

# Brain Stem Stroke & Locked In Syndrome Recovery - Greg Lewis

**Greg Lewis is recovering from a Brain Stem Stroke and locked-in syndrome at the age of 32.**

Facebook

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Transcription

Greg Lewis 0:00

But if I'm out in the middle of Walmart's parking lot, and I stumble and fall, I'm gonna be okay. But I don't know how I'm gonna get back up. And so there's that.

Bill Gasiamis 0:12

Have you had many falls?

Greg Lewis 0:14

Well, it really depends on how you define it.

Bill Gasiamis 0:17

I'm falling over onto the ground, Greg.

Greg Lewis 0:24

Well, I know. I mean, I had a medical student explained to me that a fall is going from one plane to another and not knowing how you got there.

Bill Gasiamis 0:37

Oh, okay.

Greg Lewis 0:39

And then a trip is, knowing what you did to make you get on a different plane. So, I stumbled a lot. But I haven't really fallen in a while.

Intro 0:58

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

Bill Gasiamis 1:11

Hello, and welcome to another episode of the recovery after stroke podcast. Recently, Spotify released a new feature that allows people to narrate their favorite shows in the same way that the apple podcast app allows them.

Bill Gasiamis 1:25

So if you think the recovery after stroke podcast deserves it, I'd love it if you left the show a five-star review. This will help the show rank better on search engines. And it'll help newly diagnosed stroke survivors find the show and it could make a massive difference in their recovery.

Bill Gasiamis 1:42

There's nothing better than people who are going through a tough time after stroke, listening to a podcast, about an interview about somebody who has had a bad time from stroke, and is going along in their recovery and getting through the obstacles and overcoming all the challenges and becoming better.

Bill Gasiamis 2:02

I mean, this episode today is really all about somebody who's had a major drama with regards to their stroke, ended up being locked in at the age of 32. And then is back with us to have a conversation about stroke recovery, what it's taught him and all the things that he's had to overcome.

## **Introduction**



Bill Gasiamis 2:26

I learned a few things about this episode today. This episode is episode 194. We're fast approaching episode 200. And Greg Lewis was just somebody that I really appreciated chatting to and was somebody that I really got a kick out of listening to because a little while ago, he had a brainstem stroke he was locked in.

Bill Gasiamis 2:47

And the guy was I wasn't able to communicate, now he can. So it's a real trip, just like all my episodes. But every once in a while, I really get excited to have somebody on the show that wasn't able to communicate that long ago.

Bill Gasiamis 3:02

So as I was saying, if you appreciate this podcast, if you think it makes a massive difference, if you think people should be able to find it easily and access it as they are experiencing the difficulties of stroke recovery, I'd really appreciate if you left a five-star review, you can do that on Apple or pod or your podcast app.

Bill Gasiamis 3:24

If you are listening on another platform, it doesn't matter where you listen, just if you can, that'll be much appreciated, also very much want to thank the people that have already done that. It does make a massive difference.

Bill Gasiamis 3:37

And it's obvious to me that people are leaving reviews and giving the show five stars because I'm seeing that the numbers of people downloading and the amount of episodes that are being listened to is increasing nicely and slowly. And I'm just

loving that. So thank you. And I appreciate you all for listening.

Bill Gasiamis 3:59

Now, let's just get stuck into today's episode. It's a real treat, like I said, to have a listen to somebody who is recovering from a stroke that was quite serious in the brainstem, and then woke up with locked in syndrome and is now on the way to recovery. It's on with the show. Greg Lewis, welcome to the podcast.

Greg Lewis 4:25

Thank you. How are you doing? Glad to be here.

## **Brain Stem Stroke**

Bill Gasiamis 4:28

Yeah, glad to have you. Tell me a little bit about what happened to you.

Greg Lewis 4:39

I was 32 and we just got home from family afternoon. And you know, and I lay down on the couch, take a nap and I couldn't get back up. Next thing you know I was told in the hospital, it's got to be a stroke. But the funny thing is, we knew it was a stroke because my wife was just had a class on how to recognize a stroke.

Greg Lewis 5:18

And on the way there, they thought I had OD'd because I was so young. And the ambulance drivers kept asking me about that. And it took about an hour and a half to three hours to get the right treatment.

Bill Gasiamis 5:39

Wow.

Greg Lewis 5:40

But they're able to give me a clot buster and it seemed to work. Then followed up about two and a half months of ICU, and critical care and then same amount of time, I'm just regular hospital, trying to work up the ability to get into outpatient therapy. And once I was able to go to outpatient therapy it was another eight, nine months.

Bill Gasiamis 6:27

And that was back in 2013?

Greg Lewis 6:30

Yeah, that was back in 2013.

Bill Gasiamis 6:33

So it's been some time between now and then. If you can remember back then you lay down on the couch just to have a rest. Did you notice any of the symptoms that your wife knew about? Did you notice anything that gave you any warning signs that there was something going wrong?

Greg Lewis 6:54

The only sign that I paid attention to, one that I could pay attention to at the time was I had a headache for about two weeks that no amount of ibuprofen or Tylenol or anything like that would touch?

Greg Lewis 7:17

It would kind of take the edge off. But I would just gut my way through it. And other than that no, I didn't recognize anything. When my wife was telling me, you've had a stroke, we need to call the doctor.

Greg Lewis 7:36

I can hear her just fine. And I could see her. But I could not talk to her. Apparently, all my words came out as gibberish. But to me, they sounded absolutely normal. I just kept saying all I got to do a stand up, It's alright, I'm going to be fine.

Bill Gasiamis 7:59

But you couldn't do it?

Greg Lewis 8:01

No, I could not. I couldn't stand up. And just like I was saying every word I was saying came out just gibberish. And then on the ride in the hospital, all I could do was cry.

## **Dealing With Emotions After A Brain Stem Stroke**

Greg Lewis 8:21

It was kind of interesting. I've never really talked in almost nine years, I've never really talked about my stroke. And what happened. I'm kind of bits and pieces.

Bill Gasiamis 8:37

Have you avoided it?

Greg Lewis 8:40

No, it's more that. I mean, I guess yes, I'm avoided it but because it has brought up emotions. And when I get too emotional, it's hard to talk. But after a while after thinking about it and internalizing it.

Greg Lewis 9:09

I gotten to the point where the stroke no longer defined me, who I was it was more like a refining moment. And once I hit that point, it already been so many years that nobody really cared.

Bill Gasiamis 9:25

Yeah. So the emotional side of it, was it triggering your trauma from the experience that you had or was it bringing up stuff from the past?

Greg Lewis 9:40

Kind of both and on top of that I was really for a long time I was suffering from PBA pseudobulbar affect and I still deal with that. I have a hard time watching Disney movies because I'll either laugh or break down crying at just the weirdest stuff.

Bill Gasiamis 10:22

That's familiar for a lot of people that have had a stroke. And even me, it's not as it's not as common that I do that now after 10 years, but definitely for the first few years I was doing that regularly.

Bill Gasiamis 10:41

And everyone was trying to work out, was he upset was something wrong. And there was nothing wrong. I wasn't upset. I was just crying. And I couldn't stop crying. And it was hilarious. To me it was but everyone else was uncomfortable.

Greg Lewis 10:58

Yeah, I know how you I feel.

Bill Gasiamis 10:59

So why do you reckon Greg you never really spoken about what happened to you to anybody?

Greg Lewis 11:09

Just never really, from start to finish no one's ever been too deeply interested in stuff. And they I don't know really how to explain it. I've never really gotten too deep into it.

Greg Lewis 11:33

And because one, I mean, now it doesn't really affect me to talk about it. But I know it affects other people. So I don't really avoid it. I'm just quiet about it.

Bill Gasiamis 11:49

Yep, that's okay. So did it impact your work? How did it impact your life and change your life those early days?

## **Locked-In Syndrome**

Greg Lewis 11:58

I've been in complete turnaround. I used to be a plumber, I was a journeyman plumber for 10 years. And you know, I'm going around being very physical, doing a lot of stuff that honestly other people had trouble doing.

Greg Lewis 12:20

I can do by my myself. And then I had a stroke, which was combined with locked-in syndrome. And I lost everything. I mean, I couldn't breathe on my own, my heart would regulate right.

Greg Lewis 12:38

All my muscle mass was gone or my ability to move correctly, I should say. And so now I'm at the point where I can work around the house, but it takes me a lot longer to get stuff done. And I haven't been able to go back to work.

Bill Gasiamis 13:03

How long were you locked in for?

Greg Lewis 13:07

I was locked-in completely where I couldn't move really anything but my eyes for about a month. So I am very, very lucky on that point. I know some people that have been locked-in for a lot longer.

Bill Gasiamis 13:24

A month earlier. You're supposedly fit and healthy. You're going to work you're going about your business, you're very physical. You're a married, man. You're doing all those things. And then a month later, you're locked in.

Bill Gasiamis 13:51

How is it? Are you able to comprehend what is happening? And are you thinking about how your life has changed? What goes through somebody's mind a month after something like that?

Greg Lewis 14:10

I don't think I really realized the impact of losing everything like that then until after I left the hospital. I don't know it's kind of hard because you know most men, I don't know how it is in there, but most men here and they're kind of judged by what they do, or how they do it physically. And for a long time, I really felt that there's nothing I can offer. But at the same time it drove me to gain some of it back.

Bill Gasiamis 15:02

What you described about men? It's the same everywhere. It's the same in Australia, it's the same in the United Kingdom. It's the same everywhere you're judged by things that are related to your physicality for sure.

Greg Lewis 15:18

Yeah. And then it's not that anybody's really mean or demeaning about it. It's just kind of the way we're program naturally as men, but also as society. So I didn't hold that against anybody.

Greg Lewis 15:39

In fact, it's really kind of funny, because I will do something that I shouldn't be able to do according to other people, and they'll be like, Whoa, how did you do that? Or, you know, it's okay, I could have helped.

Greg Lewis 15:55

And I'm like, Well, I know, but I need to learn how to do it. Even if I have to do it a totally different way. Even if I'm going to ask you for help. I've gotten to learn how to take those steps, and be able to one, accept your help or two, go through the messiness trying to figure it out.

Bill Gasiamis 16:19



It's how to help neuroplasticity happen. You're trying to activate neuroplasticity new pathways to generate your ability to do these tasks, whether they are simple or difficult or whatever it is.

Bill Gasiamis 16:38

That's the only way you're going to do it. You have to activate neuroplasticity. And there's only one way to do that. And that's just to be the one who does it no matter how hard or easy, it seems.

Greg Lewis 16:50

Yeah, and it's that and also, what's helped me is my insane desire, and memories to do stuff. Like when I started driving again. All I had to do was recall I mean, not all I had to do, but what I had to do was recall like, Hey, I know I can do this, because I've done it before.

Greg Lewis 17:14

So I can do it again. You know, and it took time. But now I'm in driving and you know, cooking and taking care of the kids and doing what I can in the house while my wife is out working.

Bill Gasiamis 17:34

How old are the kids now?

Greg Lewis 17:35

18, 16 and 13 now.

Bill Gasiamis 17:45

So you guys had a busy household and then you had a stroke and your wife had her hands full?

Greg Lewis 17:52

Oh, yeah. And we were very lucky that my family was in a position to offer the financial help that we needed while she was able to finish school.

Greg Lewis 18:10

I mean, everyone chipped in, they were just like it's too much for you to try to go to school work, take care of the home and take care of him. That's just too much.

Bill Gasiamis 18:24

Yeah, how did the kids manage with their dad being so unwell? Are they able to

work out what was happening to you? Were they curious, how are they responding?

## **My Kids Liked Me Better After Stroke**

Greg Lewis 18:42

First, I think because there were so young it was confusing. Now it's just a part of life, like my son, he was so young when it all happened. He's 13 now he only really remembers me this particular way.

Greg Lewis 19:03

My daughter on the other hand who's a little older remembers what it was like beforehand but they actually both told me that they liked the changes that I made they don't really mind that I'm not as physical because I've been able to approach life differently and really change my perspective and how I show up in my for them and for me.

Bill Gasiamis 19:47

Tell me about how you're different What were you like beforehand? And what are you like now?

Greg Lewis 19:54

I liked to think that I wasn't much different mentally. I came from a very traumatic background or childhood. And I would like to think that I was much the same way I am. And I know I wasn't. And I have to remind myself of that.

Bill Gasiamis 20:19

Were you violent? Were you angry? What were you?

Greg Lewis 20:24

No, I was probably a little more strict. But my kids were all so young. And I've always believed that, the younger they are the more a kind, heart and mind you have to be. Like, hey, you've got to eat all your vegetables, now and that they're older it's kind of like well if you don't like them, you're gonna live.

Bill Gasiamis 20:53

So it's just softened you a little bit. It's enabled you to be a little bit softer.

Greg Lewis 20:59

Yeah, and I always I've always believed that, hey, once they've got those principles instilled in you eat vegetables, because they're good for you.

Greg Lewis 21:08

They'll live by those principles when they get older. But they also can make their own decision, no matter how hard that is for me to understand.

Bill Gasiamis 21:21

Did you make a conscious decision to change your behavior towards them? Or is it just something that happened?

Greg Lewis 21:27

Oh, yeah, I totally had to make a conscious decision. Especially as they've gotten older and more independent, I've had to amazingly, say, hey, look, this is your decision. And I'm gonna stand by you what you decide, even if I don't like it.

Greg Lewis 21:52

And not is not easy. Because you can see when they're making bad choices, you know, excuse me, you know, because you've made them. And there's just some choices they have to make. And ways to learn for themselves.

Bill Gasiamis 22:14

And learn the hard way, I can totally relate to what you're saying I was similar my kids. They were 15 and 11, at the time. And it was quite a difficult time, because then my wife became everything, and she had her hands full.

Bill Gasiamis 22:34

And I'm definitely a different dad compared to the one that I was. And I was quite strict and very unforgiving if the line was crossed, and they heard about it, if they stepped out of line and did the wrong thing.

Bill Gasiamis 22:53

But now it's different, we have a really amazing relationship, and they get to make the wrong decisions as well. And I hate it. But that's the only way they're going to learn.

Bill Gasiamis 23:08

And then at least we can talk about it after at least we can, you know, have a chat and work out what went wrong and how to fix it and how to solve it.

Bill Gasiamis 23:18

And now they come to me for help and support without me asking them or making them. And that's really good. Whereas before they used to avoid me if they could, they always thought they'd be in trouble. And they always thought that I'd be angry.

Bill Gasiamis 23:36

And they were right, I always was angry, and they were always in trouble. But not anymore. It doesn't need to be that way in any way. They're adults now. My kids are both 25 and 21.

Bill Gasiamis 23:49

So there's no telling them what to do anymore. But it was a really good change in the last 10 years that I've been able to adjust the way that I ran the household for example.

Greg Lewis 24:06

Yeah, I know what you mean. And it's interesting in the last couple of years. I'm taking my son to school, I've been able to just have little talks with them, you know, and I'll spout off some kind of principle or something, whatever I've learned.

Greg Lewis 24:27

And he just sat there and listened to it. And so is my daughter and I didn't know they were listening. And then the next thing you know, they're randomly opening up to me in a way they've never done before.

Greg Lewis 24:43

They don't open up to their mom like that. Or rarely, and, you know, or randomly given me hugs, saying, Hey, Dad, I love you. You know, so I get to see that what I'm learning is actually good, it's good. And they're just eating it up.

Bill Gasiamis 25:07

Yeah it is one of the good things that came out of the stroke for me. So what's your mindset like these days compared to what it was like then? Where you a kind of a happy-go-lucky, cheerful type of guy? How did you go about seeing the world back then?

Intro 25:26

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.

Intro 25:36

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 25:51

If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation, stop worrying, and head to [recoveryafterstroke.com](http://recoveryafterstroke.com) where you can download a guide that will help you it's called seven questions to ask your doctor about your stroke.

Intro 26:10

These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery, head to the website. Now, [recoveryafterstroke.com](http://recoveryafterstroke.com) and download the guide. It's free.

Greg Lewis 26:31

I was a very, and I still am a very gritty person. But I think about it differently. I was a very greedy person. Because I believe that even though I had my issues, and I didn't even know what they were before my stroke, never even thought about them that I ended just keep going.

Greg Lewis 26:55

No matter what I remember on one job I stepped down in my car funny and sprained my ankle really bad. And my boss said, hey, you need to go to the hospital. And I said, no, I've got to do this job.

Greg Lewis 27:16

I've got to finish it. I told these people, I would do it, I need to do it. I'd probably still be the same way now. But at least this time, I'd be like, No, I would take a minute to recover and assess the situation. And figure out what I needed to do that would help everyone out instead of gutting through it all.

Bill Gasiamis 27:46

So you're a little bit more considering of the current situation and readjusting and evaluating things, rather than just going for it.

Greg Lewis 27:54

Yeah, exactly.

Bill Gasiamis 27:56

You know what you said about the gritty person that you were, say before the stroke, you know, the way that you would respond to being injured? That sounds like it might have really helped you get through and recover after locked-in syndrome.

Greg Lewis 28:18

Oh, yeah. I mean, holy cow. I remember the first thing I do was wiggle my right thumb. And I remember, it took forever, I could finally do it. And to do it more than once to another in a while. And then I remember being so distraught on my anniversary.

## **Accepting Your Current Situation**

Greg Lewis 29:04

Because all I could do was wiggle my thumb and that was it. I couldn't do anything else. I remember just crying for like two or three hours. And the nurses had no idea why. But I knew why in my head because I wanted to show more.

Bill Gasiamis 29:23

You couldn't tell them that you were moving your thumb?

Greg Lewis 29:28

Well, I could tell him I was moving my thumb. I just wanting to do more to show my wife or my family that hey, I can do more. But I couldn't. And I had to figure out a way to live with that.

Bill Gasiamis 29:46

Did you figure out a way to live with that or just accept the situation as it is? Because it's the most dramatic version of accepting the things you can't change that moment.

Greg Lewis 30:07

I learned how to accept it at that time. And that thought that came to me when I tried to accept it was, it doesn't matter how fast you race, but that you do raise that you show up and you keep going.

Greg Lewis 30:35

Just like what was it tough mudder when the Spartan Races were just starting about that time, and then that same principle, doesn't matter, if you come in person only matters that you finished.

Greg Lewis 30:48

It doesn't matter how long it takes. And, or that you just don't and you do it. And then it's kind of the mindset I had for a long time. And now, anything I gain comes back super slow.

Greg Lewis 31:11

Well, I mean for example, about a month ago, I finally got full motion, or full range of active motion in my left shoulder. And I mean, that took 8 and a half years. So I mean, it does happen, it just happens a lot slower. And that I've had to accept as in, this is just the way it is. And that's okay.

Bill Gasiamis 31:46

What are some of the things that helped that shoulder come back online? Was it physical therapy? What was it? How did it help?

Greg Lewis 31:58

Well, I kind of do my own physical therapy right now. And so it's probably not very good. But it's been going to the gym constantly for about three or four years.

Greg Lewis 32:18

Doing stuff that doesn't feel good I mean, if it hurts too bad, I stopped. Or, sometimes my body just stops for me. You know, when you're lifting something and you lift it up about halfway and then you stop.

Greg Lewis 32:37

But if it hurts a little bit, I just push through and I lean in the pain I go, Hey, that's a good thing. Because now I'm using something I don't normally use.

Greg Lewis 32:50

So I've got to develop that. And working with those pretty little pink, five-pound

weights, or two-pound weights. Even though everybody at the gym is using huge weight it's being comfortable with, Hey, here's where I'm at, that's where they're at so what?

Bill Gasiamis 33:17

It's not really manly is it? It's testing your manliness. But I think it's really simple to just go. We're not here to be comparing ourselves to each other. It's just me getting better, making myself better and going slow and steady.

Greg Lewis 33:37

Exactly. I'd actually like to disagree with you on that. It is testing my manliness nice. Because it's not whether or not I can do what the other guys doing. Or I can lift heavy objects. It's when they're not. I can accept myself as I am. And not been to choose how society views people.

Bill Gasiamis 34:03

Nice. I love it. Yeah, I agree with that. 100%. Now, that's a great way to reframe it. But you can imagine there's some people in the gym going, Oh my God, what's he doing with those pink weights? That's ridiculous. And I know exactly what you're saying. And I completely agree with it.

Greg Lewis 34:22

I think it looks like that all the time. Because I'm going to the gym I walk with a quad cane when I'm not home. And I go to the gym all the time with that. People look at me weird. Like, what is she doing? And I'm just like, I'm doing my thing. You do your thing.

Bill Gasiamis 34:44

What's the reason for the quad cane outside of the house? Is that because it's unfamiliar, and there's more obstacles. What's the situation with that?

Greg Lewis 34:53

It's kind of both, in the house I kind of know where I'm going. I'm comfortable. And something I know for a long time ago, if I'm comfortable being somewhere, I'm okay walking.

Greg Lewis 35:07

I mean, I still have like a foot drop, or I stumble or whatever. But I know I'm within reach if I'm gonna get myself back up. But if I'm out in the middle of



Walmart's parking lot, and I stumble and fall, I'm gonna be okay. But I don't know how I'm gonna get back up. And so there's that.

Bill Gasiamis 35:34

Have you had many fall?

Greg Lewis 35:38

Well, it really depends on how you define it.

Bill Gasiamis 35:40

Okay, falling over onto the ground Greg.

Greg Lewis 35:48

Well, I know what you mean. I just had a medical student explained to me that a fall is going from one plane to another and not knowing how you got there.

Bill Gasiamis 36:02

Oh, okay.

Greg Lewis 36:04

And then a trip is knowing what you did to make you get on a different plane. So I haven't really, I stumble a lot. But I haven't really fallen in a while.

Greg Lewis 36:21

I don't know if you can see right above my right eye. It looks a little funny. That was one of the last times I fell, I fell and cut right above my eyebrow. Right during the height of COVID, too. So that was real fun to get patched up.

Bill Gasiamis 36:40

Yeah, during the lockdowns and COVID and all the stuff that went with it. Yeah, right. Okay. So when you fell, and hit your head and got that scar? Were you're alone? Were you at home? Where were you?

Greg Lewis 36:57

I was at home. I was walking out in the garage. And I have no idea what I tripped over probably my own feet. And I hit a bike or something. Right on the gears and just split it ride open.

Bill Gasiamis 37:17

Wow did you get knocked out?

Greg Lewis 37:21

You know what, I take that back. I was alone. Because I had to patch it up myself. And then drive myself to the hospital. They actually thought I was a little crazy.

Greg Lewis 37:34

Because here I am with a head injury and a cane driving myself in get patched up. But yeah, I mean, I lucked out. I was, besides all the blood, I was okay.

Bill Gasiamis 37:52

Yeah, yeah. I've had a few falls. And now I like that distinction between a trip and a fall, a trip is you know how you got to the other side and a fall, you ended up somewhere and you don't know how you got there. That's a huge distinction.

Greg Lewis 38:13

I don't know if that's correct terminology. That's just how someone a long time ago explained it to me. And I latched on to that. So now when my wife says, oh, yeah, you fall all the time, no I don't.

Bill Gasiamis 38:30

I love it. It's a technicality. And you're gonna use it and accept it, and use it in your favor. I like it. Why not? It's a good thing to know the difference. I've definitely fallen after brain surgery, I fell at home a couple of times. It was pretty dramatic.

Bill Gasiamis 38:50

One moment I'm sitting on the couch, everything's fine. And I got up to take a plate to the kitchen. And as I got up, I couldn't feel my left leg. So it just collapsed and I fell down onto the floor broke the plate and thankfully didn't get too hurt or too damaged.

Bill Gasiamis 39:13

But it's a very common thing and it does impact a lot of people negatively. I know somebody else who had a stroke who fell and broke her leg and then that became a setback a major setback for her stroke recovery.

Greg Lewis 39:29

Oh yeah. And then I have a fall just the other day my family took us bowling and I can't really walk with the ball and so I had to throw it differently.

Greg Lewis 39:49

And I ended up hurting my shoulder my rotator cuff. I couldn't drive the next day and scared the living bejesus out of me now I was thinking I was slipping back, I was really scared.

Greg Lewis 40:06

And then took me a good day to realize that it's okay, you'll be alright. You know, I mean, that doesn't make it really feel any better. But it took me a good day to wrap my head around it.

Bill Gasiamis 40:24

And realize it's not a setback. It's just an injury to your rotator cuff.

Greg Lewis 40:31

Exactly. And that was pretty minor compared to what other people have gotten through.

## **Driving Again After A Brain Stem Stroke**

Bill Gasiamis 40:40

How long did it take for you to get back behind the wheel of a car?

Greg Lewis 40:49

Two, maybe three years. Funny thing is I can just move my feet fast enough. And but I had most of my mental faculties around, like I could look around and pay attention and whatever you need for driving, I can do that.

Greg Lewis 41:16

And I think that's mostly because I spent 10 years driving every day all around town for 10 hours. You know, going from call to call. So I think it was just so ingrained, I was able to redirect traffic with neuroplasticity a little bit.

Bill Gasiamis 41:40

So what's it like getting in the car for the first time? I imagine the doctors have said, Yep, Greg, you're allowed to drive. And you get back in the car for the first time you're behind the wheel. What's that like? Was it exciting? Was it scary?

Greg Lewis 41:56

Well, actually, there was a little snafu that happened with that they were

supposed to take my license. And they never did. So I could have gotten back in the car on day one.

Greg Lewis 42:10

But I knew I couldn't do it. And my wife knew I couldn't do it. And even when I finally you know, when you're first learning, and you take that Driver's Ed test, driving test, I finally had someone do that for me.

Greg Lewis 42:28

And he convinced my wife that, hey, this guy is okay. He's doing really good. Excellent driving. And she didn't really trust me. I had to go on little trips first to build it up.

Greg Lewis 42:50

But oh, man did feel good. Because I felt like I finally had something to offer you know, I can take the kids to school. I could go to the grocery store. I could I don't know drive to get dinner if need be.

Bill Gasiamis 43:12

And was there any mobility scooters involved? Before that? Did you have one of those little golf carty things to get you around and help you get around?

Greg Lewis 43:23

I didn't own one. But I had one even after I started driving. I used them when I went to storage for a long time. But then one day, I just went no, I'm not going to use these anymore. I'm gonna walk around the store.

Greg Lewis 43:38

And no matter how long it takes, this is going to be my exercise for the day. I mean, my mother in-law would laugh at me, because she can track on your phone where you're at.

Greg Lewis 43:52

And she goes I can see you going up and down on the map at the store. So I know you're going up and down the aisle. You know, and she's like, you're there for like, two, three hours. Like, yeah, that's how long it takes.

Bill Gasiamis 44:08

Yeah, but you do it regardless. So if your wife says go get some bread and milk.

She has to say that first thing in the morning so she can make sure that you're back by lunchtime.

Greg Lewis 44:19

Yeah, pretty much.

Bill Gasiamis 44:23

Why does your mother-in-law track you?

Greg Lewis 44:36

That was something I didn't know until that time that my wife put on my phone. It was like a little tracking app you can use for kids as soon as she told me that I found and deleted it. But it was still pretty funny. It was simultaneously scary. But nice to see that everybody was so concerned about me.

Bill Gasiamis 45:03

And they were really looking out for you, they really wanted to know, in case you fell out in public and they could get help to you, etc.

Greg Lewis 45:10

Exactly. And I just said, Hey, look if I can do this on my own, I'm gonna be able to get to my phone on my own and let you guys know what's coming up. Let you know what's going on.

Bill Gasiamis 45:22

So it sounds like you have a good relationship with your mother-in-law, though.

Greg Lewis 45:27

Yeah. Like I said I had a fairly traumatic childhood. And when I met my wife's parents, we just seem to click, we have very similar personalities and attitudes toward life. And they were always there for me through the stroke and after everything and it's kind of they're a lot like actual parents to me.

Bill Gasiamis 46:04

Yeah, that's lovely. So your childhood also, sounds like it's set you up for being able to be gritty, and also get through this really tough time. If you've been through tough times.

Bill Gasiamis 46:17

And you know, what it's like to be going through them. It probably gives you some

really good tools to get through something as serious as being locked in and having had a brainstem stroke.

Greg Lewis 46:31

Oh, yeah. I mean, it did give serious tools to help get through everything, but it also gave me a whole slew of problems I've had to figure out. Some of those men worse than the stroke.

Bill Gasiamis 46:51

If some of those problems rear their ugly head did they sort of come back to bite you on the bum?

## Using Food For Comfort

Greg Lewis 46:58

Oh, yeah. And just, for example, like my relationship with food, and I used food to regulate my emotions and stuff like that. And the next thing you know, I put on over 100 pounds.

Greg Lewis 47:15

And then when I finally figured out why I was doing that with food, I was able to get rid off almost 100 pounds by but it took me in realizing that hey, this from my childhood, because I've always been a bigger kid. This is from my childhood this is why I'm eating constantly. And this is why I'm eating this stuff. Because I hide my emotions in food.

Bill Gasiamis 47:46

So you feel a certain way and therefore you reach for a certain thing that makes that feeling go away. Does it just quiet that feeling? What does it do to that feeling when you reach out for that certain food? And what's your go-to food?

Greg Lewis 48:05

It's been so long since I've done this. I can't remember. I just can't remember the exact food. I will tell you what my weakness is. Cinnamon Bears. Those get me every time. But oh man, I can't remember your question.

Bill Gasiamis 48:29

My question was, so that situation with emotional eating? Do you feel the feeling? And then you reach out for something, you eat that thing? And then what happens

to the emotions? Do they go quiet? Do they get forgotten about? How does it help with the feeling that particular emotion that you're not enjoying?

Greg Lewis 48:55

It gives a little bit of comfort. And then it's a temporary relief. It's kind of like, oh, yeah, I feel a little bit better. I feel a little bit comfortable. And then it goes away. So you eat more.

Greg Lewis 49:11

And then yeah, that feeling come back. And you do that basically until it goes quiet, settles down, or you deal with the emotion and dealing with the emotion is the more permanent way. But it's also the harder way.

Bill Gasiamis 49:32

It's painful. Yeah. At the time. But then there's a certain amount of relief after that as well.

Greg Lewis 49:39

Exactly. It's painful to you. It's been pulled to who's ever involved. But yes, the relief is there, and it's more permanent. And when I would eat to get rid of my feelings?

Greg Lewis 50:03

I would still feel the weight of the emotion. But it would be temporary relief when I actually looked in the emotion, digested and really dissected it the weight was lifted off my shoulders.

Greg Lewis 50:26

So it wasn't just okay. I'm doing all right. It was more like, all right now I'm really seeing who I am. And when I'm willing, not just able to do but willing to do.

## **Wired For Love**

Bill Gasiamis 50:45

Yeah. Did you get help deal with those emotions? Did you go to counseling? Or did you deal with that on your own? Did you work out how to do it on your own?

Greg Lewis 50:57

At first, I started out on my own. But I go see a therapist. And unfortunately, it's

not often enough. What we do talk about stuff. She's given me some really good books to read.

Greg Lewis 51:16

Stan Tatkin. His book I think it's called Wired For Love. Excellent book. It sounds a little funny. But it's more about you. How you come to the table, and how other people are probably perceiving that and what is making you come to the table like you're doing. And then it's a total game-changer. Because he doesn't write it to his peers. He writes it to the everyday average person so they can understand it.

Bill Gasiamis 52:01

I've just looked it up here. And it's Wired For Love: How understanding your partner's brain and attachment style can help you defuse conflict and build a secure relationship. By Stan Tatkin.

Greg Lewis 52:15

Yep, Stan Tatkin and one of the reasons why I really vibe with this book is I've listened to just about every podcast he's ever been on. And he has been through it. He hasn't had a stroke or anything. But he's been through a lot of trauma. He's been through hard times in his life.

Greg Lewis 52:40

He's been through total life changing things, and he's come out of it better. And figuring all this stuff out. And he wants to help everybody else feel that same way. And I know it's really helped me. It may not solve the problems, but at least I know what the problem is.

Bill Gasiamis 53:00

Yeah, that's a great thing to know the problem because then when it's about to happen, you know, oh, my gosh, that's about to happen. And you can somehow intervene. Without food and you can start to find like circuit breakers, you can start to find circuit breakers to help you get better at finding circuit breakers, whatever they are.

Greg Lewis 53:26

Exactly. And you know I mean, the problem, what is it? The devil, you know, is better than the one you don't know, you know, on the problem, you know, if it's known, at least you know what it is. And then you can figure out how to dissect that problem. But if you don't know what it is, you have no idea how to attack it.



Bill Gasiamis 53:57

How to tackle it how to take it down, well, I mean, it sounds like you've learned a lot after your stroke sounds like you've actually grown as a human being and you've become wiser to the world.

Greg Lewis 54:18

I hope I have I've followed a lot of people and they're really big into the self-help and, and I've noticed something in the teachers that are really good. They're all saying the same thing, just a little bit differently. And find the one that you vibe with and then learn it and apply them because they're universal principles that these people are teaching.

Greg Lewis 54:46

And why once you figure out those principles, and you start living by them as best you can. It's a slow change, but you'll notice how in your life changes But the biggest and quickest change is yourself how you approach stuff. And you just have this new Hey, I know what's going on. I know what I can do. And I'm going to approach life differently. And how you show up in life really determines how, let me put it simply, you don't react to life, you act instead of react.

Bill Gasiamis 55:36

Instead of being passive, you're actually active and you're moving towards the version of life that you want, rather than reacting to a life that's not the one that you want.

Greg Lewis 55:49

Exactly.

Bill Gasiamis 55:52

So what's your purpose these days? What's the next nine years gonna be like? What are your goals?

Greg Lewis 55:59

The next nine years, I honestly have no idea. I've spent a long time praying and trying to figure out what my purpose in life was. And I always got patience. Just be patient. It'll come it'll happen. You know. And I finally realized that me being the best I can be and constantly improving, and just showing up every day is going to me enough for whatever might happen.

Greg Lewis 56:36

And you know how I can show up, I'm showing up for my kids. I'm trying to be their dad, I wanna be a good father, I'm trying to read pull my weight around the house. I mean, you know, my wife's got enough on her plate. What can I take off that plate? And, you know, she gives 100%, I have to do that too just my 100% may look different than hers.

Bill Gasiamis 57:24

That's all good. So it sounds like learning patience. Were you a patient person beforehand?

Greg Lewis 57:36

I thought I was.

Bill Gasiamis 57:37

But you weren't?

Greg Lewis 57:42

I think I approached differently. And I thought I was patient. But I think I was I just look at it totally different now.

Bill Gasiamis 58:03

Yeah. I feel like patience is something that gets thrust upon you. Like, my experience was, I never thought it was worth going through the long process of, for example, getting a, you know, a degree of any sort of a university degree, you know, what's the point of doing four years to get to that point, you know, it's too long, it takes too long.

Bill Gasiamis 58:31

But the truth is, all good things that, that you're you have to build that you build, take time to develop. And you've just got to go through the steps. And if you're able to go at a certain speed, well, your steps will take as long as they take and if you're able to go. And if somebody else is a bit quicker in the way that they do things, or slower, it'll take as long as they take. And patience is a great thing.

Bill Gasiamis 58:58

Because for me, anyway, I've learned that all I have to do is a small amount every day, I don't have to do large amounts. And then I have to just reflect on how much I've done in the last two days. And then in the last week, and then in the last

month.

Bill Gasiamis 59:14

And that little bit, just little bit, little bit a little bit adds up to being something really massive in a year or two or two years. And it doesn't matter that it took two years but it just matters that we're doing those little bits towards the goal. And eventually, we chew off enough that we've got to the end of that, and we just have the last bite.

Greg Lewis 59:39

Yeah, exactly. There was one thing I was learning from one guy who's not even in the self-help realm, he would just always say, if you're just a little bit better than than yesterday, one day and that'll make a huge difference. And he goes and he said in the context of you knew 10 10 Push-ups today, maybe you do 11. That's still better. And still more. And I was saying that in the other name is someone more is more. I mean, if you take three steps forward and two steps back, you're still pouring one. You're still going forward.

## Having Something To Share

Bill Gasiamis 1:00:20

Yeah, I agree with them. Greg, thanks so much for reaching out. What made you reach out to be on the podcast? I know, I put it out there. And I asked people to come on board. But what specifically made you reach out? It was quite a lovely email that I received from you. It was fairly, it was fairly long. What was it that made you reach my knees?

Greg Lewis 1:00:43

I honestly don't know. I have just been listening to your podcast. And it was the first one I never really heard about it, or her likeness. And I honestly I can't remember which episode I listened to. But I just finished the episode. And I saw that oh, hey, I can reach out to you. So I did it.

Greg Lewis 1:01:15

And then ever since I send that email up. I've been 100%, doubting myself, every day. I am just been going there's no way I can do this. You're not special. And well, I know I'm not special. I was like, No, I've got something I can share. Got to have something. I'm sure that's what everybody else was feeling like, what am I

going to share? What am I going to do? And I just realized, you know, after nine years, it's time to break the silence and share something speak out.

Bill Gasiamis 1:01:57

Yeah. I really appreciate the fact that you do that. I'm telling you now, there there are stroke survivors that have had a brainstem and that have been locked in, that are listening to this right now. And they are they are lapping it up. They are saying this is fantastic. This is exactly what I want to hear. The great thing about it is that you are nine years down the track.

Bill Gasiamis 1:02:19

So there's an unbelievable difference between being locked in and being where you are now. Oh, yeah. And people need to know what the future for, for locked-in syndrome sufferers is going to be like, because it's not going to be locked in forever. It's really important that you came on and share this so and you're not special. And none of my guests is special. I'm not special. But what we do is special sharing the stuff that we share that is special.

Greg Lewis 1:02:52

Exactly. You know, I just want to share something. I'm always had this feeling that I need to be smart and profound. And have everybody think that and that something from when I was a kid that I used to think and not still with me every day and I'm like, I don't have to say anything profound I don't have to think it's profound.

Greg Lewis 1:03:20

It can be just something totally average that I think that someone else finds profound, or, or smart or whatever. You know, beauty is in the eye of the beholder. Absolutely. So what this art means to me, it may mean something totally different to you, but it still is the fact that I hold the meaning.

Bill Gasiamis 1:03:43

Yeah, And you know, that thing that you said that seems benign to you could be the thing that somebody has been waiting to hear for such a long time, and it turns their recovery around. And the reason it's benign to you is maybe because you had the lesson you learned from that you move on and now you're nine years down the track. So now it kind of seems like everyday life. It's a run of the mill.

Bill Gasiamis 1:04:13

But when you first heard it, it was like, wow, I needed to know that that was amazing. And that is what I find a lot of people get, and they contact me like you do, because they've been listening for a year or two. But it was that episode it was that question. It was that answer that made him go well, I need to reach out or do something or speak to somebody or, or make a change.

Bill Gasiamis 1:04:40

And that's why we have these conversations. And they're always a similar format. You know, we've talked about what happened at the beginning, so that people can understand that it's pretty shit at the beginning. And then we talk about what it's like a little bit after, and how things start to improve. And now that you're nine years down the track Man, and you're still getting improvements in your shoulder. That's amazing.

Greg Lewis 1:05:08

Yeah, I couldn't even walk after a year, or just barely with a walker. And they're like, well, all the doctors like, well, that's all you're gonna gain. And I said, this isn't all I'm gonna gain. There's no way this is not all I'm gonna gain, I will not let it happen. And whether I gain it physically or mentally, I didn't care. I just knew I'd be more.

Bill Gasiamis 1:05:36

Yep. On that note, thank you so much for reaching out. And being my guest. And also thank you so much for reaching out and sending me the email that you did. I really do look forward to them. I love it when people reach out and send me emails and asked to be on the podcast. It just, that's exactly why I set it up to give people like you the platform to express yourself after nine years. And to break the silence.

Greg Lewis 1:06:06

Oh, yeah, I'm so appreciative of your podcast. I'm randomly look it up one day. I am never searched for podcasts like this before, randomly searched up, and I fell in love with it instantly. And it's just exactly what I needed there. And I mean, you're out there doing it. And that's what people need.

Bill Gasiamis 1:06:31

Yeah. Thanks, again for being on the podcast.

Greg Lewis 1:06:36

My pleasure. Thank you for having me.

Bill Gasiamis 1:06:39

That's a wrap, Greg. We've done it, mate. We got to the end. toilet breaks. All sorts of things happened during that interview. But it's all good. I'm going to edit this. And then I'll send you an email that you know that it's done. And I'll also put you I'll tag you on Instagram.

Bill Gasiamis 1:06:59

And then we can chat about it. Feel free to reach out anytime I'm more than happy to chat with you at any time about anything. Send me an email, whatever you like. And if you need to stay in touch, please do.

Greg Lewis 1:07:12

Oh, yeah. Thank you. I will. Oh, for Instagram. I have a totally different handle. I don't go by my name. I go by 22Cheapster. It's a little different. It's not centered on the stroke.

Bill Gasiamis 1:07:38

Okay. Okay. Done. I've followed you. And I'll tag you. When the time comes probably about three or four weeks away, I'd say because there's a few that I've done. So it's about three or four weeks away before it's ready.

Greg Lewis 1:07:58

No problem. Take Simon. Thank you.

Bill Gasiamis 1:08:00

My pleasure. Be Well, man, all the very best.

Greg Lewis 1:08:04

Right you too. Thank you.

Bill Gasiamis 1:08:10

Well, thank you so much for joining us on today's episode. I hope you got a lot out of it. I learned something that's for sure. I hope you did. And isn't it just a treat to hear somebody who was locked in from a serious brain stem stroke, speak and tell his story and tell us how he's coming along in recovery.

Bill Gasiamis 1:08:30

Unfortunately, brain stem strokes seem to go hand in hand with locked in

syndrome. And at least people are getting through them and overcoming them and getting back to life. And this is a real amazing thing for me. And I really hope that it inspires you as well. Now, if you're watching on YouTube, and you can please leave a comment. I'd love to read comments from people.

Bill Gasiamis 1:08:58

And if you're watching on YouTube, and you want to get notified of new episodes, hit the notification bell. And also hit the thumbs up, give it a like and let the YouTube search engine also rank the show better and give the podcast access to more people so that they can appreciate the amazing stories that the stroke survivors are sharing about their recovery and also the caregivers, because there's a few caregivers that have been on the podcast and they also need information and hope about stroke recovery.

Bill Gasiamis 1:09:33

So if you can interact with the YouTube video as well, I would really appreciate it it'll make a massive difference. So thanks so much for listening again. I really appreciate you being here. Thanks so much for supporting the show and for commenting and for sharing the episodes and letting people know about the podcast and that it exists. I love being here for you. I hope that you love the podcast. asked as much as I do to Thanks for being here, and I'll see you on the next episode.

Intro 1:10:05

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Intro 1:10:23

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#### Intro 1:10:45

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#### Intro 1:11:07

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#### Intro 1:11:24

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