

100. What It's Like Living With A Stroke Survivor - Christine Gasiamis

In episode 100 Bill is joined by his wife Christine Gasiamis who shares what it was like for her to go through stroke as a wife and mum and then to live through Bill's recovery and experience all the ups and down that stroke survivors go through.

Socials: https://www.instagram.com/chrissy_gas/

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Christine 0:00

Anyway, I sat down and said hello. And of course, your mom was sitting there with the boys. And she looked at me, she said, so how's Bill doing? And instead of what I may have rehearsed in my mind how to approach it and say, Oh he's fine, he's resting. I looked at her just burst out crying and said, He didn't know who I was. Well, if there was any way I could have killed my mother in law, that would have been the way to do it. I saw the devastation in her face and not to mention the boys because they were in there so caught up in my own emotion, fear that I

had felt it when I was trying so hard to calm myself down before I go into the house. It didn't work.

Intro 0:50

This is recovery after stroke with Bill Gasiamis. Helping you go from where you are to where you'd rather be.

Christine Gasiamis



Bill 0:57

Bill from recoveryafterstroke.com this is episode 100 and my guest today is the one and only Christine Gasiamis. Christine is my ever suffering better half and I changed her life as well as mine quite dramatically when in February of 2012, I was diagnosed with the first of three bleeds on the brain due to a ruptured arteriovenous malformation.

Bill 1:20

This is a great milestone episode for me and the podcast. Because as you will hear in the episode, we've had to overcome so much heartache to get to this point. And now that we are beyond the eight-year mark post-stroke, and almost six years beyond surgery, there's been so much growth and personal development. And I hope that our story will give you hope and inspire you and that no matter what you can get through and overcome a lot of what you're going through and come out on the other side.

Bill 1:54

Now recently, I have also put everything that I learned about my recovery in the last eight years into a course called 10 steps to brain health for stroke survivors, and module one is now available at recoveryafterstroke.com. This course is

included as part of my recovery after stroke coaching program. And it will help you overcome fatigue, reduce anxiety, and help support your memory amongst other things.

Bill 2:22

This 10 step program has been created to complement any medical interventions and works in conjunction with any other physical therapies that you are undergoing. It's a course that you can take from your own home so you don't have to go anywhere to participate. You only have to log in from your computer.

Bill 2:42

If you're a stroke survivor that wants to know how to heal your brain, overcome fatigue and reduce anxiety. This course is for you. If you feel like there is not enough support after you leave the hospital and you're afraid that your recovery will go backwards then this is where I can help.

Bill 2:59

While you are participating in this course I will coach you and help you gain clarity on where you are currently in your recovery journey. I will help you create a picture of where you would like to be in your recovery 12 months from now, and I will coach you to overcome what's stopping you from getting to your goal.

Bill 3:14

Right now for everyone that is interested in learning what recovery after stroke coaching is all about you will get access for seven days totally free. So take advantage of the seven-day free trial now by clicking the link below if you're watching on YouTube, or by going to recoveryafterstroke.com/coaching if you're listening online, and now it's on with the show.

Bill 3:47

Christine Gasiamis, welcome to the podcast.

Christine 3:51

Hi.

Bill 3:54

How weird is it me interviewing you while you're in our kitchen I'm and I'm in the study?

Christine 4:00

Very weird.

Bill 4:04

Every interview starts with me asking the stroke survivor basically to tell me what happened to them but because you're not a stroke survivor, thank God. I'm going to ask by asking you or what happened to me in your own words like can you give a bit of a sense of what it was like for you leading up to me actually being diagnosed that there was a bleed in my brain?

Noticing the stroke symptoms

Christine 4:29

Okay, so that will be at the beginning when you're experiencing numbness in your left foot. Which that week at the beginning of that week, you really weren't very vocal about what you were experiencing to me. It was only a few days into it when you were having appointments with the chiropractor that I realized that you were having a bit of an issue.

Christine 4:57

But it was not until the Friday of that week when you came, I think you had come back from an appointment from the chiropractor and you came to me and you said that the chiropractor suggested you go straight to emergency because you believed that the problem was not your back.

Christine 5:20

It was only at that moment when I actually watched you walk around the kitchen, that I realized that you were dragging your leg and I asked you why are you dragging your leg? And you said no I'm not. But it was pretty obvious that you were dragging that leg. But um, anyway, I did encourage you to go, you know, go to the hospital, they'll check you out and you'll be you know, sent home whatever it may be. But you're complaining that yeah big job the next day.

Christine 5:51

And you're pretty adamant you weren't too interested in the hospital. But anyway, I did encourage you to go and you did listen, for once. But I also what pushed me to do it is I didn't feel right about it. It just didn't feel right. Watching you dragging your leg, you limp was not more of a issue was the fact that you did not

realize that there was a problem.

Christine 6:22

That set alarm bells for me. And of course I have to go to Dr. Google. And the worst possible thing to do is go on to Google and search numbness and sore left foot and dragging of leg and all of that and he came up with all kinds of not so good things. Anyway. So I dropped you off, I believe at the hospital and I came home back to the boys. And that was the beginning of the stories.

Bill 6:53

Yes, that's sure was you know, how people talk about Dr. Google, and it's a bad thing for a lot of doctors don't want us to go there. But in your case, you do tend to go there for every complaint that every one of your family members has. But in this case, it actually wasn't a bad thing, was it?

Christine 6:56

No it wasn't. If anything, it just confirmed in my mind not to ignore it, not to listen to you, you know, and say, no, I'm going to work tomorrow. It just set it in my mind that I had to take you I had to convince you to go and it worked. And obviously wasn't most of the things that I had read. And I don't even think stroke was one of them that I read to be quite honest with you. It was more tumors off the spine, tumors have all kinds of things that I'm thinking of tumors the whole way. But, it turned out to be a bleed and that was not a what I read, but sure that was enough to convince you to go.

Bill 8:05

Yeah. So how good was I at being deceiving when you contacted me at about 9:30 or 10pm, at night, after you had come home, you're with the boys. And I said to you go home, go with the boys they're going to take forever. And I said to you, it's probably nothing. And then you spoke to me and I think by then I had known the results.

Bill 8:30

But again, I lied to you anyway, I said, yeah, they came back with something, but there's no real, sort of information and call me in the morning and we'll work it out in the morning. Like how good was I at lying to you and convincing you that that was the case?

Christine 8:47

Very good, because I had no idea that it was anything and as far as I knew you were just waiting for those doctors in emergency because it's usually you know, such a long wait. So to me it's a normal, it seemed okay what you were telling me. So for me it was comfortable enough to have my evening at home, go to bed, wake up in the morning.

Christine 9:09

And I think John, our youngest had a swimming lesson that morning, which was close to the hospital where you were. And it was not until that's right you sent me a message in the morning you said, bring my laptop, bring a notepad, you know, work stuff that you needed. Can you swing by the hospital and drop it off? To me that was oh okay, he's fine You know, he wants all his work here.

The moment of truth

Christine 9:36

So I remember dropping off John at the pools, and then coming to you and as soon as I came where you were I came to you and then you dropped the bombshell to me. And it wasn't as normal as I thought it would be.

Christine 9:58

Just look so my life changed in a moment. And we had no real answers at that point. It was just they gave you three scenarios. And it was one of those like the what did they say it was like a tumor in the brain. Either it was malignant or it was not. Or they said, it was that or a cavernoma at that time, but they could not tell because of the blood that was covering it.

Christine 10:33

And because the MRI cannot go see through the blood, and they couldn't actually see the cause of these bleeds. So we had no real idea what we were dealing with. So that news I was not expecting I truly believed you. When you said, Oh, it's nothing. It's nothing. It's my back. But I guess that's why we don't ignore these symptoms in life. You go to the hospital.

Bill 11:01

Am I ever gonna be able to say a lie like that again and be believed? Probably not.

Christine 11:09

You could say it but I think I might need to follow you this time to the hospital and

it might be at each other subsequent time.

Bill 11:20

So what you're saying is honesty's the best policy.

Christine 11:23

Absolutely.

Bill 11:24

All right, remember that there won't be a next time but I'll remember that just in case there is. So was I any good at telling you dropping the news and not creating concern because as your husband and then somebody who's had bad news, I got emotional about it as well that night, and then the next morning and the rest of it, but was I any good at calming you and giving you a sense of everything will be okay? Because I thought I was.

Christine 12:01

You actually were your usual self where, you know, don't worry, and this is something to actually worry about. We knew there was a bleed, we knew that but it was under control, you were in a safe environment, you were in the hospital. So that made me feel secure. And I suppose you're reassuring words of we actually don't know what it is that we're dealing with.

Christine 12:26

So until we no worry about a thing, so I think I had no choice really, but to actually take that advice on board. When I think back to that time in life, I was very at that moment, I thought my whole world was falling apart or I also knew that what was happening what happened in that moment in that room, I had to let it stay there because I also knew I had to leave you and then go pick up John from the pool and be normal and not to create and extend fear to a young child.

Bill 12:55

And John was young John was 12.

Christine 13:08

That's right. So I had to leave and just really take your words on board that we have nothing to worry about until we actually know what it is we're dealing with. And I had to believe that so that I can then go and be a mum, you know, go and drive wherever it was and pick up my child feed, then come back to the hospital

and then deal with what was happening with you.

Christine 13:32

And you were fine in the sense that you were talking you were conscious, everything you seem completely normal, other than this numb foot that progressed by that stage to I think to your arm other than that, which is really not normal to come to think of it but you were fine. You were talking you were eating you were your usual crazy self. So to me there was comfort at that point in time.

Bill 14:05

Yeah. And then you had to ring my parents and tell them to come in. Oh yeah by the way Bill's not doing too well, like, how did that go?

Christine 14:16

Without actually setting alarm bells. That was a bit difficult. But I think we did it together and they spoke to you and they heard you so I think they were fine about it. In the sense they came to the hospital, they saw you but look they were concerned, and it was not an easy thing to watch parents look at their son and wonder what is going on with him. But I felt better that it was shared. It wasn't just between you and I, I felt that they had to know, obviously, you're their child.

A false sense of security

Bill 14:50

Yeah. And then, the week progressed and you kept coming to the hospital. And then that was pretty cool because I was up on my feet. I was out and about I was running the show that doctors and nurses were always looking for me and are wondering where the heck is this guy? He's supposed to be lying down. Did that give you guys a false sense of security? Because we had no idea. We're only seven days in we had no idea what was to come. Did it give you a false sense of security?

Christine 15:22

It did, because I remember you said, the nurses and doctors were looking for you and you were downstairs at the cafeteria in the hospital. And I remember coming up at your room to visit you at some stage and of course, you would know a near the bed were you and I'd go, I went to one of the nurses is Bill somewhere. Do you know where he is?

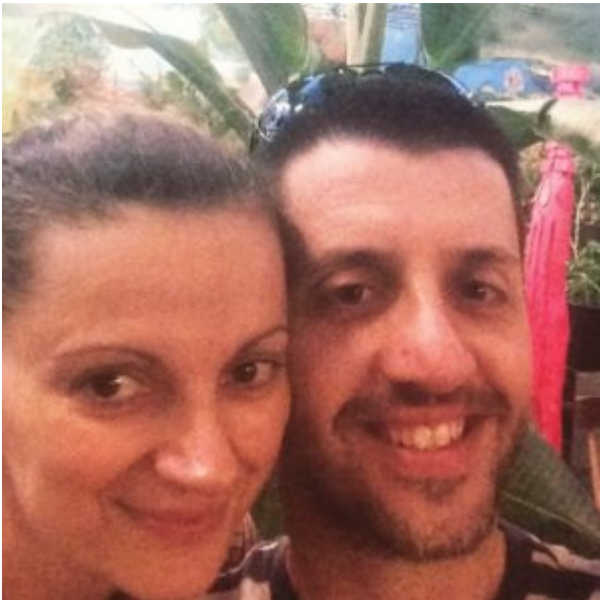
Christine 15:44

They said no, he's missing as per usual, like it was normal. I said, try the cafeteria. And sure enough, you were in the cafeteria. I think every day almost every day that I had come to see you. You were either downstairs. You're walking around the ward, you would just not in that bed so yes it did. Yeah, you were normal as far as I was concerned you were normal. You know, you were annoyed when they kept postponing your angiogram, because they had fasted you all day and there was an emergency.

Christine 16:19

And then they say it's canceled for the day, you had to have it the following day. And I remember you're very annoyed because you were downstairs again, the foyer of the hospital wanting to eat something. So, look, there was some funny moments, I must say. But yeah, which sets this false sense of security that everything's fine. You know, nothing's actually wrong. It was a bleed. It's a funny thing that happened, you'll be fine. And I whether I forced myself to believe that but the proof I felt the proof was there in how you were behaving and acting normal.

Dealing with the drug side effects



Bill 17:01

Yeah. And then as the hospital stay ended, I came home. What was it like sleeping next to me during that time when I was on dexamethasone and couldn't sleep and couldn't do anything like that drug was designed to help me with inflammation in the brain to save brain cells, but it had a whole heap of side effects and one of

them was hallucinations. What was that like?

Christine 17:30

It was pretty frightening. I remember one night that I can feel you moving around and then all of a sudden you just sat up right just staring ahead of you I was asking you Bill, what is it? What is it? And you would not respond you just kept looking ahead. It was pretty scary and think oh my god, he's possessed what's going on with him?

Christine 17:57

But I did realize it was the effects of the drug and I believe it has a whole range of side effects and you probably had 80% of them every single thing that could have possibly been a side effect that you experienced some way or another. The eating, oh the grumpiness.

Bill 18:25

The grumpiness. So tell me about the grumpiness because there was some really serious grumpy situations right? So we'll talk about that because really what I want to do is capture the carrier's perspective, right? And we were a regular couple, we argue, we fight, we yell at each other, we scream at each other, and then we're nice, we're lovely. We're caring, we're loving. We do all those things, we're kind of a little bit, you know, all over the place sometimes.

Bill 18:52

But there's usually underlying things that are going on that cause us to act out and misbehave. And then I'm getting really better at misbehaving less and apologizing more is my aim in life. And you're getting better as well at knowing what is something that you need to get cranky about and something that you don't need to get cranky about what you can ignore when I'm being silly.

Bill 19:19

And then what you can take seriously. And then there was this situation where do you maybe want to tell the story? Because I've told it from my perspective a couple of times, but remember that time when I was weighing myself and notice that I put on like eight kilos in the space of a couple of weeks, and I wanted some ice cream.

Christine 19:42

Yes. Okay. Well, I did. I thought we had no ice cream in the house at that time. So

I went off to the, you know, the supermarket to get some ice cream for you. Me being me thinking, Okay, he's putting on a fair amount of weight let's go get him a diet ice cream, same you know vanilla brand that we would normally get, but I found the light version.

Christine 20:12

Same thing you won't notice but it will be a lot less calories would be better for him. Wow. I think that was the biggest mistake I ever made because when you actually saw the light Ice cream you did go you were very upset to put very mildly it was not violent or anything you were just very annoyed how dare I buy you diet ice cream? Why would I do such a thing?

Christine 20:47

And I just realized at that point, okay, this is not an argument for me to have with you because I realize I made the biggest mistake ever but I think I just confirmed to you that you putting on weight. When I would normally just buy the normal regular ice cream, but I went and thought I was doing you the biggest favor but it was not.

Christine 21:08

It was the worst thing I could have done it should have just bought you what you would normally have. It would have affected you. If I think about on so many other levels that things were changing. And this was just another thing that I threw at you gave you a diet ice cream. And you were upset and it wasn't anger. I think you were just truly upset that I would not get you what you wanted.

Bill 21:34

Yeah, it was I think me reflecting on it was that you made a decision without consulting me A and especially about ice cream and I don't know why ice cream became the most important thing in my world at the time. But it did and when I didn't realize it was light necessarily at the beginning. I think maybe I read it on the on the package. But then when I tasted it, it didn't taste nice. And then I thought oh my god, this is disgusting. I'm not even going to eat it.

Bill 22:00

So I had worked myself up to eat it and then I couldn't eat it because it was disgusting. So I thought, nah, stuff it, I'm going to just get upset with her and yell and make the point that I don't want you to ever do that again, make sure next

time when I say give me my stuff you give me my regular stuff and there's no you're making decisions for me, you know? And I don't know what really made that happen to the extent that I did. But you thought at the beginning you thought I was joking. You thought I was kidding.

Christine 22:35

I thought it was because I thought it was such an odd thing to just get so upset about. I think, first of all, I wasn't with you to be honest going back to that time. You must have gone to the fridge when I wasn't home and it began with a text message. I looked at them and wow ha ha he's joking with me. So yes that's right, I thought it was actually a joke to begin with, until I actually came home and saw you and realized this is no joke, he's a great he's upset.

Christine 23:13

And you know, I had to think I wouldn't normally, you know, say get over at all what's your problem it's just ice cream, eat it or don't eat it at all. But I knew not to go down that path. I actually knew that this is not right. That behavior was not normal. I thought so I let it go. I just took it on board. Okay, I'll get you the proper ice cream next time and left it at that.

Bill 23:46

Yeah I know, you poor thing.

Intro 23:48

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

Intro 24:18

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

you take a more active role in your recovery. head to the website now, recovery after stroke, calm, and download the guide. It's free

Bill 25:00

So let's move forward a little bit right to that time when we came home after seven days, I came home after seven days, the prognosis was pretty good. The angiogram showed that there wasn't going to be the bleeding had stopped. The angiogram kind of revealed that this thing was probably going to pass, it wasn't going to bleed again. And then six weeks, we had the follow-up appointment.

The second stroke

Bill 25:24

And just before that follow up appointment, I'm pretty sure it was one or two days beforehand, I got bored and went to work on the way and while I was at work, I wasn't working, but I was watching my employees work painting away and all that kind of stuff. And then I started to feel dizzy. And like I needed to throw up and I realized that something was going wrong. And eventually, I convinced one of the guys to pick up what it was that they were doing and bring me home because I hadn't driven I wasn't allowed to drive and they brought me home and on the way home I called you and said hey, I'm not feeling too well, I'm on the way home. Can you be home and be ready to take me to the hospital? So what's it like to receive that phone call?

Christine 26:12

Well, I remember that day was a Friday night. So it was on a Friday that you went and it was actually the Monday that you're going to have the appointment. So, to get that phone call, it was like, here we go again. But then I thought, hold on, it could just because you said you felt nauseous. So I was sort of thinking well, maybe he's got a stomach bug, you know, he was out there, maybe got something ate something.

Christine 26:42

The symptoms were completely different from the first incident, where you just experienced numbness and no actual, you know, feeling sick, or having a headache as such, but this time was different. But again, the concern and alarm bells set off. So I remember waiting for you I got in the car and waited for you to be dropped off. You know not to waste any time I suppose. And I saw you get out

of the van, you know your co workers van and I saw you walking across to the car and you were as white as a ghost.

Christine 27:22

You just look so pale and you weren't right. Anyway, you came in the car and you said we'll just go straight to the hospital. So we're driving there and you were nauseous, and you kept saying that you felt like throwing up. Luckily the hospital's about 10 minutes away. And it was Friday. We managed to get there at a reasonable time. And I remember because you just looked like in that short time you look like you were just getting worse, you know, you were not feeling well.

Christine 27:55

So drove you all the way to the front door of emergency and I say Bill, just go in. Rather than waste time me looking for a car space to leave the car and then try to walk you it's best to just drop you off. So I would say by the time you walked into the doors of emergency by the time I found a car space to leave the car and get back 10 minutes maybe had lapsed.

Christine 28:24

I remember going to triage where the emergency desk is and I said that I just dropped my husband off about 10 minutes ago. And she asked what's his name? I said it's Bill. And she said, okay, go straight through the doors. He's on bed. I can't remember the bed number I went straight there so I thought that was quick that he got in there, you know right away. Usually there's such a long wait to get through those doors. So went in and you were lying down, I remember there was a nurse there you know, attaching things on you getting you all ready.

Christine 29:05

So you well, you had just I think just went downhill very quickly. And you weren't really responsive to me even though I came to you and you seem to be like you realize that there was someone else in that room. You weren't right. And I just had that sinking feeling in my gut that I knew this was not just a stomach bug because of the way that you were responding or not responding really.

Christine 29:38

And I remember at the time, the nurse, she after she attached, whatever she was doing to you put the blood pressure cuff on you and then she asked you, she goes Bill, can you please touch your chin and you looked at her and then looked at me

and you said who is chin. And I looked at the nurse and the nurse just ran out of the room and here was I left alone with you a person who did not know what a chin was and I thought, oh my god and a went close to you I remember coming close to your face and I said Bill no where is your chin? Where is your chin? And you looked at me so blank (inaudible) and it was the most devastating moment because I thought how could he not know who I was?

Christine 30:38

And I remember I just looked at you and I said, oh my god, there is something seriously wrong here. I ran out of that cubicle to look for this nurse who just abandoned me with this person who didn't know who his chin was or what his chin was. And sure enough, she was running back with the doctor so she ran off to get the doctor because I think she realized at that point that you were not in a good place they feel something seriously wrong with you.

Christine 31:05

So the doctor, they came running and they said we need, to take him to CT. So in the process, it was just mayhem. You know, they're pushing your bed out to, you know, take you straight to CT. And I said to the nurse, he doesn't know who I am. And she said, It's okay, we're going to get a CAT scan of his brain. We'll see what is going on.

Christine 31:05

And I remember they're wheeling you and I had to be locked out the room, of course, and just waiting for those moments just to find out and remember the doctor opened the door. He came to me and he said, there's another bleed and is actually bleeding at the moment, but they said that there were it was a slow leak, but it was a fresh one. So here we go again. And I was thinking but it was never meant to happen again. They said it was rare to happen again. So sure enough, these rare things tend to happen. And he was bleeding again. And that was the beginning of the journey.

Bill 32:09

It was definitely chapter two, wasn't it? And for me, my version of that is I remember walking to the triage nurse and that's it. And everything else that you tell me. I, it's like their memories, but they're not really I don't really remember being in that situation. I was out of it. And I think the only reason why I kind of tell people, what may have happened is because I've heard it from you a number

of times now. But then I was in hospital for three days and I honestly I only remember a very small amount of those next three days. What was that like? What was it like when I was in hospital in that next three day period?

Christine 32:56

Well, to me this incident felt like the most serious one, because we knew it was another bleed. So we realized there was another level of seriousness because it was something that was not supposed to happen a second time. And this just showed that whatever was there in your brain was quite volatile. He had its own little planning place, I guess you could say. In that time, I remember that evening. And I suppose this is the moment where I realized it was going to maybe get out ahead was well after you had your CT they brought you back. They put some drugs into you. I think they gave you a whole lot of anti-nausea because you kept throwing up and I'm not very good with people throwing up.

Bill 33:53

You're the worst with people throwing up.

Christine 33:56

And I remember the nurse had given me one of those bag so that I can help you. I didn't (inaudible) helped you out. But I remember that you were dry reaching and I swear I felt that I needed a bag for myself. Say I could think back and laugh at it now, but it would have looked pretty funny. I'm pretty sure if anyone else was watching. And soon after that, I remember a lady came into the room and she had this clipboard with forms. And I remember she went to one of the last pages and gave me a pen and she said you need to sign here. And to this day I have I didn't even read it. But she made me sign it so I signed the paperwork and she said this is in case you need emergency surgery.

Christine 34:47

So they were preparing for their while they're trying to get in contact with the neurosurgeon that you were supposed to see for the follow-up appointment and all of that. So they were trying to work out what I guess you know, Get all the paperwork for, I suppose the possibility of having to open up yourself that night and I remember signing those documents and leaving and I said, I just signed these documents. I didn't even read them properly and I'm a person that I need to read but under those circumstances, always forced into it.

Christine 35:22

And I was hoping, oh my god, I hope he does not need surgery. Not now, you know, I just didn't feel like it was the right thing that I did. Signing them I don't know why that's how I felt at the time. But that night they found you a bed in the special units as high dependency unit. And I remember I was there till it was late at night by that stage.

Christine 35:51

And I remember the nurse said you know, he's resting easy by that stage you were communicating with me you remembered who I was the again so I think after all the drugs whatever they had given you, calms you down. Maybe even helped your brain I'm not sure if they gave you any anti-inflammatories at the time. I'm not too sure about that. But you did start to recognize that you were talking more so again, when the nurse said you know, go home and rest you know, we're here with him all night. We've got your number. If anything happens, we'll call you.

Christine 36:27

So I sort of felt all right. Okay, I'm leaving, because I had to go collect the boys from your parents, because they picked them up from home that evening. So I remember leaving the hospital and just feeling I did know, to be honest, when I think back I don't know. I'm not too sure what I was feeling or thinking. I just thought it was an uneasiness.

Christine 37:00

I thought, here we go again. But this one did not feel the same. It did not feel the same as the first one the first time, I think I was more optimistic this time around, I actually did not feel optimistic because of the fact that you didn't recognize me. And I thought in those moments that that's it I had last year, I lost you. You know, it was the same. You didn't know who I was, you didn't know your chin. I thought, can this just keep happening? You know, when we'll remain that way.

Bill 37:35

To make you feel better, I was really good. I wasn't concerned or worried about anything. And that's one of the things that a lot of stroke survivors talk about like you're in another world. You're just spaced out there's no fear or concern or worry or anything like that. So that comes later. That seems to set in later. Remember, I'm gonna just track back a little bit. Remember when we told my

parents I was in the hospital and they got ready to come and see me the first time?

Christine 38:06

Yes.

Bill 38:08

Remember what happened to my dad?

Christine 38:09

Oh my goodness. Yes, I do remember what happened to your dad. Those about two days after you being in the hospital you were upstairs in the ward. And I was supposed to come and visit later on that afternoon. But I think it was your brother had called and said they've taken dad to the hospital because he fainted or he collapsed at home. I could not believe it. Anyway they had brought him to the same hospital in emergency. And we had you on one label in the ward and then we had you know your dad downstairs in emergency. And it was like you kidding me? You know, I think we had taken you downstairs.

Bill 39:08

I went for a walk. I went to find him in emergency. And I said to him, what the hell are you doing in here? And he looked at me, and he was so upset. And I remember him telling me, you know, you need me for the first time in your life, you know, really serious stuff. And look at me, I can't even I can't even be on my feet. Now. Dad was in his early 70s by then more late 60s. And he was on some blood pressure medication and he would need to eat and he hadn't eaten or something. And that made him dizzy and he fainted and he fell in the backyard. Now, dad weighs 150 kilos. That's probably double what I weigh. And my mom couldn't lift him so they had to bring an ambulance to the house to bring him to hospital.

Christine 39:52

Yeah, so that was a bit shocking, because look after they did all the tests on him and it just so happened to be the fact that he had no food it was from my memory was a hot day, as well. So those two things, so he had a bit of a fainting spell, but couldn't get himself back up again. And I guess that was the most concerning thing. You know, his blood pressure was probably all over the place. But it all turned out well for him. He was discharged later on that evening, if I remember

correctly, but it all worked out well for him. So I think it was more of a lesson that he had to look after himself and not he was so stressed and worried about you that I think he forgot to eat and do all the right things for himself.

The second post-stroke aftermath

Bill 40:43

Imagine being my mum like, at the time imagine being my mum. And you've been there because we're going to get to that in a minute, right? And then what was it like because I started to go on this I took the approach so I remember coming out of hospital that second time and then being a little bit fuzzy about my memory, I wasn't able to concentrate type fatigue had kicked in. I couldn't go back to work I couldn't drive I couldn't do all those things. What was it like for you to experience me being in that situation?

Christine 41:25

Well see you did become pretty dependent for you to whether it was really not a choice, you know, that was taken away from you really. So it's just having to do more things for you. You know, if you wanted to go somewhere, I will take you there. If it wasn't me, it was your dad that would take you if you needed things, you know, your appointments. I took you to most of them, if not all of them.

Christine 41:59

Yeah, you have to give up going to work so that was a big one that was actually quite hard to watch that because that was taking away all just even the basic driving you know just driving from here to there to get milk when needed in the house. And you couldn't do that because it wasn't safe to do that. And I remember the frustration in you, you know, as the time went by that you just wanted to drive and I think that's where you had had enough of the hospital that we went to initially because you weren't getting your answers and I think a lot of it was driven by your lack of all having your independence taken away from you.

Christine 42:50

And you wanted answers you wanted to drive again you wanted to go back to work. You wanted us supposed life to be normal again. That was really at a it was all at a standstill. So it was hard to watch you go through that I, to watch you go through it, but I can't actually imagine what it was that you actually felt. You know, at that time, you know how difficulty it would have actually been?

Bill 43:22

Yeah, stroke survivors talk about it as being really a difficult time because you become reliant on other people and when you've been independent you don't want to rely on other people. On reflection. I think it's good to be able to rely on people and ask for help. But at the time, you're mourning your old life and people are telling you this might be your new life forever.

Bill 43:45

And we haven't adapted our identity to be this new version of ourselves. We are our identity is still the one that was before the bleed in the brain before the stroke, what we were able to do what we were able to participate in how we how we worked. We form our identities around I am, for example, that that was a painting business of mine, I was a painter. I went out and I did these things and those things, and I was a dad and I went to sports and I did all those things with my kids and I had all these ideas of what I am based around the things that I could do now that I couldn't do them who was I what type of person was I?

Bill 44:25

And a lot of stroke survivors struggle with that transition. And it's fair enough, because you've got to give up a lot if you become, you know, severely incapacitated. If you can't do stuff, you've got to give up so much. And it's not gradual. You can't give it up slowly and then feel like okay, I'm getting used to this new me. Just, it's immediate, and then how the heck are you gonna deal with that?

Bill 44:53

So that was one of the challenges now. Part of me wanting answers then I think started doing the research it was started to what can I do to support myself to heal my own brain. And I found that the best way to do that and this is what I coach a lot of people about now is take control of the things that they can and one of the things that I did that I really got a lot out of was I think my mindset was pretty cool because

Bill 45:20

I've done a lot of counseling and coaching work up until that time just because there was the kind of guy I was. But then I took I took diet was my thing I became obsessed about what went into my mouth. And I started to notice some really really cool result. observing that from your perspective your husband going from

this place of not being able to do too much after that second incident to being able to take a lot of control back what was that like?

Christine 45:50

That was really good to see. So with your so you were learning a lot you got on to the internet you would read anything that you know try and find information you know about stopping the consumption of sugar was a big one, you know, doing things that were like cutting out gluten and you became pretty obsessed with that to the point where you would, you know, maybe drill those sort of things to me and I love my sweet so that was a bit hard.

Bill 46:24

Sugar and gluten went away.

Christine 46:29

But it worked for you, you seem to become a lot clearer. And I guess it did help you on a physical level because after that second incident, I guess you were having your very, you know, your checkups were pretty often after you had changed doctors and everything. But you had cut out all of those nasty things and you had lost quite a bit of weight.

Christine 46:59

And if you seemed, we'll clearer about everything that you were doing, and pretty determined on getting yourself fitter and better and stronger. And I guess it gave you a sense of purpose, you know, you found something that made you feel better. And I guess, you weren't as foggy in the brain, you know, because you, would say at the beginning that you would try and type up an email and you'll be staring at the screen for so long and maybe type two words, something like that.

Christine 47:35

So you, all of a sudden, we're able to start doing things that you weren't able to. So I noticed a lot of that sort of thing and I guess I didn't know where there was focusing on something that was actually working for you. They gave you more of I guess, the passion to follow through with it, because you found something that was working for you.

The gut-brain access



Bill 48:00

Yeah, you know what I found? I found something that nobody else told me about. No Doctors, no physiotherapist. And I think it was very early in the technology in the discussion in the papers that were available of the gut-brain access, and the connection between a healthy gut and a healthy brain and how to influence the healthy brain.

Bill 48:20

And I thought, well, like in the past, I would have had to go to a neurologist and give my life to them and tell them to tell me what I needed to do right now I can go to the neurologist for the doctory stuff. But for that other stuff, I can do it on my own, and I could prepare my brain so that it gets better and better and better as long as I can, you know. And basically, that's what it was. And the diet was something that I was really able to give up foods that I was addicted to.

Bill 48:49

To be honest, I think. I used to drink a can of Coke, almost every single day and sometimes more than one and sometimes more than two. And that was my go to for everything and then so was bread, bread was 90% of my diet instead of, you know, like putting one piece of salad in there one piece of cold meat and one piece of cheese wasn't really nutritious for me it was just you know layers of bread over bread over bread.

Bill 49:19

And and when I got rid of that stuff, I felt like I was lighter, less bloated. My clarity came back and I discovered that what I was doing, which I didn't understand at the beginning was actually healing my gut and that was helping to heal my brain. And then that was pumping me with all those neurotransmitters that endorphins and dopamine and serotonin.

Bill 49:41

And that was really helping my brain and my mindset to become one of man let's get focused on what I can do to impact my life. And I was also a little bit worried about the fact that I had maybe intervened in a way to make myself unwell because I used to smoke from time to time, more often than not, you know, like I used to smoke more than one or two cigarettes a day when I've, you know, felt like it. I used to go to the gym but not really to get fitter to make muscles so I can feel like I was a muscle man so you could love me more.

Bill 50:20

You know, and all that kind of stuff and it wasn't really ever about. I didn't really understand what health and well being was. I thought that it was something that you get when you buy a program from somebody who's trying to sell you their service and that's about it. Right and I totally get it some of those programs are a great way for people to start getting curious about what health and well being used for them and there's a place for them, but for me, it was very superficial.

Bill 50:47

There wasn't a lot of detail or depth about it. And then I started to lose weight and thought this is the first time ever I've lost weight without needing to go to a gym and exercise and pay for membership. And then it became my mantra just don't eat gluten, don't eat sugar. And that's 90% of the job done. The rest of it is eat heaps more veggies, heaps more fresh food and less processed food and then eat protein.

Bill 51:01

And it was simple, simple to do simple to follow. And it just made the world of difference. And it's roughly, it's basically how I eat now. And I always talk to other stroke survivors on the podcast and say something along the lines of like, I'm healthier than I've ever been. Even though I'm living with all these symptoms of stroke, his left side numbness and the burning sensation that I feel on my skin.

Bill 51:19

And and then when I get tired when I get wonky and can't walk, like exactly 100% I start to feel a little bit wonky right? So what what kind of conversations were you having with the boys though? Because I don't remember having too many of them. Maybe they avoided it, but were you having convos with them?

Christine 52:08

We did. It was mostly. To be honest, I think I spent most of my time protecting them in the sense of not really saying anything that may scare them. But of course, I would let them know that if you were (inaudible) incident, the second incident when I went to pick up the boys from your mother's house that evening after you didn't know who I was, by the time I reached your mom's house, you know, I tried so hard before going in to get the kids to be normal, you know, not look upset or fazed.

Christine 52:50

Anyway, I sat down and I said hello, and of course your mum was sitting there with the boys and she looked at me, she said, oh so how's Bill doing? And instead of what I may have rehearsed in my mind how to approach it and say, oh, yeah he's fine, he's resting. I looked at her just burst out crying and said, he didn't know who I was, well, if there was any way I could have killed my mother in law, that would have been the way to do it, I saw the devastation in her face, and not to mention the boys because they were in there so caught up in my own emotion, fear that I had felt when I was trying so hard to calm myself down before I go into the house. It didn't work, you know, it just didn't work.

Christine 53:41

And all I remember is your dad got up from the kitchen table and walked out of the room. I thought, okay, but then I just realized, okay, I've got to change this, I said, but he's fine. He remembered me afterwards, you know, try to make them feel better. But it was just all that fear. That I felt that my own devastation and then I looked at the kids that had their eyes are so open wide horrified basically so I think from that point I was I made myself be very careful what I said in front of them and how I approached them.

Christine 54:22

Because because of my own fears I think I'd devastated the whole lot of them and at the time maybe I needed it was my own release but you know, I spent that

night telling them you know, I did say sorry, while we're driving home I didn't mean to, you know, say it like that. But dad did is a lot better now. He was talking to me before I left and he knew who I was. So that was okay. And I believe the next day I brought them there they saw you. You recognized them luckily then it was okay but yeah.

Christine 54:59

They were young and you know what, even though whatever we said to help them feel comfortable or not worry about it and only tell them things if you weren't coming home because you're in hospitals need to explain that and they were fine about it. But I do believe to this day that they have you know, the emotional baggage because of it.

Bill 55:32

Yeah, for sure. And they still go to counseling and they've been to counseling. They've got the emotional baggage because of it because so much other stuff happened during that time right? And you became my spokeswoman like you had to answer for me you had to speak on my behalf to everybody. My brother who's probably not the easiest person to talk to about emotional stuff because he's an emotional guy, but struggles to have the emotional conversation or at least back then did more so than it does now. Then you had to tell your parents you had to tell your sisters you basically had to, like become like my media person. What was that like?

Christine 56:21

Not nice actually? Yeah, having to drop all these bombshells each time you know, but I felt it was better coming from me just let them know not to upset or stress you out in having to do it. So I'll just say it but everything's all right he'll be all right and don't worry about it that was my attitude sort of thing because what I found it was hard enough dealing with my own uncertainty of what was happening, to have to deal with everyone else's worry and stress was also a very hard to deal with. I knew it had to be that disconnect from it so that I could survive. I felt, you know, I would maybe make things sound better out when I told other people than what I actually believed myself. Just so that I didn't have to deal with the worry, concern, questions I had no answers for. So I guess I sort of always had a rosier twist to the story when I was relaying what was happening to others.

Bill 57:38

Now that I've got you on a podcast, and I can ask you questions that I can ask you in private. I want to know like, you don't do much talking about what's going on in your life, what your problems are, and I'm the forever talker. I talk about everything right? Would it be accurate to say that I've dragged you to counseling sessions, and we never had like marriage counseling. But we had just counseling sessions where I would involve a third person so that I can say things that I didn't know how to say to express myself.

Bill 58:17

So it's fair to say that I dragged you to those. What is it about you and I'm not trying to be facetious or nasty or anything like that. But like, curiously, what is it about you that you can't have those conversations with a third person because they're so helpful for me, and I kind of wanted to force you to go because I thought if it's useful for me, it's going to be useful for you. So just go and speak to the counselor. Like, how come you couldn't bring yourself to do that and still are reluctant I feel like doing that kind of stuff?

Dealing with things personally

Christine 58:53

Okay, well, first, let me just elaborate on the point you made that you had to drag me to see counselor well, yes, for the first one you probably did. But thereafter, I think I was pretty willing participant because after the first one, I actually realized, okay, this is not so bad. And I'm getting a better understanding of how you're feeling about things or how you process things. So it is helpful, just to put it out there.

Christine 59:27

So anyone listening who is afraid to get a counsel to please go. But for me, I am a person that feels I need to process things in my own mind. First, maybe whether it's to get a good understanding of what it is that's going on whatever the issue may be, I feel a need to process it on my own. And if I then need further help, then I'm more than willing to reach out for it, so by the time that may happen, my issues gone, or I've forgotten about and I move on. So I guess that's how I work. So I do process, I guess, internalize a lot. And I guess that's just my way of doing things.

Bill 1:00:21

Is it then not accurate of me when I say stuff like that that puts you at risk of being the kind of person who sweeps things under the carpet, so to speak, and then they catch up with you later on in life? Does therefore you forgetting about it and moving on, potentially create that situation where later it's overwhelmed, because there's too much stuff that you've forgotten about or haven't dealt with?

Christine 1:00:48

I'd say in some instances, yes. I guess it depends what the issue is that you've swept under the carpet. Yes, things do come up and they can bite you on the butt when you least expect them? I guess for that it depends what the problem is or what the issue is that you ignore. You know, but as I said, I try to process things in my own way my own mind. And, you know, I won't say that I'm perfect with everything because I am not. And things have come up that have come out at a later stage and I find it difficult to deal with. And it could be because I never dealt with it to begin with.

Bill 1:01:41

You're not perfect as if I'm not perfect I think I'm perfect. Why would you say that? You're not?

Christine 1:01:49

Oh, no reality.

Bill 1:01:51

Yeah, all right. I'm not perfect either. So our stroke journey has been really, really interesting. And then there's a lot of people involved we're Greeks right? So we don't do things on our own. I don't have a stroke on my own. I involve the entire family. My dad collapses. A whole bunch of stuff goes on. And we kind of, we kind of take all that stuff for granted. And then as life continued to go on, I got to about nearly three years, it was just before the three year mark from the initial bleed, it was November of 2014, where I had another blade. And in that time, if I remember correctly, everything had kind of gone back to normal.

Christine 1:02:47

Yeah, it did they almost became a distant memory. You know what you had gone through.

Bill 1:02:55

Things started to come back on board. I was back to work. You were back to work. Not caring for me at that level.

Christine 1:03:02

I started Uni. Remember I started my psychology course on it was May of 2014 when I started my course so is that Yeah, yeah. I thought well and well and secure in our lives that I was able to, you know, start doing something that I felt motivated to do. So yes, that was a very big year 2014 That's for sure.

Bill 1:03:31

Yeah. And I remember during that time, the one thing that I struggled with was the amount of time that you put into your studies and you're a great student compared to what I ever was, but that meant that I had to do more around the home and then I started to notice the fatigue and started to notice some of those issues, and I started to act up a lot. Do you remember that time as, like the way that I just described it that I started to act up and kind of be a little bit more.

Christine 1:04:01

Yeah a lot more frustrated with you wanted things, I guess, well organized so that you didn't have to put too much brainpower into thinking like for you was what food would you like so I don't have to think for you. And I'm actually quite easy just don't cook me meat, I'm fine. But I was the type of person that once I got onto my computer to start doing my studies, I could have been there all day and the whole day can pass by and I wouldn't realize that it was dinner time. So yes, you were getting pretty frustrated that I, you know, didn't put any thought into certain things. And that was a suppose bothering you quite a bit.

Bill 1:04:51

Yeah, and you not only that you were you're looking after the boys. Yeah, you're going to work you were studying, I mean, and you weren't studying until, you know, 9pm you're studying until one or two in the morning, and then you were going to work first thing in the morning.

Christine 1:05:13

Yeah, there was a lot I did take on a lot. But I guess for me, it was something that I enjoyed. And if you're going to do something, do it right, I guess, maybe to the point where I was burning myself out, but I loved it. And I felt more productive during the, you know, the night time hours when everyone else was asleep. I was

able to get work done. It was incredible.

Bill 1:05:38

And it was the perfect distraction because you'd been through a lot. Now, a few months into that November 2014. So you started your course in May, June, July, August, September, October, November. That's six months later, I had another episode so I was at work, and I experienced numbness in my left side burning sensation on my left side like I was in the sun, like I'd been sunburned, dragged myself to hospital rang you and said, Hey, I'm feeling a little bit weird. I'm on the way to the hospital. Meet me there at some point is that how you recall it?

Christine 1:06:14

Yeah, I think at that point you were walking towards emergency and you said I could tell from your voice that you weren't quite right. That you sounded concerned and that you said I'm thinking that there's something that I'm having another stroke because I feel a funny sensation on my left side again I'm just walking to emergency. I just want to talk to you until I get there.

Christine 1:06:41

And I remember you said I'm at the desk. I heard a lady speak to you, you said I'm going now come to the hospital. And I thought, here we go. Take three. So it was in the morning. I don't even think it was even nine o'clock. I remember I was having my breakfast on the couch and on a Monday is my day off and I work. So it was literally morning having my coffee and breakfast and I get that call.

Christine 1:07:09

So it's like, Alright, get up, put some clothes on and go. So I did that. And sure enough, by the time I got there, you had already done your scan and all of that. And you know, when I saw you sitting up there laughing away, I think with the nurse or the doctor that was in there. So again, you seemed it was a different experience the third time around again.

Christine 1:07:34

So this time, you're a lot more alert you were still with it. You just said you had a burning sensation on your left side. But they did confirm it started bleeding again. And it was just unbelievable. And I remember the doctor he was looking at your results on the computer and I said I'll look he goes come and I'll show you where the bleed is and it was pretty obvious when you saw the imaging It was

back.

Christine 1:08:01

And I said, oh, that's interesting because I'm doing psychology and we just finished the neuro psych. And it was, you know, all the structures of the brain. And it was here we go, an actual tutorial right there in front of me. I mean, really did not need my own husband's brain there. But anyway, it was just another one another blow really, because at that time, I thought we had it behind us. I honestly thought that you were fine.

Christine 1:08:36

That it was almost three years. No incident, you felt perfectly fine. I mean, wasn't it the day before you went on a bike ride? But I'm not even sure how long but you had a really yeah. And you were probably at your fittest, strongest time and then it happened again. So now, it doesn't discriminate. Clearly It doesn't matter you know how good you think you are or you feel it can happen at any stage.

Bill 1:09:07

Yeah. And then you have to tell everybody again. And we went through that whole process again.

The loss on top of the 3rd stroke



Christine 1:09:12

Yeah. And that was hard. But again, it was just a normal conversation. And I said, you know, Bill's in hospital again because it's bled again. And I remember hearing

my mom's voice and she said, you know, she was saying is he alright? I said, Yes, mom. But I think this time he has to have surgery. And she said, I would rather die have anything happened to him. I said mom what are you talking about? He'll be fine.

Bill 1:09:14

And you had to tell you're mum.

Christine 1:09:52

But five days, later she actually dies and it was the hardest thing to after obviously experience but obviously had to deal with what was happening with you I had to deal with the loss but in a way I think because all was grieving for my mom that what was happening with you just fell almost became I don't know if numb's the right or appropriate word for it but it just sedated my feelings towards what was happening with you, it made the impending surgery that was scheduled for two weeks later or something like that. As though it wasn't actually happening to us.

Christine 1:11:20

So the thing it felt it was like a total disconnect. You were there with me throughout the whole journey and it made it feel that awkward to cope. Believe it or not. Mourning my mom made me feel that I could cope with you and what was happening with you. Because I think I didn't put so much effort into thinking or worrying or stressing about you because not only was I morning my mom, all of a sudden became a carer to my dad.

Christine 1:11:58

So I had to You know, myself and my two sisters had to care for him and because my mum was his full time carer. So I had concerns for my dad. So they seemed like the most immediate things like I honestly thought, oh my god has my dad going to survive this, how's he going to survive the loss of my mom said there was all that focus there dealing with the funeral dealing with everything that and it was not until I think after the funeral that I had to actually put some thought towards you.

Bill 1:13:08

I couldn't feel my face. My eyes started to play up. I couldn't see with my left eye. And I said maybe we shouldn't go home and we were on the way home to my

parents house. They had cooked some dinner. We were gonna go there we had to ring them and tell them we're not coming. And then and then we're sitting there and it probably was the first time I actually got scared because it started to affect my eye and my vision and it was a little bit more weird.

Bill 1:13:51

And I was fully conscious. There was no spaced out or any of that stuff. And it was freakier than anything I had experienced. Previously. And I remember sitting there and while we were sitting there, at one point I forgot while we were waiting to go back through the emergency back into hospital because, of course once you've left all those people doing all those tests that's got nothing to do with admitting people.

Bill 1:14:22

And we went back to emergency told them what the issue was they told us to wait and there was this time where I did forget about your mum's passing the stroke or my issues. Do you remember when there was? It was when I sat down. Next to somebody whose mum had looked at him and said, Did you wash your hands after you went to the toilet and he was touching the chair that I was touching. And all of a sudden, I had forgotten everything because I think he was an autistic boy and he must have gone to the toilet and not washed his hands. It was just I got up and walked away and I completely forgot about everything. After that brain surgery was nothing. I was touching the chair that potentially could have had other stuff on it.

Christine 1:15:11

Yes remember that I was more concerned than you were making it obvious for the kid and didn't want the kid to feel uncomfortable because this man just got up out of nowhere after the mother said what she said oh my god.

Bill 1:15:26

That was one of the funny things that happened. But before that, I was really upset because at your mom's funeral I had realized that she said that, and she had made this most amazing gesture, and then I felt like she actually did sacrifice herself for me. And I thought, My God, that's just the most unbelievable thing. How can you make such a statement and then that coming true? It was far from being flippant, I felt like that she did something for me and I have to repay her.

Bill 1:16:04

And this is part of what I'm doing every day and living this, you know, stroke recovery journey and then sharing the knowledge and then having the podcast and coaching stroke survivors like that is as a result of what everybody has done for me but most importantly your mom's sacrifice how I feel about it, you know?

Bill 1:16:25

So I was really upset because I couldn't be a pallbearer that wouldn't allow me to put myself in a situation where pressure from lifting anything would potentially make another bleed. So I had to sit that out. So that was a really tough time for me. I know it was a tough time for you. But then we had to go to surgery we had to prepare for surgery. And that was how many days do you remember how many days after your mom's funeral?

Christine 1:16:57

It was close to two weeks. After about possibly less than that, so it was soon after it was at least over a week. we'll just say, close to two weeks after that.

Bill 1:17:16

Yeah. And then I went into surgery and we went into the pre op, I was first cab off the rank, so to speak. I was going to be first surgery for the day.

Bill 1:17:27

I had a really cool conversation with Kate Drummond, my neurosurgeon and, she had a whole team there, and she was quizzing them on. Okay, so where's the entry point? Where are we gonna go into this guy's head from and I was there you were listening. And then for the guy that she asked. He said that we're gonna go in from one angle, and it was the wrong one. She said no you idiot and she started to yell.

Christine 1:17:58

But I'm sure that we're just I don't know, God I hope she doesn't normally her younger doctors, but it was, I don't know whether it was actually done to relax us or make it a bit comical. But all I remembers, oh my God, do they actually know what they're doing? Are they going to do it right? Then I'm thinking surely not as if they would anyway we know that they didn't do it right and they did a wonderful job.

Bill 1:18:29

Did you find that you had any concerns me going into surgery so we had just been through your mom's funeral, Did you have any concerns? Was any of that on your mind?

Christine 1:18:40

It was. I mean, it was a very busy morning and obviously being with you was I wasn't going to put any of my fears on you. But all I remember is there was a certain point that I could be with you and then I had to go, obviously, so because it was very early early in the morning. Cuz you were one of the first ones there, I think I was probably went down to the cafeteria, it was maybe about 7am or something like that.

Christine 1:19:09

So I thought I might as well have something to eat. And at that stage I think I was eating very little or probably food was not really something I needed or wanted, but I thought I've got a whole lot of time to kill because they said it will be quite a few hours before I get to see you. So I remember going to get a coffee and some of the toast and just sitting there eating and you know, almost fighting my thoughts because I did not want to think about anything.

Christine 1:19:39

And I mean anything, not my mom, not you just wanted a blank mind. Because I needed to basically survive those hours. And that's what it was it was survive. So I ate and I remember just walking around the hospital and I found a chapel that was in the hospitals, just the chapel room. Okay, just go in there. It just seems such a relaxing serene room. There was no one in there. But there were chairs and I had some books in there. I thought you know what, I'm might just sit here some peace and quiet, you know?

Christine 1:20:20

And I did and I was there for a bit of time I picked up a book I was just reading, and then all of a sudden, I think it was about 9. You know, I think I killed a bit of time, about 9am some people started coming in and there were nuns, and they all coming in and they'll putting chairs around setting up the room. And I remember one of them coming up to me. They said, oh, I hope you don't mind but we're just setting up for our morning mass.

Christine 1:20:47

And I thought, Oh, no, that's fine. And then they invited me to join them. I thought, okay, since I'm in your space, I'll sit in your circle too. So I sat there with them and I handed out I think it was prayers. And we just started the morning prayer and I was so I believe in God that I can't exactly claim that I'm very religious.

Christine 1:21:18

But let me tell you, it got me through the morning, being in that space and hearing them you know when they're prayers, so I guess it's something that they do each morning. I'm not too sure didn't quite ask. But I remember one of the opening prayers was a prayer for all the patients that are in the hospital for everyone that works there and for the surgeons and to God bless they had so that each surgery is a success, something along those lines and I just go oh my God, yes, please, please bless they're hands, you know.

Christine 1:21:59

So I think it went for about half an hour and I remember at the end when it all finished one of the nuns came up to me and she asked me she said why are you in here? You know, why are you here this morning and I said that my husband's in surgery at the moment and I remember she knelt down and got my hands and just started praying for you and they did give me strength and I thought you know what he'll be all right and she just said that you know that I pray for his healing and for everything to go well and I just felt like I needed it. And I guess you needed too we all needed it.

Christine 1:22:43

So anyway, then I thought okay, it was getting closer towards you know, the surgery to hopefully start winding up so I went up to the space where the level of the surgery where the level that you would have been I found some couches there. There was a waiting area. So I just waited there for some time, I thought the doctor will call soon enough to let me know that it's you know that it's finished. So I just sat there.

Christine 1:23:11

And then those thoughts started coming into my mind. I thought, what if it's not successful? You know, what, if he actually doesn't make it and I never allowed myself to think and not know how that thought managed to get into my brain, but it did. And all I remember was thinking, no way my mom would not want him dead

there's no way and I had to stop it, whether it's real or not, you know, we all know bad things can still happen.

The surgery was a success

Christine 1:23:42

You know, two bad things happen already. But I had to your mind does funny things, whatever it is to help you get through it. And I just put that thought aside and I thought they'll contact me soon enough and actually, it wasn't too much longer when Dr. Leon did call and said that the surgery was a success, and that everything went well. And then they'll go in to send you to recovery, you know, to the high dependency unit. And the nurses will call me when they're ready, you know, to have you there and I said oh my God he's alive. And then that's when I actually felt the relief.

Bill 1:24:29

Yeah, that was pretty cool. Waking up being alive after brain surgery. Let me tell you, having you guys there was nice and all that. And I realized that I had to learn how to walk again. So that was probably a few days later. But in that time in my recovery, you got finally fed up of all of this thing being about me and you had to make it about you. So what happened now if it's not my dad doing weird stuff to make it about him when I'm unwell, like somebody else has to take my limelight. What happened to you? After I woke up from surgery was a couple of days later?

Christine 1:25:13

It was a few days later, it was probably about four days later. Not right away. I didn't want to take away the limelight from you immediately, just a few days later. Oh, what happened? Well, it started off as a normal day and I believe it was a Sunday and I came to visit you as per normal. And I remember it was between 12 and two is when they wanted the patients to actually rest in the neurology unit. So I thought all I'll just go for a walk. So went for a walk towards the market. I remember walking it but it just turned out to be quite a hot day.

Christine 1:25:53

I had wasn't prepared with any water or anything of the sort and it was probably well two hours is the time that you rested for I'd say about two hours of walking with no word and I remember towards end I thought all my mouth's a bit dry so when I got a small bottle of sparkling water that I sculpt really quickly, and then

continued my journey back towards the hospital.

Christine 1:26:19

I remember that day you had a friend come to visit you we brought you down to the cafeteria so we can sit with your friend you didn't want to be in the room you wanted to be with, even with your head open. you thought, let's socialize downstairs in the cafeteria. So we went down there.

Bill 1:26:37

In the wheelchair I got pushed out in the wheelchair.

Christine 1:26:38

Yes, with the wheelchair and we'll sitting there you having a conversation and all of a sudden I can see the room blacking out. I felt dizzy. And I could feel myself just moving to the side and I said Bill I'm not feeling well. And I remember your friend had some peppermint tea or something. In the water, and he just gave me some to drink. And that sort of helped me and I try to breathe in and breathe out. And I just felt my heart just palpitating It was not a pleasant experience, but then it passed. Anyway, we continued. Then we went back up, and I think you had another friend visit you.

Bill 1:26:39

I think it was Louise was it Louise at the time, maybe.

Christine 1:27:09

No, it was the girl that did the marathon. The other.

Bill 1:27:33

Donna Campisi, who had a stroke when she was a kid. She was on one of the early podcast episodes around Episode 22 or something. And she had a she had a stroke, and she ran a marathon with foot drop. So she's an amazing girl. Yeah.

Christine 1:27:52

So you were talking and I was just sitting there and again, I started the same sort of feeling, feeling a bit dizzy. So that happened, but then I regain because I had some water next to me. So I drank because I felt the water was actually helping me. And then it happened again and each time you pushed your buzzer to get the nurse, the nurse thought there was something wrong with you. And you said, No, No, I'm fine. But someone has to help my wife. She gets fainty. And I thought and

they said we can help her here but I remember they sit an orderly or someone with a wheelchair and they wheeled me down to emergency.

Bill 1:28:35

They ran a whole bunch of tests to work out what was wrong with you. I remember so vividly. And I'm not sure who pushed me down to the the area where you were but I ended up being in your little cubicle where they were looking. And I remember quite vividly, like just looking at the cubicle in the in the corridor and then this doctor comes past doctor Leon, who was part of the surgical team with me only a few days earlier, he looked at me and he kind of thought, I remember that guy's head type of thing.

Bill 1:29:08

And then he looked further around, and he saw you laying on the ground and he goes, What's going on here? Then I said to him I don't know something's wrong with my wife, you know, she's lying down here. And he was really concerned. And he said, and he asked a few questions to try and work out what was going on. But what you had done was basically neglect yourself like my dad had done. And you had started to faint because you were low in.

Stroke carers tend to neglect self-care

Christine 1:29:35

Potassium. So basically, I was dehydrated, as simple as that. But that caused a lot of havoc in me where my heart was, my heart rate was extremely high. But they ruled out any heart issues because I was on the ECG. So the test showed that I was very low in potassium, so I had more potassium they gave food, which I was quite fussy because I don't eat meat, they bring me meat.

Christine 1:30:04

So that was pretty funny. And I remember the young doctor, she looked at me and I sort of told her what I was experiencing. I think I almost made her cry when I told her what was happening. And she said, but you've got to make sure you look after yourself. You need to eat and make sure you drink, you know. And, and then I thought I was, but you just you don't think, as I said, That's why I keep saying, I just had to survive each day. And whichever way, however, I could manage it, I did it. But then that really scared me because I thought if anything was to happen to me if I neglected myself, anything happened to me as well. What about the

kids?

Bill 1:30:52

Yeah, they would have done it tough. And I remember my parents coming to visit me that day, and then again, not finding me and then being brought down to you and then having to explain to them why you were there. And that it wasn't really that serious was only dehydration but it's such a difficult thing to do.

Christine 1:31:13

Yeah. I know it was hard. It was definitely hard and I remember lying there on the bed and with your mom, because your mom wouldn't leave. But just looking at her face and the worry. And I was trying to say it's nothing. It's nothing, don't worry about it. But at the time, I wasn't feeling that it was nothing. I just felt that everything was I was losing control of everything.

Christine 1:31:41

That's what it felt like and because physically I was losing control, I couldn't control myself from sitting upright, you know, my body was leaning, you know, to the left. It was insane. You know, all I had to do was make sure I drank some water or had some food but I I didn't even think to do that. Yeah, but I made sure I did after that, that was definitely a lesson.

Bill 1:32:08

Yeah. And then I went to rehab and how were you with the fact that I wasn't going to walk straight away that I needed to actually learn how to walk again and use my left arm?

Christine 1:32:24

You know, honestly, I was grateful you're alive, and that you were able to move whatever you could do. But I don't think there was a moment that I actually I didn't believe for a moment that you wouldn't be able to, because I know who you are. You know, you're pretty determined person. I mean, you couldn't drive and you're angry because you couldn't drive a car when you wanted to. There is no way this guy is not going to walk.

Christine 1:32:52

Looking might not be perfect at it. But I was quite certain that you would you know I don't think I allowed myself I was pretty good at stopping those negative thoughts from entering my mind, they may have entered. But I stopped them from

continuing. So I had to because I think it can become a very dark place if you focus on if things weren't to work out the way you would have hoped. And I literally took one day at a time, you know, and every day you did improve, and to me, that was amazing. That was amazing.

Christine 1:33:42

Compared to, you know, day one after the surgery, when you're hooked up to machines, and, you know, really, I guess a lot of it would have been the effects of the drugs that you were not really responding too I although you were but you weren't at your full capacity. So I always thought it was the drugs. It's all of that. But yes, you fell out of bed and you know when they thought that you would be fine at walking, but you weren't.

Bill 1:34:12

That was rough. That was me trying to go to the toilet for the first time after surgery and getting out of bed, stepping on my left leg and then like fresh out of surgery ending up on my bum. On the floor in the ward. Like That was pretty scary for me. You guys weren't in the room. But then also in recovery. They did that chest scan and they found a lump in my throat you remember what that was like?

Christine 1:34:38

Yes. Honestly, how much more can you possibly throw at us is what I thought there was more like it wasn't they didn't really say it was a lump. It was more you had a deviated windpipe and they ran in they said can you breathe? Can you swallow? And I'm thinking why are they asking such questions? But they had done a chest scan to make sure you did not have pneumonia or something that makes sure that your lungs were clear.

Christine 1:35:07

But instead, your lungs was perfectly clear, but they found that your windpipe and I think your esophagus were all deviated because you had a giant goiter that we never knew about. And remember the doctor said, have you ever noticed a lump in his throat? I said, no, never. It was just unbelievable.

Bill 1:35:28

Yeah, you hadn't noticed that? Neither had I there was that lump the size of a golf ball in my throat and I had never noticed it.

Christine 1:35:35

It was inwards, the goiter that came out.

Bill 1:35:40

Yeah, so that was pretty, nuts. Going through all of that. I finally went home and let's fast forward like we've been through a lot. But then now it's may of 2020. And there's been nearly there's been six years nearly beyond the surgery, November this year will be six years beyond surgery and things are pretty good.

Bill 1:36:08

I can't complain about anything. And I'm so grateful to have had you the most amazing, caring, compassionate person that I know even though I get cranky at you and yell at you and, you know, we do the husband and wife stuff like the truth is that it's a team effort and I probably could have done it without you but I don't think I could have done it as well as I had without you because you took some of those other things that you made your responsibility and you ran with those and that meant that I could really focus on my own stuff. And I think I hit the jackpot. You know, when I met you all those years ago and decided to.

Christine 1:36:54

I'm glad you recognize that.

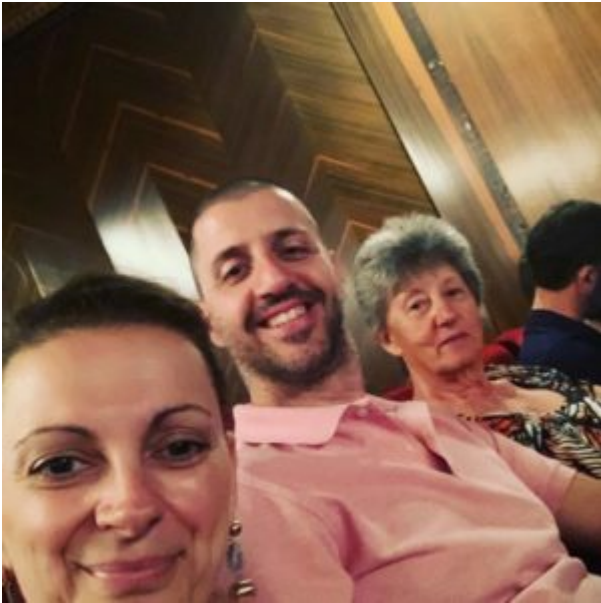
Bill 1:36:58

Decided to make you an honest lady and I can't thank you enough and I love you. And, now I'm lost for words.

Christine 1:37:12

Well, I love you too my darling. And I'm glad you're well just keep it that way. Please. No more dramas, no dramas.

Appreciation for stroke carers



Bill 1:37:22

You too. This has been one of the most amazing episodes, it's so good to interview you and get an insight into what a stroke survivor carer goes through because it is, you know, just as traumatic I imagine as for the carer as it is for the stroke survivor, the patient and at the same time that I'm going on my crazy journey of illness and you know being unwell and all that sort of stuff you're going through all your normal life as well as the hurt and the challenges of losing your mom and all that kind of stuff dealing with the children.

Bill 1:38:03

And you almost have to put a backseat, you have to put everything on your plate away aside and just deal with somebody else and be selfless. And I think, hopefully, stroke survivors will get an appreciation for the carer the person who's helping them out. And also, hopefully, carers will get an appreciation for the fact that they're not alone. And that we do think of them and that we do feel for them. And we want to acknowledge them. And I want to say thank you, to you and to them. Because it's really not possible for stroke survivors to do everything on their own. So you did a great job. You still do a great job and, thank you.

Christine 1:38:46

Thank you. Thank you for having me.

Bill 1:38:50

Yeah, thanks for being on the podcast.

Christine 1:38:53

Awesome. Maybe we can do podcast number 200 together.

Bill 1:38:59

Absolutely. I would love to do that. Looking forward to it. That'll be fun. Thank you for being the most special guest on the podcast and all the other guests have been amazing, but you're the most specialest.

Christine 1:39:11

Thank you. You're pretty special too.

Bill 1:39:17

See you in a second.

Intro 1:39:20

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