

A Brain Aneurysm That Burst At 40 - Claudia Faulkenberry

Albert Rand Faulkenberry was watching TV when he experienced a hemorrhagic stroke due to a ruptured brain aneurysm and that's about when Claudia Faulkenberry became the caregiver to a stroke survivor.

Socials: www.instagram.com/braineurysmlife/

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Transcription:

Claudia 0:00

Yeah, while there were a lot of personality changes, his personality is different, his likes are different, his responses to things are different than they were before. And we were married for three years before he had a stroke. So we weren't married for very long and had newborn twins.

Claudia 0:21

They were nine months old, but when he had a stroke, so I had figured out how to be with this new person. And we went through, he came home in a wheelchair, he came home in a hospital bed, we were transferring and bathing and not to be too, you know, wiping and going through all of that, as a newly married couple in all honesty, I mean, you know, three years in is not very long.

Claudia 0:56

And we were trying to figure out how to be married to each other before all of that happened, especially with kids and then to have that kind of come in with a challenge.

Intro 1:08

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

Introduction



Bill 1:21

Bill from recoveryafterstroke.com This is Episode 119. And my guest today is Claudia Faulkenberry, as a mom of nine-month-old twin girls. The last thing Claudia imagined was that Rand her husband of just three years would end up also being dependent on her full time due to a burst brain aneurysm.

Bill 1:45

Now before we get started, if you have ever wondered what else I can do to help you with your stroke recovery, you should know that you can now get recovery after stroke coaching right from the comfort of your own home. I too am a three times stroke survivor and brain surgery survivor.

Bill 2:00

And I have built for you what I was missing when I was sitting home from hospital in the hopes that you don't have to do stroke recovery as tough as I did. Support packages give you access to a variety of tools 24 hours a day, seven days a week,

so that you can also work on other areas of stroke recovery that you don't get the chance to at physical therapy, or rehab.

Bill 2:23

With tailored support available for less than \$8.50 per week, all recovery after stroke support packages, bring stroke recovery to you in the comfort of your own home. To try out recovery after stroke support and see if it is right for you. You will also get the first seven days free as well as a 30-day money-back guarantee no questions asked.

Bill 2:44

As a bonus, you will also get to face to face zoom support calls with myself to take your recovery to the next level. Go to recoveryafterstroke.com/support to sign up. It won't cost you anything for the first seven days, and you will get a full refund. If you're not happy after 30 days. You have nothing to lose and everything to gain. Now it's on with the show. Claudia Faulkenberry, welcome to the podcast.

Claudia 3:11

Thank you happy to be here.

Bill 3:13

Yeah, happy to have you. My wife, I reckon has competition now because I was definitely hard her in the running for the award of best wife for a stroke survivor ever. But you're very, I don't know, you might convince me but right now you're very close second.

Claudia 3:34

Oh, well, thank you. Thank you. You might want to ask my husband about that. But yeah, thank you.

Hemorrhagic stroke

Bill 3:41

Tell me a little bit about what happened to him. What's his name?

Claudia 3:45

Rand. Well, his first name is Albert. But he goes by Rand his middle name. And he had a hemorrhagic stroke on the evening of January 27, in 2015. So he was working the night before, had a really late night and then I had gone to bed. He

was up watching TV and the dog woke me up.

Claudia 4:08

And later I realized he was having a grand mal seizure and went to a very nice University Hospital down the street from us and had multiple surgeries and spent a lot of time there.

Bill 4:22

Was it dramatic in that situation at that time was a dramatic or was it pretty sort of calm. Did you have time or was he out?

Claudia 4:33

No it was, we didn't even realize what was going on, the emergency team came. He ended up actually having recovering very well and responding very well to the point where they laughed and said, if you don't feel better, I will come back.

Claudia 4:51

So he was complaining as we went to bed of tingling in his hand and a really bad headache. And so we called them back in and he went from there. By the time He got to the hospital he had. And before he could get in and just do a coil, he had a second bleed.

Bill 5:07

Yeah. Right. And it was an aneurysm that burst.

Claudia 5:12

Yes.

Bill 5:13

Did he ever have any symptoms, any idea that that was sitting in his head?

Claudia 5:18

I know, we, we think back and notice a couple of different changes that happened. He had some blood that started appearing in his eye, and we just kind of blamed it on allergies. And he was having some headaches. But again, we were kind of blaming it on lifestyle and allergies. And we had a couple of episodes of high blood pressure, but it all kind of, you know, if they put a new cuff on, and he sat down for a little bit, it was fine.

Bill 5:46

Those symptoms and those things that happened are sometimes things that we can look at, in hindsight and say, maybe that was related to the stroke. But sometimes, maybe it wasn't. And did you find yourself going back and going, that definitely was something that was related?

Claudia 6:02

No, I mean, we just kind of discussed it a little bit, but there really were no, two signs now. lifestyle-wise, we own some restaurants and a bar, and she was getting up early to work really early at the restaurants. And he was staying up really late to work late at the bar. And you know, I think that had a lot to do with that as well. And then genetics is my thought.

Bill 6:28

Yeah.

Claudia 6:30

I have thought about getting them tested to see if there isn't any sort of genetic link, because they're coming up with more and more genes that may be a sign of a increased risk for an actual rupture. But I haven't found a place to do that yet.

Bill 6:44

Yeah, I'm sure there'll be one is, there'll be one in the next two or three weeks that'll pop up. They seem to be happening more and more. That's one of the really good things that's happening now with the stroke recovery, stroke survival, preventing stroke and finding causes for stroke that previously weren't unable to be found.

Bill 7:05

This new technology is just changing the game. And it's happening really quickly. And it's making a lot of difference for people who are going through that, that what if it happens again, I don't know what caused it and the anxiety that is created for people that not knowing about how they got into this situation in the first place.

Claudia 7:24

We've asked a lot of questions. We've asked a lot of medical staff, especially as it was going on, and we felt like it was not, you know, everybody just said it's genetics. It seems to be all we can answer at this time. You had a weak area. A lot of people have weak areas, and they don't ever rupture and unfortunately, his did.

Bill 7:46

Yeah, sometimes it's that way. That's what happened to me. Mine wasn't an aneurysm. It was a faulty blood vessel. So it was malformed. So that means it couldn't cope under the regular process of blood pressure, not the high blood pressure, low blood pressure, just the regular blood pressure was too much for it.

Bill 8:06

So in the end, it just gave way and it popped. It's one of the smaller ones. But it was genetic. I was born with it. And for a lot of people, these things that I had, which was called an arteriovenous malformation. They hang around for a long, long time. They stay benign, they do nothing for some people they pop and they don't only appear in the head, they don't only exist in the head AVMs can happen anywhere in the body. And I imagine that's similar to aneurisms because you hear some people have an aneurysm on the blood vessels around their heart or near their heart. Luck of the draw.

Claudia 8:45

Yes.

Bill 8:47

It's a draw you don't want to be in, but it is the luck of the draw.

Claudia 8:51

It is well I tease him and tell my husband that you know he's a bull, people have tried to knock him down and he just gets right back up and keeps going. So I don't know that anything will ever take him out. He'll live forever. It's great. I mean, he really has done an amazing job of recovering.

Bill 9:12

So how badly affected was he during that hospital stay and then and then the short time after hospital what were the symptoms that he was experiencing?

Claudia 9:22

Well, they because of his ICPs being so high and the hospital the majority of the time we were there he was pretty much comatose they had pretty much put him in a an induced coma throughout that. They threw everything in the kitchen sink at him during that time.

Claudia 9:38

A lot of fluid issues in the brain a lot of problems with balancing everything. He ended up having a sculpt back on early just because of all those problems. Went to a Shepherd Center here in Atlanta, which is a fabulous center for brain and for spinal injury and I'm he was very, very out of it horrible left side neglect, wheelchair, had a lot of trouble with hallucinations and understanding everything that was going on around him.

Claudia 10:13

Decided that we had two sets of twins, twin girls and new born twin boys, which we don't have, and had four dogs, I was very busy in his life, in his mind. And that took time. But as time went on the brains had an amazing job of really fixing and healing about, we had some difficulties, because everybody kept telling me to go with that and to go with the flow.

Claudia 10:41

And to just keep saying, uhuh, uhuh. And I had made a promise to him when we were doing our vows that we would not lie to each other. Even if it was the hardest thing to say to somebody, we would always be as honest with each other as possible. And I think that's something that's really served our relationship well, in all of this that's going on, it's not always the easiest thing to do.

Bill 11:01

So when you're being honest with him, and saying, darling, you're imagining our kids and 25 dogs and all that stuff, what was he coming back with?

Claudia 11:11

He kept saying, but I know, I had names for the twin boys, Andy and Jacob, we just brought him to work in his mind to show everybody all of his friends in New York, and it must have been something that was going on in his mind while he was in that induced coma, because he had an entire story together.

Claudia 11:30

And we actually have really good friends. And we only allowed one of our very good friends into the neuro view, you know, intensive care unit with him. And she has a husband named Andy and a child named Jacob. And I think that's where he got the names of the kids.

Claudia 11:48

And they were very good friends in New York. So I think that's where that came

from, too, but it comes around. I mean, he was seeing robots and samurai swords, and all sorts of craziness. And then the left side neglect, because the way the brain bleed was, you have a lot of trouble losing things.

Claudia 12:08

So something you would see and then would disappear. And then he would see it and see it disappear again. And that was very hard for him to to grasp and understand. But that seems to have corrected itself. As well, again, the brain has been fascinating to me.

Bill 12:25

Yeah. So a lot of that would have been as a result of the secondary part of the impact of the brain. So the bleed usually affects, you know, one really precise point where the bleed's occurring, and then there's this outer area that gets affected it kind of is collateral damage to what happened in that little section, then that's the first thing that comes back online, this outer area that's been impacted, but not damaged, severely.

Bill 12:48

And then as recovery and healing and inflammation decreases. It comes back on and you get these things come back. But what's really important is how quickly you get somebody back to the hospital, and how long that outer area was out of action and starved of oxygen or interfered with.

Quick emergency stroke treatment

Bill 13:04

So the quicker you can get somebody at a hospital the better. How quickly Did you guys end up getting into hospital? I know that you had some care, someone came and had a look at him and then said to him, you'll be right. But then how quickly after that, did he end up going?

Claudia 13:17

Oh, I think we call them back within an hour, it was not very long. And so they came back in and I asked him a bunch of questions he walked out of our house told me where his keys were to move his car and all that, call my parents get them over here, blah, blah, blah.

Claudia 13:32

And we actually live less than a mile away from the hospital. So once the ambulance got there and got him in now the process of scanning him and looking at it and then deciding to coil and then by the time they were ready to get them off to the OR coil him and having a second bleed.

Claudia 13:52

You know, there was more time within their hours. You know, but I think having such a fine institution right down the street from our house really saved his life and made it so that he can be back at work and walking and driving and all those things. And then obviously, the rehab center that we went to.

Bill 14:12

Yeah, and obviously you.

Claudia 14:16

And his parents and our children, there's a lot that goes on. It takes a village, right?

Bill 14:22

It sure does. So what was it like for you though? Was it scary? You seem like a very upbeat, positive person. And you probably pushed through most issues and dramas in life. But was it really like?

Claudia 14:37

Terrifying. I knew it was brain thing by the time he was leaving. And I was worried it was a brain tumor. In all honesty, I work in cancer in the medical field, and so I of course went to a brain tumor. By the time they told me it was a second bleed I broke down. I lost it. I knew with the first bleed that there were chances of him leaving within a few days even of being in the hospital and just needing a little bit of rehab.

Claudia 15:06

But by the time they informed us of the second lead I lost it. And I knew he was never going to be the same. I mean, that was the biggest thing. So I had a lot of ups and downs. There was I remember a wonderful woman whose husband was in the room next door, who came over and sat with me.

Claudia 15:29

And there was one day I just completely fell apart. It's gotten much easier over

the five years. But I will be very honest, there were some really tough, tough times, and I did not always keep it together.

Bill 15:45

Who did you call on to get you through those tough times your husband's out of action? Who do you call on?

Claudia 15:52

We luckily have a wonderful support system here. And then from where I'm from, as well, we had people coming out of the Woodworks from every direction, which was wonderful. I had caringbridge set up and I had meal train set up. And I had people who would just come and sit next to me.

Claudia 16:13

I have friends who left their families and flew in and stayed with my kids and our house to help us get through all of it. It was an incredible, beautiful thing to see and experience, especially now when I look back on it. I've tried to thank everybody 1000 times, and I know I haven't done anywhere near the thank yous that I should have as a good Southern woman.

Bill 16:39

Just tell them, thank you and then just multiply it by infinity. So you don't have to keep saying it.

Claudia 16:45

Yes, definitely. And I had moments of realizing everything that went on and happens and that I'd forgotten about too. So luckily, our kids were really, really young. They don't remember any of it. I mean, they remember their daddy being in a wheelchair. And they remember kind of having some hard times and the name for my Instagram page braineurism is our daughter's saying that that's what their daddy had was a brain aneurysm.

Claudia 17:10

So that was kind of cute, fun name that I went with. But there's still times that I cry. In all honesty, there's still times that it's hard. You know, we went from having a very tight partner in life that really was taking 50% If not, sometimes more of the load. And all of a sudden you find yourself doing it all and having to take care of somebody it's really tough.

Bill 17:38

So it's good for the kids that they were young, but you're a mum looking after really young kids, and now caring for your husband, and you're not a carer. In the definition of a carer, you're not a caregiver, until really, you come home. And now you've got all the tasks to do you've got everything on your plate. What was it like? trying to juggle everything and be there for your husband? Did you experience any feelings of guilt or pushing yourself too far? Or was there any challenges like that?

Claudia 18:12

There were, we hired a nanny to come help with our girls. We felt like that's what we needed to do. And she was fantastic. If if there was something that God sent me, it was our nanny, she was wonderful. But I definitely felt like she was raising our kids. And I wasn't necessarily I had to be the breadwinner, obviously.

Regaining fine motor skills after stroke



Claudia 18:31

So I had to go to work. I needed the insurance so I was working before all of this, I had to stay working. And then a lot of times the tasks that had to be done at home were all on me as well. So it was tough. Luckily, one great way to rehab your loved one is to give them things to do around the house.

Claudia 18:54

So Rand took on some of the things pretty early on of washing clothes, and you know, getting back involved in cooking, and we're really pushing that with him,

especially something I have to be there with him for but working closely with that to get more of a partnership going again.

Bill 19:16

It really is part of the rehabilitation. I remember being in rehab, and they took us into a I was in for a month and they took us into a kitchen and they made us make our own breakfast. And at the beginning I was so annoyed because why am I making my own breakfast I'm in a hospital, they should be making me breakfast.

Bill 19:33

But I didn't realize it's part of the rehabilitation process. And they're assessing us the whole time to see how we can manage at home to cook a meal or have a tea or do anything like that. So it was interesting. I was frustrated but it hadn't occurred to me that it was part of the rehabilitation. I just thought they were making us make our own meals I thought it was nuts.

Claudia 19:59

Sounds like my husband the first time they asked him to put a shirt on, he looked at them like they were crazy. Been putting my shirt on for decades. Why do you need me to put a shirt on? And then he did it and they rolled the mirror in front of him. And he had missed half of his body with the shirt. And he realized, maybe I need a little bit of help with that.

Bill 20:19

Yeah, so gets him to understand that your training has to go into your hand and those little fine motor skills, that put a button into a little tiny hole on a shirt and make sure that it's straight.

Claudia 20:31

It's still tough. I mean, five years later, it's still really tough for him. He's was left-handed before the stroke, and so having a right side bleed, put the left hand in jeopardy, and he's really learning as much as he can with his right and his left, but it's been tough.

Bill 20:52

What kind of deficits does he still have five years later?

Claudia 20:56

Memory is a is a big one. Memory is really tough, short term memory. And we did

some evaluations to find out that he's not coding the memory. So I learned communication made it very difficult. So I learned to communicate with him that I needed to tell him something three or four times in a very short period of time just for that code in his mind.

Claudia 21:17

And it usually works very well, sometimes it doesn't. But for the most part, he's still got a left side deficit got a lot of pain, as well, some spasticity that he deals with. Sleep issues can still be a problem. And then every once in a while, in addition, like not fully paying attention to that left side and having some problems leaving his arm out of a sleeve or cutting a corner to close, but not nearly as bad as it used to be.

Bill 21:54

How old is he?

Claudia 21:55

He is 45, he turned 40 in the hospital.

Bill 22:01

Yeah, so I'm 46. I had brain surgery in nearly six years ago. In November, it'll be six years I was 40. And I still have trouble with that stuff as well. So I don't have left-hand deficits that anyone can see. But my hand feels numb, and stings and burns and does all of that stuff.

Bill 22:22

But then when I get tired, and if I'm not aware that I've just become tired, I will tend to lean towards the left. So when I walk through a doorway, if I'm not paying attention, I might bump into the top of the doorframe. And sometimes when I get to take my pants off, I'm one of those really, I do two things at once I take my pants off and my socks off at the same time.

Bill 22:52

This amazing skill, right? But sometimes if my left sock doesn't come off my left foot, I won't know that it's not off. It feels weird, it feels strange. And if I don't make myself look down, I might get into bed, or wherever, and not know that that sock has come off my foot or is still on my foot.

Bill 23:15

So there's some of the things that sort of still hanging around. But that have got better and better as time goes by. And but what I think I've noticed more than anything is that I'm noticing my deficits less. So if I'm having a productive day where I'm doing things speaking to people going places, I'm noticing them less, which means maybe I'm getting used to it more. Or I'm finding ways to adapt and get around them.

Stroke neurological fatigue

Claudia 23:46

I believe Rand's adapting, he's finding different ways to kind of move around and understand and a conversation was difficult for him initially, especially multiple conversations. So socially, we were used to big parties and going a lot of places and he would find himself sitting I would find him or he would find his way into a corner and just kind of sit because it was overwhelming for him.

Claudia 24:11

So being able to communicate and listen and make sure he's not interrupting and staying on the same topic and, and really understanding the conversation we found, in the beginning, had to be more of a one on one, just another couple coming over for dinner. And even in that meal, he might get up and go into the bedroom and just lay down. He just couldn't handle it and wouldn't even realize he was really doing it. It just was something that he knew he needed to do.

Bill 24:40

Yeah, it's just brain overwhelm. It's just too many inputs coming in at the same time while the brains trying to recover while the brain is trying to heal while it's trying to work out what's going on with all the missing bits and all the things that it needs to rewire. So it becomes overwhelming and then also becomes energetically tiring because that takes a lot of physical energy.

Bill 25:03

Because it just does, I'm not exactly sure why but the brain is the one of the biggest users of energy in the body. So when it's trying to do too much and trying to recover at the same time, it can't cope, we're trying to do the same tasks we did before with a portion of our brain not actually there.

Bill 25:21

And therefore, it's, you know, finding all these difficulties. So the best way to help is to go and step away from all the external issues, the things that are causing that challenge, and then go and rest. And even sleep it off and then recharge the brain get more energy, and allow you to come back, you know, and that was my routine as well. And I often well not refuse but avoided going to loud places, even family and friends and parties and that kind of stuff. We'd be there for a couple of hours, and I would be let's go home. I've had enough.

Claudia 26:04

Yes, that's still, he's gotten better. But that's still not uncommon for that to happen. And then a nap in the middle of the day is still pretty common as well, he, um, what about apathy? Do you have any problems with that?

Bill 26:21

I don't have any problems with it. But, it was something that you have to go through, you kind of do have to go through I did. So my issue was that if somebody came to me to whinge about, I don't know, you know, the length of the blades of grass, that the the guy who cut the grass didn't do the right job or something, I'd be like, move on, like, whatever.

Bill 26:44

You're wasting my brains processing ability with junk and stuff that does not interest me and shouldn't interest you just get over it and move on with your life. So I was kind of apathetic in that way. I had no time for small talk and rubbish talk that didn't make it worthwhile for that person to be around me now it was usually personalities that I did that too.

Bill 27:14

So people that were like that, anyway, are the ones that I became empathetic to that I kind of made it obvious. I stopped pretending that I was enjoying the conversation. I know, just put it out there that I'm not interested in hearing what you got to say basically.

Claudia 27:29

What about before the brain injury? Would you have felt the same way?

Bill 27:32

No, I was kind of polite. I used to try not to annoy people, especially if they were kind hearted, and they had good intentions. I tried not to annoy them and be

nasty. And if I didn't have the permission to correct them, or bring them in line, I wouldn't. I'm somebody who I've learned to be a coach.

Bill 27:51

So I coach people through some, you know, challenges in their life. But not every opportunity is a coaching opportunity. You don't tell people what you're thinking all the time, especially if they're nice, and they haven't given you permission to give them that kind of feedback.

Claudia 28:07

Okay, my husband would have told them off. Probably would have looked at them and said, I don't care. Sorry, not in a really mean way. But he's not one to sit and let it kind of go on for too long.

Bill 28:24

Yeah, I think I annoyed my wife a few times, because I didn't give her the kind of response in certain situations that she required. Because of probably multiple reasons. Either I couldn't or I didn't have the energy or I didn't want to, or I didn't want to waste my energy.

Bill 28:45

But there was a lot going on in that healing and recovering brain where I was trying to protect myself as much as I could. So if I appeared, you know, apathetic it came across the wrong way and pissed people off. But it wasn't about them. It was about me, and I couldn't make it about them. They had to deal with whatever issues they were feeling their own way. And they had to overcome it. If they could, if they couldn't, well, that was all right to you know, whatever.

Claudia 29:10

Right? No, I tell people who call me and want to talk about their husbands or their wives that are actually going through rehab or in the hospital. And I say, and I mean, this. I'm going to say this. I hope it doesn't come the wrong way. But a brain injury is the most selfish recovery of anything I've ever known.

Claudia 29:37

And it took my husband three years to look at me and say, how was your day? Are you doing okay? It's not that he might not have even been thinking about it. And it's not like he didn't care. It just, it didn't come to mind or if it did, he was too tired to even think about bringing it up. So I tell them often that I remember the

day where I was when he said, hey, how are you today? And I, I was blown away and so excited that those words came out his mouth.

Bill 30:10

Stroke is the, if you compared it to a sport, it's the tennis player's analogy, tennis player is all about themselves. It's about nobody else, there's no real team discussion or anything else it's all about them. So is stroke recovery. And, it has to be because there's so much going on. And it's so difficult to explain it to anybody who hasn't gone through it, that you just have to get to the point of going, blah, whatever this is it, I can't do it, I'm not interested, I'm not going there, it's not going to happen.

Bill 30:47

You have to be extremely selfish. And that I know, for a fact makes it extremely difficult for caregivers, because caregivers are dealing with this new version of their partner or their loved one. And then they are trying to somehow understand their role. But then why is this person behaving differently to me, and then they've got to deal with their own emotions.

Bill 31:15

And it seems like what we're doing is not caring about their emotions. And that might be the case like, we might not be caring about it, but not because we don't care. It's because we can't care. So hard to care for what other people are going through when I remember the first day of rehabilitation not even 10 minutes of effort to recover my ability to walk again, had me out for the entire day.

Bill 31:21

And that means that I've got nothing for you or anybody else. I don't care who they are and how much I love them. And it's got nothing to do with you. It's all to do with me now that you go from being caring and loving to your spouse, to literally a week later not be.

Bill 31:51

And it's not because I'm not loving them. It's because I can't and then how do you bridge that gap between this is what they were like, I'm feeling all these emotions, the caregiver, the wife, the partner, whomever is going, I don't recognize this person anymore. And that's scary.

Intro 32:22

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'll make matters worse, doctors will explain things that obviously, you've never had a stroke before, you probably don't know what questions to ask.

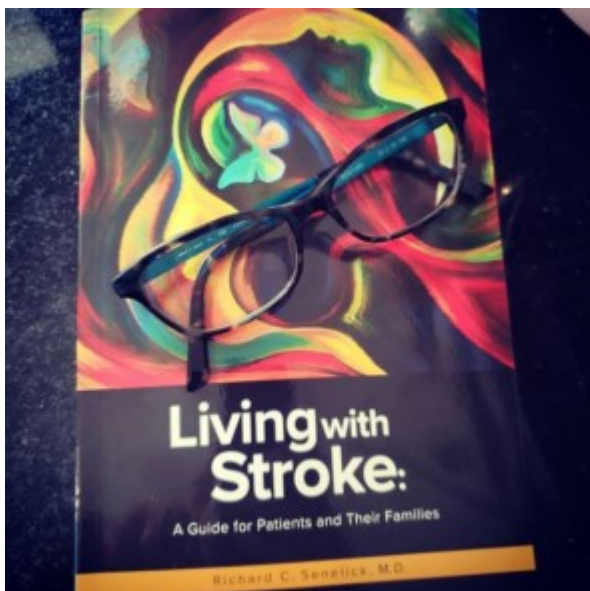
Intro 32:47

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 Seven questions to ask your doctor about your stroke.

Intro 33:06

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

Dealing with stroke changes



Claudia 33:25

Yeah, well there were a lot of personality changes, he's his personality is different, his likes are different, his responses to things are different than they were before. And we were married for three years before he had a stroke. So we weren't married for very long and had newborn twins. You know, there were nine

months old, but when he had the stroke.

Claudia 33:51

So I had to figure out how to be with this new person. And we went through he came home in a wheelchair, he came home in a hospital bed, we were transferring and bathing and not to be too, you know, wiping and going through all of that as a newly married couple in all honesty. I mean, you know, three years in is not very long.

Claudia 34:21

And we were trying to figure out how to be married to each other before all of that happened, especially with kids. And then to have that kind of come in was was a challenge. And it forces again, to have some very serious conversations that I think most relationships would not have had at that point.

Bill 34:40

There's no it's not rare for relationships to break down after stroke when the stroke survivor comes home, because the character can't deal with it or doesn't want to deal with it or all sorts of different things and the many people that I've spoken to whose relationships have broken apart because of that, they do in hindsight, say they're better for now.

Bill 35:05

Because imagine trying to recover in a difficult relationship at the same time, I mean, recovery would not work. So if there's distance, and there's less issues to deal with, then that person can recover, and can focus on being a bit selfish.

Bill 35:22

But if you're somebody who has, if you're a caregiver who has values around being spoken to a certain way or feel a certain way, or treated a certain way, and you're not getting that, especially in those short years after marriage, it's like, I didn't sign up for this. And if death do us part is down the track, like that's far away. So what's this junk coming to me right now? It's too soon.

Claudia 35:56

One of the books I read talked about if marriage doesn't work out after stroke, it probably wasn't doing so well before it. And I mean, we didn't have a perfect marriage before it. We don't have a perfect marriage now. But we're working hard on it. We really are.

Claudia 36:14

And there's challenges and there's days that I'm angry and fed up. And there's days he's angry and fed up. I think the other day, he looked at me said, well, do I do anything? Right? Yes, you do. But right now, I'm only going over the things you're not doing correctly for me. So you know, and I think I get it, I think that conversation could have happened, whether he'd had a stroke or not. Because I being a nagging wife.

Bill 36:40

I know what you mean, I feel you I'm probably the nagging one in our relationship. So my nagging maybe went up a notch or two after the stroke, right, because I couldn't do as much as I as I wanted to. And I used to get frustrated, and we had teenage boys. So they didn't do anything.

Bill 36:59

And they didn't care to do anything. So it was like, I need help. And I didn't know how to ask for help. So I would just get really, really tired and frustrated, and then just take it out on everybody and anybody who was in front of me. And of course, Christine, who was the one who was doing most of the hard lifting with cop the brunt of that.

Bill 37:18

And then she would be like, what am I doing? Like, what else do I need to do to make this thing better or to get through it, and at the same time, she lost her mum. In those three years when I was in recovery, and just before surgery, and you can't even imagine I'd say to people, you can't imagine what it was like to be a stroke survivor, because it never happened to you.

Bill 37:41

But I can't imagine what it was like to be a caregiver because I was not the caregiver. And I wonder about that so much. And that's why I love to encourage caregivers to come onto the show so we can explore it and get the message out there so that some stroke survivors who are like me, a little bit nasty, can be less nasty, perhaps.

Claudia 38:03

I do remember I broke down one time with Rand went even a year after his stroke and said you don't know what I went through, like I hear from you. But you don't

know when you were laying in the coma at the hospital for 30 plus days, and I was just signing white paper after white paper for you to have whatever surgery they decided was going to be thrown at you.

Claudia 38:26

And I didn't ask me any questions, I just kind of kept going with it. You know, I was going through taking care of the kids working trying to be at the hospital trying to make sure insurance was covering whatever was going on next, hoping you were going to survive and survive to a point that was going to be worth it for him right.

Claudia 38:26

And I didn't want to just keep throwing everything in the kitchen sink at him and have him you know, not be happy with the situation. I wanted to be doing the right thing for him. And we did have that conversation as well of, hey, I can do this with you. And I understand you are grieving and you're unhappy.

Claudia 39:06

But I need you to find happy if we're going to stay together. We got to find happy. And it doesn't have to happen tomorrow. But we need to know that down the road. We're going to be happy and I can't make you happy, you're going to have to figure out how to be happy with your new situation. And I think that's what really has kept our relationship together is finding happy and being happy with where we are.

Bill 39:35

Yeah. And then having that goal for happy out there somewhere that you just work towards. It's not something that you actually achieve. It's something that you always work towards. And at that time you're increasing your level of happiness because that is your outcome. It's not happy when I get to this stage in life or this milestone. It's like I'm working towards happiness and let's see how many milestones there are in there. along the path.

Claudia 40:02

Right. And, you know, can you be happy with where you are in this very moment, even though you don't have everything back that you really want to have back, let's keep working on that. And it may come back beautifully. It may not I mean, Rand really wanted to drive and everybody at rehab kept telling him, don't count

on it, don't count on it, don't count on it.

Claudia 40:26

And that was really bumming him out. And I said, You're you might not and we need to talk about this and what that means. And how you are going to be okay. And he's had setbacks. He's had some issues with medication, and it caused him to have a seizure again, and had to stay out of driving again for another six months and be seizure free, all that kind of stuff.

Claudia 40:50

And that's been tough, but he's been able to figure it, we've been able to figure it out. It's not exactly where we thought we would be. But again, finding the happiness and where we are at this time, and setting those goals and moving forward from there.

Bill 41:06

Has Rand sought out other people to help him get through those psychological challenges that stroke throws?

Claudia 41:17

No.

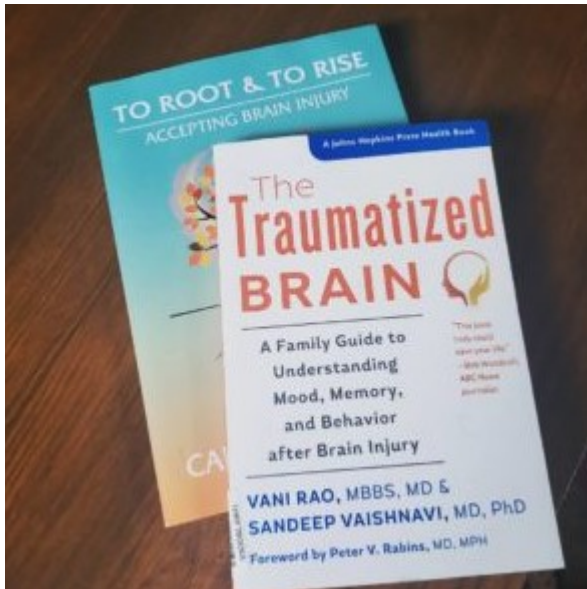
Bill 41:19

Something that Claudia definitely wants him to do.

Claudia 41:23

Yes, I am the, if you haven't noticed the outgoing, kind of go getting. He is more of the introvert. And more of the I can do it myself, I don't need any help kind of person. And he does I mean, he pushes through what he wants to accomplish. But no, he hasn't really reached out to anybody else. Now, we did have some people when we were in rehab, and he connected with some of those people, and he's kept in touch with them.

Seeking help



Bill 41:57

All right. This is me giving Rand unsolicited advice and support. So what I'm going to say to him is, he can push through the things he's aware of, the things he's not aware of are beyond his peripheral vision, he's got no idea that they're things that are slowing him down and stopping him from doing.

Bill 42:19

So they're the things that he needs to seek help for the ones that he's not aware of. Because if you don't know, what's stopping you from feeling happier, better, or recovering, you know, faster or whatever. How are you going to actually push through or tackle those things? So Bill out, Rand, take that advice, or don't take it. It's just we're having a chat. That's it.

Claudia 42:47

I love it. I mean, I think if you ask him, how much he's recovered, he would give you a much higher percentage number than I would. And again, I think it's because he sees the physical difficulties in the physical side of things, but some of the mental stuff is a little bit harder for him to realize.

Bill 43:09

Yeah, absolutely. Because when you're going through it, it's tough. And for me, I used to, I remember saying, so I've been on this journey now for more than eight years. And I remember saying all the time, I'm about 99%. And if I compare my 99% today to my 99%, back then, back then it was nowhere near 50%.

Bill 43:31

That's the illusion that I had it was that I was 99% recovered. But man, let me tell

you that 1% getting that back, is the part where the lifelong journey starts. Because it's not something that you can just get back. It's like that Formula One car, you know, to get it to go one second quicker around that whole check.

Bill 43:52

They've got to spend millions and billions of dollars. I don't know what and to get that one second, they might not even get it. So that's kind of where I'm at. And at five years in, I can understand why he thinks he's maybe you know, 90% or more recovered. Because I don't know why because that's how you feel and think it's bizarre. I don't know.

Claudia 44:13

I mean, to go from where he was, and when he went into rehab, he thought he could walk still. And they went to stand him up about a week and a half after being there. And it took him 10 seconds and he just went right back down. He lost all ability. Laying in a bed for a month didn't have help, either.

Claudia 44:38

But, you know, I think that was a huge shock. And so the physical side he worked on and worked on and worked on, and then the mental side. It came with all of the rehab that he did from speech and occupational and everything but also it's still improving.

Claudia 44:56

Five years later, I'm finding things that he wouldn't ever have remembered or done or thought or, you know, some of my sarcasm. Initially, he had a lot of trouble with and couldn't understand he was taking a very literally. And I'd have to say, Oh, no, no, no, that's let's step back, let's talk about it, you know, so. And he started to get my sarcasm again, which is kind of fun.

Bill 45:23

That's great. So you've thrown yourself into learning a lot, though, haven't you? I mean, your Instagram is full of books with living with stroke. Jill Bolte Taylor's My Stroke of Insight, your traumatized brain, you've spent a lot of time really learning about and trying to get an understanding of what it is that's going on. How's that helped guide you with regards to how to deal with Rand and his challenges?

Claudia 45:59

It's been interesting. So I didn't even open the computer or Google anything. When all of this was started. And everybody was shocked. They couldn't believe that I wasn't looking up everything. And I kept saying, we keep being told these low percentage chances of him surviving and him waking up of him, you know, all of these things, and it keeps happening.

Claudia 46:20

So why am I going to go read that he's not going to recover, and he's not going to live if he keeps doing it. So I didn't do any research. And then with him coming home and having the girls and trying to work and everything we just kind of went through and did the best we could for a long time. And I have been asked to be a part of your mentor program that's getting started at the rehab center that Rand went to, and that got me back into it.

Claudia 46:53

And I was answering the same questions over and over again, to each person that I spoke to, and I thought, you know, would it be nice to have some videos that are already done up so that if somebody else has experienced this, that I don't get a chance to talk to listen to those videos and learn from them and, hopefully get something from it.

Claudia 47:12

And then I found I was learning from it more than probably anybody else's is helping me more than anybody. And I started kind of reading books to try to find books to help better Rand's brain or my understanding or some of the small issues that we're having still that I could maybe learn a little bit more and make some differences from that standpoint.

Claudia 47:36

So we are drinking more water and eating a little bit better and decluttering some places and, you know, I did a calendar up that I had done initially, when we first got home, it was more work for me. And we're stress and poor man, it didn't even know it existed.

Claudia 47:53

And I would show it to him every day. And we would talk about it every day. And it's still the next morning wake up and had no idea was there. So I think some of the things I initially started didn't work so well. So now having that ability to go

back and to do these things to make our communication and our relationship honestly better, and hopefully Rand better in the long run. And me drinking more water is great for me too. I feel better.

Bill 48:22

Yeah. I started out sharing these types of stories, because I thought it was going to help other people as well. And I did it partly just to get a better understanding as well of what the complex nature of stroke is. Because when you hear a stroke story, it's similar and as in something happened, but then after that, it's completely different for everybody.

Bill 48:47

So I found that every time I do an episode and listen episode, that it does help me more than I expected that it would and it's a really great outcome from doing this whole I'm gonna make it about somebody else. But no, actually what it is, it's really about me, that caught me off guard. So I hear that that's similar to what's happening to you, you thought you were gonna go help others and now here you are getting this beautiful gift back.

Claudia 49:16

Very true. And I told my mom I said, I think this is better for me than it is for anyone else, you know, I'm pushing more date nights and asking Rand to do more things and committing myself on social media to work on things and having me follow through with it because I'm being held accountable in my own mind by I think I had 200 followers.

The growing stroke community

Bill 49:41

Yeah, 223 followers, you'll be surprised how quickly that grows. Because the stroke community is pretty big. It's pretty active on Instagram, and they looking for people that are going to share stories about their version of recovery or what it is that they're going through because we can relate to it but also we've been from it, so it grows, it grows rapidly. And, they're really active, they love to engage and share what it is that they're going through. And, that's really, really helpful, especially when you make a post, like I did recently, which was about Are you okay day? Do you know?

Claudia 50:18

I saw that I loved it. I thought it was great.

Emotional and psychological recovery

Bill 50:20

Yeah. So from that what actually came was people step forward in sent me a private message and said, No, I'm not okay. So that was amazing. So those people were in New York, on the other side of the planet, I'm in Australia, I mean, we couldn't be further away. But to get that, and then to be on a zoom call with them within 10 minutes of them sending that is really amazing, because that's why I did it so that people know that they can reach out.

Bill 50:47

So then what that shows me is that, yes, there's a lot of people doing the physical recovery, very few of them are really going and doing the emotional recovery, and that very few of them are doing the psychological recovery. And that means you're only doing one third of the recovery, if that's all you're doing, you're missing out on these two important parts, the emotional recovery, and the psychological recovery are the most important parts to to healing.

Bill 51:12

And I say that from experience, because I think so my first bleed, had been in hospital for seven days. And then on the 10th day from being admitted to hospital, I was in a counselor's office and seeing a psychologist. I just got onto it straightaway. And I think that the mindset that it gave me, seeing this counseling psychologist for such a long time, afterwards, was able to stop me from having the anxiety episodes was able to stop me from having these thoughts in my head about what happens next.

Bill 51:51

And I didn't even know that it was going to happen another two times, and then I was going to have brain surgery. But it just put all that junk out of my head. And then it made me start to focus on emotionally what I needed to do to heal. And what I needed to do was, I needed to apologize to my wife more I needed to tell her I loved her more, I needed to, you know, do the same thing with my family, extended family, friends, people who came to see me the messages, I needed to actually express that stuff.

Bill 52:18

So they knew in case I did kick the bucket that Bill hadn't left anything unsaid, we're not going to have any regrets. And that's kind of what I really worked on because I got the most enjoyment out of that. I know I got a lot of enjoyment out of being able to walk again. But I got the fuzzies you know about doing the emotional stuff. And that was something I hadn't really experienced much before my stroke.

Claudia 52:48

Right, The Traumatized Brain was the most recent book that I finished. And they talked a lot about how you're not going to fully recover. If you're having any sort of issues with anxiety or depression, it's going to hinder your outcomes. And that you definitely need to find some way whether it's through counseling, going to your neurologist and talking about medications or whatever is needed to help you cope and recover from that.

Claudia 53:24

Well, we'll hopefully be the benefit out Rand got put on a drug that I don't like and I wish I could get them off of it. I'm having trouble getting off of it. But he seems to be, he probably should be talking to somebody he has before. We we did some cat he did some single counseling, and we did some a couple of counseling. And but it's been a while. I always love counseling. I think it's a good thing.

Bill 53:49

Look, it's tough for guys to do I know a lot of guys struggle with it. Because they fear being emotional, or, you know, having feelings and feeling things because they've been raised being told you're tougher than that or get over it. You don't need to be crying and all that kind of junk.

Bill 54:07

But the relief that you get like the pain it's more painful in the not going there. So in the in that stage of thinking about oh my god, it's going to be difficult if I go there, you know, I can't be vulnerable, all that kind of stuff. Like, before you go there, it's so much harder than when you're actually there.

Bill 54:30

When you're actually there, you get relief. It's like you know that the floodgates open and the relief valve goes and then it's done and you never get that pain

anymore that concern about what if I go there and experience this emotion. Experiencing the emotion is not as much pain as not experiencing it.

Bill 54:53

So all those people who are afraid to go there who are watching now and listening. That's a story that hopefully They can trust me about and maybe if they feel vulnerable in the right space with the right person at the right time. Just go there, just test it, don't test it on the biggest worst problem you've ever had in your life, just do a little one, on the one where you lied about something, and that made that person feel bad.

Bill 55:19

Do it about that one, and then test yourself and see if you can go to the next level in a session or two or three down the track, you know, not, don't do it all at once. It doesn't have to be that kind of journey. It's gentle, and it's and it's soft, and it's caring. But that just changes the body's ability to heal as well. Because that stuff's gone. And then all of a sudden, there's just space there for healing and for other things to occur.

Claudia 55:48

I mean, as a caregiver, I'm going to say the same thing, you need to go, yeah, take care of yourself. I did not do it during the time that Rand was in rehab. And I was invited multiple times to go to group sessions and peer support sessions. Funny that now I'm on the whole mentor peer support side of things.

Claudia 56:08

But I remember telling the case manager, I didn't have time to hold hands and sing Kumbaya, I had other things that needed to I was out of there. As soon as, as I got everything needed to be done, I was on to my next task, and I was moving on, and it wasn't taking care of myself.

Claudia 56:22

And everybody knew it. That's why I had so much support. But I did go to some counseling, after I Rand was back home, I made some time we set it up where the nanny would stay late. And I would go on one night a week and talk to somebody. And that I think was extremely helpful for me to for me to be able to come back and say, Hey, I'm in for this, but we got to find happy or you need to realize what I went through and to be able to have kind of pushed those tougher conversations

to get those emotions out of me.

Claudia 56:55

And not feel like I was saying the wrong thing or hurting his feelings, because he's a little bit more sensitive than it used to be or making him more stressed out or upset. Because that was not what I wanted to be doing to him at the time is he needed to recover. But I needed to say it, and he needed to hear it. So it was very important to do.

Bill 57:17

What do you think? I know what the thinking was. And I know you're in solving problems mode early on. But why do you think you used that excuse, the excuse of I'm too busy, I've got stuff to do.

Claudia 57:32

I didn't want to face it. I didn't want to break down I needed to just go and stay strong. And I think I felt like if I started hearing other people's situations on top of my situation, that I was just gonna roll over into a ball and you know, sit in a corner, and suck my thumb, rock back and forth.

Claudia 57:52

I had my place and my moments where I would let out a little bit you know, if I was finally got the girls to bed and I was, you know, going to sleep in a quiet, I would probably cry. Then I say my dog was my therapist. The dog knew more about everything that was going on than anyone or when he was in ICU, and it was finally quiet and nobody else was around. I would cry then too. I mean, I had some good hard cries in ICU late at night. So in church, I also cried some at church, just kind of quiet. You know when I could get there and do it?

Bill 58:34

Yeah. And there's nothing wrong with that. Christine says the same thing she went through. And I interviewed her on on episode 100

Claudia 58:41

Oh I have to watch that.

Bill 58:43

Yeah, that's a good one. Because she gets really, really deep into what she was going through. And trying to get through and trying to overcome while things

were uncertain and unknown. And she says the same thing. She just had stuff to do. She had stuff to be on the go for. And she felt like she couldn't take a backward step because she needed to keep the momentum going of whatever we were trying to achieve and all the things that we needed to do.

Bill 59:14

She became you know, the main breadwinner, she became the carer she became the mom, she became all these things. And then what I realized which I didn't comprehend at the beginning, because I didn't get to questions, she still have to manage the emotions of everybody who contacted her to find out how is Bill doing.

Claudia 59:34

I haven't thought about that, and that's kind of true, you do.

Bill 59:38

And that was tough, right? Because she knows that they are most of them can't deal with it. And because they're not close to me, they don't have first hand experience of where I'm at and however, and how I'm going. So they're always in this heightened state of anxiety and they're more wanting to know the good news so that they're in anxiety levels can be decreased more than anything else. And Christine's finding herself trying to keep them feeling good. And neglecting herself at the whole time.

Claudia 1:00:13

Interesting, I hadn't thought about that. That's funny we we did a caringbridge page and anyone who would ask me questions that, or calling me that had questions, a lot of times, I would send them to the caringbridge page, which helped but close people, you know, that really wanted to talk or were coming to see me, I talked on the Instagram page a little bit about how I remember people coming to sit with me in the intensive care unit, to wait for a surgery to get done or to wait for the doctors to come by.

Claudia 1:00:46

And it was so nice to have somebody there. Because if you needed to go get something to eat, or you just needed to get fresh air, you always were afraid you were going to miss somebody or something. And I really didn't want them to talk to me. I didn't want to have to think about anything else. I just wanted to kind of

just be there, but I don't want to be alone.

Claudia 1:01:07

So a lot of, no a few of my friends understood that. And we're great about that. And that helped a lot. It was the I hear Christine side, it was the ones that were kind of needy, that really wanted to talk to me and really wanted to, like get into these deep conversations that I didn't have the energy, I didn't have the energy, the patience, or, could emotionally handle it and keep it together.

Bill 1:01:34

If I could, and there was people that would take the course, I would have a course on how to be a friend during a crisis, so that people didn't come with their baggage and make the crisis even worse, because now the caregiver, and the person recovering has to deal with their baggage as well as everything else.

Bill 1:01:53

And, if you were ever allowed to. And it was just known that when you turn up to be a friend to somebody who's partner's in hospital, there's this rule that says if you don't have the right kind of attitude, we can kick you out and you can't get offended. Like if we could have done that, that would have been amazing, because I had some people in the hospital waiting room, or in my bloody room as well, which I used to tell Christine, like, Is it possible to make them not come again?

Claudia 1:02:30

But it is it is possible, you can ask them not to that was one of my things. I was too nice during all of it. No, you can you can ask them not to, you can say this was great. We love seeing you, but it was too much or we can't do it.

Bill 1:02:46

And that was Christine's responsibility. And she's not that kind of gal.

Claudia 1:02:50

Well, I didn't do it either. I'm just saying now to anybody who's watching this or listening to this it is okay. You don't have to be the nicest person, you can do it. You can say hey, I know you said you wanted to come help take care of the kids. But I'm socializing with you and I'm not getting anything out.

Claudia 1:03:06

I'm taking care of the kids, you need somebody who's going to be like, Hey, I got

this, go take a nap, go for a run, go, you know, read a book, go see Rand, go see your loved one, I got the kids. So, you know, putting those certain people in charge of understanding that people who have been through the crisis are the best people to have on your team. And they know they got it.

Bill 1:03:29

Yeah, that's part of the reason for the podcast as well is to paint the picture of it's pretty bad at the beginning and then it gets better. As time passes, things change and things improve and you adapt and you learn and you grow and, it gets better. So hopefully, when people are listening, that's they're listening with that frame in mind and that they're getting the whole okay. All right, I got that shitty part at the beginning of that first 10 minutes or so. But then the rest of it is about what we needed, what we grew from how we learned how we adapted. Hopefully, that's how your story has evolved as well.

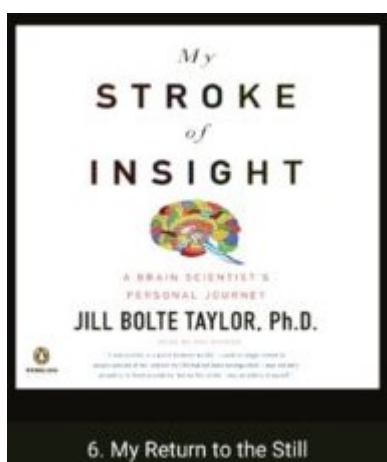
Claudia 1:04:07

Yes, no, it was horrible in the beginning, but again I never thought I never thought he would be so well back into what we were doing before me. It's a little different. It looks different. But it's the same. You know, it's nice.

Bill 1:04:26

What has stroke taught you about you though, what has his experience taught you about you?

What we learn from stroke



Claudia 1:04:34

Oh, that's an interesting question. I can get it done when I have to get it done. I'm definitely a multitasker. I'm the organized one. I think that I'm surprised to what I

was capable of doing. And I think I've surprised a lot of people of what I was capable of doing. I wasn't a meek person before, obviously.

Claudia 1:05:07

But I think that what we've been able to accomplish and do and have two young girls who have gotten through it as well and to be happy and easy kids that don't really see a difference. I think that's been pretty amazing as well. I couldn't have done it without my support. I mean, Rands parents lived down the street, my parents came, our friends, my brothers, I couldn't have done it without everybody.

Bill 1:05:41

Sounds like there was a lot of things, a very good foundation there to support anyone through some sort of a crisis anyway. So it sounds like that. Whether you guys plan that or just happened, to have so many people so close to you makes a massive difference in sharing the responsibility for each other.

Bill 1:06:03

Really, that's what it is. It's not about one person doing it on their own. And I know, life these days, you know, does make it hard, because we live in cities. And we live in all these weird situations that are so different to perhaps, you know, the village of the old, but it's really what's required isn't.

Claudia 1:06:25

It is we needed it for the girls guiding twins, we needed a village and then on top of that, so it was kind of in place from that. And then, yeah, I, I didn't realize Rands friends were so amazing. I knew I liked them. They were nice. And I enjoyed being with them. But the day that he went into the hospital, he was in surgery for seven hours, and I sat in that waiting room.

Claudia 1:06:50

And I remember, within the first 30 minutes, all of a sudden, his friends just started walking in their suits with, you know, they just came in, and they just sat down. And they didn't even really say much. But I think that there were 10 guys in that room, they all dropped everything they were doing, and they just showed up to sit with me.

Claudia 1:06:50

And I didn't know them very well, it still brings chills to my arms and tears in the

back of my eyes. And the idea that these guys dropped everything just to come and sit with me for seven hours to wait and see what was going to come out of the surgery and how their friend Rand is going to be was a beautiful thing.

Bill 1:07:20

That is amazing. That is amazing. The best kind of support is that support, which is just the in body and nothing much else. Because you don't need to talk at that time. You don't need anything. You just need people that you can lean on if you need to lean on them. And the fact that they were so aware that they didn't have to talk maybe they just men and they don't know how to talk.

Claudia 1:07:59

It was great. They've been guys but it was great.

Bill 1:08:05

Claudia I really enjoyed our conversation. Thank you so much for being on the podcast and sharing your story. I wish Rand all the best for his recovery from me. I haven't met him. But hopefully he gets to listen to this. And he gets to really understand how much you care for him what you went through and you know, what you've been prepared to do, and how much his recovery is important to you.

Claudia 1:08:32

Thank you. Yes, I've enjoyed it and he's definitely gonna watch it.

Bill 1:08:35

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Bill 1:08:54

Doing that will make the podcast more visible to other stroke survivors that are doing a tough right now. And it could help them feel inspired and feel better about the road ahead. Thanks for tuning in.

Intro 1:09:11

Discover how to heal your brain after stroke go to recoveryafterstroke.com.

Intro 1:09:20

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Intro 1:09:37

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Intro 1:10:00

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Intro 1:10:15

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Intro 1:10:29

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Intro 1:10:52

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