

66. But You Look So Normal - Chris & Kara Russo

BUT YOU LOOK SO NORMAL...

**A true story of living with brain injuries,
beating the odds, and finding love.**



Kara Ellsworth and Chris Russo

Kara suffered a massive stroke, and Chris was in a coma that left him paralyzed after a bout with Meningitis and Encephalitis. Who would have thought that, those circumstances could lead to Chris and Kara meeting in speech therapy, falling in love, getting married within a couple of years and writing a book.

It's a love story to rival Shakespeare, with a happy ending.

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I think that was probably one of my biggest struggles is trying to get back to work. I was a nurse beforehand and I was working full time things are going great and then this all of a sudden hit and that was the biggest struggle because once I figured I was gonna, you know, I was able to walk I was able to do things I'm going to get back right into nursing and be able to go out without a problem. And what I found was just challenges mostly that multitasking and through a long haul many ups and downs you know, I finally found that you know, I'm still able to work as a nurse, but I've been having to adapt and you know what works, what doesn't work. You know, the hours I work the time of day I can work just having to figure all that out.

Intro 0:47

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

Bill 0:55

Bill Gasiamis here and welcome to recovery after stroke.

Bill 0:59

This is Episode 66. And this is a very interesting episode. Today I have with me, Chris and Kara Russo, who are both survivors of different types of brain injuries and who became married after they met in rehabilitation. Chris and Kara, welcome to the podcast.

Chris R. 1:25

Thank you for having us.

Bill 1:27

Kara, you and I met on Instagram, because your Instagram label or handle is “But You Look so Normal?”

Kara 1:39

Correct!

Bill 1:43

I get that a lot. So I really related to what you’re saying. Can you tell me a little bit about what happened to you. And then we’ll talk about what happened to Chris.

Straight through



Kara 1:50

Sure, sure. I was back up when I was 27 and I was having some health issues. I had lost most of my vision. And I was having headaches and a little bit of difficulty walking and the doctors just couldn’t figure out what was what was going on. They had some ideas, and one of the ideas was this disease called vasculitis. And the way that they would check for it would be what they do is a cerebral angiogram. So what that is, is they thread a catheter from your femoral artery, so in your thigh all the way up to your brain. And once it’s up in your brain, and they can shoot some dye in and then your arteries can all light up and they can see what’s going on. Well, during the procedure, the radiologist was having a difficult time going through getting navigating through my arteries, and she ended up going through the artery straight through it causing the stroke. So...

Bill 2:50

Oh my Lord.

Kara 2:53

Right? so it was it's a known risk of having the procedure is less than a 1% chance and it's kind of ironic.

Kara 2:59

I remember joking with the doctor before i had actually signed all the consent forms and we were joking about oh, that's, that's not going to happen. That never happens. And it ended up happening.

Bill 3:32

Wow, I remember having an angiogram, the whole process and being you know, strapped down and all that kind of stuff it was quite an interesting experience but i had already experienced the bleed in the brain so they probably couldn't make matters worse could they have punctured another hole in my blood vessels. So, what was the process for you after that? And by the way, were you awake during your angiogram because I was, so were you awake?

Kara 3:46

Yes i was awake and actually feeling pretty good during it.

Bill 3:54

Even after they punctured the hole in the artery?

Kara 3:55

Yes, I don't. I don't really remember most of that.

Chris R. 3:59

They used some good drugs right?

Kara 3:59

Yeah I was on some pretty good medicine for that. So there's a bit of a blur in there. What i do remember is waking up in the post op room, and i remember i was nauseous, i was vomitting, i was dizzy, headache, and i remember telling the nurse there wow i really just dont feel good and she's like "Oh ok it's fine, its normal i'll just let the doctor know.

Kara 3:59

And they came back a few minutes later and they're like " Oh yeah they said it's

fine we're gonna release you. So i got released and i was actually headed over to see a different specialist at another hospital. And by the time i got to see that specialist, when i got into the room i had actually passed out. And so they had to call 911 from there, so i went to that hospital's E.R.

Kara 4:00

And then in the course of things I went to like two or three E.Rs before they finally admitted me for dehydration, not even thinking that i possibly had a stroke, they were just thinking it was dehydration for all the vomitting, and so i was admitted to the hospital and about three days later i was still vomitting, still had dizziness, still had headaches, still couldn't sit up, still couldn't do anything and they finally were like, well i guess we should probably figure out whats causing all of this.

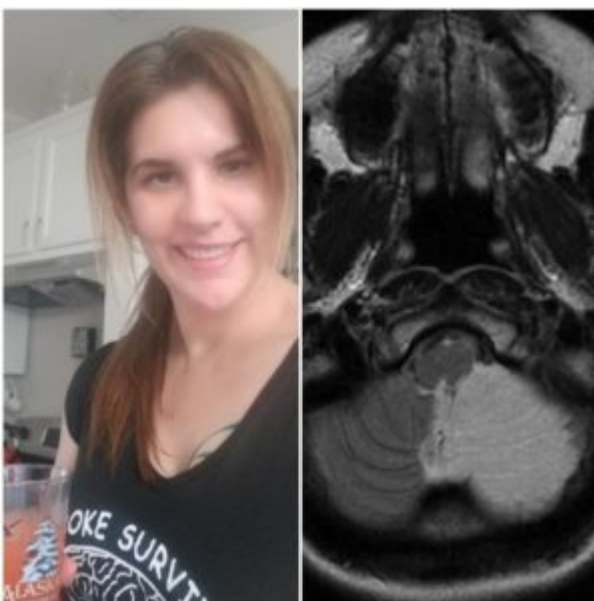
Kara 5:25

And so thats when they finally did a CT Scan. And then they realized looks like its a stroke.

Bill 5:28

Wow! so they didn't notice that they had done that during the procedure. It took them four days to work out that they had done something?

Young and not at risk



Kara 5:36

Yes, about four days and the sad part was that I was in the hospital the entire

time. So they had plenty of time to look at the symptoms and say, Oh, this might be a stroke but they just never never put it together because I was 27 that time so they considered me young and not at risk for having a stroke. So they just completely brushed off all my symptoms.

Bill 6:04

I find that staggering. You're in a hospital with doctors who make mistakes from time to time and accept that they do and that's okay. They're all good, normal, but nobody was able to go. This is a person who had a procedure into their brain. Now they feel unwell. Let's find out why. No one said that.

Bill 6:24

Bill Gasiamis here. I just wanted to share with you this short message, and then it's back to the interview. Now, if you or someone you know, has experienced a stroke, and are in recovery, you 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 these things to you but obviously because you've never had a stroke before. You may not know what question to ask. If this is you, you may be missing out on doing the things that could help speedup 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 "7 questions to ask your doctor about your stroke" these are the 7 questions that i wished i had asked when i was recovering from my stroke. They'll not only help better understand your condition, they'll help you take a more active role in your recovery.

Bill 7:29

Head to the website now recoveryafterstroke.com and download the guide, its free.

Kara 7:35

It seems so simple now. But yeah, they just weren't getting it. They just weren't connecting it. And I wasn't in a state to put it together.

Bill 7:45

Yeah ofcourse you weren't

Kara 7:45

I'm actually I was actually really relieved when they after they did the CT and it came back. Oh, you had a stroke because I was starting to think, God What the heck is wrong with me? I can't figure out where I am in space. I can't sit up. I was like what is going on with me?

Kara 8:00

So when they actually said that yeah, you had a stroke. I was like, "Oh, they found something".

Bill 8:05

It's funny how we need to know what it is that we're struggling with so that we can label it for some reason. And then I don't know it's probably like Ground Zero today. It's like the start of going forward like you know where you're at. And that's what let's go forward from there even if it's a terrible diagnosis.

Kara 8:24

Absolutely. And I think anyone who's who struggled with trying to get a diagnosis and and at the time just to put it in perspective I had was going through some other symptoms with the I lost my eyesight with the headaches and all that and they weren't able to come up with a diagnosis I was going to test and test and not coming up with one so for them to actually come back and say oh yeah, we found something I actually was was pretty happy about it until I realized oh you guys completely missed a stroke and you could have given me TPA to stop it but, yeah.

Bill 8:59

Wow, Chris what happened to you?

I didn't know who she was



Chris R. 9:03

Oh, well, I got really sick I thought I had Mono you know sore throat neck ache backache that kind of thing went to the doctor, gave me amoxicillin, And was in the week course of it. getting worse back to the doctor again. gave me more amoxicillin. The next week go back in again, did more blood work that time another throat culture, more amoxicillin. Apparently on the fourth week, I went back in and got another bottle of amoxicillin they don't remember at all whatsoever getting. And the following day, after I got that and I was driving around myself by the week. So that was fine. You know, for 20 years old and fine, good health. And, so let's see, the next morning my mom came to check on me I was living at home Thank God. And she said I didn't know who she was and then she asked me you know, you know what your name is and what year it is, she said I looked terrified I had no idea who I was who she is anything at all.

Chris R. 10:04

And 12 hours later in the hospital they released me from E.R. Because my blood work came back fine. And my dad threw off a fit. And you know, yelled the whole who's in charge here kind of thing. Because he asked a nurse to how things are going with me because i was there for 12 hours, no fluids are given to me nothing really at all. They've put a catheter in me and sent me on my way. In the corner room, my dad said and so he was like kind of freaking out a little bit he said my urine was turning brown. He's like, that's not a good sign.

Bill 10:32

Your what was turning brown?

Chris R. 10:34

My urine was turning brown in the catheter bag. And that's like, that's not a good sign. I'm not a doctor, but I don't think that looks good. And he told a nurse about that. And a nurse said he was apparently not very competent, apparent, you know? And so he's like, yeah, his blood work came back fine and they're gonna release me soon. Yes. So that's a funny thing to hear. My dad said he's like, he's a vegetable does not know who anybody is, doesn't know his own name and you said he's fine? And so the head doctor overheard my dad yelling and ran up and said, Where's your son, I'm not seeing this case at all. And so he said he's been ignored in that corner. And she went in there and apparently right away said, Get me in the ICU, do lumbar puncture, do an MRI, this, this and this, she saw some signs of meningitis, possibly. And they did lumbar puncture, and came back that meningitis and encephalitis. So it's a good double whammy of illnesses that usually leave you pretty paralyzed. They told my parents I was definitely going to be in a wheelchair and I left you know, if not a bad kind of it was bad.

Chris R. 11:37

And so my parents we did arrange my bedroom made all accessible. And so my mom, i was in ICU for over a month. And so the social worker came in one day and tell my mom You know, the check to see if they prepared for me. And mom said "Yeah, we made his room very accessible, you know, it's all, our house is one story we already did all this and that we have a shower chair, we things like that. And the social worker said, Yeah, that's great, but he might not make it out of here.

Chris R. 12:05

And my mom kind of, she said, I just said I felt myself turned red and very angry says that almost hope like and said, My son will not die before me. And the social worker, just kind of said, okay, and backed out of the room slowly. And, they sent me off to rehab center where they should have sent her but she got hidden up from the side. And a month and a half later I walked out of there.

Bill 12:34

Well, that's good to hear man

Chris R. 12:36

Shocked everybody there too, because they all thought I was never gonna walk again also. So

Bill 12:41

Good work. Good work. Let's go back a little bit what's meningitis? And what's encephalitis?

Chris R. 12:46

meningitis is illness attacks outside lining of your brain, the meninges and encephalitis is actually what West Nile is, it's the West Nile encephalitis virus. And so they didn't know what strand it was. So that actually goes inside your brain eats away every particles getting in the way. And you know, it takes bad new things, a lot of stuff with it. So you know, there are no good medicines for either because i had the viral version of everything. So, yeah, so they had to wait it out and hope you didn't do too much damage. So that's fun and scary to know about these days. Yeah.

Bill 13:23

So when, when you went through the process of dealing with the encephalitis and the meningitis, what were you left with that you had to recover from?

Chris R. 13:32

I had really bad short term memory issues, like I meet somebody and a second later, forget their name, and stuff like that. And just you know, what else did it go through? Just I think the speech Yeah, the speech. Also, I had a lot of I still talk too fast when I get excited. And people don't understand me very well. Sorry about that. That's happening here at all.

Chris R. 13:56

Just that kind of stuff. Nothing, too. I'm really, really lucky. really lucky.

Bill 14:00

Yeah. So no visual problems, no inability to walk, no loss of function from the hands or anything like that.

Chris R. 14:07

No. They were worried about that. But now,

Bill 14:11

man, that is excellent. Such a great come.

Chris R. 14:14

Yeah, we've been called The miracle couple on many occasions.

Bill 14:20

Well, I'm going to call you the dynamic duo.

Chris R. 14:22

I like that. That's awesome.

Bill 14:25

Yeah, that's way better than the miracle couple, the dynamic duo, you guys are doing an amazing things. So Kara, tell me about what you had to deal with, after they finally discovered what your challenge was? And did you have deficits that you had to recover from? What was going on there?

Kara 14:42

Sure. So, so mine was, you know, I think I touched a little bit how they they missed my my stroke. And there was a little bit of a little bit of malpractice issues going on there. So what they did is, once they once they discovered the stroke, I think there was a little bit of a little bit of a cover up, they didn't really go into how big the stroke was, or what exactly happened, I think they tried to shove me in a corner and minimize everything that was happening. And they said, Oh, you have a stroke, you're young, you'll be fine. Boom! send you we'll, you know, we'll release you. So I didn't have, I had to learn how to walk again. And I had some obviously I was still having my my issues with with my vision. So I had a little bit of speech issues, my big thing with with balance and dizziness, because my stroke affected my cerebellum. So I had a lot of spatial issues as well. Meaning I didn't really know where it was in a room. So, you know, I would get the input that I'd be sitting in the middle of the room or I was laying in bed, but then my brain would tell me that I'm up on the ceiling. So I had a lot of a lot of strange things like that, to try to work with and figure out why was.

Kara 16:03

So just a lot of PT lot of speech therapy, a lot of occupational therapy. Am I moving around? that was what a few months of that, about six months or so I learned learn how to walk again, learn how to do how to put everything together, trying to figure out. And I actually think that was one of the big things is trying to figure out what my challenges were, once I got over the the physical, the physical problems with with walking and being able to have a hard time with with picking

up things and grabbing things correctly. Sometimes I'll go to reach for things I'm not, you know, I don't pick it up correctly, I miss things.

Kara 16:52

So I think once I got through the physical things going through, and I think the surprises were

Kara 17:01

things like learning how to multitask again. And learning that loud noises are not good for me. crowds are not good for me things that I didn't realize that I would be affected by. I think those and I think you have some Yeah, I think that was the you know, you get told you have something you have a stroke or you have this illness. And they focus on on physical, physical issues. And they don't tell you about all the other things that you'll that you'll encounter. Yes.

Chris R. 17:31

Be tired as hell in 1pm

Kara 17:34

Yeah. Yeah, the fatigue. And, yes, you're going to be sleeping all the time, you're going to be tired for no reason. And yeah,

Bill 17:42

Yeah, well, you're tired for a reason. There is an issue, brain is healing, and it's trying to keep up with the body. That's trying to do all the normal tasks, but it's obviously struggling to do all the normal tasks plus heal from being injured. So it sounds like you guys had a lot of similarities in what you experience before we get to those similarities, because that's what I want to talk about because the different conditions, but what people don't realize is that neurological conditions often create the same symptoms for people who got there in a different from a different path. But how did you two crazy kids meet?

Chris R. 18:19

Why don't you do it

Kara 18:21

So we actually met in therapy, or what I lovingly call rehab, we met in rehab. And then this is where people whenever I say that people always look at us and they kind of look us up and down and they try to figure out what rehab it was.

Kara 18:38

And then after a few seconds I like Oh yes, we met in speech therapy. So

Kara 18:43

so there was a group they had put together all this happened at the same hospital. And they had put together a group for young young brain injury survivors, and there were like five or six of us? 4? Yeah something like that. And, that's how we met.

Kara 19:02

And we've been.

Chris R. 19:04

I walked in the room and saw her and just knew right away i want to marry her like, no joke just right away. Yeah.

Chris R. 19:12

I was 21 years old. I'm like, Okay, that's it. Like I was done.

Bill 19:19

Jackpot. Job done.

Chris R. 19:21

Okay. I can. Yeah, I was done.

Kara 19:25

Same thing for me as well.

Bill 19:27

How old were you, Kara?

Kara 19:30

I was when I was 27 when I had my stroke, but I was still in speech therapy. I was 29? 30?

Chris R. 19:36

Yeah, I met her. She's just turning 30 when i met her. She's 29. I was 21. And yeah.

Bill 19:43

That was big, brave thoughts of you for you.

Chris R. 19:46

Right? I was like, Yeah, yeah, that was it. I'm telling you.

Bill 19:51

I like it. Well done, man. Like he's thought I can't speak I'm in therapy, something wrong with my brain. Like, I don't know what's happening in the world, but married this girl! Beautiful.

Chris R. 20:01

Exactly yeah, no joke!

Bill 20:03

I love it. Man. Well done. And you achieved your goal. Congratulations

Chris R. 20:07

I did couple of years later, we got married, yeah!

Bill 20:12

Yeah, that is so good to hear. So tell me a little bit about the similarities of what you guys experienced. And you know, what's good about you to meeting and get it together and having a brain injury? Both having a venger, what's good about that is you understand what is going on for each other. And it's not foreign. And one of the things I say is like, nobody ever understands me, but of course, the only way they're going to understand me is if they're unwell, and I don't want them to be unwell. And there's no point in that. But you guys were already unwell. So tell me about the similarities.

Kara 20:56

So many I think, so many, the fatigue.

Chris R. 21:02

The crowd thing we do we both hate crowds, loud, especially loud ones. Like it's just a lot in my brain you understand that? I'm sure. When you know, it just becomes too much and just kind of look at each other. And we can I can look at her and and tell right away how she's doing. So we're gonna be eyes on like, let's go. Cuz she don't speak up cuz you know, She was fine. I'm like, you're not good. Let's go like that. So

Kara 21:30

I think the the helping, I think just recognizing when the other one is struggling, so if you're. So he knows my signals when I'm getting overwhelmed over fatigue, and he picks up on those, he can say, No, God, I gotta get out of here. We're going to do a rest day today, or we're not doing anything. And the same with with with him would be like, wake up and would do anything. Or, yes, we're gonna take advantage of this. And we're gonna go out for a drive or yeah.

Bill 21:57

Yeah, that's really good. So on, I remember early on I used to have, you know, we'd make plans to go somewhere and do something. And I would say, Well, today, I'm feeling great. Let's go and do something. And then we get there. And then I'd be feeling terrible. Because I don't know what happened, something changed in the, in the time that I decided that we're going to do something until the time we got there. And then it was kind of like I was a bit of a bummer to be around at that time. But then other times when I said, don't make any plans for today, we're not doing anything. I'm just going to flake it on the couch. And then I'd say, hey, actually, I'm feeling really good. Let's go and do something. That'd be like, my thought we weren't doing anything. And it's like, well, we are now I'm feeling great. Make the most of this, you know, and I would spend, I could spend hours and way longer than I thought. Being able to be out and about and exercising by walking and being around people and by being in crowds. So I had these very strange experiences where what I thought often didn't happen.

Bill 23:03

And it was challenging for my wife because she doesn't get it like before they it was were either on or off. But you guys have this beautiful thing where you understand each other. And you can both really appreciate doing nothing for a day. Yeah. So what's it like? What's it like when you both have fatigued, and stuff needs to be done? I know that sometimes I'll ask him, I'd say look, I'm completely spent. Can you do x for me? And she'll jump in and help out but what do you guys do? Or what's that like? Sounds really strange, but I'm finding this extremely fascinating. I don't even know what questions to ask.

Kara 23:47

I don't know that we've ever had an issue because we both you know, understand if I know he's not feeling well, I'll jump in and do something and he's not doing well or Yeah.

Chris R. 23:57

Usually one of us is okay, not to get stuff done.

Kara 24:01

I don't know if we've ever both been down for the count together. Okay. Which I'm that won't happen.

Chris R. 24:09

(inaudible) thanks you for that you know, then knock on some wood, or something..

Chris R. 24:14

Now it's gonna happen.

Bill 24:17

It's not gonna happen, but i made assumption that maybe it already has. And it might just be a timing thing. It's nothing like Forget it. Pretend I never said it.

Kara 24:30

Never heard it.

Bill 24:32

So what do you guys do? What do you guys do day to day? both working?

Kara 24:39

Oh, good question. Good question. So that was, I think that was probably one of my biggest struggles is trying to get back to work, I was a, I was a nurse beforehand, and I was working full time, things are going great. And then this all of a sudden hit. And that was the biggest struggle. Because once I figured I was gonna, you know, I was able to walk, I was able to do things I'm going to get back right into into nursing and be able to go out of home without a problem. And what I found was just challenges mostly that multitasking and, and through a long, long haul many ups and downs, I, you know, I finally found that, you know, I'm still able to work as a nurse, but I've been having to adapt, and you know, what works, what doesn't work, you know, the hours I work the time of day, I can work just having to figure all that out. So I'm able to work now, what I do is I go to patients homes, and I do some education. So patients who have chronic conditions, I'm able to sit down with them and teach them all about it. Hopefully get them a little bit more comfortable with, you know, the direction they're going their health care

plan, all that kind of stuff. So it's a good good mix for me. Yeah, I finally found

Bill 25:56

that sounds amazing. It sounds like it's really supportive of your health and well being because of course shift work wouldn't work for you with it.

Kara 26:03

No, I found out that's not good. It doesn't work well for me. Doesn't work well for me. I get overwhelmed, overloaded. And then I had another incident where I had another stroke, actually. So I learned that the hard way.

Bill 26:17

You had another stroke?

Kara 26:19

I did. I was actually at work, ironically. And that's a good story, too. Yeah, I was at work. And I

Bill 26:26

Tell me that story.

Kara 26:28

Yeah so I was at work. And I was actually talking to a patient and then all of a sudden, Bleh, this word vomit, and I couldn't, talk couldn't do anything. And I had to have another nurse come in and kind of take over. And then you know, a few seconds later, I'm, I'm really feeling dizzy again. And boom, I passed out on the floor. So they had to call 911. Again, for us get our ambulance over and took me to the hospital, same hospital where I had the first one. And I which, ironically, is now our local stroke center. So so I get to the emergency room, and they know my symptoms, and they do a CAT scan. And the doctor comes back and says, oh, everything looks okay. Thankfully, Chris was there. And he looked at the doctor. He's like, so everything looks okay, including the previous stroke. And the doctor looked at him like what stroke.

Chris R. 27:28

"She's too young" those were his words

Kara 27:31

Yeah, So once once again, he had to, you know, he got the two young. And so of

course, the doctor had to go back and look at the scan. He's like, Oh, yeah, well, I saw that. I saw that from both.

Chris R. 27:42

"I meant it was fine from the previous stroke" is I'm like, Don't try to lie. I know what you said. You didn't look at her scan because she looks pretty and she's 32 years old, or whatever. I'm like, No, it doesn't work that way. Yeah. Yeah. all bad.

Bill 27:57

Wow. What was the after effects of that second episode.

Kara 28:02

So that one really affected my speech. So I had to was back in back in speech therapy back with my good friends. So so back out, back, not working again for a few months, and then had to change again, what I was doing for work, and.

Bill 28:23

You guys. Amazing. So Chris, what do you do for work? How did you navigate being 21? And then I imagine you hadn't really sorted yourself out at 21 yet?

Chris R. 28:34

Yeah, I was already set. Yeah, I already had a

Chris R. 28:39

family business actually. Started working working I was about 12, 13 years old. Yeah, pretty much. And so I was doing that I was making a lot of money, actually, before I got sick, because we had sold our store and I was running the business and for the people that bought it. And I was doing really good for myself. And then I went away.

Bill 29:00

Right. Okay. So then how long did it take you to get back on your feet and then overcome what you experiencing and then move back into something that resembled being independent and work again?

Chris R. 29:13

About a year? Give or take over a year? Back to be you know?

Bill 29:21

And did you move into a different area of work?

Chris R. 29:23

No, I thought I'd make old competitors business that I grew up hating because these are Yeah. But yeah. And turn that around. Got that, Yeah.

Bill 29:34

Nice man These, guys.

Chris R. 29:37

And then sold that off. And that's been gone and had random jobs here and there. And yeah, it's, We're having fun, it's working, we're doing good.

Bill 29:48

Awesome. So you guys, were able to really

Bill 29:52

get through this. still able to achieve a fair amount of things that you needed to do able to buy a business, sell a business, you able to just continue on the process. After your big cut. You've been unwell for a little bit. Seems like there was a period of time to heal, recover. You pay attention to your body, you pay attention to your needs, and then you kind of regroup and then you move on.

Kara 30:16

There you go, that's our story. And here we are.

Chris R. 30:22

13 years later.

Kara 30:24

But it's interesting. I just celebrated by my 15 year anniversary for my stroke. And it's people will ask me, oh, 15 years, aren't you completely recovered? isn't everything all better? And sort of tell people I spend a lot of time educating my friends or family members is that I think it's a it's a lifelong process when you've had any type of stroke or brain injury or anything. I think you're always learning, especially when you're when you're so young, and you have it. You're always adapting and relearning things and having to adjust.

Bill 30:58

Yeah but you look so good. You look so normal.

Bill 31:03

Now tell me a little bit about but you look so normal. That it, hold it up, hold it up, and a little bit further back. That's it. But Chris and Kara Russo, awesome. Tell me about how you guys come about to write a book.

Kara 31:24

I think people when we would meet people, we're always together. But that's...

Chris R. 31:28

That's our issue.

Kara 31:29

Yeah, we're always together. And people would always ask, How did you meet? What's your story? And then, you know, there, you know, then we go into our story, then people just kind of lock into us. And they, they're, a little bit people fascinated or really interested. So we start telling it and then we started hearing, oh, you should write a book, you should do something. And we're like, oh, okay. So we just decided to write down our write down our stories. And because yeah, we would get Oh, you went through so much. But you guys look so good. You must not have any other issues right now.

Oh but you look so normal



Chris R. 32:02

Oh, but you look so normal. You had a stroke, it's always, oh, but look so normal. It's just, that's one of the things you hate to hear constantly. So I thought to look normal, just acknowledge that.

Kara 32:14

I mean, it's hard because you want to look normal, and you want to hear that. But

then you also want to acknowledge there's a lot of other stuff going on, up in the brain and your body. That's, that's still healing.

Bill 32:26

Yeah, the invisible disability stuff. It's something that I've become fascinated in, I just completed a couple of weekends of doing a program, where we were learning about how to model the behaviors of people that we wanted to replicate. So in the corporate world, our model leadership and our model all these things, but I want to model stroke survivors. And the ones who can say that stroke was the worst thing that happened to them. But at some point, it moved to the best thing that happened to them, regardless of the deficits and the challenges that they live with every day, right? And I say that and I come. And the reason I say this, because I come from the point of it was a massive growth opportunity for me. So I know other people can't say that yet. And that's okay. I don't have an issue with that. So what we're trying to do is model the behaviors of how people go from that to being able to say, those types of words.

Bill 33:24

And I also want to model people that are considered to be the best type of the best therapists in the community, who are the best occupational therapists are the best speech therapist, etc. so that we can learn about that. And that's the challenge is the invisible disability conversation is a massive one. And I want to get people to that point where they look at somebody and normal, shouldn't be looking normal shouldn't be the trigger that says, everything Alright, with that person, we hear about the challenges that people face with mental illness. And everyone saying, Well, you know, you can't tell he looks great, but he acts like a bit of a crazy person, sometimes we want to get the message across that the that everyone is going through their own challenge in life somewhere somehow. And just because they acted out a certain way, doesn't mean that they are nasty, or they are rude or whatever, there's probably something else going on that triggered that response.

Bill 34:32

So I also met a gentleman in that course, he was talking about how they want to make transportation accessible here in Melbourne, our transportation systems, amazing. If you're in a wheelchair, you can roll into any one of our buses into our trains. And we have trains, and you can take those, you can go almost anywhere in the city, anywhere at all. Yeah, it's really cool. One of the things that they don't

do those, they don't talk about the invisible disabilities, like the challenges that people face with lighting after a neurological condition, some lighting causes massive problems for people. They also don't talk about noise and the impact that that has there and talk about how crowded buses and trains make people feel. So we're kind of starting this discussion about invisible disability. Does your book do that? Does it shine a light on the invisible side of this and stroke?

Kara 35:33

It does, we you know, we're actually working on a second one to really going to go into more depth we kind of touch on it a little bit. Just to make people aware that and I think to also educate caregivers, just friends, family and the healthcare professional community as well. I think a lot of times, healthcare professionals, you go in the hospital, you you're going to rehab and all they focus on is the physical, which is which is fine, you know, both needs to be addressed. And but you can see the physical and that's easy to look at and say okay, we've gone from here to here, we've made progress, you're good to go. But the you know, the the psychological, the noises, the overstimulation, all of that the all would have been so helpful. getting discharged from the hospital, knowing Okay, this might be hard for you or this might be difficult, you know, all the things that you don't think about.

Kara 36:29

It took us what it took me was 14 like 13, 14 years to get neuro psych testing done after the stroke. Yeah. no, I really had a tough recovery. I had a tough recovery. But I did with what I had. But I just that's kind of a one of our missions, as well as we would love to get the healthcare community to get that really addressed and looked at for people who just had fresh injuries and to get them going down that right path, get them to that neuro psych testing. I can't even tell you how helpful that would have been to have been, you know, just that one piece of information. Yeah, crowds are going to be hard places are going to be hard that would have saved years and years of frustrations. Yeah, I mean, I went from job to job to job and struggling through social situations. And that would have been so helpful to just been given that piece of information.

Bill 37:31

Yeah, if you're somebody who's had a brain injury, and you're listening to this, or watching this on YouTube, and you haven't had a neuro psychological evaluation or assessment, go and see a neuro psychologist, I waited, I was told by my

psychiatrist, to go and have a neuro psychological assessment. And when I booked one in, I didn't realize it was going to take nine months to see that person on the public system here in Australia. But I would have happily paid upfront, To see one in a week, but I didn't have the hour, I didn't have the brain capacity to comprehend that. So I waited and by the time I got there, there was very few deficits, the deficits had started to go away the first time you know, so that was strange. So 14 years to go and see a neuro psych. Chris, did you go and see somebody like that?

Chris R. 38:28

No.

Bill 38:31

It seems kind of really important step I think, doesn't it because it's good to know where you're going to struggle and it's good for your parents and your family, friends to know these are the areas they're going to struggle and this is how you can support them.

Kara 38:46

Good so even though you know what area you might have been affected by the stroke you may not have so mine was in the cerebellum I should have only had problems with balance and movement, dizziness, that type of thing. But when I was showing up with with problems with speech and memory and processing, you know, friends and my parents were like, what's what's going on? Why is this happening? This shouldn't be a part of that.

Bill 39:13

Yeah, couple extra things that you always get that are not typical of the area of the brain that's been injured. So did you guys have any any other physical challenges that you had to overcome was still dealing with I've got numbness on the left side, you guys have any of those strange types of things?

Kara 39:34

I do. I have weird numbness, tingling, weird sensations that will happen on one side of, my brain. I have a lot of weird eye movements, which is why.

Chris R. 39:46

Her eyes tend to go a little haywire here and there. She's going to warn you ahead of time of this video but she didn't. That they might if they go crazy. Just

don't worry about it.

Kara 39:57

That's just part of me. So eye movement problems and then headaches. You know, anything really when when I get fatigued is when things start to start to kick in.

Bill 40:08

Yeah. How do you deal with fatigue? Chris, are you do you go through that process now?

Chris R. 40:15

Yeah, I deal with it.

Kara 40:19

I think we have our moments where we realized where a day is going to be yeah we're going to sit and we're going to watch Netflix.

Chris R. 40:27

We had those days last week we didn't do anything. I mean,

Kara 40:31

We're very good with with our calendars planning things out if we know something big is coming up a lot like an airline trip, flight or something.

Chris R. 40:40

I make her rest the whole day beforehand.

Kara 40:42

Right. And we know not to, We know how to schedule we're very good about scheduling things and and then yeah.

Bill 40:48

Yeah, wow. Cool. Tell me about the book and how it's been received and the type of people that have bought it and are there any amazing stories that you've had people contact you about?

Kara 41:01

We have, we've had some people who have reached out to us both brain injury survivors and not brain injury survivors so people who may have been caregivers or friends have have brain injuries or even people who've had chronic conditions,

autoimmune conditions who liked talked about you know.

Chris R. 41:19

Her lupus and.

Kara 41:20

And so we talked about that a little bit and so we've had a really really good reception we've been really happy really it's amazing to hear some of the stories of what other people go through you know, there's similarities and there's so many differences as well that you know, you can bond with people yeah.

Bill 41:41

Did you say her lupus Chris?

Chris R. 41:44

Yes, she has lupus

Bill 41:45

Okay. There is a massive connection between stroke and lupus right?

Kara 41:51

Yes.

Bill 41:51

Can you shed some light on that?

Kara 41:55

Sorry. So my first stroke was with what they call a not a natural stroke it was caused all purely by by the doctors. My second stroke was probably related to lupus vasculitis and I was at a greater risk since I already had a stroke, so yeah.

Bill 42:17

So what does lupus do and what is lupus vasculitis? What does that cause

Kara 42:24

So with with lupus and vasculitis they're both autoimmune diseases. Vasculitis can affect any of it's just a generic it can affect any of your blood vessels. So it can attack anywhere. When I get vasculitis I tend to get bruising, I get rashing and I get you know, horrible late cramping that type of thing.

Bill 42:47

Is it a restriction of the blood vessels vasculitis? What happens?

Kara 42:51

Yes, so when you have an attack your immune system is just on overdrive, like other autoimmune diseases. And what happens is your blood vessels just they constrict into you're not getting that blood flow. So depending on where it where it can attack, some people may have issues with lungs or kidneys or you just never know.

Bill 43:12

Okay, and then lupus, what does that do?

Kara 43:15

So lupus is an autoimmune condition as well. And for me, my trigger is sun. A lot of people with lupus can't be out in the sun. You're almost allergic to the sun, so when I'm out in the sun, I get rashes, I get fatigue, I get joint pain, muscle pain, and sometimes that's a little bit hard to try to figure out if i have a new pain is it? Is it lupus? Is it vasculitis? Is it old stuff from my stroke acting up? So that's part of the fun as well. And challenge doctors like the packs pass the buck a lot too.

Chris R. 43:49

Neurologist "Oh go see your rheumatologist" rheumatologist "go see your neurologist" the circle continues because people don't want to deal with it. So they pass it off to somebody else.

Bill 44:00

You'd do really well living in England where there's hardly no sun.

Kara 44:04

We should move.

Bill 44:08

Wow, so you guys have got a full book of stuff that you've got to overcome and deal with. And you know what you sound like normal people. Most normal people have stuff to deal with, right and stuff to overcome. I just love your attitude. I just love the way that you guys go about overcoming all the challenges that you need to overcome smiling, laughing about it. doing crazy things.

Kara 44:36

Right. It's either you can be negative and be sad about what happened or which I mean, there are days Yeah, absolutely. Yeah, always days were like, Oh, no. But you have to, you have to make that conscious choice of say, I'm going to be positive, and I'm going to make the best of this, you're not going to change that you had a stroke or brain injury. So you just got to make the best and go with it.

Bill 44:59

Yeah, I love how you then have turned that into something positive and created a book out of that and sharing your story in hopes that other people will be able to relate feel like they can reach out or feel understood or, you know, learn something from that for carers and for people that are going through something similar. Is it important to have purpose?

Kara 45:23

Yes.

Bill 45:24

How important is having purpose. What would be different if you didn't write the book?

Kara 45:32

I think writing the book gave his goals and then made it and put it in there. And in concrete, this is what we want to do. And it made us realize, yeah, we had our you know, our stuff happened, it was bad it was shouldn't have happened. But you know, we gotta move on go forward. I think I'm from the the type of nursing that I do now going up to patients homes and spending that time educating people with chronic conditions. I really, I think we both talked about this, we we would love to be able to have some kind of stroke, chronic condition, you know, management, take it to the hospitals and have people where they are they get, you know, when they're finally discharged or, you know, fresh injury, fresh survivor.

Chris R. 46:16

Yeah, this might rings these problems like that, kind.

Kara 46:21

So I would we would love to do something like that get people make sure because, it's so overwhelming in the in the beginning, you don't know what to do, you're confused. So many things going on, and to be able to help people kind of put them

on the right path or get them going.

Kara 46:37

helpful. Help them know what kind of questions to ask their doctors and that type of thing. Yeah.

Bill 46:42

What what kind of things Chris, do you think that your parents would have loved to know, at that time?

They're not alone



Chris R. 46:50

That they're not alone, and that other parents are going through such things? And I don't know, because mine was scary as hell my like, that was. My dad started videotaping me my fourth day in ICU. And he was telling me Chris like, the nurses one night, he's like, I'm not gonna lie, I broke down crying. Like I was like, it was bad. The doctors were warning us that you might not make it out. They said never walk again. Like I'm thinking about how you would be not walking like, you probably know somebody in the street. Probably, you know, cuz I cannot stand that. It's bad. You know, it's not good. And so he's brought in his camera, and the next day, his video camera and started taping me and the first scene is my mom, asking me to blink my eyes. I was staying up in space for good a minute or so. Till he finally turn the camera. You know, it's caught me to do something else. But I'm not blinking my eyes. I'm just vegetable, it was terrible. And so they were you know, if they could talk to somebody back then or somebody else? Like, I don't

know, it's just tough. We know.

Bill 47:52

Yeah, I think that's one of the biggest things. It's unknown. When we came home. When I came home, I was doing things that we didn't know if it was normal, or normal as part of the process of healing, or if things were getting worse, and my wife would often look at me and go like, Is that meant to be happening? What do we do? And I was like, Well, most of the time it was let's not do anything yet. Let's just see what happens. And then if it went too long, and for us too long, was probably half an hour or an hour back then, you know, we didn't really sit things out and wait to see what would happen for days or anything. We just go to the doctor back to the hospital and say, This is what he's presenting with. These are the challenges, what do we do? and usually it was just some more tests and confirm everything. And if it subsided or went away, then it was okay.

Bill 48:44

But we didn't know how to navigate that either. And they never said to us, if you have any concerns, call or do any of that was just, it was also go home, and we'll see you in six weeks. I don't know that they meant literally in that don't come back for six weeks. But that's kind of how we took it. We took it as if we were done fixing you for now and then see you in six weeks. And it was like, we'll wait then. It's not really the key thing. And I remember after my first stroke the second time I had a bleed which was six weeks later, and just before my appointment, I ignored it again for another half a day before I did anything about it. Because I didn't have that confidence of ah, there probably is something wrong with me. Let me go back and tell them that something else is occurring. I was still in the zone of is probably nothing.

Bill 49:46

And when you had a bleed in the brain, You shouldn't be thinking like that, if possible. Now people around you need to know that the way that they should be thinking is if anything strange is happening. Do something about it immediately. Just go to the doctor go to the hospital, actually not the doctor. So it's been really interesting getting to know you guys and learning a little bit about your story. Fascinating. And you guys are definitely the dynamic duo.

Chris R. 50:12

Thank you. I like that name. It works.

Bill 50:16

I can see you're wearing some capes, and some masks.

Bill 50:20

Maybe a mask with half a brain exposed or something. Something like that.

Kara 50:25

We're going to get on it. Yeah, i like that.

Bill 50:29

You know, that would be fun.

Bill 50:33

Where can people find out more about you guys? And where can they get a copy of the book.

Kara 50:42

butyoulooksonormal.com or Instagram or Facebook, But You Look so Normal, Amazon for the book. Or you can certainly reach out to us and we might be able to get a team as well.

Bill 50:56

Excellent. We'll get a we get all the links posted on the show notes. So anyone that wants to come across and find it, they can go there and they can get in touch with you guys as well. Thank you so much for being on the podcast guys. Well done on overcoming all your challenges and continue to have a smile on your face.

Kara 51:17

It's all fake. (laughter)

Bill 51:22

Thanks again.

Intro 51:26

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