

# **But You Look So Normal - Chris & Kara Russo**

**It is a true story of living with brain injuries, beating the odds, and finding love after a stroke.**



Kara Ellsworth and Chris Russo

But You Look So Normal - 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.

Get the book here!

Follow Chris on Instagram. Follow Kara on Instagram

To discover how to support your Recovery After a Stroke, go to [RecoveryAfterStroke.com/](http://RecoveryAfterStroke.com/)

## Transcription:

1:50 Straight through  
5:36 Young and not at risk  
9:03 I didn't know who she was  
10:34 Double Whammy  
21:02 We both hate crowds  
24:39 Biggest struggles  
32:02 Oh, but you look so normal  
42:24 Lupus vasculitis  
46:50 They're not alone

Kara Russo 0:00

I think one of my biggest struggles was trying to get back to work. I was a nurse beforehand, and I was working full-time. Things were going great, Then this all of a sudden hit, and that was the biggest struggle because once I figured I was going to, 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 had 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 RRecovery after stroke.

Bill 0:59

This is Episode 66. And this is an exciting episode. Today, I have Chris and Kara Russo, survivors of different types of brain injuries who married after they met in rehabilitation. Chris and Kara, welcome to the podcast.

Chris Russo 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 Russo 1:39

Correct!

Bill 1:43

I get that a lot. So, I 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 Russo 1:50

Sure, sure. I was back up when I was 27 and had some health issues. I had lost most of my vision. I had headaches and difficulty walking, and the doctors couldn’t figure out what was happening. 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, they thread a catheter from your femoral artery in your thigh up to your brain. And once it’s up in your brain, they can shoot some dye in, and then your streets can all light up, and they can see what’s going on. During the procedure, the radiologist was having difficulty navigating through my arteries, and she went through the route straight through it, causing the stroke. So...

Bill 2:50

Oh, my Lord.

Kara Russo 2:53

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

Kara Russo 2:59

I remember joking with the doctor before I had signed all the consent forms, and we were joking about, oh, 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 exciting experience, but I had already experienced the bleeding 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 Russo 3:46

Yes, I was awake and feeling pretty good during it.

Bill 3:54

Even after they punctured the hole in the artery?

Kara Russo 3:55

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

Chris Russo 3:59

They used some excellent drugs, right?

Kara Russo 3:59

Yeah, I was on some pretty good medicine for that. So, there's an excellent bit of a blur in there. , I do remember waking up in the post-op room, and I remember I was nauseous, I was vomiting, I was dizzy, headache, a post-op member telling the nurse, Wow, I'm doing. She's like, "Oh okay, it's okay, it's normal. I'll just let the dice.

Kara Russo 3:59

And they returned a few minutes later, like, " Oh yeah, they said it's OK. We're going to release you. So, I got fired and was headed over to see a different specialist at another hospital. And I had passed out when I got to know that

specialist when I entered the room. And so they had to call 911 from there, so I went to that hospital's E.R.

Kara Russo 4:00

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

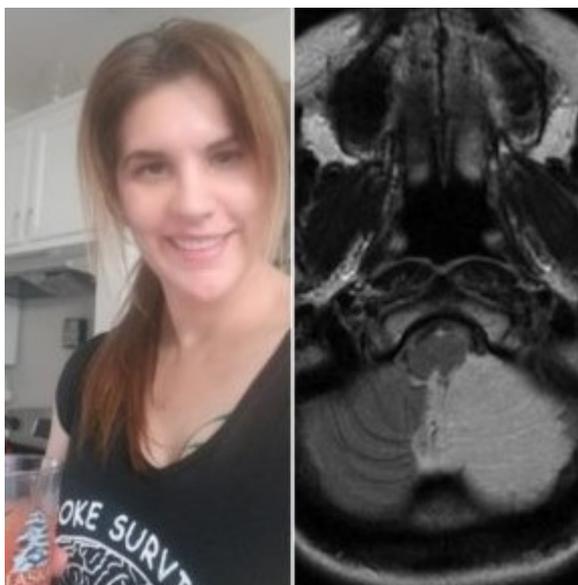
Kara Russo 5:25

And so that's when they finally did a CT scan. And then they realized it looked like it was a stroke.

Bill 5:28

Wow! 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 Russo 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 never put it together because I was 27 then, so they considered me young and not at risk for a stroke. So they just wholly 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 excellent and average, but nobody was able to go. This is a person who had a procedure in 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 recovering, you know what a scary and confusing time it can be. You're likely to have many questions going through your mind, like how long will it take to recover? Will I 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 miss out on doing the things that could help speed up your recovery.

If you're finding yourself in that situation, stop worrying and head to [recoveryafterstroke.com](http://recoveryafterstroke.com), where you can download a guide to help you. It's called "7 Questions to ask your doctor about your stroke." These are the seven questions I wish I had asked when recovering from my stroke. They'll not only help you better understand your condition, but they'll also help you take a more active role in your Recovery.

Bill Recoveryad to the website now, [recoveryafterstroke.com](http://recoveryafterstroke.com), and download the guide; it's free.

Kara Russo 7:35

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

Bill 7:45

Yeah, of course, you weren't

Kara Russo 7:45

I was relieved when it came back after they did the C.T.C.T... You had a stroke

because I thought, 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 Russo 8:00

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

Bill 8:05

It's funny how we need to know what we're struggling with so 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 see where you are. And that's what let's go forward from there, even if it's a terrible diagnosis.

Kara Russo 8:24

Absolutely. And I think anyone who's who struggled with trying to get a diagnosis 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. They weren't able to come up with a diagnosis. I was going to test and test and not come up with one, so for them to come back and say, "Oh yeah, we found something, " I was pretty happy about it until I realized you guys completely missed a stroke. 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 Russo 9:03

Oh, well, I got sick. I thought I had Mono, you know, sore throat, neck ache, backache, that kind of thing. He went to the doctor, who gave him amoxicillin, and he was in the weak course of getting word; I went back to the doctor again. Gave me more amoxicillin. The following week, I returned and did more blood work, another throat culture, and more amoxicillin. Apparently, on the fourth week, I returned and got another bottle of amoxicillin, which they don't remember.

The following day, after I got that, I was driving around myself by the week. So that was fine. You know, for 20 years old and delicate, good health. And, let's see, the following day, my n me. I was living at home, and she said I didn't know who she was, and then she asked me, you know what your name is and what year it is, she said I looked terrified. I had no idea who I was or who she was.

Chris Russo 10:04

And 12 hours later, in the hospital, they released me from E.E.R. blood work returned fine. And my dad threw a fit. And you know, yelled the whole who's in charge here. He asked a nurse how things were going with me because I was there for 12 hours, and no fluids were given to me. They've put a catheter in me and sent me on my way. In the corner room, my dad said, and he was freaking out and said my urine was turning brown. He's like, that's not a good sign.

Bill 10:32

Your what was turning brown?

Chris Russo 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 not very competent, you know? And so he's like, yeah, his blood work returned fine, and they will 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 name, and you said he's OK? And so the head doctor overheard my dad yelling and ran up and said, Where's your son? I don't see a case at all.

And so he said he's been ignored in that corner. And she went in there and immediately said, Get me in the ICU, do a lumbar puncture, do an MRI, this, this an,d this, s; shew some signs of meningitis, possibly. And they did a lumbar

puncture and came back with meningitis and encephalitis. So it's an excellent double whammy of illnesses that usually paralyzes you. They told my parents I was in a wheelchair, and I left, you know, I not a wrong kind of it was terrible.

Chris Russo 11:37

And so my parents arranged my bedroom to make anything accessible. And so my mom, I was in ICU for over a month. And so the social worker came in one day and told 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, having a shower chair and things like that. And the social worker said, Yeah, that's great, but he might not make it out of here.

Chris Russo 12:05

And my mom kind of, she said, I just said I felt turned red and very angry says that almost hope like and said, My son, will not die before me. And the social worker said, Okay, and slowly backed out of the room. They sent me to a rehab center where they should have sent her, but she got hidden on 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 Russo 12:36

It Shocked everybody there because they all thought I would never do it again. So

Bill 12:41

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

Chris Russo 12:46

Meningitis is an illness that attacks the outside lining of your brain. The meninges and encephalitis are actually what West Nile is; it's the West Nile virus. And so they didn't know what strand it was. So that goes inside your brain and eats away every particle getting in the way. And you know, it takes terrible new things, a lot of stuff with it. So, you know, there are no excellent medicines for either because I had the viral version of everything. So, yeah, 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

When you dealt with the encephalitis and the meningitis, what were you left with that you had to recover from?

Chris Russo 13:32

I had horrible short-term memory issues, like I met somebody and a second later forgot their name. And just you know, what else did it go through? I think the speech, Yeah, the address. 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 Russo 13:56

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

Bill 14:00

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

Chris Russo 14:07

No. They were worried about that. But now,

Bill 14:11

Man, that is excellent. Such a great come.

Chris Russo 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 Russo 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 amazing things. So, Kara, tell me what you had to deal with after they finally discovered your challenge. And did you have deficits that you had to recover from? What was going on there?

Kara 14:42

Sure. So, mine was, I think I touched on how they missed my stroke a little bit. And there was a little bit of a little bit of malpractice issues going on there. So what they did is, once they discovered the stroke, I think there was a little bit of a line-up, theyn't go into how big the stroke was, or what exactly happened, I; Ink 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 to; I had to learn to walk again. And I had some. I was still having my eyes with my vision. So I had lisomeech issues; my big thing was balance and dizziness because my stroke affected my cerebellum.

So, I had a lot of the ial problems as well. Meaning I didn't know where it was in a rothem. So, you know, I would get the input that I'd be sitting in the middle of the room or lying in bed, but then my brain would tell me I was up on the ceiling. So I had many strange things like that to try to work with and figure out why it was.

Kara Russo 16:03

So just,t a lot of P.T.P.T.a, each and occupational therapy. AP.T. Am I moving around? That was what, a few months of that, about six months or so, I learned to walk again, how to put everything together, trying to figure it out. I think that one of the big things is trying to figure out what my challenges were once I got over the physical problems with walking and having difficulty picking up things and grabbing things correctly. Sometimes I'll go to reach for something I'm not, you know, I don't pick it up correctly, I miss something.

Kara Russo 16:52

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

Kara Russo 17:01

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

Chris Russo 17:31

Be tired as hell at 1 pm

Kara Russo 17:34

Yeah. Yeah, the fatigue. And, yes, you are always sleeping; you'll tired for no reason. And yeah,

Bill 17:42

Yeah, well, you're tired for a reason. There is an issue: the brain is healing and trying to keep up with the body. That's trying to do all the everyday tasks but struggling to do all the evstandardunctions plus healing from injury.

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 of the different conditions, but what people don't realize is that neurological disorders often create the same symptoms for people who got there in an extra from a different path. But how did you two crazy kids meet?

Chris Russo 18:19

Why don't you do it

Kara Russo 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, always look at us, hook us up and down, and try to figure out what rehab it was.

Kara Russo 18:38

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

Kara Russo 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 brain injury survivors, and there were five or six of us? 4? Yeah, something like that. And that's how we met.

Kara Russo 19:02

And we've been.

Chris Russo 19:04

I walked into the room and saw her and knew right away I wanted to marry her, like, no joke, just right away. Yeah.

Chris Russo 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 Russo 19:21

Okay. I can. Yeah, I was done.

Kara Russo 19:25

Same thing for me as well.

Bill 19:27

How old were you, Kara?

Kara Russo 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 Russo 19:36

Yeah, I met her. She was 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 Russo 19:46

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

Bill 19:51

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

Chris Russo 20:01

Exactly, yeah, no joke!

Bill 20:03

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

Chris Russo 20:07

I did a 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 you guys experienced. And you know, what's good about you to meet and get it together and having a brain injury? Both have a finger; what's good about that is you understand what is going on for each other. And it's not foreign. And one thing I say is 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 ill. And there's no point in that. But you guys were already sick. So tell me about the similarities.

Kara Russo 20:56

So many, I think, so many, the fatigue.

Chris Russo 21:02

The crowd thing we do is we both hate crowds, loud, noisy ones. It's just a lot in my brain; do you understand that? I'm sure. It becomes too much when you know and look at each other. And we can look at her and tell right away how she's doing. So we'll be eyes on, like, let's go because she doesn't speak up. After all, She was fine. I'm like, you're not good. Let's go like that. So

Kara Russo 21:30

I think the helping, 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 have to 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 going to take advantage of this. And we're going to go out for a drive, or yeah.

Bill 21:57

Yeah, that's 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 the time that I decided that we were going to do something until the time we got there. And then it was like I was a bit of a bummer to be around then.

But 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, I'm feeling perfect. 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. I am being out and about and exercising by walking, being around people, and being in crowds. So, I had these extraordinary 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 with, er, on or off. But you guys have this beautiful thing where you understand each other.

And you can both appreciate doing nothing for a day. Yeah. So what's it like? What's it like when you are both suffering? Sometimes I'll ask him, I'd say, Look, I'm completely spent.

Can you do x for me? And she'll help, but what do you guys do? Or what's that like? It sounds strange, but I'm finding this extremely fascinating. I don't even know what questions to ask.

Kara Russo 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 Russo 23:57

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

Kara Russo 24:01

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

Chris Russo 24:09

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

Chris Russo 24:14

Now it's going to happen.

Bill 24:17

It won't happen, but I assumed 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 Russo 24:30

I have never heard of it.

Bill 24:32

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

Kara Russo 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, 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 going to, you know, I was able to walk, I was able to do things, I'm going to get back into nursing and go out of home without a problem.

And what I found was just challenges primarily that multitasking and, through a long, long haul, many ups and downs, I, you know, finally found that I'm still able to work as a nurse. Still, I've had to adapt, and you know, what doesn't work, the hours I work, the time of day I can work, have 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, for patients who have chronic conditions, I can 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 stuff. So it's an excellent good mix for me. Yeah, I finally found

Bill 25:56

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

Kara Russo 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 and overloaded. And then I had another incident where I had another stroke. So, I learned that the hard way.

Bill 26:17

You had another stroke?

Kara Russo 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 Russo 26:28

Yeah, so I was at work. And I was talking to a patient, and then suddenly, Bleh, this word vomit, and I couldn't speak or do anything. And I had to have another nurse come in and take over. And then, a few seconds later, I'm feeling dizzy again. And boom, I passed out on the floor. So they had to call 911.

Furthermore, we got our ambulance over and took me to the same hospital where I had the first one. And I, which, ironically, is now our local stroke center. So I get to the emergency room, and they know my symptoms and 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 OK, including the previous stroke. And the doctor looked at him like, what stroke?

Chris Russo 27:28

"She's too young" those were his words

Kara Russo 27:31

Yeah, so once again, he had to, you know, he got the two young. And so, 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 Russo 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, 32 years old. I'm like, No, it doesn't work that way. Yeah. Yeah. All bad.

Bill 27:57

Wow. What were the after-effects of that second episode?

Kara Russo 28:02

So, that one affected my speech. So, I had to return to speech therapy with my good friends. Soba,ck out since I was not working again for a few months, and then had to change what I was doing for work.

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 sorted yourself out at 21 yet?

Chris Russo 28:34

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

Chris Russo 28:39

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

Bill 29:00

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

Chris Russo 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 Russo 29:23

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

Bill 29:34

Nice man. These guys.

Chris Russo 29:37

And it then sold that off. And that's been gone, and I 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. You can still achieve a fair amount of things you need to do: buy

a business, sell a business, and continue the process after your big cut. You've been unwell for a little bit. It seems like there was a period to heal and recover. You pay attention to your body, you pay attention to your needs, and then you regroup, and then you move on.

Kara Russo 30:16

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

Chris Russo 30:22

13 years later.

Kara Russo 30:24

But it's interesting. I just celebrated the 15th anniversary of my stroke. And people will ask me, oh, 15 years, aren't you wholly recovered? Isn't everything all better? I tell people I spend a lot of time educating my friends or family members that I think it's a lifelong process when you've had any 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 constantly adapting and relearning things and having to adjust.

Bill 30:58

Yeah, but you look so good. You look so typical.

Bill 31:03

Tell me a little about it, but you look so typical. That is, hold it up, hold it up, and a little bit further back. That's it. But Chris and Kara Russo are excellent. Tell me about how you guys came about to write a book.

Kara Russo 31:24

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

Chris Russo 31:28

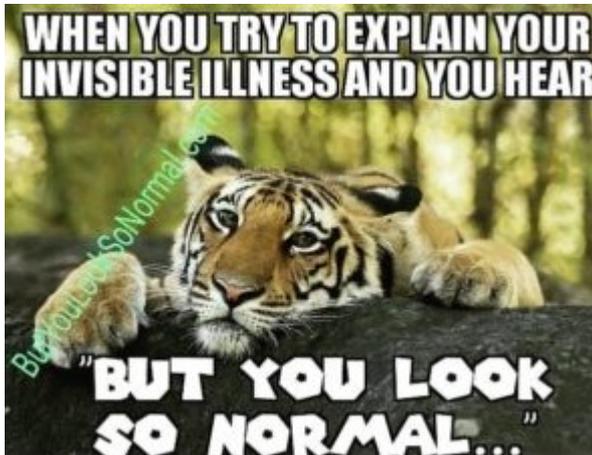
That's our issue.

Kara Russo 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 lock into us. And they're a little bit of people fascinated or interested. So we started telling it, then hearing, you should write a book and do

something. And we're like, oh, okay. So we just decided to write down our write down our stories. And because 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 typical.



Chris Russo 32:02

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

Kara Russo 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 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 with; 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 those 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. I say this because I come from the point that 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

I also want to model people considered to be the best type of therapists in the community, the best occupational therapists, the best speech therapists, etc., so that we can learn about that. And that's the challenge: the invisible disability conversation is massive. 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 people face with mental illness. And everyone saying, Well, you know, you can't tell he looks excellent, but he acts like a bit of a crazy person; sometimes we want to get the message across that everyone is going through their challenge in life somewhere somehow. And just because they acted out a certain way doesn't mean they are nasty, rude, or whatever; something else probably triggered that response.

Bill 34:32

I also met a gentleman in that course; he talked about how they want to make transportation accessible here in Melbourne, making our transportation systems unforgettable. If you're in a wheelchair, you can roll into any of our buses and trains. And we have parades; you can take those and go almost anywhere in the city. Yeah, it's fantastic. One of the things that they don't do is talk about invisible disabilities, like the challenges 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 it has there and talk about how crowded buses and trains make people feel. So, we're starting this discussion about invisible disability. Does your book do that? Does it shine a light on the hidden side of this and stroke?

Kara Russo 35:33

It does; we're working on a second one to go into more depth. We kind of touch on it a little bit. I also think of educating caregivers, friends, family, and the healthcare professional community to make people aware. I think a lot of times, healthcare professionals, you go in the hospital, you're going to rehab, and all they focus on is the physical, 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 you, know, the psychological, the noises, the overstimulation, all of that would have been so helpful. Getting discharged from the hospital, knowing okay, this might be hard

for you, or not easy, you know, all the things you don't think about.

Kara Russo 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 had a tough recovery. I had a tough recovery. But I did with what I had. But I just that's kind of one of our missions, as well as we would love to get the healthcare community to get that addressed and looked at for people who just had fresh injuries and get them going down that right path 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 will be challenging, and places will be demanding. That would have saved years and years of frustration. Yeah, I went from job to job to position and struggled through social situations. And it would have been so helpful just to be given that 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 neuropsychological evaluation or assessment, go and see a neuropsychologist, I waited, I was told by my psychiatrist, to go and have a neuropsychological evaluation. And when I booked one in, I didn't realize it would take nine months to see that person on the public system here in Australia. I would have happily paid upfront To see one in a week, but I didn't have the hour or brain capacity to comprehend that. So I waited, and by the time I got there, there were very few deficits; the deficits had started to go away the first time, which was strange. So, 14 years to go and see a neuro-psych. Chris, did you go and see somebody like that?

Chris Russo 38:28

No.

Bill 38:31

I think it seems kind of a crucial step. It's good to know where you're going to struggle, and it's suitable for your parents, r family, and friends to know these are the areas they're going to work in and this is how you can support them.

Kara Russo 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 speech and memory and processing issues, you know, friends and my parents were like, what's going on? Why is this happening? This shouldn't be a part of that.

Bill 39:13

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

Kara 39:34

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

Chris Russo 39:46

Her eyes tend to go a little haywire here and there. She will 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 Russo 39:57

That's just part of me—eye movement problems and headaches. You know, anything really 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 going through that process now?

Chris Russo 40:15

Yeah, I deal with it.

Kara Russo 40:19

I think we have moments where we realize where a day will be. Yeah, we're going to sit, and we're going to watch Netflix.

Chris Russo 40:27

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

Kara 40:31

We're very good with our calendars, planning things out if we know something

big is coming up, like an airline trip, flight, or something.

Chris Russo 40:40

I make her rest the whole day beforehand.

Kara Russo 40:42

Right. And we know not to; we know how to schedule. We're perfect about planning things, and then yeah.

Bill 40:48

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

Kara Russo 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 had brain injuries or even people who've had chronic conditions, autoimmune conditions who liked talked about, you know.

Chris Russo 41:19

Her lupus and.

Kara Russo 41:20

And so we talked about that a bit, and we've had a good reception. We've been delighted. It's fantastic to hear some of the stories of what other people go through. You know, there are similarities and so many differences that you can bond with people.

Bill 41:41

Did you say her lupus, Chris?

Chris Russo 41:44

Yes, she has lupus

Bill 41:45

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

Kara Russo 41:51

Yes.

Bill 41:51

Can you shed some light on that?

Kara Russo 41:55

Sorry. So, my first stroke was what they call a not natural stroke. It was caused purely 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.

Bill 42:17

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

Kara Russo 42:24

So, 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, rashes, and horrible late cramping.

Bill 42:47

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

Kara Russo 42:51

Yes, so when you have an attack, your system is in overdrive, like other autoimmune diseases. And your blood vessels constrict because you're not getting that blood flow. So, depending on where it can attack, some people may have lung or kidney issues, or you never know.

Bill 43:12

Okay, and then lupus, what does that do?

Kara Russo 43:15

So, lupus is an autoimmune condition as well. And for me, my trigger is the 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, tiredness, joint pain, muscle pain, and sometimes that's a little bit hard to figure out if I have a new pest. 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 to pass the buck a lot, too.

Chris Russo 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 well living in England, where there’s hardly any sun.

Kara Russo 44:04

We should move.

Bill 44:08

Wow, you guys have got a whole book of stuff you’ve got to overcome and deal with. And you know what? You sound like ordinary people. Most normal people have stuff to deal with, rights, and property to overcome. I love your attitude. I love how you guys overcome all the challenges you must overcome, smiling, laughing about it, and Doing crazy things.

Kara Russo 44:36

Right. It’s either you can be damaged and be sad about what happened or, which I mean, there are days. Yeah. 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 shared 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 necessary to have a purpose?

Kara Russo 45:23

Yes.

Bill 45:24

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

Kara Russo 45:32

Writing the book gave him goals, and then he made them and put them 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 terrible it shouldn't have happened. But you know, we have to move on and go forward. I think I'm from the type of nursing I do now, going to patients' homes and spending that time educating people with chronic conditions. I think we both talked about this. We would love to be able to have some stroke, chronic disease, 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 Russo 46:16

Yeah, this might ring these problems like that, kind of.

Kara Russo 46:21

So I would love to do something like that to get people to make sure because it's so overwhelming initially; you don't know what to do, and you're confused. So many things going on, and to be able to help people put them on the right path or get them going.

Kara Russo 46:37

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

Bill 46:42

What kind of things, Chris, do you think your parents would have loved to know then?

**They're not alone.**



Chris Russo 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 on my fourth day in ICU. And he was telling me Chris, like, the nurses one night, he's like, I'm not going to lie, I broke down crying. Like I was like, it was terrible.

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 not walk, you probably know somebody in the street. Probably, you know, because I cannot stand that.

It isn't good. You see, it's not good. He brought in his camera, and the next day, his video camera started taping me. The first scene was my mom asking me to blink my eyes. I was staying up in space for a good minute or so. Till he finally turns the camera. You know, it's caught me to do something else. But I'm not blinking my eyes. I'm just a 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 were expected or standard as part of the healing process, or if things were getting worse, my wife would often look at me and ask, 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 see what happens. And then if it went too long, and for us too long, it was probably half an hour or an hour back then, we didn't sit things out and wait to see what would happen for days. We 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? Usually, it was just some more tests and confirming 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 going 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 the critical thing. I remember after my first stroke, the second time I had a bleed, 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 perhaps nothing.

Bill 49:46

And when you have a bleed in the brain, You shouldn't think 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. Please do something about it immediately. Just go to the doctor, go to the hospital, not the doctor. So, getting to know you guys and learning about your story has been exciting. Fascinating. And you guys are the dynamic duo.

Chris Russo 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 Russo 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 Russo 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 all the links posted on the show notes. So anyone who wants to come across and find it can go there and contact you guys. 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 Russo 51:17

It's all fake. (laughter)

Bill 51:22

Thanks again.

Intro 51:26

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