Thin by Dr. Mark Hyman. And I know that the book says Eat Fat Get Thin. And it's not about weight loss, actually, it's actually about how we metabolize food and how the body deals with certain foods. And then why fat is a good thing to add to your diet, especially saturated fats that come in a form of vegetable or from animals that have been pasteurized and all that kind of stuff. So I'm not sure. Have you had some time to look into that yet?

Jason 45:38

No, you know what I find interesting, and Jeremy has commented on this a few times as well. All of the doctors that I've been treated by and I've now been hospitalized at four different hospitals. I've seen probably 30 doctors of all different specialties. Not one person has mentioned diet to me and I found that interesting.

Jason 46:00

And I didn't have tons of concerns about that. Initially, because I was a marathon runner, I was already a very healthy eater. But now after this most recent episode and trying to sort out and figure out why it happened, I'm definitely more curious about that because nobody's mentioned anything about diet to me.

Bill 46:19

I'll tell you, I'll give you the hint, I'll tell you why. I'll give you the tip of the reason that doctors don't have that conversation is they're more interested in keeping you alive and getting you out of the hospital. And they do that well, so they don't have time to look at diet. However, in Australia, there was a Doctor who, and I've interviewed his wife, Belinda Fettke. And I'll add these links to the podcast show notes so people can find them easily.

Bill 46:47

And I'll send you a couple of links as well. Basically, what happened is this particular surgeon, Dr. Gary Fettke, was somebody who experienced a brain tumor I think it was somewhere in the front of his brain somewhere there, pituitary tumor. And as a result of him realizing that his time was potentially limited, he started to research how he can support his brain, while he was going through all the treatments, he found that a low carb diet was going to support his brain.

Bill 47:21

There was no guarantees of solutions or overcoming everything. And he started to feel better while he was recovering, also going through the medical process, and a number of years after he started feeling better, he started to tell his own patients who were diabetic patients, and he used to be amputating their, their limbs because they had diabetes, and it got so bad that he started telling them about diet.

Bill 47:48

And as a result of that, somebody didn't appreciate him as a doctor who was not a qualified nutritionist doing that and they took him to court. And while he was recovering from a brain tumor, and all the things that were associated with that, and also trying to treat his patients he was being vilified and taken to court and sued, because he was giving nutritional advice.

Jason 48:17

Oh, good, Lord.

Bill 48:18

So now you know why that's the reason why now over the years, he beat all of those charges. He was not sued, and he's now giving nutritional advice to his patients, and therefore, he's not amputating as much as many limbs as he used to. And it's an amazing thing. But that is one of the issues as to why doctors don't do that.

Bill 48:41

And what that means is that we miss out on really important information very early on in our recovery. And one of those things is the nutritional part of it. And I remember being almost beyond the almost three years into my stroke journey. While I was recovering from brain surgery, the craniotomy and I was in the hospital and I was learning how to walk again. And they were bringing me you know, white bread with margarine, with sugar infested, custards, and all these types of foods that I knew were doing nothing to support me getting out of the hospital sooner, so I stopped eating their food.

Bill 49:25

And I asked mum and dad to create meals for me and bring them in on a daily basis, and that's what I ate. And when I was in that space, it was a number of

years ago. So it was very early on in the whole low carb nutritional kind of thing. And there wasn't enough information. So I just spent the majority of my time researching and then I created the podcast so I can share this kind of information and bring those types of people in.

Bill 49:53

That is one of the things that we can control the most, our diet. And we can make a massive difference to how we support our brain in the recovery. And that means that we can have better outcomes, get out of the hospital sooner and get back to work sooner, get back to a productive life sooner. So I love that you're so curious and you're willing to look at anything. Because these interventions don't cost us anything to do. We don't have to employ anybody to pay anybody, we just have to buy less things or different things and put different things in our shopping basket.

Jason 50:34

No, I definitely agree with that. I mean, it is kind of that taking responsibility for your own recovery kind of idea again, and I think, one of the reasons also why doctors don't necessarily address that issue is I think a lot of doctors, maybe not all of them, but a lot of doctors don't have training in that area either. They know their specialty, they're good at their specialty.

Jason 51:00

But I know, one specific neurosurgeon that sort of my main doctor, absolutely love this guy. He's a fantastic doctor for so many reasons. And one of the things that I appreciate about him is he knows what he's an expert in and what he's not an expert in. And we've had conversations where I'll ask, you know, I'll ask him X, Y, and Z. And he'll say, that's not my expertise, I really would prefer you talk to a specialist about that. And then he provides me with the referral to that person. And I appreciate that because if you don't know the answer, I don't want you to give me a bullshit answer you know what I mean?

Bill 51:38

I get really annoyed about it because they spend so much time, money, effort, resources, technology, all the things that go into bringing a stroke survivor back to life and back to the world and then they undermine all of that effort with not having this next crucial part of the puzzle.

Bill 52:04

And it's a similar thing that some of those doctors do, who go out of their way to keep us alive, open our heads up, you know, take parts of our brain out and do all these things. And then they say something like, you'll probably never walk again. You know, what's the point of doing all of that? What's the point of going to that much effort to get me out of hospital alive and then potentially tell me that I'm never gonna walk again.

Bill 52:36

It might be the case, but don't tell me that. Tell me that with a lot of work and effort. I might walk again, and I might actually achieve that. And that's kind of where I go on this tangent and get so passionate about it. And you can hear about that. In all my other podcast episodes. I always have something to say about these small bits of the puzzle that they just missed.

Bill 53:00

That could just dramatically improve the lives of a lot of people. But I know they're doing their best. And I'm grateful for them because if it wasn't for them, you and I wouldn't be here.

Jason 53:11

Absolutely.

Bill 53:13

So I want to as we come to the end of the episode, I want to ask you about why it was important for you to get on the podcast. Why did you reach out?

Jason 53:27

I recently, it was very recently, as a matter of fact created a specific Instagram profile that's just for stroke and aneurism survivors because when I was first diagnosed with this, and I was first trying to figure it out, I had never I didn't personally know anybody that was a stroke survivor. I didn't personally know anybody that was an aneurysm survivor.

Jason 53:48

And I was sort of reaching out trying to find information. I couldn't find anything positive. Everything that I found was scary and negative and horrible. And doom and gloom. So I created an interview. profile that was specifically for stroke and aneurism survivors. And the intent was to be positive and share what's working and what you know.

Jason 54:09

And then it's just in its infancy. I mean, I have very few followers because I just created it right before you and I were sort of introduced. And that's also why I'm writing the book right now about my journey as well to kind of share, because I recognize I've been extraordinarily lucky throughout this journey. A lot of people that have been through what you and I've been through, are not as lucky as we have been.

Jason 54:32

But there are a lot of things that don't have to be as scary that can be more positive that can be, you know, they can give you some hope and some future. So that's why anything that I can do that can if there's somebody out there going through this that maybe doesn't have the level of support that I do, that hasn't had the positive experience with the doctors that I've had, and just need some direction.

Bill 55:00

Yeah, I think that's a great thing. And it's so, so common you see it again and again and again stroke survivors that, you know, in the community that we've got on Instagram. They, go out of their way to support other people. And they might be doing it tougher than anybody. And that's just so interesting and amazing to me that that is the first port of call for most stroke survivors is to make it about somebody else.

Bill 55:35

And it's so fascinating and bizarre at the same time and it's such a beautiful thing that comes from stroke almost immediately people think about okay, what have I learned that would help somebody else. It's just, it leaves me speechless, and it happens all the time and I still am not used to that fact. I got to that stage as well.

Bill 56:01

But it took me quite some time to get there. And, it was because I had to solve a lot of problems on my own before I could start helping other people. But then when I realized that I had this information, this is not the kind of guy that I was before. I didn't keep that information to myself. I thought, No, this could be handy for a lot of other people. Let me get it out there. And let me tell them about it. So I really relate to what you're saying. I can appreciate why you're doing it. And I think it's an amazing thing that you're doing. Have you got a title for the book

yet?

Be Here Now



Jason 56:34

I do. In fact, the rough draft is finished. I'm in the editing and revising process. Now. The title of the book is Be Here Now. And the thinking behind that the reason I've called it that is because, one of the many, many, many lessons that I've learned throughout this whole process. Probably the most important lesson is to be present to not worry about the past. not worry about the future, live right here right now. And that's why I called the book that.

Bill 57:05

Why is that important? In a few words, tell me why is living here right now important and how does that help you in your recovery?

Jason 57:17

Because I don't have control over what happened. I can't change the fact that I had a stroke. I can't change the fact that I had the aneurism that I had the TIA. So worrying about that is not helpful. And I don't have control over what's going to happen in the future.

Jason 57:34

Worrying about what may or may not happen is wasted energy and is probably detrimental to my health. I have control over right here and right now I have control both from the standpoint of my recovery, but also from the standpoint of

just enjoying the moment and not wasting the chances that I've been given in you know, I've been really fortunate. I don't want to waste it.

Bill 58:01

That sounds like a perfect way to end this podcast episode. Thank you so much for being on the podcast for reaching out for doing all the things that you're doing for writing the book and for taking responsibility for your own healing journey and your own recovery. And I look forward to the book getting finished. I'd love to have you back on the podcast when it's done, so that we can tell other people about it and we can talk about it. And I just wish you well ongoing.

Jason 58:32

Thank you so much.

Intro 58:38

Discover how to heal your brain after stroke. Go to recoveryafterstroke.com. Importantly, we present many podcasts designed to give you an insight and understanding into the experiences of other individuals. Opinions and treatment protocols discussed during any podcast are the individual's own experiences.

Intro 59:00

We do not necessarily share the same opinion nor do we recommend any treatment protocol discussed all content on this website at any linked blog, podcast or video material control this website or content is created and produced for informational purposes only and is largely based on the personal experience of Bill Gasiamis.

Intro 59:17

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Intro 59:33

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Intro 59:49

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 things you might be called triple zero If in Australia or your local emergency number immediately for emergency assistance or go to the nearest hospital emergency department.

Intro 1:00:06

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