A Link Between Contraceptive Pill And Stroke? - Priya Sharma

Priya Sharma was 24 years old when multiple blood clots caused an Ischemic Stroke. There is some suspicion that the stroke, may have been caused by the contraceptive pill.

Socials: www.instagram.com/mystrokeofinspiration/

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Did they know what caused those clots?

Priya 0:03

They haven't actually found out yet, a factor of it was just the contraceptive pill. The thing is if you read the little dockets that come in medication packets and stuff that no one reads because it's very small writing.

Priya 0:24

It's actually in there that a side effect could be blood clots. But I wasn't told that like my doctor didn't say anything when I was prescribed it either. So it is kind of an, I guess, not normal, but it does happen. It's just that people aren't told that it could be a potential side effect when they're prescribed the pill.

Intro 0:52

This is the Recovery After Stroke Podcast, with Bill Gasiamis, helping you navigate recovery after stroke.

Introduction



Bill 1:04

Bill from recoveryafterstroke.com This is Episode 118. And my guest today is Priya Sharma. Although Priya doesn't have all the answers about what may have caused her to have an ischemic stroke at age 24, she does suspect that the contraceptive pill she was prescribed by her GP to treat a skin condition may have played a role.

Bill 1:25

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

Bill 1:36

I too am a three times stroke survivor and a brain surgery survivor and I have built for you. But I was missing when I was sent home from hospital in the hope that you don't have to do stroke recovery as tough as I did.

Bill 1:49

Support packages give you access to a variety of tools 24 hours a day, seven days a week, so that you can also work on other areas of stroke recovery that you don't get the chance to at physical therapy or rehabilitation.

Bill 2:02

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

Bill 2:22

As a bonus, you will also get to face to face zoom support calls with myself to help take your recovery to the next level. Go to recoveryafterstroke.com/support to sign up. It won't cost you anything for the first seven days and you will get a full refund if you're not happy after 30 days.

Bill 2:39

You have nothing to lose and everything to gain. And now it's on the show. Priya Sharma. Welcome to the podcast.

Priya 2:45

Thank you.

Bill 2:46

Lovely to meet you. We've known each other for a little while on social media. And you did some volunteering for the Stroke Foundation, which I also do.

Priya 3:01

Oh, okay. So as much as I can, I guess I've got two jobs at the moment. And I'm studying as well. So it's sort of whatever time I can get.

Bill 3:13

Tell me a little bit about what happened to you.

No signs of stroke



Priya 3:16

So I had my stroke in July 2015. I had gastritis the week before, so I was already off work. I didn't really have any of the signs. And of course, I didn't expect a stroke at 24. So I was pretty weak already and kind of not eating and stuff. So I got taken to the hospital.

Priya 3:50

And then it was in the emergency department. While we were waiting. They sort of wheeled me to get some blood tests, and I started having a seizure. So that's when they took me out to ICU and I had like MRIs and CT scans, which is how they found they found quite a few clots in my brain, which obviously caused the stroke.

Priya 4:19

And then I was transferred to a different hospital just that had kind of a better stroke came and everything. And then just during my stay there, they found kind of more clots. So I had two Thrombectomies. And I think that when they were taking the clots out of my brain it must have traveled. So they later found clots in my legs and my lungs as well.

Contraceptive Pill and Stroke risk

Bill 4:53

Wow, did they know what caused those clots?

Priya 4:56

And they haven't actually found out yet, a factor of it was just the contraceptive

pill. But they don't know the full cause yet. And I'm still on blood thinners so they can't. Like they ruled out blood disorders and everything. They tested me for all that in genetics and everything. And it was none of that. So it's still like a mystery.

Bill 5:26

It's interesting that you said the contraceptive pill maybe, because you're not any person who I've interviewed who said that, that they think that the contraceptive pill might have something to do with it. And it's still kind of this thing where maybe it has something to do with it. And I don't really know.

Priya 5:44

It does. The thing is if you read the little dockets that come in medication packets and stuff that no one reads, because it's very small writing. It's actually in there that a side effect, could be blood clots. But I wasn't told that like, my doctor didn't say anything when I was prescribed it either. So it is kind of an I guess, not normal. But it does happen. It's just that people aren't told that it could be a potential side effect when they're prescribed the pill.

Bill 6:23

Wow. If you had known that, I know, you were 24. So let's just pretend that you were aware of the issue of stroke as a side effect of taking the contraceptive pill. Do you think you would have taken that seriously that you could have a stroke? Or do you think you maybe would have ignored it and taken the medication anyway?

Priya 6:48

Well, that's the thing. Like, I'm kind of on the fence about that, because I was only taking it from my skin. So to me, it wouldn't have mattered if I didn't take it or not. But then, I guess back then, I didn't think a stroke could happen to someone so young.

Priya 7:10

And it's only since I've had it that I've met so many people around my age, with similar stories. It's because I guess, young story isn't publicized. So what you see in the media is just that it happens to like elderly people.

Bill 7:29

So this is the thing about the contraceptive pill, a lot of people think that it's taken just for contraception purposes, but I know lots of people have taken it for

many other reasons that are not related to contraception, and babies and intercourse.

Bill 7:50

And it's just crazy that this pill is so widely used for so many things. And it interferes with the body in so many ways. And it's still considered to be okay to prescribe to people, even though it says it on the paperwork that you can have a stroke.

Priya 8:09

And I think so the particular one that I was prescribed has actually got a higher risk of clots than all the other ones. And I think there's actually, I don't know if it's still around, but a local MP, I can't remember what state he's from. But his daughter had the same problems. And he created a petition to get it banned.

Priya 8:36

Because it's kind of I need that particular one that was more dangerous than the others. I had a higher risk. But no one's told that when they go to their doctor, or their doctor prescribes it.

Bill 8:51

So you haven't had that conversation with your doctor prior to taking the medication. Did you have a conversation like that with your doctor after?

Priya 8:59

No, because I changed doctors after. And, and that wasn't the reason why I changed doctors. But I've got a different doctor now. And I feel like he's a bit more like he listens and is more understanding as well. So basically, the reason I changed doctors was because obviously when I came out of hospital, the nurses were like, make sure you've just got a doctor who will see you kind of straightaway.

Priya 9:35

And you won't have to wait too long, especially I guess at that stage, like, I guess you would know you get tired easily and all that. And so we kind of went to this doctor twice and both times I was waiting over an hour to see her. So that's when we kind of changed doctors obviously, I'm never allowed to take it again. And I was only on it for I think, three months before my stroke. So that's kind of the more shocking bit is that it only took that amount of time.

Bill 10:19

Yeah to cause a reaction. So how has life changed now that you're recovering from the blood clots and the strokes that they caused?

Priya 10:32

I guess, like my story is not too, I guess not much the same as everyone else. I pretty much physically recovered when I got out of rehab. So I guess the main things for me, I just kind of when I'm, like walking long distances, I've still got kind of stuff muscles. So I guess that's the main thing. And then just, I just had anxiety since then. And I think those are the main things for me.

Bill 11:10

And the anxiety, what do you think that's in relation to is that something you're concerned that something terrible might happen? Or what brings that on? Do you know?

Priya 11:20

Well, yeah, that's probably a point because we don't know their cause yet. And I guess my kind of thoughts are like, I don't know, what sort of things to avoid, or not do to bring on I guess, because of everything I went through, I'm at a much higher risk now of having a second one. And so I guess, yeah, that's probably one of the main things.

Bill 11:51

So you're kind of thinking in the background, that maybe there's something going on? And maybe I'll have another one?

Priya 11:58

Yeah, exactly. But I think that's everyone's, everyone's scared of that. I think, for me, it's just not knowing the cause. Every year, I go see my hematologist and they still haven't figured it out. So it's just, I guess, in the back of my head, it'd be nice to just have answers as well.

Lifestyle change after stroke

Bill 12:24

A little bit of the unknown, it can be a drama. I know a lot of stroke survivors do talk about the thought, the concern that there might be another one around the corner or something like that. But a lot of them as a result of that take some

dramatic steps to change the way that they live their life, you know, the things that they do, for example, you know, if they drink, or smoke, they might stop smoking and drinking, and they might change their diet. Have you done some things like that to sort of support your health?

Priya 12:54

Well, no, because I was already like that I was before my stroke, I was going to the gym five times a week, I was eating healthy, like I drink more than enough water. So it's not really a change for me. And I think that's probably what helped me recover really well, as well.

Priya 13:16

So yeah, that hasn't really been a change. And I guess aside from the basic things that you learn, or that you know, can reduce your risk. I've still got that unknown, of not knowing the cause and not knowing, like not being able to exactly pinpoint what I can avoid or do different.

Bill 13:42

Yeah. I think you're on the right track, though. It sounds like you're doing all the right things anyway. And your most serious risk of stroke, I think, but I know you and from just from our conversation. Sounds like it's been already taken out of the picture. So you haven't, you're doing that now. You know, you're not taking that medication. So it's not likely.

Priya 14:10

That's the thing though, that was only a kind of small factor. They did say there's no way it can be the full cause. So I guess trying to pinpoint it would be great, and have answers, but I guess doctors can only do so much as well.

Bill 14:32

Yeah. So you were 24 What were you in the middle of? Were you doing studies? Were you working? What were you up to?

Priya 14:39

I was working full time at the time. So I was working for Serco. So like transport info in New South Wales. But then I was sick that whole week. So I was at home anyway. They actually they're not sure when I had the stroke because I had it before I got into the hospital as well.

Bill 15:06

Do you think you went to work? And well?

Priya 15:11

Well, I don't know, possibly because I guess with the amount of blood clots I had, it could be possible. But yeah, I'm really not sure. I don't even the first few days of me being an ICU, I don't have much recollection, I was pretty out of it. Which I'm sure most people are at that point.

Bill 15:38

It's pretty common after the stroke. Most people are out of it. So you're in hospital for how long?

Priya 15:46

I was in the hospital for three and a half weeks. I was then in inpatient rehab for two weeks. And then I was in outpatient rehab for four weeks, but sort of only twice a week.

Initial stroke deficits

Bill 16:03

When you were, in rehab, what was it that you needed to get back or overcome?

Priya 16:10

So the main thing was walking, and definitely walking up and downstairs, because we have a two-story house. And I guess just my speech, my speech was quite slow compared to what it was before. And then just basic things like learning how to use a fork and knife again to eat.

Priya 16:39

And then just the physio, and that goes with the walking I guess. I'm just getting my strength back and walking without losing my balance all the time. And then, yeah, I think those are the main things I had a bit of occupational therapy as well. But that was more so like, we had a thing where we had to show them that we could make a meal ourselves. Because, and I'm sure you went through that as well.

Bill 17:16

And I was so annoyed, because they were making me make my own meals and my

hand wasn't working properly. I was thinking why they making us cook our own meals.

Intro 17:24

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like how long will it take to recover? Will I actually recover? What things should I avoid In case I'll make matters worse?

Intro 17:41

Doctors will explain things that obviously, 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. 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.

Intro 18:04

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, recoveryafterstroke.com and download the guide. It's free.

Priya 18:27

Yeah, so I think that was just a way for them to make sure that if you were alone in your house, you could do like you could at least make yourself food. And even if it was like just a basic toast.

Bill 18:43

I did ask them that. And then they explained it to me. And then I understood why they were doing that to us. And they weren't being nasty, or lazy. So how long did it take you to get back to work?

Priya 18:55

So I, I had five months off. So I guess three months if you take out like the hospital and rehab part of it. And then yeah, just had the three months off. And then yeah, when I went back gradually, so I started off with like, two days a week, four hours and then I just kept building up from that.

Priya 19:22

I was pretty lucky with my workplace they will or like my contract manager was quite supportive. And when I asked her like I said, I have to come back gradually, because that's obviously what my doctor had said. And they were very accommodating with that.

Bill 19:43

When you got back to work was fatigue, an issue sitting in front of a screen and trying to do you work during the day?

Priya 19:49

Yeah, for sure i am and i think that i did ask my neurosurgeon about this and he did say sometimes it doesn't go away. All I don't know if you still experience fatigue. But yeah, I definitely have some times where I'm still, I get fatigued a lot. And I guess that's the difference. Trying to explain it to other people is hard because fatigue is different from neuro fatigue is not just I guess tiredness.

Bill 20:29

Right? That's actually a really interesting point because neuro fatigue is something completely different. I've not experienced up until my surgery and brain hemorrhages. I never experienced neuro fatigue before, but I did experience fatigue. And that was really hard. But usually it came from doing too much work or a hard day's work or putting in too much effort somewhere. But neuro fatigue is just there. And it's not physical fatigue, isn't it? It's just got nothing to do with that.

Priya 21:00

Yeah, it's not always physical. Like it's just like, I guess, mental fatigue as well. I guess just wanting to switch off and, like not being able to concentrate and things like that.

Bill 21:17

So did that affect you at work and the amount of time that it took you to get back to, you know, "normal"?

Priya 21:26

Um, yes, I would say so. However, I guess because my recovery was, was quite done quite well. And I, like recovered pretty quickly. I, I think so I went back to work in November 2015. And then I was by, I think, July 2016. I was back at full-

time work. Yeah. Okay. So, to me, it didn't take too long. It was just sort of, I guess, liaising with my doctor and making sure I was okay to increase my hours every so often.

Bill 22:11

Were you living at home during that time when you were unwell? With mom and dad is what I mean.

Priya 22:17

Yeah, I'm living with mom and dad. And I guess that was a good thing as well. Because if I wasn't, I'd have been alone at that point. And I guess, because I didn't know I had this stroke. It's good, because I got treatment quickly. Whereas if I was alone, I wouldn't have known and it might be very different.

Having family and friends during stroke recovery



Bill 22:44

Yeah. What are some of the things that you missed out on during that recovery time? When you were kind of out of it? And you weren't working properly? Was there people that you couldn't catch up with? What types of issues did you have to face?

Priya 22:59

Not really, so kind of my friends that. I'm the kind of person that will keep like, I'll have a close group of friends and I'm kind of more so now I'm very, very picky about who I sort of hang out with, or who I invited out to dinners and stuff. But, um, to my friends at that point, obviously, I'm still friends with them, but they kind of more accommodated me as well.

Priya 23:33

So obviously, my mom was pretty worried about me going out to the city or like, being by myself and stuff. Because this is only a few months after, but they were pretty good. Like they come meet me at the station or something. So I wouldn't be alone. So that didn't really change much. I've thought, I've always kind of been that person like that. I'm quite picky and like, I don't go out a lot.

Bill 24:10

So is it kind of business as usual? Not too much changed.

Priya 24:15

Yeah, not too much changed. I guess kind of the main thing would have been just work just increasing my hours just trying not to let the fatigue affect me too much. because like you said earlier, staring at a screen for so long. A day does give you the mental fatigue as well.

Bill 24:43

Yep. Were you a driver?

Priya 24:45

No.

Bill 24:46

So you didn't miss out on driving and learning how to drive again wasn't an issue?

Priya 24:53

No, that hasn't been an issue for me. No.

Bill 24:56

Yeah. That's pretty cool. Most people have real big disruption to their life. Yeah, strike because they, I'm not sure. I'm not sure why? Because maybe because they do so much. And they do. And they cram so many things into their day, and they have to play so many roles, you know, pick up kids drop off, whatever, all that kind of stuff. So although it was quite a difficult time for you, it caused some disruption for sure. You didn't really change the way that you went about your life for a long period of time.

Priya 25:31

No, not really. And I suppose like you mentioned, like, I don't have kids, I don't have any, like, I don't have dependents. So I don't have that in my life that would

be disrupted. And yeah, I don't drive anyway, because I don't feel the need to. Really, um, so especially now, I guess that everyone's well, working from home.

Bill 26:03

You did well there. So tell me about did it motivate you in different ways, though, it seems like you're potentially doing things that you haven't done before was the kind of work that you did for the Stroke Foundation, which is presenting stroke safe talks. Have you done anything like that before? Had you ever considered volunteering or anything like that?

Priya 26:27

No, I actually never heard of the Stroke Foundation until I did my own research. afterwards. I joined a couple of like stroke survivor groups. And I do see a lot of obviously questions for like, has anyone had this kind of strike? And like, how was your recovery and things like that? So I guess Yes, in a way I did. Because I'm getting my story out there as well.

Priya 27:00

And letting people know that strike can happen at any age. I've had quite a few people message me on social media, just being like your story. So inspiring. And just asking more questions and stuff. And then, yeah, with, like I mentioned earlier with my muscle weaknesses, kind of, does motivate me to do more like this year was five years for me.

Priya 27:31

So I did the Sydney Harbour Bridge climb, which I probably would have never done because I'm terrified of heights. But I was like that will be a good kind of celebration. My friend suggested it as well. And he's like, you'll be at the like, highest point in Sydney. Like, what else would you want to do? Like, that's an amazing celebration? Because I'm the I'm one of those ones that celebrate each year. Because I look at it, like, I survived this major thing that I probably shouldn't have.

Bill 28:14

Yeah, absolutely. It's definitely something to celebrate. At the top of the Sydney Harbour Bridge, how long does it take to get there?

Priya 28:26

Probably about just over an hour, because the whole climb is three and a half

hours. But that being said, we do stop a lot along the way, to hear like the history and stuff of the bridge and the area around it. So it's not like a continuous walk. So I probably say even less than that if we weren't if we didn't stop along the way.

Bill 29:00

That's quite a few steps up, I would imagine. And you can see a 360 degree view of Sydney Harbour. I mean, was it a good day that you went out there was the sun out?

Priya 29:13

So I did the sunset climb, and we had an amazing sunset, which was really nice. I do have some photos on my Instagram as well of it.

My Stroke of Inspiration



Bill 29:25

Wow. Yeah. I'll have a look at those. And maybe we can post some as well. And have a look at them. Now. your Instagram is a stroke of inspiration. Is that right?

Priya 29:36

My Stroke of Inspiration.

Bill 29:39

Why was stroke an inspiration to you?

Priya 29:44

I think it's more because I use the platform to share my story and stuff. And obviously I've had a lot of people saying it's an inspiring story and stuff and I'm like, it makes sense and it's a different name. I don't like using my, like full name or just my name on my social media handles.

Bill 30:15

Yeah, fair enough. It's a great name. It really makes people pay attention, especially with regards to, you know, something from stroke becoming inspiring to other people. That's a great thing.

Priya 30:28

And I think it's brought up a lot of conversations as well. Like, when I tell people my handle, it sort of gets a conversation going as to like, why you have that name. And then I tell them, and I share my story as well. So I guess it is, in a way, getting the story out there a bit more as well.

Bill 30:50

Yeah, that's awesome. Why not? I like that it creates a conversation without really meaning to raising awareness and telling people of something that's serious, that maybe will help somebody at some point in time.

Priya 31:04

Yeah, definitely. I've had, I think there's been a couple of people that have reached out because they're, my speakers, people have, like an AVM or something like that, that have caused their stroke. And I think my story is a bit unique. And I've had a few people reach out to me being like, I've never met anyone with a similar story to mine, as well. So I guess in that way, it's good as well. And because other people are finding someone that's had that similar story to them.

Bill 31:45

Yeah. I mean, that's one of the best things that happened to me is I found people that were, I suppose that was like me, and then they understood me. They got what I was saying. They understood what fatigue meant, you know, when we talk about fatigue, yeah. And it made a huge difference to the way that I was feeling. And then it allowed me to have conversations with that person that I wasn't able to have with anybody else.

Priya 32:15

That's exactly right. Like I was saying this the other day to someone as much as I guess our other friends and family tried to understand they just won't because they haven't been through a similar situation. Whereas I guess the people I've met since they obviously have similar stories, or then they've been through the same thing, just a different situation. So then know exactly like what you're

talking about.

Bill 32:51

Yeah. About, probably about 18 interviews ago, I interviewed a lady called Kelly. And she had an ischemic stroke as well, she was 32. Now one of the things that she said, which was similar to you was that she was also taking the pill.

Bill 33:10

And then after the stroke, again, she became aware of the fact that there's a possible side effect, which causes stroke for some people and blood clots for some people. And she was a bit shocked and surprised as well. And she hadn't really come across anybody else that had been in that situation. So yeah, it is uncommon for sure that people experienced stroke. But it sounds like there's still too many of them out there, that experienced stroke because of potentially a medication.

Priya 33:42

And I guess I'm just going back to what I was saying before, it's more because it's not publicized. And I'm finding more information about stroke now than I ever would have, like, five, six years ago.

Priya 34:04

There's a lot more information out there now for people. But I also think, doctors should be going through that with you if they're prescribing your medication.

Bill 34:17

Absolutely, they should they should be telling you, I'm going to prescribe this medication, this is what it's for, and have the conversation with you so that you're informed and you can make a decision at the time whether you want to take that risk or not.

Bill 34:31

If you don't what's the alternative? Can they present another version or some other alternative? Instead of just going for the one that might cause another health issue? Because what we're trying to do is fix a health issue, not create more.

Priya 34:47

Create another one Exactly. And like, I guess it's going to if it was someone quite young, like say 17, 18 They wouldn't, I guess like me, they wouldn't think that a

stroke could happen to them and they won't research it, they would just say like I need this, can you prescribe it to me and the doctors just do it.

Bill 35:17

Yeah. It's pretty sad. I yeah, I think there's a couple of things that we need to work towards fixing with the way that doctors become informed about the kind of medication that they should be prescribing. And then their duty of care to go out of their way to explain what they're actually giving that person to swallow.

Priya 35:43

And I think also, like triage nurses in the hospital. So when I went in, it was a Saturday night. I was 24 years old. I was unable to walk, I couldn't talk properly. So they probably just thought I had taken something or I was drunk. And then they're like, it's gonna be like, a two and a half hour wait to see someone.

Priya 36:13

And then obviously, we waited. But if it hadn't been for me having that seizure, then we would have just waited for the two and a half hours. And like, you know, how quickly you need treatment after a stroke.

Bill 36:35

Minutes count. You sit on the chair, outside of triage at a hospital. It's the craziest thing. But it is true that they do generally they do a good job, but sometimes the wrong person at the wrong time.

Priya 36:53

Yeah, exactly.

Bill 36:55

Too much pressure, and maybe before you maybe five or six other people that came in drunk or on drugs?

Priya 37:02

Well, I think it was also quite busy that night as well. So I definitely understand that. But it's just, I guess a bit of education is probably needed, as well.

Bill 37:18

And maybe some questions of the people that you're with, Has she taken anything? Is she drunk?

Priya 37:22

Yeah, exactly. Like if they'd done that, they would know I was home. Like, I couldn't even get out of bed. I guess, like you said, unless they asked that they won't know. So that's why I say it was lucky I had the seizure. Right? Not that it's lucky, I had one in the first place. But that's what led them to find the clots and everything. And then I got started on a heparin drip straightaway. Which obviously would not have happened if I didn't have that seizure.

Considering mortality

Bill 38:03

Yeah, that's nuts. Are you the kind of person who did the whole thing at the beginning? Did you consider your mortality all of a sudden? Did you start thinking about, Oh, my God, I might not be here next week or in a month or has that played on your mind at all?

Priya 38:21

Not really, because I think I always have that kind of mentality that can be for anyone, whether you've been through health issues or not. I don't want to be too morbid, but you could drop dead at any moment, no matter who you are. So that, I guess that's always been a mentality. And that's why I guess especially now, I'm also do the things like the bridge climb, I'm doing a hike with the Stroke Foundation next year as well.

Bill 38:59

So what you're saying is that you were the kind of person that lived in the moment, understanding that life to be lived and perhaps it may be short. So similar mentality. Your you're going forward with now and it was just who you were before, anyway.

Priya 39:20

Yeah, it was and like, I've lost a cousin at 17 years old. So I guess that's kind of what started that kind of mentality. Like I obviously firsthand, I know, life can be really short. And you don't have to have health issues for that to be a true statement.

Bill 39:45

Where you 17 at the time or was it your cousin that was 17?

Priya 39:49

I was 17. He was 16.

Bill 39:52

Yeah, so close in age. So that would have been a big wake up call.

Priya 39:57

Yeah, um, and yeah. What probably started that mentality. So it hasn't really come about after I had my stroke, it's always been there.

Positive Mindset



Bill 40:10

So you pretty positive kind of person?

Priya 40:14

Yeah. And I think that's what my nurses were saying that they think that's what helped me as well, because and I guess that's true. Your mindset does help you or break you.

Bill 40:29

Yeah, absolutely some people get stuck in a negative mindset and a negative mindset won't help growth occur. Positive mindset isn't gonna make anything worse, it's going to encourage you to be curious and to find, you know, new ways of looking at things and potentially finding new ways to overcome some of the challenges that you have.

Priya 40:57

Yeah, I think, yeah, the positivity was something they said would have helped me a lot. Because I did see a lot of pain, obviously, in the ward I was in was shared with three other people. So I guess looking from the outside, you would have seen such a difference with me, as opposed to the other members in the ward. Obviously, they will all die as well, so. And I like I don't know, their lifestyles or anything like that. But if you'd come in, you would have seen, I guess the difference.

Priya 41:39

Yeah, I know, you may know, I had all the people in my ward as well. And now, in the beds next to me in the public hospital, they were not getting up and about they weren't doing much. As I was up and about us walking after the first time, not the second time, and not the third time. But wasn't walking after the first time. So it was this really weird experience to be in a hospital in a stroke ward, where I'm supposed to be really sick, but I don't look it to anybody and don't feel it other than numbness on my left side.

Priya 42:22

This lady I was talking to the other day, I was actually saying that, because she has no physical disabilities or anything. So like, sometimes she just feels like a kind of a fraud, calling herself like a stroke survivor. And I'm like, it's not always physical, though. Yeah. And I guess that's, I guess this is all disabilities. So people don't know it's there unless they can physically see it.

Bill 42:56

Yeah, it's the biggest issue that we have with mental health across the planet, not just in Australia. But also then, with people who recover from stroke and may have a limp or an arm that's not extending fully. Even people like that find it difficult to explain to other people have the neurological fatigue is a problem for them, even though we can see some kind of sign that they've had a stroke in the past or they've experienced a stroke. I was pretty dumb like that. Like I didn't understand before I was unwell. That somebody's in a wheelchair, for example. was doing a tough in many other ways. They weren't just sitting in a wheelchair. They had all these other issues.

Priya 43:47

What, once you've gone through an experience, something like that, I think

everyone's kind of like that as well. Unless you've experienced it yourself, or you've like, a close friend or family member has experienced it, you don't understand it. And I do sometimes I feel like that as well. Like I can, walk I can talk I can use my arms, everything's functional. So I don't, when you look at me, you don't know that I've had a stroke. Unless you've obviously read my blogs and my social media.

Bill 44:31

That would confuse a few people and shock them as well, wouldn't it? because they'd look at you and go you look like you've had a stroke. What do you mean, you've had a stroke? Like What's all that about?

Priya 44:41

Oh, you're too young or like those kind of comments. Yeah, definitely. I've gotten those. I've gotten a couple of negative comments as well because I was doing so well after my stroke.

Bill 44:59

A negative thing. How come somebody would say something negative about that.

Priya 45:04

So, I, about a year after. So, just before I went back to full time at work, my doctor cleared me to go back to the gym. And so I was going to a strength gym that time so I was lifting like pretty heavy weights and stuff. And my PT was a neuro psych. He worked in a lot of neuro awards as well. So he was also a physio, so neuro physio as well.

Priya 45:40

So that was kind of good for me as well, because I had someone training me that knew what I had been through. So I kind of was posting some videos on stroke survivor group that I was on at that time. And I guess, people are just kind of upset at themselves that they're not, if people don't work on their recovery, or they're not, because no one's exactly the same.

Priya 46:10

So my recovery is not going to be the same as yours. And if I'm cleared to go, lift weights and do that kind of stuff, then I'll do it. Like, I'm the kind of person that will always listen to my doctors, I won't. So my doctor said, I can't go like skydiving or anything because of the pressure to your head.

Priya 46:38

I'm not going to be the person that then will go skydiving. So I just got a lot of comments like, Oh, you shouldn't be doing that. It's only been like 10 months after your stroke, bla bla bla. And like, when you have another stroke, then don't come crawling back to us.

Priya 46:58

And I'm like, this should be a group to like, motivate each other. Like, majority of the comments I got were like, Well done, congratulations and all that. But then it's always I guess the negative ones that do stand out and they were quite negative, like quite rude as well.

Priya 47:21

And I'm like, look, I'm listening to my doctor, if he said I can do this, then I'm gonna do it. I'm not gonna listen to someone that doesn't know my story. And then I had this one saying, oh, not all strokes are the same. You can't say like, you're doing this like 10 months after. And then I kind of went on to list every single thing that happened while I was in hospital. And then I didn't hear anything after that.

Bill 47:51

Yeah, sounds like those people. Were those kind of people before stroke anyway, it sounds like everything was a competition for them.

Priya 47:59

Exactly. And it shouldn't be like everyone, like I said, everyone's recovery is different. And especially with a stroke, you should be lifting people up. You shouldn't be like saying stuff like that, because like you said, you never know what else is going on for someone.

Bill 48:20

Yeah, it's nuts that somebody would compare themselves to you. And then complain about what you're doing and that you shouldn't tell people to get back on to their lives or with their life. If they can. It's not like it's the rules are not for everybody. They don't have to do what you did. But just have to be happy that you can do it that's all.

Priya 48:39

Yeah, exactly. And I would be like, if it was someone else, I'd be like, that's great.

You don't go and sort of tear people down after something like this as well. But then a few people message like privately messaged me, and they're just like, just ignore it, which I do anyway. But they're like, they're probably just unhappy in their own sort of recovery and stuff like that. Which makes sense.

How to deal with negative comments

Bill 49:06

They would be unhappy somewhere. And stroke makes things worse, it doesn't make things better. So if you've got a bad relationship, or if you've had some trouble in the past, stroke doesn't come in and make it all better. It makes it worse. And therefore it might highlight some of the issues that people have in their lives. And therefore make them act out and choose to get offended where it's not a place to get offended.

Bill 49:34

That's not somewhere where you need to take offense that somebody is perhaps doing well. And I think what it should do is those people should pay attention to why they're getting offended with somebody posting that they've achieved something amazing after the stroke. I mean, that's where the lesson is for them more than anyone.

Priya 49:53

Yeah exactly. That's what I was saying. Not everyone's going to be the same. Like everyone. Even looking back to the ward I was in, like he said, everyone's different.

Bill 50:07

And it's just pure luck that the blood clot went into that part of your brain, that it didn't go into just, you know, one other part one, how to re over the left or to the right or to the front or to the back. That's just pure luck, luck that my brain hemorrhage happened, where it happened.

Bill 50:25

And therefore I can be mostly active, and out and about and do all those things, and very rarely suffer from any dramatic problems. And, and I often think about, like how close it came to just being worse somewhere else. And the timing was on my side. And the people I was with, at the times that I happen to was on my side,

like, everything that could go right, during a really, really bad time went right.

Priya 50:56

Yeah, that I guess that's how I look at it as well, like I had, obviously, it was multiple clots in my brain. And then I had the clots in my legs and my lungs. And obviously, the lungs can be deadly as well. And so my doctors were actually quite surprised that I had no chest pain, I could breathe properly. Like there was no other signs. And, and I guess just luck that I got there in time because my surgeons did say if you had waited any longer, you wouldn't be here today.

Bill 51:36

Unbelievable. So did you go into surgery and they retrieved a lot of those clots or some of them?

Priya 51:43

Yes, I had to clot retrievals. And so they did the first one about two date on the Monday because I got in on Saturday. And then they transferred me overnight to a different hospital. Then they did it first thing on Monday. And then they did another scan and they saw there was still quite a lot. So they did a second one on the Wednesday and got pretty much all of that out. Well, I was actually discharged from my new year last year, because it's all clear, which is great.

Bill 52:25

Okay, so until last year, you were going in doing new scans and just checking everything out.

Priya 52:30

Yeah, just sort of every year my scans were always clear though it was more they were wanting to make sure and everything. So I still see my hematologist once a year as well.

Bill 52:45

Yeah, and the hematologist is just checkup confirm that everything's going okay that you're still taking the medication?

Priya 52:57

Basically, he manages my blood thinners. So, and he just kind of checks to see if like my legs are swelling and stuff like that, to see if anything's come back. So it's more just making sure everything's okay. Honestly, I think I'll be on the blood

thinners for a while. So I'll probably be seeing him for like the next few years. Just because he's like, you had so many problems. We don't want to take you off them. And then you have the same issues again.

Bill 53:38

Yeah. So steady as she goes. And let's just focus on on paying attention to what changes occur in your body, if any. And address things rather than being kind of blazar about it because yeah, serious.

Priya 53:54

I have heard a lot of stories like that with a doctors have been just so like, just dismissive, or they don't listen, and it just makes me feel lucky to have the specialists and the doctors that I do.

Bill 54:12

Yeah. I think it's important for people if they're not happy with the doctors as well, to find another doctor. Like get rid of that doctor, sack that doctor so to speak.

Priya 54:21

Yeah. changed. Like there's no issue and changing doctors.

Bill 54:25

Yeah, they just take the record from the previous doctor and move on. I like it so you're a pretty positive person. You have had a miraculous recovery. It has been an absolute miracle that you didn't have any lung issues, any brain issues ongoing and all those dramas ongoing apart from a couple of little things that you're dealing with. What has I know this is a loaded question like has stroke taught you anything like what has it taught you? What have you got out of this holiday experience other than the obvious?

Priya 55:03

I guess yeah, like it is just more the obvious like, life is too short part, I guess a bit more now. So and, just I keep, I guess a tighter group of friends as well. Whereas I'm kind of like people in my group that I know that are there for me or that have been there for me.

Priya 55:34

Especially, I guess people that if I want to talk about something related to my

stroke, they're there to listen, they're not just going to be like, Oh, you're always talking about this and things like that. Because I guess if, if you know me, I guess anyone's like this right? And correct me if I'm wrong if you're not this way. But after such a big life event, it's always going to come up in even little conversations you have, you're always going to make some kind of reference to it.

Bill 56:11

Yeah, absolutely. I mean, I have a podcast about it. I don't stop talking about I talk about it with everybody forever. You know, there's 117 episodes with this one. So it does come up because there's some times at dinner, for example, I may not have an alcoholic drink, or something.

Explaining to people that you've had a stroke

Bill 56:32

And people who don't know me, we'll ask why aren't you drinking? And of course, you can give them the just don't feel like it's story or whatever. Or if they're the right person, and you think that they might listen, you might say, because, look, I've had a brain injury, and I can't drink because it makes me feel like I'm having another stroke again, or something like that.

Bill 56:55

And that's how it comes up for me all the time. People notice how I'm different than them. And then they ask me, why am I different? And then I give them an explanation.

Priya 57:08

But it I guess it also educates people as well. When you bring that up, like the other day I had friends over. And I am allowed to drink I just have to kind of be careful how much I drink and just to space it out. But then my friends, like, they're always like, Are you allowed to drink? If they don't know that I'm allowed. And then they not in a nasty way either. Like, why are you drinking? It's more like caring and understanding, like, Are you allowed to? And then it does sort of start a bit more conversation as well.

Bill 57:55

Yeah, it comes in the same way to me. It's, and I'm not trying to educate everybody all the time. But sometimes they don't mind listening to a little bit of

my story. If if we go down that path, only if they allow me to go down that path, do you not? I mean, like, I don't shove it down their throats and say, this is what blah, blah, blah.

Bill 58:16

You know, if they know me, because they've met me elsewhere, they know that I have a stroke podcast, then it's not a shock to them that I'm not drinking because I had the stroke years ago. Okay. Yeah. And they're not really going to have a conversation with me about all of the stroke-related stuff.

Bill 58:33

But somebody who doesn't know about my podcast, who asks at dinner, who is a friend of a friend, you know, we have a little conversation if it doesn't go any further, it doesn't go any further. I'm okay with that. I'm not there to educate them on stroke at a party. And let's have a party but.

Priya 58:48

Yeah, exactly. Now, I'm like that, like I wont sort of go further unless they ask more questions about it. And I guess, so when I went back to work after I had a lot of people coming up and asking me cuz obviously, no one knew where I was and things like that.

Priya 59:11

And at that point, it was really fresh, and I didn't really want to talk about it. So I just wrote a blog. Whereas now I'm kind of more I get my story out there if someone asked, I will tell them but then, because there's so much of my story, I won't just kind of spill it out if you ask me sort of certain questions then. Because I guess for my story, there's a lot to digest. Especially for someone new.

Bill 59:49

Yeah. And stroke is a massive thing to just for anybody because most of them are like us. Most people are like us before we had a stroke. They had no idea what a stroke was. So they, you know, get stunned and then and then some people don't want to deal with that kind of information at that point in time.

Bill 1:00:07

So that's all good. I know why you do it. It's the same reason why I do it. So, look, I'm really pleased to have gotten the opportunity to chat with you and to meet you and to learn about your story. Thanks for sharing on the podcast, I really

appreciate it.

Priya 1:00:22

No worries, thanks for having me.

Intro 1:00:30

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Intro 1:00:39

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Intro 1:00:56

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Intro 1:01:13

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Intro 1:01:34

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Intro 1:01:48

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