

85. Carotid Artery Dissection - Marcia Moran

Marcia Moran woke one morning after having experienced a stroke in her sleep due to a carotid artery dissection. Marcia had to drag herself on the floor with one hand to raise the alarm.

Website: <https://www.strokeforward.com>

Facebook: <https://www.facebook.com/StrokeForward/>

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Bill 0:00

Putting yourself in a situation like you did where you talk to somebody and you know you're going to have potentially an episode, or you're going to forget something. I think that's the best thing to do is to put yourself in deep and to deal with the frustration with the challenges and forget about the embarrassment and all the bullshit that you know, we worry about.

Bill 0:25

Just forget about all of that stuff and just allow the conversation to occur because that's how conversations occur. They occur by going in and starting and then if something goes away, just wait for it to come back. If it doesn't come back, start talking about something else.

Intro 0:42

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

Bill 0:49

Bill from recoveryafterstroke.com. This is Episode 85 and my guest today is Marcia Moran. Marcia experienced a strike while sleeping and had to drag herself out of bed and onto the floor with one hand to raise the alarm. Marcia has written a book about her experience called *Stroke Forward How to Become Your Own Health Care Advocate One Step at a Time*.

Bill 1:14

Now just before I get started, I wanted to let you know that you can now download all the words of this episode as a PDF. It's perfect if you prefer to read and take notes or highlight different parts of the interview for future reference. It is a great way to learn and help retain new information to memory. Just go to recoveryafterstroke.com click on the image of the episode you have just listened to. And at the very beginning of the page, you will see a button that says Download transcription.

Bill 1:44

Click the button, enter your email address and the PDF will begin to download. Also a few weeks ago I launched recovery after stroke coaching the people who signed up and now being coached by me and are being helped to overcome challenges including fatigue anger isolation, amongst other things. So if you're a stroke survivor that wants to know how to heal your brain overcome fatigue, and reduce anxiety, recovery after stroke coaching might be perfect for you.

Bill 2:12

If you have fallen in the cracks between hospital and home care, and desire to gain momentum in your recovery, but did not know where to start, this is where I can help. I will coach you and help you gain clarity on where you are currently in your recovery journey. I'll help you create a picture of where you'd 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 2:38

During coaching I will also teach you the 10 steps to brain health for stroke survivors and guide you through each step with supporting interviews from

experts and information that is based on the latest scientific research. If you take up this offer, you will get a one on one private coaching thread with me access to the course 10 steps of brain health to stroke survivors when released.

Bill 3:00

Access to member in the monthly group training calls and access to the stroke survivors private forum. Be one of the first 10 people who joined recovery after stroke coaching now and get the first seven days free to get recovery after stroke coaching, click the link below if you're watching on YouTube, or go to recoveryafterstroke.com/coaching if you are listening online, and now it's on with the show. Marcia Moran, welcome to the podcast.

Marcia 3:28

It's nice to be here Bill.

Bill 3:30

Tell me a little bit about what happened to you.

What happened to Marcia



Marcia 3:32

So it was a Sunday morning when I woke up and I felt just weird. So I reached over and grabbed my phone and texted my friend Rochelle because we were scheduled to have breakfast. And no matter how many times I put my message in the phone, it came out garbled. So I just said I'll text her later and I put the phone down rolled over. And I got the most incredible pain in the left side of my head.

Marcia 4:07

And despite this annoying pain, I fell asleep. And I don't know how long it was. But when I woke up, I knew I was in real trouble. Because my right side was completely paralyzed from my toes, all the way up through my head. But I heard that my husband was downstairs, listening to the TV. So I knew that if I got to him, he could take me to the hospital.

Marcia 4:42

So I rolled out of the bed and dragged myself with the carpet with my left hand until I got to the door. And unfortunately, the door was closed. So I reached up for the handle. And the problem is the right side didn't work. So I was a little too short. And finally, I guess maybe I got my butt off the floor, and I reached the door handle and it snuck open. And I was so thrilled that it was open, but I was also tired.

Marcia 5:24

So I had to take a break for a while. And when I finally got enough energy back, I started dragging myself down the hallway. And I thought that the hallway would be easier because it's wood, It wasn't easier. So I got to the top of the stairs and I totally ran out of gas. I mean, it was just I just laid there.

Bill 5:51

So did you go to bed feeling normal?

Marcia 5:55

Yeah, it was completely normal. I have no idea. What happened that night.

Bill 6:01

Did you feel any symptoms? Any signs anything the day before, like, looking back reflecting, How was there any opportunity for you to kind of be aware that maybe something was going wrong?

Marcia 6:15

Absolutely none.

Bill 6:19

So, did you have the presence of mind to think about the situation that you found yourself in when you woke up? You couldn't feel your right side it wasn't working. Did you feel? Did you think about it at all? What happened?

Marcia 6:34

So the only thing I could think of is I have to get to help. I thought if I laid there in bed, I would probably die. So nobody even thought of the word stroke until the paramedics came to the house and they walked to the door saw me and said, Oh, stroke. And my husband and I were flabbergasted because we had no idea but, I mean, I was 53. I ran every day. So I didn't have high blood pressure I didn't have. Well, I didn't have high blood pressure anymore because I started working out every day.

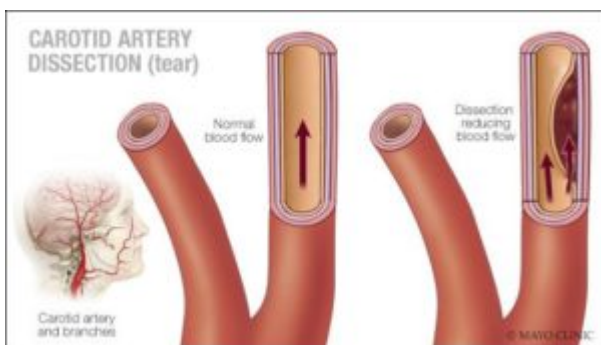
Marcia 7:18

I didn't have high cholesterol, so I had no idea that this was coming.

Bill 7:24

So what type of a stroke was it?

Carotid Artery Dissection



Marcia 7:26

It was a carotid artery dissection. And 1 to 2% of people have it. There's no way of knowing when it's coming. And unfortunately, you just are one of those people that have them.

Bill 7:43

So what is it exactly?

Marcia 7:45

So the carotid artery has, I think it has three layers to it. And so it's when one layer breaks away from the other and there's a false lumen or a piece of blood that gets collected in there. And then it creates a it either it disintegrates over time, or else the false lumen just it goes up to your head.

Bill 8:18

Yeah. So the false lumen is pretty much a gathering the blood clot. And it just forms because of the shape of the vessel has changed. And then as a result, it just gets too big air releases and it goes up. And then the other possibility dissected carotid artery is that a piece of the artery actually goes up. Sometimes they come away, depending on where the artery has started to not work.

Marcia 8:51

Oh interesting.

Bill 8:52

Yeah. So sometimes if it's a piece of the artery that's on the inside of the artery, that if it's the layer on the inside, and that could come on So the first time that somebody suspected a stroke was when the paramedics arrived, found you make a place I imagine your husband found you and then and then what happened? Do you have any recollection of the places after that?

Marcia 9:18

So I remember that they bundled me in to the ambulance and I lost consciousness when we started driving off. And I actually didn't awake until after I was in the hospital. They had a hospital gown on me, and I needle in my arm. And that's the first time I was even awake. So it was actually not as traumatic as you think. Because my husband was there in the hospital room with me. And when I saw him, I just said, That's okay, and I fell asleep again.

Bill 10:01

Did you end up having surgery. How did they resolve the issue?

Marcia 10:05

No

Bill 10:05

Okay, they didn't.

Marcia 10:06

Yeah, they just they said that the artery was dissected and there would be no blood flow through it. The interesting thing is when I went in for my scan the next year, there was blood flow through it again, so they misdiagnosed me.

Bill 10:28

Okay, so they misdiagnosed you thinking that your carotid artery had stopped working? Wow Is it possible that it stopped working and then started working again?

Marcia 10:42

No, for a while, like when they took my cat scans, you can see that there's no blood going through there. Um, it's just I guess it reconnected again and started working now. It's smaller than the other carotid artery. Um, but it's still working. which is I think it helps me.

Bill 11:08

Well, yeah, if you have a blood vessel that works and tends to take blood to your brain, I think that helps you a lot. Marcia that's awesome. Tell me about you woke up. What were you dealing with? What was the body like, what did you have to recover from?

Marcia 11:26

So like I said, my right side was completely paralyzed from the toes all the way up to my head. And I didn't speak well at all. I mean, I spoke a little bit. Sometimes you could understand me sometimes I I guess I spoke jibberish. So the things that hurt were my shoulder, which hurt the worst. My hip, my hand and wrist, my elbow, my knee and my foot. In fact, my foot still crunches together every day, all day.

Bill 12:18

What do you mean by that crunches together?

Marcia 12:20

So it's like I have a spasm in my foot. So if anyone knows of anything that will get it over. I would like to know.

Bill 12:34

So it's kind of like, Is it just muscles contracting, expanding?

Marcia 12:40

Yeah, it's just like that. It's like when you have a cramp.

Bill 12:45

Therefore, is it still painful?

Marcia 12:48

Oh, there's some pain on my right hand side. But most of the time I ignore it now. Because there's so many things I want to do. So if I have focus on the pain, I think it will take my focus away. And all the things I want to do like I wrote a book. I'm talking to people at stroke centers that will go away. So I'm gonna just ignore the pain and move on.

Bill 13:21

That's a good approach, I suppose. no different to what most people do is they just either become used to it or they become more able to deal with to tolerate more pain. So ignoring it. That's another way to deal with it. So how many years ago was the stroke?

Marcia 13:40

Almost six years.

Bill 13:42

Okay, so you've come quite a way. And when you woke from surgery did you need from your hospital stay? Did you need rehabilitation Did you have a time where you went to recover any parts of your physical

Intro 14:01

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

Intro 14:26

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. 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.com](http://recoveryafterstroke.com) and download guide, it's free.

Not feeling whole after stroke

Marcia 15:13

Yeah. So I was in the hospital for five days. And then I went to a rehab hospital and I was there for two weeks. Then I had home health care for six weeks, and then I went to another rehab hospital as an outpatient for another six to eight weeks. So, and I found that I was better, but I wasn't quite whole, like it takes a long time to get over something like this. So I actually hired my own physical therapist, and we worked for a year. She worked for me.

Bill 15:57

It's interesting about where you said you didn't feel whole, I suppose it was a long time for me to feel whole. And I don't know if I do still and it's been eight years nearly since the first time I had a bleed in the brain. And I feel like I've come a really long way. The more time that passes, the better I feel about my body, the better I feel about all the issues that I have.

Bill 16:27

But being whole this has a different connotation now doesn't mean what it meant before. Because I'm feeling different on both sides of my body. I don't I don't feel whole again, I feel two different versions of myself. And together they come together. But I don't know if they make a whole me they make a different version of me.

Marcia 16:56

So how do you get over that?

Bill 16:59

I'm not sure that I will or even if I have to, I just like you, I just accept it as being what it is and I move on. And I get my things done and I do my interviews and you know, I support people want to do everything I have to do. And I noticed it more when I am paying attention to it, for example, like now we're speaking about it, of course, I'm noticing it. And I noticing it when I'm standing up in one spot for a long time, which is what I do when I record most of my podcast because the leg starts to change.

Bill 17:36

And give me feedback let you know this is a little bit uncomfortable. And even if it

is uncomfortable, I'm not going to sit down because the other side is not uncomfortable. And the other side, the normal side or the side that hasn't been affected by the stroke doesn't feel any different. It doesn't feel tired. Therefore I don't believe my other side. My other side is just making up stories.

Marcia 18:01

Right.

Bill 18:03

That's kind of how I reconcile it, you know. And it's interesting because I went to the gym for the first time, two weeks ago, and I went on a Saturday morning, and I went for half an hour. And within a minute, my left side was, let's, let's, let's go home. Let's get out of here. And my right side, of course, is still going and not feeling any of the pain or the drama or anything like that. And it was just a matter of me convincing my my left side to just be quiet and stay the course because really, you might think you're tired, but you're not really tired because the right side is not showing any signs of tiredness.

Bill 18:49

Now I do. I say that that's a way of me to communicate to my body to do the mind over matter things. That's that's that's kind of how I do that. The reality is that there's a difference going on in my brain, there is a part of the brain that's not there, there is a part of the brain that's been interfered with because of the surgery. So therefore, there is definitely something different physiologically happening to me. But it's not an excuse that I'm going to accept from my left side.

Bill 19:21

Similar to you, you know, that I'm going to ignore it. I think that's the best approach when necessary. But it's also important to not ignore the body. When your body is saying, Hey, we need to either rest or we need to take stock or we need to sit down or or we need to stop pushing ourselves. It's important to have the ability to read the context appropriately and then say, Okay, I'm going to risk now even though I told my body to be quiet for a little bit and tag along for the ride.

Having a Super Sleep helps stroke recovery

Marcia 19:59

Yeah. So for the first three years when I had to rest, my body told me, this is enough. And I laid down and I rested. And I noticed that every now and then I had, what I call them super sleeps. And the next time I woke up, it's like something else came online. It's like, wow, I can do this again. And I wish I still had them. Because there are a few more things. I'd like to come online. But it was interesting, because I thought I had gotten to be the whole me again, or not whole, but the new me and suddenly I had a super sleep and it's like, Wow, look at that. I can think again. And I hadn't realized that I wasn't really thinking for a while, believe it or not.

Bill 21:03

Yeah, I believe that. So what is a super sleep?

Marcia 21:07

So I got really tired, and I went to sleep and it was probably an 18 hour sleep. And when I woke up whatever was happening, like I had something else came back in my body.

Bill 21:27

You might have another super slip. You never know. It might not be over.

Marcia 21:31

That's true. But it's been two years since I've had one.

Bill 21:36

You never know. What's interesting is that I speak to lots of people about stroke every day, every week. And I've interviewed a number of people who told me that something came back online for them. Five years later, 10 years later, 20 years later. So there's no such thing as it's never going to come back again. Nobody knows It's all Likely, if you've got more time ahead of you, it's likely that more and more things will come back online because the brain just rewires it reroutes.

Bill 22:09

It finds new ways to do things. And when people tell me that they overcome aphasia 20 years later, when people tell me that they have arm movement for the first time in 10 years, all those things let's be a little bit woowoo about it, all those things are just you know, right time, right place, you know, the universal line, all that kind of stuff for this thing to occur again, maybe that person was in the right frame of mind. Or right. frame of body? I'm not sure. So super sleep might be

around the corner.

Marcia 22:50

Maybe I'll let you know.

Bill 22:54

So how's your husband dealing with all of this drama that you created?

Marcia 23:00

Well, actually, he was quite he was a real sweetheart. He put aside his work. So he called his boss and his boss gave him as much time office he needed. So he was with me for two weeks. And then he had a schedule that he worked for six hours a day and he had the rest of the day off. And I thought that was really fabulous. When I came home, he worked from home.

Marcia 23:37

So I had him until August 15 or something, which is really wonderful. When I had to go to the hospital for therapy, he took time off, so I had nothing to complain about. In fact, I finally got my at him it after almost three years. So two and three quarter years, no fights. I was sometimes annoyed, but not so annoyed that I was really all that mad at him.

Bill 24:22

That's quite the record.

Marcia 24:24

Yeah. For us it is.

Bill 24:27

So you, didn't have the capacity to be mad or it just, you were able to take the high road.

Marcia 24:36

When I looked at things, it didn't seem that it was such a big deal that I just let it go.

Bill 24:46

And then one day, You couldn't deal with it anymore.

Marcia 24:51

So it's weird because he wanted to go to one of our favorite restaurants and he didn't want to take a highway so he asked me how to get there. So it was texting in my phone. And it took me too long to text. So he just said (scoff) and he took the highway. It's like, that little thing made me mad.

Bill 25:11

Because he didn't have patience to wait for another text. Sometimes men don't have patience to wait for text, you know, that's just how it is.

Marcia 25:22

Yeah. Well, and if that's the little thing makes me mad, and that's the only thing. That's okay.

Bill 25:30

Yeah, that's pretty cool. So did were you working before your stroke? What were you up to what type of a life were you leading?

Marcia 25:41

So I had my own business. Just one person. And we had. I'd started three years before, and I had 100 probably close to \$100,000 scheduled for this year. And my stroke happened in March. So my business closed. And when I thought about reopening it, I just didn't have any energy anymore. So I actually started thinking, I could work for somebody. So in August 2015, which is a year and a quarter after my stroke, I started sending out resumes.

Marcia 26:33

And two companies said, Yeah, we'll give you an interview. And I was so excited. It's like woohoo, when the phone called, or phone rang, and I picked it up for the first interview, and they asked the first question, what do you do? I said nothing. I couldn't get a word out. Nothing, I had aphasia.

Marcia 27:04

And so the interview was over after one question, and no answer. So, that night, my husband came home and I told him about it. He said, Look, you've had a stroke. Give yourself a chance. I said, Okay. So I thought, I will interview much better next time. So I practiced, and I practiced. And so when the phone rang the next time, and I picked it up, I started answering questions. Until halfway through the interview, I had aphasia again, and nothing else came out. And that was it. At that point, I realized that I just didn't have the capacity to work again because I

couldn't get through an interview. So I needed to take some time off and work on myself working on my language skills.

Bill 28:09

What kind of work were you doing beforehand?

Marcia 28:12

Marketing? Yeah.

Bill 28:16

Really need to be able to communicate if you're doing marketing.

Marcia 28:20

Yes, you do.

Dealing with aphasia

Bill 28:21

Yeah. It's one of those things. I mean, aphasia tends to be an interesting thing. I hear about people who actually I request a lot of people to come on the podcast who won't come on because they have a aphasia. And, and of course, I respect that, but I'm not sure why they won't come on, whether they're afraid or whether they think that they can't make a relevant podcast episode or I'm not sure what the thinking is.

Bill 28:51

But putting yourself in a situation like you did where you talk to somebody and you know, you're going to have potentially an episode, or you're going to forget something, I think that's the best thing to do is to put yourself in deep and to deal with the frustration with the challenges and forget about the embarrassment and all the bullshit that, you know, we worry about, just forget about all of that stuff and just allow the conversation to occur, because that's how conversations occur.

Bill 29:22

They occur by going in and starting, and then if something goes away, just wait for it to come back. If it doesn't come back, start talking about something else. But I understand that and at the same time, as a, somebody who didn't experience it. To that extent where I couldn't continue a conversation.

Bill 29:46

I just thought, Well, I'm going to whatever I'll talk my wife would wait for me sometimes she would say, okay finish the sentence. And I would go well, was there a sentence at the beginning? I didn't even know there was one sorry. What were we talking about? And she'd say we were talking about this and I'll go, Oh, no, that's going off. No idea what I was talking about next conversation.

Marcia 30:13

That's interesting, because so I joined Toastmasters. And I actually didn't do any speaking, other than off the cuff speaking for seven months, and finally, they said, you gotta do something. So, I had my speech prepared. And I had PowerPoint slides. And I remember the day so they called me up and I stood in front of the audience, and I made sure that the PowerPoint slides were working.

Marcia 30:52

I started my speech, and I got the first sentence out and I got woohoo I got the half of the second sentence out and boom, nothing. I started that set sentence six times. I finally got through it. I finished my speech, I sat down and I was so proud of myself because that was the first speech I'd given. And despite the fact that I had trouble getting through it, I still got through it. I was really proud of that.

Bill 31:32

Yeah, I don't want to give people a hard time. I don't want to make them feel like I'm putting any pressure on or judging them or anything like that. But the reality is, is that you in stroke recovery, you have to push yourself and you got to push yourself to overcome things and some of the things we have become our own limitations. We're going to overcome those could overcome physical limitations, and we got to overcome Actual brain, you know, problem limitations.

Bill 32:04

And there's only one way to overcome that and to grow new neurons or to grow new pathways is to just do it. And no one's really going to judge you. If you forget the words to a sentence, people haven't had a stroke forget words that they're about to say or what they were talking about, or way their case where, you know, that's pretty normal stuff. Everyone does it, and we just do it a lot better than other people.

Bill 32:32

You know, we're really good at forgetting. We need to be not so you know, experts at forgetting we need to be experts at trying to remember. Now, you're in marketing and you had, you know, this \$100,000 job that you're pitching for, or that you had just one you had a stroke. What happened to that hundred thousand dollars.

Marcia 33:03

Went bye bye you know, It's amazing that so when my husband called people and told them, you know, I'm sorry she's had a stroke. I was amazed that how pleasant people were. I mean, they were so compassionate towards me. I didn't know how many people actually love me. And I think that is probably one of the most important things I take from my time in the hospital is all these people who sent me flowers and cards, love me. And sometimes when I'm upset right now, I step back and I say, okay, just remember how much people cared about you. And they still care. So get over it.

Bill 34:11

And that money that didn't come your way? How much? I don't know. I don't need financial details of that, but how much of an impact did that then have later on? Because if you can't work, you can't earn any money and you have to support yourself or your, your bit for the family. How does that impact the way that you then go about, you know, family life or what was normal beforehand.

Marcia 34:42

So it took a toll on our finances. I mean, I didn't work for five years. And I started working. I wrote a book. Okay, that was my work. There's more to getting it published than just the printing of it you have to have an audience. So it's going to take me time to actually make money from the point where I published my book.

Bill 35:23

Yeah, so you took your project into a long term project so that you've got something that you're working on that's going to be ready down the track. Because really, we can't really plan after a stroke. You have to look forward to long term projects and this is what the podcast is exactly about. It's my way of doing something that's not that I love that that I can use to express myself etc. And if it does make me money, where I'm making a living from it, it will happen down the road.

Bill 35:59

Definitely not happening now. It's costing me money to run this. And I didn't work properly, for the best part of about, I would say six years. And that has a massive impact on every part of your life and your family. And it's interesting. I had just won we have we had a property maintenance business then that I'm still involved with partly. And I just won \$170,000 contract. And that job was due to start two weeks before I had a stroke. And I had to ring my clients and tell them the same thing and say to them. Sorry I can't get them in hospital. I don't know what the future holds. You'll need to find somebody else.

Marcia 36:42

Yeah, that was breaking.

Bill 36:44

That was heartbreaking because you work towards that for such a long time. And 170,000 is a fair amount of revenue. And I had never ever had a contract of that size. I had put so much work into having that type of opportunity, and then it was all just taken away. And of course, I didn't dwell on it at the time wasn't something that really bothered me. What bothered me was that I might not be around in a few years. Then reflecting on a few years later, I thought, jeez, that was shit.

Bill 37:19

Why? Why did I need to lose that contract as well, you know, couldn't the timing, I did the job, we got paid. And then I had a stroke, played those types of stories in my head. But of course, you can't achieve anything by doing the what ifs the what ifs don't mean anything. And then it was five years of working intermittently and then just getting any money I can from wherever I can, when I can do it.

Bill 37:47

And that was the hardest part. That's what people who come around and love you and support you don't realize is that your capacity to earn can be impacted for many, many, many years. And for some people Forever it's such a challenging thing. So, now that you're, I think, is it six years down the track Marcia?

Marcia 38:10

It's almost six years.

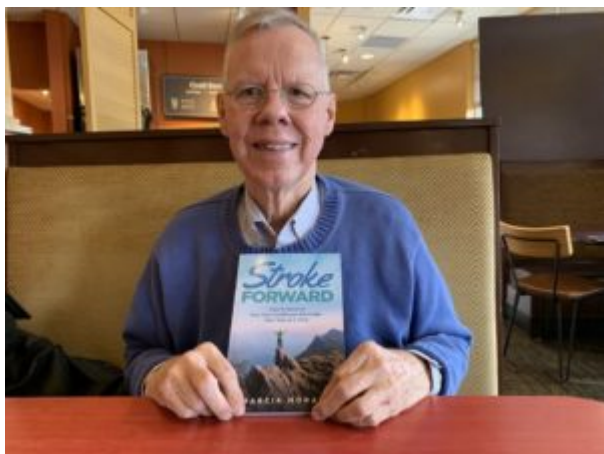
Bill 38:12

Have you moved back into any form of work other than writing the book and we'll talk about the book in a sec.

Marcia 38:18

Well, I want to speak, because I think a lot of people don't really understand, what it's like to have a stroke. If I can prevent strokes from happening, even better. So I'm starting to do podcasts. I'm starting to do interviews, so that I can get the message out and I'm hoping that over the next year or so I will start making enough money where I can make I can feel like I'm making a difference in people's lives and in my own home life.

Stroke Forward One Step at a Time



Bill 39:00

Yeah, that's important. Absolutely. So speaking of books and things that you want to do show me the book. it is called stroke forward one step at a time. Congratulations on getting it out.

Marcia 39:15

Thank you.

Bill 39:16

How long did it take you to get it out?

Marcia 39:19

It took me four and a half years to get published. And I feel like that's a real accomplishment, because I started in January of last year, and I thought, if I'm not getting it published this year, I may as well just put it aside. Okay. That means I have to get it published. Because I'm not putting Well, okay, so with my aphasia, only I didn't talk right, I didn't understand how to write.

Marcia 39:56

So I'd start writing a word and maybe it started with the right structure. And then I go, oh, but that's not how it's really written. Or maybe I wouldn't even know how to start it. So after nine months of my stroke, I could type two paragraphs, and it took me all day. I mean, literally, all day.

Bill 40:27

Might be a lesson in perseverance.

Marcia 40:30

Well, yeah, but I mean, what else did I have to do? Yeah, I could watch TV. I could learn to type again.

Bill 40:41

I remember sitting and typing my first email after the second time I was in hospital for a bleed in the brain. And it literally to do two or three lines It literally took literally took eight hours like it just took forever. And I start it and I thought I knew what I was going to say I got to the end of it. I went back read the question already email response from the other person.

Bill 41:09

So I don't have no idea what I've just written here. I don't even know how I responded. It took forever. And I felt and I went to the office and I did the work in the same in my mind the same way that I had done it before, but it was nothing like that. It was not productive. It was not efficient. It was nothing. But you're reading a book. And I only wrote a line or two. How many words is the book? How many pages is that?

Marcia 41:41

It's about 160 pages. Okay. So that's not well, it's not that much, you know? But I think it tells what I want to say, yeah,

Bill 41:57

So what do you want to say?

The message



Marcia 42:00

So, so it's about three things, actually. It's to the stroke patient. And what I want to tell them is never give up. Because as soon as you give up, you start regressing. So I don't care how many times the sun's really bad, but if you fallen down, get up, if you fall down again, get up. And yes, I've fallen down a few times. And it's for the caregiver. It's so that they understand what it's like to have a stroke and I have my husband and speaking on it, I've got my sister speaks in it. I've got three doctors who speak in it. So it's really how they view their position in the stroke. And thirdly, it's for caregivers, to want to

Marcia 43:04

learn how to be health care givers. So when my husband went to the hospital for the first time, he knew absolutely nothing about how to be an advocate. And unfortunately, I think that's the way it is for many of them. So that's why I wanted to give at least a small snippet of this is where you should start.

Marcia 43:32

Because if they have a place where they can go and they can go, Okay, I need to be cognizant of most people don't swallow well, after a stroke and they can choke. Most people, or at least I couldn't go to the bathroom by myself. Well, what does that mean? So most people I know have conversations with the doctor. He leaves and they know have no clue what the conversation was about.

Bill 44:05

That's me. Yeah.

Marcia 44:07

So this is, at least for you can start is by having something where you don't have to go through it bit by bit by bit. And over two or three years, you can go, Oh, now I can be an advocate. This gives you a snapshot and oh, this is a place where I can be an advocate now, and I can grow from here. Does that make sense?

Bill 44:32

It does. It's a great idea. It's the whole purpose for the podcast. It's to create a catalogue of different versions of what's happened so that people who experience stroke which for everybody, it's different can go and find an interview that they relate to and listen to that and then get more of an understanding of perhaps how their journey will evolve, how the process will go.

Bill 45:04

You've got some really good key headings on your website. The book first is called Stroke Forward. One Step at a Time. That's really important one step at a time is the the best way to describe it to people and I know it sounds cliché and all that kind of stuff, but it's so true, it is literally one minute step at a time because they all add up at the end of the year, those one minute steps become a massive big. If you look back and reflect and you look at where you came from, they become a really big journey.

Bill 45:42

That's really important. And then the other one of your heading says, small movements every day, and then you've got success. And it's so true. That's what it is and that it doesn't matter what you think success looks like. It looks different in stroke, and stroke recovery success looks different. I know some people think they've succeeded when they can tie a bow tie in their daughter's hair. I mean, how about that for being successful, you know, or this shoe laces or they can put their, tie on the males can can, you know, put a tie on? Or for females, it's when they find a bra that works that doesn't need two hands.

Bill 46:24

You know, because that is something that men don't think about. Certainly the doctors aren't thinking about it. And it's not a conversation that people often have. They don't have that conversation now. So when you find ways to achieve success, what's amazing about this stroke community is that everyone wants to share their version of this is what you can do because I did it and it helped me.

Bill 46:50

And I thought, wow, you know, I'm the only one who's sharing amazing things about stroke but every person I've met, has had a stroke, that try to recover or they're still recovering, there's certain part down the way but at some point, they all go and decide, I'm going to speak about this or I'm going to tell other people how to prevent stroke.

Bill 47:10

I'm going to tell people how to help the carers, and all these other things. And I think it's just fascinating that so many stroke survivors get to that point. And what a beautiful way to bring all of that information into a book. Something that somebody can buy and have on the shelf and refer back to it whenever they want and then hand it to the next person if Unfortunately, they come across somebody who has a stroke.

Bill 47:42

Your your your story is really important to put in writing as well. I think it for me or to put for me verbally because I didn't do writing very well. I didn't enjoy that. How was it writing the book for you? How did it make you feel telling your story in this way.

Marcia 48:05

Well, at first, I didn't feel very good. And that's because I couldn't write. Like, there was any emotion in there. So the first version of the book was just this happened, this happened, this happened. And it was very boring to read. So, I put it aside for a while because I wanted people to actually read it. And if I found it boring, everybody would find it boring.

Marcia 48:41

So I picked it up about six months later, and I started writing it again and it was better. fact it was pretty good. But I still couldn't write about my own family. And that told me that something was still off. So I put it again, down for about Six months, I picked it up again. And after about it had been about a year, year and a half, I could finally actually write about everything. And some things were not so good to write about.

Marcia 49:20

Like the choking in the hospital, but I wrote about them anyway, because they

happen to me. And I had to be honest about the little things because if I'm not getting honest about the things that happened to me, then why write a book at all.

Bill 49:37

Without giving away too much what was the choking incident?

Choking on hospital food

Marcia 49:41

So I had a weakness on my right hand side. So I had turned to the left. Whenever I drink something, and I was in the hospital and I was on fluids. Only, and the kitchen, got it wrong and set up real food for me. And so I was really excited because it's something I could eat. And I choked on it because I wasn't supposed to have real food I was supposed to have liquids.

Marcia 50:17

And unfortunately, or fortunately, I got it out. I don't remember how they got it out. But that was the only time I feel like I scared my husband. Because I could have died. Yeah so after that every time I choked, or started looking like I was gonna choke. He always asked me are you okay? Are you okay? for a couple of years?

Bill 50:57

Amazing and scary and Really important for people to hear that, you know, sometimes these things are the things that put stroke survivors at risk. It wasn't the stroke, it is the inability to be able to swallow or chew food etc. How does that swallowing come back? How do you re learn how to swallow?

Marcia 51:24

For what I don't know of anyone who hasn't learned to swallow? But for me, it was just practicing. I probably had my swallowing capability back within two weeks. So have you heard of anyone who hasn't been able to get it back?

Bill 51:49

No, I haven't heard that. I know a lot of people who have had the same challenge with the losing the ability to swallow usually I hear it because they've had a whatever that thing is down a tube in the throat? No, because they were unwell for quite some time. And then that impacts on the swallowing. But everyone I've seen has everyone I've spoken to you about it or have ever heard of has always

got a back. I never had that. I didn't lose the ability to swallow. And Was it scary for you? How would you describe that state of being?

Marcia 52:38

I think my husband was more scared than I was. And that's because I think they didn't tell me that I would choke if I didn't follow the rules. Now, maybe they told me and I forgot. But I think the way my husband was they forgot he didn't tell me Yeah. So I didn't even know it.

Bill 53:04

Yeah. You had to learn the hard way.

Marcia 53:08

Had to learn the hard way. Exactly.

Bill 53:11

Well, it's just fascinating. I mean, the strikes of I was going through so much. And I said all the time, I think it's amazing that people go through that experience come out the other side. And then all they want to do is share and help. So right that you do this, if somebody wanted to get a copy of the book, stroke forward one step at a time, show us the copy again. For those people who are watching on YouTube, just lift it up a bit higher. So we can see it properly. I'll put all the links to the book on the show in the show notes, but if somebody wanted to get a copy of where would they go how they get a copy?

Marcia 53:52

They would go to Amazon.com and look for Stroke Forward.

Bill 53:58

And you can get that in hard copy. And you can also get it in a soft copy.

Marcia 54:03

Yes, it's on E book and inside soft copy like this, so it's not a hardbound.

Bill 54:11

Yeah. Okay. Amazing. So tell me about what the future holds.

Marcia 54:19

Well, I think this year, I want to be on 100 podcasts. Wow. And you're number one.

Bill 54:30

Well, I'm honored thank you.

Marcia 54:35

And I want to speak 30 times.

Bill 54:41

Perfect.

Marcia 54:43

And I think that will set the stage for my being recognized as someone who speaks and hopefully I will get paid eventually. Um, so I think next year I want to speak at a conference and be paid.

Bill 55:04

Why not? That is great time to aim for your the marketing expert for those marketing skills into play to market yourself, how about that for advice from me?

Marcia 55:17

Excellent.

Bill 55:21

Marcia thank you so much for being on the podcast. I really appreciate you connecting. I really am honored that I'm the first person that started the podcast roller coaster for you. Thank you though. I really wish you all the best success and in both your recovery and launching of your new career and your book to have you here. Sharing your stories, it's gonna make a massive difference.

Marcia 55:50

Thank you so much Bill.

Intro 55:51

Discover how to support your recovery after stroke. Go to recoveryafterstroke.com