

Cryptogenic Stroke Recovery - Karen Moorman

The last thing Karen Moorman expected after a Stroke was that the Cryptogenic Stroke Recovery would make her migraine headaches go away for good.

Socials:

www.instagram.com/stroke_sur_vivor/

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Transcription:

Karen 0:00

I saw that and I thought that that's just so fitting for all of the stroke survivors that, you know, we don't have to be perfect. We can be perfectly imperfect. So yeah, that's my take on it is you don't have to be perfect. You know, everyone struggles with something.

Intro 0:24

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

Introduction



Bill 0:37

Bill from recoveryafterstroke.com. This is Episode 139, and my guest today is Karen Moorman. When Karen made a return appointment to the chiropractor to help out with her most recent migraine headache, she never would have guessed that she was not destined to walk out of that appointment on her own free will.

Bill 0:55

Now just before we get started, if you enjoyed the recovery after stroke podcast, and you think that others should hear the amazing stories of these excellent stroke survivors, please tell everybody and anybody that will listen to you about it, and share the podcast link, www.recoveryafterstroke.com on your favorite social media app.

Bill 1:20

Also leave the recovery after stroke podcast, a five-star review on iTunes, or your favorite podcast app. And if you're watching on YouTube, click the thumbs up button and subscribe to get notified of new episodes. Thank you so much for listening. And now it's on with the show. Karen Moorman welcome to the podcast.

Karen 1:41

Hi, thank you.

Migraine leads to Cryptogenic stroke



Bill 1:42

Thank you for being here. I really appreciate it. You somebody who had a cryptogenic stroke, a stroke, where there doesn't seem to be an underlying cause. Tell me a little bit about what happened to you.

Karen 1:59

Well, I had a really bad migraine. And then all night, and then I went to go to the chiropractor in the morning because that used to relieve my headaches. And I was sitting in the chiropractor's office when the girl called me up to go to his room and I didn't answer her.

Karen 2:18

And then the chiropractor came in and he said you know that I was having a stroke. And they called 911. And I was so fortunate that the ambulance was right outside the door of the chiropractor's office because they're going for breakfast. And so I was in for surgery within the first hour.

Bill 2:38

Oh, wow. That's amazing. Now, you did what I did when I was feeling unwell, left side numbness and all that kind of stuff. I went to my chiropractor as well.

Karen 2:49

Really, yeah that's crazy.

Bill 2:51

And at the beginning, I didn't have the symptoms that you had, I had a very different kind of lead up to my brain hemorrhage and the symptoms were just

numbness in my leg, and then kind of crept up and then by day seven, the entire left side was numb now I was ignoring all those symptoms the whole time.

Bill 3:11

But eventually when I got there, the chiropractor said you need to go to the hospital because this is not neurological sorry he said this is not your back. It's neurological. And I argued with him and I went eventually after I argued with my wife and everybody else who told me to go. These headaches that you were getting was there any previous signs that perhaps this was a different headache and looking back now you're seeing those signs and they're more obvious than they were at the time?

Karen 3:45

No, not like I had a really sharp like I always suffered from migraines my whole entire life. And but about a month before my stroke happened, I had this migraine that only lasted a few seconds, but it felt like it was from the center of my head coming out my ear.

Karen 4:08

And I went to my doctor the next morning and they said something drastically wrong because it scared the pants off me. And he sent me a whole bunch of tests that all came back fine. And then that night that I had my wicked migraine, that was my only symptom. And then I went in and then they told me I had a stroke and you know, the rest was after that.

Bill 4:40

How old were you?

Karen 4:42

45

Bill 4:44

So last thing you expect to hear from hospital or a doctor or anybody when you're going in for just a bad migraine or migraine that you've had forever and all of a sudden it just feels a bit worse. What do you tell your family? So I was in a situation where I had news to share with them that was pretty dramatic and drastic. How do you break the news? When A you're suffering B there's this really serious health issue. And now you got to tell your family.

Karen 5:18

Actually, I couldn't tell my family because I had no speech after my stroke. So they told me.

Bill 5:30

So were you conscious that your speech was gone? And that you couldn't communicate? Or were you not conscious of that?

Karen 5:38

No, I was in and out of consciousness in the ambulance. And then I went for surgery right away. And then when I came out of surgery, my husband was standing there, and I couldn't get any words out. So it's pretty scary.

Bill 5:56

I can't imagine what that's like. I was able to speak and communicate the whole time, I was a bit hazy. And I didn't really know what was happening. Yeah. But everything that happened to me was planned over a number of years. By the time I had surgery, and by the time I woke up from hospital, I kind of had the whole process planned, but yours was really sudden. And then when you woke up, you weren't able to speak but what else weren't you able to do?

Karen 6:20

Well, I kept go at that they were trying to figure out what happened to me. So they kept sending me for all these tests, I was in the hospital for seven or eight days. And my whole time there, I spent getting shuffled between, you know, all these different tests being run on me. And then, my speech started to slowly come back when I was in the hospital. And then they got me up and walking and like, I could walk but, I had right foot drop. So my affected side was my right side.

Bill 7:04

So you had right foot drop. And you were rehabilitated straight after that? Was it around the same time? Or was there a delay between you had the opportunity to sort of get back on your feet?

Karen 7:19

Yeah, they had me up on my feet when I was in the hospital. And then, I got to come home after eight days in the hospital, actually happened right before Christmas. So I got to come home and spend Christmas at home. And I went for physio therapy, speech therapy and occupational therapy, for the next following

two months after my stroke.

Bill 7:48

How else did it interfere with your life? Were you somebody that went to work? Did you have a job? Did you do all those things?

Karen 7:54

Yeah, I actually went back to work about six weeks after my stroke, very, very part-time, just to get me out of the house. And I love my job. So it's a great place to work. And they're really great with me. So yeah, I was happy to be back there. And I wasn't back to my position for probably four months.

Cryptogenic stroke recovery deficits

Bill 8:23

How did you find that transition of going back to work? Was it difficult? Fatigue? Was there any issues that you were having to deal with while you're at work?

Karen 8:32

Yeah, well, my speech was my biggest thing. Because I work for a company that we do all the gym equipment, and my job is I build all the jerseys for all the schools in Western Canada. And I have to talk on the phone, and I have to go into meetings. And so that was my hesitancy was going back full time was that I could never find my right words. So that was my biggest thing. And then my typing my handwriting still have yet to come back, but I can make do.

Bill 9:10

It sounds like the speech has definitely come back and hesitancy around that, how long has it been now since the stroke?

Karen 9:18

It's just two years in December.

Bill 9:24

So things have progressed quite well. What about physically Where are you at with the foot drop and your ability to walk?

Karen 9:32

My foot drop's pretty minor now. I don't have to go to physiotherapy anymore for

my foot drop. Um, I walk every day. Except today because it's snowing totally terribly here right now. But yeah, we walk every day and I work out every morning. And so that helps me. Like I can only do so many laps before my foot drop really kicks in but you Yeah,

Bill 10:01

So the fatigue kind of exaggerates the challenges that you have. That's pretty standard. That's what most people describe is that they start off looking or feeling quite, you know, normal, I would say, you know, whatever that word is what baseline and then as the fatigue and the tiredness kicks in and the day wears on, then the symptoms start to become more pronounced and more obvious.

Bill 10:27

And that's exactly me, I have a left side issue with my foot and my leg. And yesterday, we were at the football, our Australian rules football with four big sticks where they run and hold the ball and kick a ball through the sticks. And it was really, really cold, it was really cold.

Bill 10:51

And when I got up, my left leg was completely just out of action, didn't want to participate, didn't want to be part of anything. So I couldn't feel it the whole time and trying to walk without feeling it is possible. But it's focus, I have to focus on it, I have to concentrate on it.

Bill 11:08

And that is annoying, because when I'm walking in focusing on just my leg, I can't really be involved in what's happening around me. But that's kind of the extent of it. So your foot drop gets worse. Do you then do you have other symptoms that also get a little bit worse? Is there some challenges that come back that are sort of lingering?

Karen 11:36

I'm not with my like, not with my bottom half of my body, my hand. When I get tired, my printing is atrocious. My typing is atrocious. My handshaking is really bad when I'm trying to eat those kinds of things. It makes it a really fun time.

Bill 11:56

Yeah. And you solve that handshaking problem, though, with a special kind of fork. I noticed on Instagram.

Karen 12:03

Yeah I just bought that and it works a lot better. But still, sometimes I'm still shaking and it's way heavier. Right? So then it's really bouncing.

Bill 12:16

You were properly showing off. You were really happy with yourself eating with your book shaking a bit It's so good to see that such a simple thing can bring back so much happiness or joy. How did it make you feel when you found this fork?

Karen 12:39

Well, it feels really good. Because I mean, not that I'm probably going to be taking my fork with me to a restaurant. Like it's really embarrassing when you're standing there and you're shaking so much trying to get your food in your mouth. So yeah, it's really a great accomplishment. Right?

Bill 12:55

It is. And it's such a weird thing, that all that had to do to the fork to make it better for people was making it heavier.

Karen 13:04

Yeah. That's crazy.

Bill 13:06

Who would have thought that the solution was so simple for a lot of people that's going to make a massive difference in the quality of their life?

Karen 13:13

Well, I am very challenged with my left hand, I've never been able to use my left hand for anything. So that's why me being a right side effect. It really stinks for me, because like, I do photography too. And, you know, with my right hand to have to use the, for pushing the button for taking pictures, right. And so, it's really quite challenging with that.

Bill 13:42

Does that make the camera then shake a little bit as you're about to press it?

Karen 13:47

Yeah.

Bill 13:48

You could create this new genre of photography, call it like out of focus genre.

Karen 13:54

That's right. Yeah, that's a great idea.

Bill 13:59

I have a feeling that there are cameras that have a remote control now that you could,

Karen 14:05

yeah, yeah, I can do that, too. I have a studio in our basement that I still use at times. But I don't do nearly as much photography as I used to do.

Bill 14:17

And is that because of the challenges and the concerns that you have around your hand? And is it the stroke that has led to that?

Karen 14:23

I'm a little bit and the economy in Alberta in Canada, drastically changed probably five years ago with the oil and everything. So I that's why I went to work about five years ago. So I was still doing photography on the side a little bit, but after my stroke, not so much.

Bill 14:46

Yeah. I also see that on your Instagram, which for people who are curious to connect with you, Karen. I'll have the link in the show notes. They'll be able to find that and connect with you. Your Instagram here. lucid stroke underscore ser su r underscore Viber.

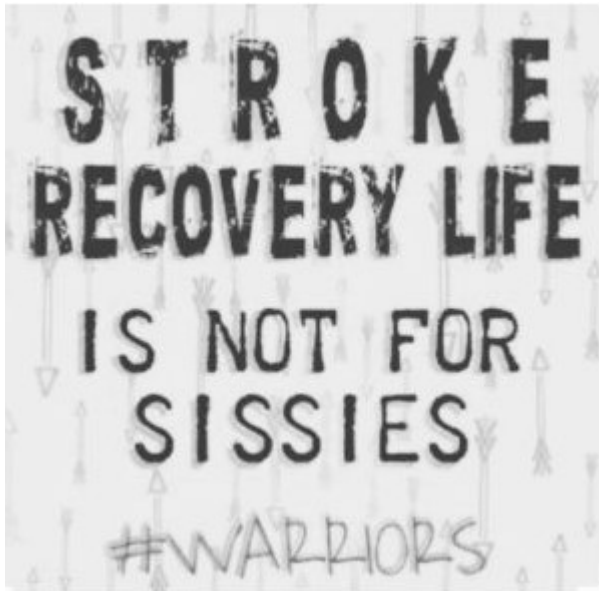
Bill 15:05

You also have a post there that says, stroke recovery life is not for sissies hashtag warriors. I love that it's kind of a different way to look at it. You don't look like you're a sissy previously, it looks like you've just taken this on the chin so to speak, and you've become somebody who has problems to solve, and you're just trying to find ways to solve them. Is that the kind of person you always were? And have you applied those skills to this recovery? How have you approached the recovery?

Karen 15:41

Yeah, I think that's exactly how I was before. And I've never had one day where I've gone why me? I've just gone What can I do to make this better? So yeah. I always take things I don't know how to say that. Sorry I never take anything too. Seriously. Like, everything. I just let everything roll, you know?

Stroke recovery mindset



Bill 16:31

Is it because your, your mindset is about problem-solving? It's not about the problem. It's about the solutions to the problem. Does that accurately describe it?

Karen 16:42

Yeah, that's right. Yeah. And when I was in the hospital, and I wasn't speaking, I knew that I would speak I knew that I will walk again. I don't know why I knew that. Because then I, I didn't know anybody who had ever had a stroke before. I just assumed that I would be totally fine.

Bill 17:01

Yeah, sometimes that type of assumption could be good because it could just open the path for things to come into your goal to allow you to get better. And thankfully, it all lined up for you that the stroke wasn't, well, it's always a serious thing. But it wasn't that dramatic in that you didn't end up in locked-in syndrome, you didn't have all those other things you just rolled with it and whatever came, came.

Bill 17:26

If it was more serious. And I know this is hypothetical and difficult. Do you think it

could have shaken your core? You the core person that you are the one that doesn't sit in the problem doesn't say why me? If it was worse, do you think it might have been able to shake up that old version of you?

Karen 17:46

Might have Yeah, I'm hard to say because it didn't happen to me. But, you know, we've had a lot of other medical things in our family. And, you know, we all just roll with it.

Bill 18:02

That's really helpful. that's similar to me, I didn't really worry about future strikes. Although I had three brain hemorrhages over three years, I didn't really worry about them, but I prepared for them. In that I did what I could to make myself as healthy as possible.

Bill 18:18

So if it did happen, again, I didn't have so far to come to be healthy. And then to heal my brain, I was kind of already in the zone of being really well and therefore, hopefully, minimize the negative side of another bleed. Start from a bit of baseline. And then it happened again, and then it happened again. And then I had brain surgery. And then I had to learn how to walk again and use my arm again, and all that type of thing.

Bill 18:49

I just felt like the only part of the process that I could control was what I did to myself how I managed I my body and also my mindset, are you the kind of person that actively looks at ways of quote unquote, remaining healthy and eating well, and doing all those types of things?

Karen 19:07

Yeah, I mean, like, I was saying, I there was no reason for my stroke. I never have smoked, I never really drink. I'm not overweight, you know, I didn't have any heart issues, nothing like that. We eat really healthy. So you know, I think that I was doing everything right before so I just carried on with it.

Bill 19:32

Yeah. Well, that is really bizarre and strange and you're not in the risk category. If you went and did a health check the day before. They would have said you would have had a clean bill of health everything would have been perfectly fine.

Karen 19:45

Yeah. The neurologists kept asking me if I did judo or lacrosse but no.

Bill 19:54

In case that somehow impacted.

Karen 19:57

Yeah, I don't know. Yeah.

Bill 19:58

Okay. So you got hit on something.

Karen 20:01

Yeah, that's what he kept thinking was I got hit, but I didn't.

Bill 20:08

I know you have a family. You have kids? How many kids are there?

Karen 20:13

I have two children. I have a 22-year-old and a 20-year-old.

Bill 20:18

And how do you tell them? How do you have that conversation with them about what's happened to you? And how do they deal with it?

Karen 20:25

Well, my son was living elsewhere. And he was coming home for Christmas. So my husband broke the news to him. And, you know, they were both quite concerned about me, but they both been super great with helping me my son's actually, he's a personal trainer. So he helps me with all my training and everything. And my daughter's always in there with me working out.

Bill 20:50

Yeah, Sounds like they're a good bunch of kids to have around as well as they are knowledgeable about what they can do to actually help.

Karen 21:00

That's right. Yeah, they both are. Yeah.

Bill 21:02

That's brilliant. How did your husband handle the whole thing?

Karen 21:06

I think my husband took it the worst. Because, like, he said, I'm the rock of the family. Because I'm the one who, you know, knew what was happening within the family. I was the one who kept the calendar. And then when I had my stroke, he's like, I don't know how to pay the bills. I don't know how to do anything, because he never had to. So yeah, he took it probably the worst, but he's recovered quite well.

Bill 21:34

Has he stepped up?

Karen 21:35

Yeah, he did. He stepped up big time.

Bill 21:38

Does he know how to pay a Bill now?

Karen 21:41

Actually, yes, he does.

Bill 21:43

I know we're joking about him. And hopefully, if he listens to this, he doesn't feel like we're being too nasty. But that is quite common, that whole thing that we have roles within our family, we do certain things that the other person just because we do that thing doesn't need to do it.

Bill 22:03

And it never gets discussed, and we never cross boundaries, and people don't do each other's tasks. So it becomes a real problem. So imagine the biggest problem for your husband being as well as dealing with your wife and who's unwell. And what does that all look like in mean for the future and all that kind of thing? Imagine the other biggest problem being the electricity might get turned off because I don't know how to pay the bill.

Karen 22:33

Yeah, that was pretty funny, because he was trying to cancel some appointments for me, and he didn't know how to phone anybody. And so yeah, he may do very

well, though. He enlisted my daughter to help them. Actually, it's like the password thing. You know, how you always have a million passwords?

Bill 22:57

Yeah.

Karen 22:57

I had all the passwords in my brain. Right. So they were never written down anywhere. So now we have all written down.

Bill 23:05

Yeah, the password thing is real difficult one. My wife and I had that conversation just a few days ago, she said, I don't know the password to your computer. There's a bank account. There's this, there's that? And I'm like, yeah. And she said, What if we needed one day, you know, God forbid, all that kind of stuff. And I said, Okay, so I think I need to contact the bank and get them to put you on to this particular account.

Bill 23:27

And I need to do this, and I need to do that. And I think that's a good idea. Because if we don't do it, if I don't do it, it creates a real struggle of getting information out of things that could possibly be useful for all sorts of situations, doctors and legal matters.

Social media as catharsis

Bill 23:44

And yeah, maybe something worth considering. For the people who are listening and watching this. Why did you decide to start creating posts on your Instagram that was stroke-related? What are you getting out of posting about this part of your life, this recovery stage?

Karen 24:10

I think it helps me because I'm, like, I was telling you, I didn't know anybody who'd ever had a stroke before. I didn't know any of the symptoms of a stroke. You know, I didn't know any of the recovery processes of a stroke. And after having my stroke, I stayed silent for a long time. Because I was just, you know, getting used to it. All right. And then I decided just a few months ago that I was going to start posting. And yeah, I really like it now, because I think it helps me I

think it would help other people.

Bill 24:48

Yeah, it's a selfish thing. Initially, you do it and you think I'm going to get something out of this and you do, but then you realize there's a massive loop that happens is other people get a lot out of it. And then it just create this amazing loop of I'm benefiting from doing this. And so is the other person reading this, and therefore, they're doing this because I benefit and they keep benefiting.

Bill 25:10

And that's how I got stuck in this loop of almost 140 episodes of the podcast because I get so much out of it, each interaction with everybody. And they get so much out of it. And then the people listening, get so much out of it. And they respond to me, and they tell me how much they loved a particular episode. And it's almost impossible to stop.

Karen 25:33

That's right.

Bill 25:35

And all the people that I interviewed have had a stroke, something really serious has happened to them in their life. They're struggling a lot of them a lot more than what I might be, or you might be but we're all thinking about other people as well as themselves.

Bill 25:49

And it's really strange. I never expected to see that in so many people that they come on the podcast, often to share their story. And also, maybe it will make somebody else feel better. And that is really bizarre to me that maybe it'll make somebody else feel better. How do you get to that stage, though? Like, why is it so important that other people are also going to be okay, going through something similar to what you're going through?

Karen 26:23

Yeah, I mean, I'm not really sure how to answer that. Yeah, sorry, I don't really know how to answer it.

Bill 26:32

That's okay. I don't expect you to 100% have an answer to it. But it's kind of a

question that I'm putting out there. I'm somehow, that stimulates something that makes me get an answer to that as well. I didn't really have the answer to it either but it's really strange that we're in that position. So I love it it's a good thing.

Karen 26:54

I think it's a great thing. Yeah.

Bill 26:57

So what are your plans? Are you forward thinker? Are you looking into the future about how you'd like things to progress from here?

Karen 27:08

With my stroke, recovering?

Bill 27:09

Yeah, with all things?

Karen 27:12

Yeah, I am a planner. But we like to travel. And obviously, right now, no one's traveling. But, you know, we love to travel. And that's my husband's looking at his retirement soon. And, you know, so we're looking at that forward thinking, right, looking towards the happiness of getting to be out there in the world and checking things out.

Bill 27:44

Okay. And COVID has interrupted all of that, of course, for everybody, and everyone. So it's a little bit further away than it was perhaps, before 2019 it happened? Or 2020 really, actually happened. So it has COVID interrupted your recovery in any way. Did you struggle to access services in those days?

Karen 28:13

No, the only I was going to a hand physiotherapist. And that was the only thing that got stuck on me with the COVID thing. But yeah, all my appointments were pretty much done. And I've been doing all my doctor's appointments over the phone. So I mean, it hasn't really affected me, I know, other people right now.

Karen 28:36

Like my husband was saying, it's so lucky that I had my stroke when I did. Because I think that if it had happened during COVID, it would have been so

much harder to access everything and to be in the hospital. And you know.

Bill 28:51

It sounds like luck has gone your way a few times. And I'm not sure that there's luck in a stroke. Exactly. But you were at the chiropractor at the right time the ambulance was there at the right time.

Karen 29:06

Yeah.

Bill 29:08

Did you ever think about that? Does that ever play on your mind?

Karen 29:13

Yeah, I truly believe in luck, because I am super thankful that I'm still here. And that the ambulance drivers were in the right place at the right time that you know, that I had made it to the chiropractor's office because, like I had just walked in the door and I just sat down. I had been driving, you know, 15 minutes over to the chiropractor's office at seven o'clock in the morning.

Bill 29:40

It could've ended a lot worse.

Karen 29:43

That's right. And my husband was working so I would have I could have fallen at home. You know what I mean? I would have been all by myself. So, you know, the endless things that go through my mind but you think what if what if, what if, but I'm just super thankful and lucky that everything happened the way did.

Bill 30:02

Have you put any thought into your mortality? If this is a difficult question, and you can't answer it, that's fine. I started doing that I thought about I might not be here and it just put some things in place and set some things straight. Have you done any of that kind of work? Did you find yourself in that space at all?

Karen 30:20

Not really. No my daughter was always mentioned that, you know, she is super thankful that I'm still here. And the what ifs? Because she's that kind of kid that she's always worried about everybody. Right? But no, I, that's not my thinking

typically,

Bill 30:40

It's not your thing?

Karen 30:41

No.

Bill 30:42

Yeah. I love it, you are actually quite different than a lot of the other stroke survivors, because I feel like what stroke does is it enhances for most people our worst traits in that if we've got stuff that's left over from a lifetime of trauma, or suffering, or emotional distress, or whatever, you have a stroke, and then that just makes it 10 times worse.

Bill 31:11

I went through a little bit of those things becoming a little worse. But I was always on the path of self development and learning about myself and being a better version of myself and all that kind of stuff. So I quickly realized the things that I had to remedy and the and the few things I had to remedy. Were not about me, per se, they were about how I interacted with certain people, my family, the people, I loved that type of thing.

Bill 31:37

So I went about going out of my way to remedy that apologizing when I was being an idiot, which was regular. And just letting people know how I felt about them. And just making sure that I gave people the opportunity to express themselves around me and tell me what I needed to do. So to speak to fix things.

Karen 31:59

Yeah.

Bill 32:02

You're I'm sensing you're just a really laid back chilled out kind of person anyway. So you don't have a lot of that stuff. Is it accurate? Does it feel like it didn't bring with you a lot of stuff from your past that has exacerbated been exacerbated because of the stroke?

Karen 32:22

No, no. I don't feel like I did.

Bill 32:26

What do you put that down to? Can you explain why you're not that kind of person who carries that type of stuff with you into the future?

Years of debilitating migraines

Karen 32:38

No I can't really explain it. The only thing that I'm really grateful for is, like I was saying earlier, I used to have these bad migraines my entire life. Since I was 16. I had these horrible migraines from a car accident I was in.

Karen 32:59

And now I hardly ever get them. And I used to get them like daily, I would have like, for 25 years I had these wicked migraines almost every day. And I hardly have them anymore. So I think I'm just super grateful. And that I can think without my brain hurting every day.

Karen 33:23

That you know. So I don't have that pain of my head hurting every day. I do still get like little migraines, but they're not anything. They're not the same. They're like little sharp, zapping kind of migraines now. Like it used to consume my whole head like I would I couldn't see anything, I'd have to be in a dark room. I'd have to you know, sometimes they'd even lose my hearing on one side.

Bill 33:54

That it would be difficult living the life under those conditions. But somehow you've managed to do all of that raise a family, work, be a full time human and live with this condition. And did it get you down? Did it make you feel?

Karen 34:14

Oh yeah, it was terrible. Because every day My head hurts. And you can only take so much medicine before your gut starts hurting and then it you know, it messes with other things right?

Karen 34:25

So yeah, every day for that many years was so daunting on me that now I'm headache free and happy. And all you needed to do was have a stroke to get rid of

it. That's right. And that's why I'm actually kind of happy I had my stroke because I'm living a life now. Instead of hiding out my bedroom in a black room, right.

Bill 34:50

Wow, that is just intensely nuts. That is such a good thing. It's so bizarre. You've rewritten the book, let me tell you on most things like in our discussion, we've only been talking for about 30 minutes or so you've just flipped everything upside down and have this outcome from a stroke is just amazing.

Bill 35:16

And ridiculous and great. You know, when you were living with this headache, and you were interacting with people all the time, did they know that you were experiencing this headache from your migraines all the time? Or were they oblivious to you? Because you were really good at hiding it?

Karen 35:36

Yep, I was pretty good at hiding it. I mean, some days, there was no hiding it. Because, you know, I couldn't see anything or I couldn't be in a room with people, you know what I mean? But nope, I was pretty good at hiding.

Bill 35:51

Yeah. And that is similar to you know, what's interesting is you've kind of had that similar experience, the stroke survivors get you had it because of migraines. But a lot of stroke survivors have headaches as a result of their brain surgery or the stroke you had?

Bill 36:10

And externally, they look all, you know, quote, unquote, normal. And there's the invisible side of the disability that people don't pick up on, and they can't possibly understand. Did you have that experience that invisible disability kind of experience, although it wasn't, per se a disability in the explanation? It kind of was because it's stopping you from living your fullest.

Karen 36:40

That's right. For sure it was.

Bill 36:44

Did people misunderstand you and judge you because you had a headache again?

Karen 36:49

Yep. Like my family said, Oh, you have another migraine? Oh, you know.

Bill 36:58

You kind of had all of the stuff that stroke survivors experienced before you strike. You've done everything backwards. And now it's gone because of the stroke.

Karen 37:05

That's right. Yeah, I'm backwards.

Life after having Cryptogenic stroke



Bill 37:09

Wow. That's good. That's really good. And, and now, you can go about having this different kind of experience in your life, a different kind of clarity about your head? How has that changed your life? What do you see now that you couldn't see before? Or how has it impacted your life in a positive way?

Karen 37:30

Well, I can be out in the world and not have my head hurting. It feels great. And yeah, I mean, it's totally changed my life, though. To think having a stroke has changed my life for the better. seems really weird to say, but that's what I always say.

Bill 37:54

A lot of people say that even people living with quite serious disabilities, they'll say the stroke was the best thing that happened to them. Of course, at the time,

it's the scariest. It's one of the worst things it's one of the hardest things, but after some time elapses, and they go on some kind of a path of self discovery and healing and learning about you know, how to support themselves and overcome challenges and how tough they really are.

Bill 38:22

They're not sissies you know, they're stroke survivors like you say they kind of reflect and some times it just it just enters their mind that oh my gosh, the stroke was one of the best things that happened to me because it led to all these other things occurring.

Bill 38:41

And it sounds like you're got there a lot quicker than most stroke survivors, but it definitely has led to you discovering parts of yourself that you didn't know were impossible. Painkillers, paracetamol, any of that stuff did it ever ease the headache symptoms? Did it ever give you some kind of ability to get back to your day and feel okay?

Karen 39:11

No, I mean, I lived on Advil, Tylenol, Tylenol twos, like everything. I would take Imitrex I took all the migraine medicines. They might help for a day or two, but they never cured it.

Bill 39:31

And now, are you taking those medications at all with those little ones that you experience?

Karen 39:35

No.

Bill 39:37

That's fantastic. And just your pocket as well. You probably gonna have more money left in your pocket.

Karen 39:44

That's right. Yeah.

Bill 39:47

It's like a smoker who stopped smoking and all of a sudden they have all this

spare cash.

Karen 39:51

That's right. That's what we're traveling on. All my headache medicines we're going to be traveling on.

Bill 39:59

Sounds brilliant, that is so heartwarming to hear. The other thing that you posted about one day was and I love the words that you use in your posts, one of them is perfectly imperfect. And I think that's a really important thing. What does that mean for you perfectly imperfect?

Intro 40:21

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.

Intro 40:40

But 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 it's called the seven questions to ask your doctor about your stroke.

Intro 41:05

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

Perfectly imperfect

MY LEGS ARE HUNGOVER

Karen 41:24

I saw that. And I thought that that's just so fitting for all of the stroke survivors that, you know, we don't have to be perfect. We can be perfectly imperfect. So yeah, that's my take on it is you don't have to be perfect. You know, everyone struggles with something.

Bill 41:48

Be okay with it be okay with not being perfect or normal, or whatever the word is that you use that limits you from getting further along in your journey, because aiming for perfection, I reckon closes the window on other possibilities that we're not seeing, because we're trying to get to this one point.

Karen 42:10

Yeah, that's right.

Bill 42:12

Yeah, I agree with that one, perfectly imperfect. And even before the stroke we're nowhere near perfect. We were just, I don't know, stumbling towards some kind of strange version of perfection that we were never going to get to anyway.

Bill 42:26

And now, if that's the one thing that's occupying your mind of getting back to where you were beforehand, maybe you just need to let go of that and just live the moment that you're in and experience what you're experiencing. Because there's a real richness in your current experience.

Bill 42:44

Even if it's a shit one, pardon my French, it's still a lot of richness there, there is

still something you can gain from it. And the way that I extract a good thing out of a really bad time, is by asking if, and by trying to trick myself sometimes in saying stuff. Like, if it was possible for something to good to come out of this situation. If it was possible, what might it be?

Bill 43:14

And that automatically trains the mind to say, Okay, well, I'm experiencing pain and suffering and all this type of thing. But a lovely person came up to me and said, Hello, and spoke to me. And that's a good thing that came out of that painful situation. The other thing that you did really well was you explain this thing that I can't explain to people.

Bill 43:34

So my left leg, it becomes really stiff and numb, and it then starts to hurt. And this is where I contacted you because you posted a post, which says my legs are hungover. And that, to me was I never had the words that describes my legs. How did you get to that? Or did you find that somewhere else in Pinterest?

Karen 44:01

Yeah, I think it's on Pinterest. But yeah, I found that and I thought that was so fitting because, you know, we had walked along that day, and we had bike ride and yeah, my legs were totally done. My right leg was totally done that night. I wish I would put my leg is hung over but those legs.

Bill 44:21

I knew exactly what you meant, though. Like, I totally understood that when you're riding a bike, is it easier to keep the effected leg on the pedal? Because I really struggled with that for a long time.

Karen 44:31

Yeah, I really struggled with that. In the beginning my husband kept saying to me that I was just using my toes to pedal my bike on my right side. And but this year, I've only been bike riding a few times because we just lost our snow but we've just gained it all back today but yeah.

Karen 44:55

The bike rides that have gone on this year. I can place my foot on the pedal properly.

Bill 45:04

And how quickly does your leg get tired? Because what I noticed about my leg was I might start off the first few minutes or fine, even 10 minutes. And then if I do one, even just a minor incline or a small hill, then it gets really tired. And then my right leg is out of the picture. My left leg is out of the picture. And my right leg is trying to do more work to keep it going.

Karen 45:31

That's right. Yeah, that's me, too.

Bill 45:32

Yeah, I solved that problem with at the beginning with a stirrup before my left foot. So, you know, the pedals have they have straps to hold fit in for bike riders who are more serious than us. And I used to put my foot in the stirrup and then forget that it was in the stirrup, and then go to try and put my foot down.

Bill 45:54

And of course, I couldn't get it out quick enough. And I'd fall over. And that was really challenging. Because I was trying to solve the problem of my foot not staying on the pedal, and I solved that problem. And then I created another problem. And I got sick of it. And I gave the bike away for a little while, I stopped riding. And then somebody said to me, have you ever tried an electric bike?

Bill 46:16

And I always thought that was a bit weird on No, I don't know what they do. Like, I don't get it. And I went and tried one. And what I realized was the electric bike in those first early parts of the of the pedaling process. So in the first, I'd say, the hardest part of the pedal. In the hardest part, it assists you with the electric motor. And you don't feel that strain, and therefore my leg doesn't get fatigued. And I can ride for an hour or more, and I just come back and everything is okay.

Karen 46:51

That's right. So my husband, we were in Hawaii a year, just over a year ago. And we rented electric bikes. And it totally impressed my husband so much that he's buying us electric bikes. Well, at least me so then I can keep up with him. Because he always does like a nine or 10-kilometer bike ride every morning. Yes. And there's no way I can keep up with him. But if I had my electric bike, then I could.

Bill 47:18

Yeah, so ours are pre-programed to support you up to 25 kilometers an hour, and then the electric motor switches off. But which by then you're cruising along. And it's really a comfortable sort of speed to be riding, it's not too fast, and it's not too slow. And then as you get a little bit fatigued or tired, and you drop under 25 kilometers, it kicks in again.

Bill 47:43

So you don't really need to actually put a lot of effort into staying at 25 kilometres an hour. So I rediscovered my love of bike riding with that electric bike, and it can do up to up to about 100 kilometres, or if I put it on the very high level of support or help or whatever they call it, it does maybe 30 or 40 kilometres, which is way more than I'll do on a single day.

Bill 48:12

And I just crank it up to the full level of support so that I don't have to get tired at all really? So you're going to love that when you get it. And that's going to mean that you're going to be able to put your foot on the pedal better it'll be much easier. Now for people listening who might have given up bike riding, for whatever reason, say that you can't balance on a bike on two wheels.

Bill 48:36

And maybe if you get a three wheeled bike with two wheels at the back, one of the fun and you can get an electric motor that will really help. But also, I think they're available on those bikes where people lie down. And they sit in a seat and they look like they're almost lying down. You can get it in those bikes as well. So what I find is that, although I can drive, it gives me a sense of independence. That's a little different from getting in a car. It's more freeing. It's a more spiritual independence.

Karen 49:06

Yeah. That's awesome.

Bill 49:11

Were you not able to drive for a while? And how did you experience that? How did you feel about that?

Karen 49:18

Well, I don't know what it's like in other countries, but in Canada, automatically

when you have a stroke, you lose your license for a month minimum. And so I got my car after my one month to the day and I said to my husband and my allowed to drive like I was so nervous. And my husband's like yes, you're allowed to drive. Just get in the car and drive so I drove around our area and yeah, you just pick it up like no problem but it was really nerve racking for the first little Little bit but no problems after that.

Bill 50:03

How about the right foot on the pedal? Were you able to get back to being able to work out how much pressure to put on?

Karen 50:10

Yeah. I don't know what it's called. But my right three toes are I think it's called spasticity or? So that was my big struggle, in the beginning, was how to put my toes onto the pedal. So I actually use my cruise control quite a bit in the very beginning, because my toes kept cramping up, and then my foot would cramp up, and then you know, I'd have to stop my car and get out because I have to put my foot flat to get the crap out. So yeah, that was probably my biggest hurdle with driving.

Bill 50:56

Well, you've come such a long way, you've actually had a fair amount to overcome. We make it sound like you got there really easily. But I can't imagine that this was all just as breezy as you make it sound.

Karen 51:13

Yeah, it's not as breezy. But it was pretty. Like I look at other people's Instagram stories, and I think I have it so much easier. I have nothing to complain about.

Bill 51:24

So you're in which part of Canada?

Karen 51:30

Alberta

Bill 51:32

Is at the top?

Karen 51:35

So Canada goes like this. And we're over the next province over to BC. British Columbia, Vancouver. So we're in Edmonton.

Bill 51:47

Is that near the border of the United States?

Karen 51:50

No, we're North probably about seven hours from the border.

Bill 51:59

How does the weather impact your stroke in any way? Does the cold bother you and annoy you?

Karen 52:09

Yeah, that creates some fun times. Because it's, I mean, it's beautiful it's cold. Some days. We didn't have that much cold weather. This winter. We had a really nice winter this year. We had only a couple of days of 40 below, which is totally fine with me if it's only a few days.

Karen 52:37

But yeah, it's been a great winter. We've had we're heading into our spring like this is actually spring now but yeah, we still get snow and probably till May. We'll have on and off snowstorms. We were outside in the yard today. We were raking it up. It was beautiful all day today.

Bill 53:01

How much snow?

Karen 53:02

So probably three inches out there.

Dealing with cold temperatures

Bill 53:10

Yeah. That's a fair bit. And does that impact the stroke recovery? Does that make you feel colder on one side or the other side?

Karen 53:19

Oh, yeah, for sure. My right side for my first winter after my stroke. I was under like four blankets every day, because I just couldn't warm up and my right foot

would freeze instantly. So and my right hands. So yeah, it definitely impacts that. I don't know if it's like that for you. Was it?

Bill 53:44

That is very common that one side of the body is colder than the other for a lot of strokes. If I was I'm not sure why that is. But it's so common. Here we don't get to minus 40 which is four degrees Celsius that often where I live in Melbourne. We do get Arctic winds coming up from the South Pole.

Bill 54:08

And our weather is we're kind of stuck in between the desert of the majority of our country, which if there's a northerly wind brings hot temperatures and hot conditions. But then in winter when things switch around, we get the subtleties and those subtleties are ice cold I imagine it's similar to what you guys feel from the North Pole, right?

Bill 54:34

And I can tell you that I can be like you under every kind of blanket is so warm and then feel the chill still penetrating all those layers and getting to my skin and somehow making that part of my body feel freezing. And you can actually measure the difference in the temperature with a thermometer on one side of my body to the other.

Bill 55:01

And it's usually a couple of degrees lower or one and a bit degrees. So it's very common. And I never really liked the cold. And I love summer. And I don't know how anyone lives in a part of the world where it snows, I don't know how they do it all power to you guys, but I can ever imagine myself doing it. And my wife made me go. And I say made me go, we traveled to New York for new years in 2012, 2013.

Bill 55:38

And it was around 40 below every day. It was around 40 Fahrenheit every day. So it was about Okay, so we're Celsius.

Karen 55:50

So 40 below is like

Bill 55:53

40 Fahrenheit

Karen 55:54

40 below is like 40 below Celsius.

Bill 55:58

Oh, oh, not zero, not near zero degrees Celsius.

Karen 56:03

No. 40 below.

Bill 56:06

And you think that's okay for a few days? So 40 below minus 40 Fahrenheit?

Karen 56:15

Celsius, 40 below Celsius and 40 below Fahrenheit would be about the same. Here it is right here. Yeah, 40 degrees below zero is 40 degrees Celsius and Fahrenheit is exactly the same.

Bill 56:37

So we're talking about freezing.

Karen 56:39

The freezing point is zero degrees Celsius means 32. Fahrenheit. Is our freezing.

Bill 56:49

Okay? So are you talking below 32 Fahrenheit.

Karen 56:56

I'm talking 40 degrees below.

Bill 57:03

Oh, my gosh.

Karen 57:04

And we used to live nine hours north of here. And if we get to 50 below. And one day, it was like 52 below zero. And I said to my husband, it's time to move. I'm done with this. We need to move we moved down here. And it's way better here.

Bill 57:26

We need to move to a warmer climate where it only gets to 40 below. Everything

is relative that is absolutely crazy. I cannot imagine. I don't know why people do. But isn't that amazing how it's a great example of how humans can adapt to anything. And if you can adapt to those types of temperature decreases, then you can adapt to anything and stroke should be one of those things that we can somehow find a way to adapt to we've got no other choice. So we've got to just adopt to it.

Karen 58:01

My mum and I moved from Vancouver BC. Have you ever checked out the weather in Vancouver? It's quite rainy. And it's just north of Seattle. So it's kind of that wet, rainy, it hardly ever gets below zero there. It's you know, it's pretty mild. And my mom and I moved to Fort St. JOHN BC, which is I think it's 18 hours north of Vancouver.

Karen 58:32

And our first winter there. My mom said that's it, we're moving because all the windows froze up. Like we had thick ice on every window. And it felt like it was 40 below in our house. But my mom had turned up the humidifier. So we ended up staying but.

Karen 59:02

So, yeah, we've learned a few rules of the way right so.

Bill 59:06

Yeah, good on you. I don't know. How you do it, have you ever dreamt up? I'm gonna go to Miami, Florida and spend a year there one day?

Karen 59:16

No. I would like to probably go if I'm dreaming of somewhere probably be Hawaii. We love going to Hawaii. We've been there many times now. That would be my dream location to live.

Bill 59:28

Yeah, I've been to Hawaii. And the temperature there was amazing. It was pretty consistent. And from what I hear doesn't fluctuate a lot, does it?

Karen 59:34

That's right. Yeah. It's awesome.

Bill 59:36

Yeah. Okay. So somebody like you that comes from such a cold climate could really settle into something like.

Karen 59:43

Oh, I could totally leave the cold weather in the dust. No problem.

Bill 59:49

All right. I'm glad to hear it. I'm glad to hear I didn't want you to be one of those crazy people who loves the cold.

Karen 59:55

No, I don't love the cold but I can live with it. Right? And you know, it makes you appreciate the warmer days because we've had this great winter here. And, you know, I have this lady at work, who loves to complain about everything. She's like, Oh, it's so cold and like, it's a really beautiful day. It's up 50 below. So you know it's great.

Bill 1:00:19

Sounds like she's living in the wrong part of the world.

Karen 1:00:22

That's Yeah, I think she'd probably be one to live in Miami, right?

Bill 1:00:26

So about three-hour plane flight north from where I live. So around 3 and a half thousand kilometers from where I live is the Gold Coast, the Sunshine Coast is the Queensland and it's where all the Victorians and Melburnians leave in winter to go to to get away from the cold weather.

Bill 1:00:52

I could really see myself just finding a little shack somewhere near a beach over there and just plunking my butt there and being there for the rest of my life like quite happily because it gets warm, but it never gets below about 20 degrees Celsius. And when it does get below that it's quite cold for them. They whinge about it. But in Melbourne, 20 degrees Celsius in winter would be just unbelievable that would be amazing.

Bill 1:01:19

And I remember traveling there one year, and it was winter in Melbourne and I went up for a conference. And while I was there, it was about 22 degrees Celsius. And I took I was in shorts and a T shirt and flip flops and everything was amazing. And this guy walks past me with a jacket and a scarf. It was cold. And I was in shorts. And I was looking at him thinking, what are you doing? Like, why are you wearing a scarf? It's 20 degrees Celsius, the sun is out. It's a completely amazing day.

Karen 1:01:54

We went down to Los Angeles to Disneyland when our kids were young. And the day we got there, our kids are, you know, in their shorts and tank tops. And it was like, I don't know, maybe April, we were looking at these people that were from LA. They're wearing a winter coats.

Karen 1:02:19

And we're like, why are you wearing your winter coat? Like, this is so stupid because it was so beautiful. They're like, Oh, this is so cold. We're like, we just left 40 below like we're wearing shorts and T shirts and tank tops and sandals. And that's all we took. Right? So it's really funny.

Bill 1:02:39

That's fair enough. Yeah. I really appreciate you connecting with me and agreeing to be on the podcast.

Karen 1:02:46

No problem.

Bill 1:02:47

It's really lovely to hear your story and how some strange thing called the cryptogenic stroke has created a few problems for you but solved some other ones for you. That is rare and wonderful to hear about. And I wish you all the best and I hope everything goes really well for you in your recovery. From here on.

Karen 1:03:09

Thank you very much.

Intro 1:03:15

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understanding into the experiences of other individuals opinions and treatment protocols discussed during any podcast or the individuals own experience and we do not necessarily share the same opinion nor do we recommend any treatment protocol discussed.

Intro 1:03:42

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Intro 1:04:05

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Intro 1:04:20

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Intro 1:04:44

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