

Teenage Stroke and Recovery - Eric Hinwood

These days Eric Hinwood is an actor, director, producer, editor, model, & filmmaker but not that long ago he was a teenage stroke survivor

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Eric 0:00

If someone wanted to, you know, make out with me at a party or, you know, something like that, I would just do it because that was what they wanted. And I was just kind of, you know, responding to stimuli not really making decisions for myself. So there was definitely this sense of like, I may not remember the last interaction I had with this person.

Eric 0:21

If I did, I may not realize how that fits into the overarching like broad picture of things. And even later on in future relationships, I did have someone who said, Hey, the symptoms that you go through are too difficult for me to handle. Like I don't think I can be with someone that is a stroke survivor.

Intro 0:49

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

Bill 0:56

Bill from recoveryafterstroke.com. This is episode 89 and my guest today is Eric Hinwood. Eric is an actor, director, producer, editor, model and all around nice guy. Eric experienced two strokes at the age of 19. And six years on is doing well and making great progress on the recovery.

Bill 1:18

Just before the interview gets started, did you know that you can now download all the words of any of the recovery after stroke podcast episodes as a PDF? It's perfect if you prefer to read and take notes, or highlight different parts of the interview for future reference.

Bill 1:34

It's a great way to learn and helps retain new information to memory. Just go to recoveryafterstroke.com. Click on the image of the episode you have just listened to. And at the very beginning of the page, you will see a button that says Download transcript. Click the button, enter your email address and the PDF will begin to download.

Bill 1:55

Also, a few weeks ago, I launched the recovery after stroke coaching people who have signed up and now being coached by me and are being helped to overcome challenges, including fatigue, and anxiety amongst other things. So if you are a stroke survivor that wants to know how to heal your brain, overcome fatigue and reduce anxiety, recovery after stroke coaching might be perfect for you.

Bill 2:18

If you have fallen in the cracks between hospital and home care, and desire to gain momentum in your recovery, but do not know where to start, this may be where I can help. I will coach you and help you gain clarity on where you are currently in your recovery journey I will help you create a picture of where you'd like to be in your recovery 12 months from now.

Bill 2:38

And I will coach you to overcome what's stopping you from getting to your goal.

Want to know more? Just send an email to Bill@recoveryafterstroke.com and I will arrange a time to speak with you in person about how recovery after stroke coaching can work for you. Now it's on with the show.

Bill 3:07

Eric henwood Welcome to the podcast.

Eric 3:11

Hi, great to be here.

Bill 3:12

Great to have you here Man, thank you so much for coming on the podcast. I really, really appreciate it when I come across people that talk about what they do and really sort of share with the world, all the amazing things that they're doing. And then at the bottom, they say, I'm also a stroke warrior that really touches me you know and I need to connect for me to find out more about that person. So tell me a little bit about what happened to you.

Subarachnoid hemorrhage and Intraparenchymal hemorrhage



Eric 3:44

So I had kind of an unusual stroke experience. I was 19 when I had to stroke. So I won't get into too much of the details of it but basically, there was an accident I fell off a cliff. I ended up fracturing my skull ended up with a subarachnoid hemorrhage and an intraparenchymal, hemorrhage I believe are the two types of

strokes that I had.

Eric 4:10

And it kind of wreak some havoc on my body. You know, I used to be half an inch taller before the fall. I lost half the hearing in my left ear. I see what else I lost 40 pounds. I was about 167 going into the hospital and about 127 leaving, I lost about half the blood in my body I had organ failure It was you know, quite an quite an experience.

Bill 4:46

Wow. I feel like this is a miracle that you're here even right?

Eric 4:51

Yeah, I'm not really sure how I'm here. Doctors weren't either. There is a moment when they said you know if he makes through the night well be very surprised. And you know here i am i guess almost six and a half years later.

Bill 5:11

Yeah man good to have you here. What did your parents go through with all of this was there loved ones in your family that needed to deal with this and kind of what was that all about now that you have had time to reflect at the time I'm sure you would have been out of it but but what was it like for them?

Eric 5:33

Yeah, I kind of had to piece together what happened from you know, different people trying to get the big picture I ended up writing it down. So I had you know, like this is what happened in the part of my life but I don't remember. But uh, basically my parents stayed at the hospital with the, for the time that I was there was a six days total and my dad immediately had to go back work because I end up trying to pay for everything. Insurance didn't cover.

Eric 6:06

Well, it covered a lot but not nearly enough. And the kind of unfortunate thing that is kind of unique in my experience is unfortunately, my mother was a drug addict. And so I was in a unique situation of after returning home. She was using some of my medication as well as giving it to me at times.

Eric 6:36

And when I went into the neurologist a couple weeks later on, they said that, you

know, if I was a minor, this would have been felony level malpractice, you know, neglect and I almost died because I ended up detoxing in like a three weeks, I guess, would have been about three weeks after the initial strokes. So a lot of my first experience back was how do I get out of this house? How do I get back to school? Which was I was in college at the time sophomore.

Don't judge other people



Bill 7:11

So people, who are listening who have not apparently had anything happened to them in their lives and they've never had a problem, don't judge people at all. We never ever know what people go through do we and stroke survivors, are no different to any other human on the planet.

Bill 7:26

They're still going through regular stuff, daily issues with family, friends, whoever in life, and it doesn't stop just because you had a stroke. People don't just feel sorry for you and forget to be you know, nasty to you or talk aggressively to you or take things from you it just doesn't stop when you have a stroke and you've got to deal with all of the regular stuff and stroke, right?

Eric 7:51

Yeah, I actually I what I've noticed is that because I was so young and because my physical recovery was as good as it is a lot of people seem to discount what I've gone through like, Oh, it's Yeah, I've had two strokes but oh, you seem fine now like you're, you seem coherent you seem able to do things.

Eric 8:11

Whereas they don't realize that, you know, just under the surface, you know, I'm dealing with things like late onset PTSD because of the accident, different things like that, that continue to affect me every day, energy levels, motivation, things like that. Stuff that because it's, you know, considered more mental health and physical health. People really just try to, to ignore it or just push past it is what I what I've noticed.

Bill 8:39

Yeah. And you're shorter as well.

Eric 8:44

Yeah, that happens. You know, I didn't think I'd noticed that but I used to be taller than my dad and he's taller than me.

Bill 8:52

Im glad we can laugh about that, but it's true. People don't see they see the visual. They see everything looks good on the outside. They expect that the inside is just as good. And you know, we're going through my sister in law's dad just had a stroke maybe six weeks ago. And the family has been through it with me. And yet they still ask the same questions that they asked back then or make the same statements that they asked back then.

Bill 9:21

And I found myself yesterday at dinner being a little bit short with my wife and saying stuff like, No, no, no, no, no, no, no, stop. Don't say that. That's not what he needs. He doesn't need more of that. He needs less of that. And it still takes people by surprise that they are completely oblivious to the stroke survivor and how they're experiencing the world now that they're dealing with this brain that's healing.

Bill 9:52

And, you know, this person is trying to get back on his feet he's trying to get use of his right arm again. And his lacking the motivation, and it appears that he's lacking the motivation, but I'm certain that it's got way more to do with, you know, energy levels, and the cognitive processing of getting up and using his leg again, and learning how to use his arm again. But he doesn't have the words to communicate that back to his family and loved ones. So they just assume that it's

lack of motivation or his being lazy or being grumpy or being set in his ways.

Eric 10:34

Yeah, I definitely think that a lot of people, they'll see the average stroke survivor and look at them as the average human unless they know better, they won't see or they won't be aware or they won't even try to become aware of the differences. Like in also that certain differences can be unique to certain individuals.

Eric 10:59

Like for me, because mine was, you know, group together with the whole accident happening. I have digestive tract issues, getting calories into my body is a difficult experience. I don't feel hunger or the need to go to the bathroom the way that most people do. So things like that. It's just like, Oh, well, you know, even if you're familiar with people that have had strokes, you would never know that without asking about. So. I think that is one of the other issues is that strokes will affect people in different ways, though, depending on where it is in the brain, depending on what else happened around it. All that.

Unable to feel hunger anymore



Bill 11:39

Yeah, I've had conversations with stroke survivors, this is probably going to be Episode 88 or 89 or something like that, have no concept of intimacy, zero, it just doesn't exist anymore. There's no they're not missing it because they don't have it. I've met stroke survivors personally who lost half their body weight because they don't feel hunger anymore at all.

Eric 12:07

And that's I actually I don't feel hunger either. That's not something I experience.

Bill 12:11

Yeah, there you go, right. And this person told me that they ate when other people they just said that they can eat.

Eric 12:21

The habit. The the time of this is when people eat well, I guess that's when I should be with these people eating because it seems like it's normal. It seems like yeah, that's just when it happens. Yeah, but great creating a situation where you're eating alone for yourself without it seeming like oh, this is when this shouldn't happen. Yeah, it can be difficult.

Bill 12:43

Well, you could be a ketosis warrior as well. Like, you could tell people you could run courses and sell stuff you know about like, I just don't eat man because I don't need to.

Eric 12:57

The funny thing though, that I do like is a my dad. He's a non insulin dependent diabetic. So the the one cool thing is I'm very aware of diets and you know, what people should and shouldn't be putting into their body. Also, you know, stroke diets, that sort of thing. So I am Luckily, aware of like, this is what I should be putting in if I can actually do it. So I'm glad to have learned more about things that I was just previously. Never thought I'd need to know this. But now, you know, becomes more important.

Bill 13:38

So do you feel hunger? You don't feel hunger I beg your pardon. But do you feel fullness when you begin to eat do you kind of feel like I've had enough.

Eric 13:47

Um, so my brain it seems like it replaced four specific thing. It replaced the feeling of hunger with I guess maybe the best way I can describe It is like a hollow pain, kind of feeling. like something's missing on the inside and that hurts and you're not sure what it is. And I've kind of been trying to train myself like, Hey, this is hunger.

Eric 14:13

That's what hunger feels like. That means you need to go eat food, because it doesn't seem to have that automatic if hungry then eat. I guess the equation that I

had before. fullness is more just like kind of imagine a balloon that's too full. Like I almost have that sort of feeling on the inside but it's also a pain sensation and nausea. That's the other way that I know that I'm either full or need to go poop or things like that.

Eric 14:54

It seemed like certain feelings that I wouldn't have had anymore. Seems like my brain found new routes new way is to tell me what's going on because otherwise I probably would have needed adult diapers. And I'm very glad that I didn't have that situation because that would be another whole complexity.

The gut has neurons

Bill 15:15

Let me give you a bit of an insight into the gut. So the gut has neurons in it as well just like the head, right? You aware of that?

Eric 15:23

No I wasn't.

Bill 15:25

Okay. So the gut has the same amount of neurons that a cat's brain has. So it's quite an intelligent organ. And it does things for us. Like it gives us you know, that gut feeling that something's not right. Have you ever said I haven't got the guts to do that. So we have these expressions where we refer to our gut a lot like I took gutsy action.

Bill 16:01

So, when you're referring to that part of your body in conversation about how you're taking action and doing things, what you're doing is you're accessing the intelligence of your gut and you're giving information to your brain about why you may or may not be taking certain action or doing certain things or able to absorb certain bits of information, etc.

Bill 16:28

And the fact that the gut has neurons. We can retrain the gut just like we can retrain the brain through neuroplasticity, it also has neuroplasticity. And there's this amazing book called mBraining using your multiple brains to do cool stuff. That if you looked into and read, talk specifically about the intelligence of the gut

brain, and then it also talks about the heart brain, which has the same similar types of neurons, and it talks about the head brain.

Bill 17:03

And it talks about how we use them together instead of separately, and how they all interact with each other to help us make decisions, do things, you know, just be ourselves. So, there's a possibility what I'm saying, and I'm not a scientist or a doctor, and nobody should take anything I say seriously. But there is a possibility that with time, you'll be able to retrain your belly and your gut, to be able to understand those things that it's not understanding at the moment about hunger, about fullness about time to poop.

Eric 17:41

Sounds like I've got some reading to do because I hadn't. I haven't heard of that book or about that before.

Bill 17:46

Yeah. have a look at that book. And then for people listening who also might be interested in this topic, listen, check out for the book called The second brain and I'll make a list of these books in the show notes so that people can go to them easily and I'll send you Eric an email at the end and give you some food for thought there mate.

Eric 18:12

Sounds great.

Bill 18:13

But at 19 life is starting to pick, you know, you're starting to discover things about yourself. You're getting independent. you're out and about, and you end up having this dramatic incident. What is it like for you to experience all the things that you experienced? And what are you thinking about? In the short term about all the challenges that you're, you know, from the challenges that you're overcoming and facing? What's it like for you at 19 to go through such a traumatic experience?

Eric 18:54

Well, I think my experience of it was almost like an autopilot. It felt like I was going through the motions, you know, following whatever was seemed like was supposed to be happening, you know, I would just follow a conversation wherever

it was headed follow a group of people I was with wherever they were going. It was very much reactionary lifestyle compared to how I had been before.

Eric 19:17

I wasn't coming up with new ideas on my own. I wasn't thinking, well do I think this would be a good idea. It was, well, let me bounce this off of anyone in the room and take a general group consensus of is this a good idea? You know, that kind of thing. And it took a few years for me to get mental clarity back, I'd say until maybe around like late 2016, maybe three years.

Eric 19:42

And during that time, there's all sorts of moments where I'm like, wow, I wish I had been clear there. But I wish I had understood what this person was feeling at that time. Because you know, I was still in classes. Trying to keep relationships going trying to get places in a career. Unfortunately, a creative career because I work in filmmaking.

Eric 20:06

So, you know, made it all the more difficult. But, um, yeah, I guess that was kind of what my experience was like. I also had a time constraint, because before I had had the accident, I had planned to study abroad. And that flight was supposed to leave in June of that year, and so I had been given a new have kind of a 25% chance of making it through the next six months.

Eric 20:39

If you make it through that window, your chances of making it to like 25 30 that increases but they told me like before leaving the hospital, like, you know, if you make it through retirement age, that will be insane like if you, you know, make it to one of the big ones was 25, and I've passed that now, that's, you know, very happy about that. But, but I left before the six months were up to go overseas because I kind of had this decision.

Eric 21:12

Well, if, you know, they're telling me if I see a sunrise, I may not see that sunset. I'm gonna go overseas and have a good time. So that was a kind of like a goal of mine that, you know, I just make it through this time. And then I go over there, and then maybe I get to come back, we'll see.

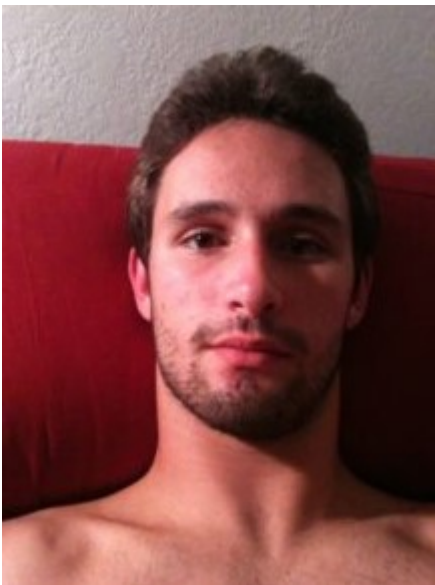
Bill 21:32

That's, I think that's a great thing that you did that in that. That's a great thing to aim for. So you're setting yourself up for achieving an outcome and getting there and making it. And I think that helps you by default, do the right things about your recovery so that you can get to that point where you're good enough to go.

Bill 21:54

And then if you're good enough to go and you're having an amazing time, that's really going to make a difference on your mindset. It's really going to make a difference on how your body feels and you know, all the amazing neuro chemicals that are in your body and how they're going to help heal the brain because it's starting to feel like you know, perhaps is light at the end of the tunnel. That's a positive outlook. That seems like it was a solid move to make the decision to go anyway.

Identity shift caused be stroke



Eric 22:22

Yeah, I guess it did get to give me that motivation of, you know, you'll end up in Europe, if you can make it through this. You can, can get to have this experience that you wanted before. Although the one kind of interesting thing I was going through at the time was kind of a sense of the person that this accident happened to wanted this before the accident.

Eric 22:46

I should do that because that's what they would have wanted almost seeing myself as a as a unique individual. Which was kind of odd, but it made sense

because, you know, I woke up in a body where the legs were different links I was a different height I was different weight, it really did kind of almost feel like a reincarnating into a body with the same face. You know, it was very odd.

Bill 23:13

So massive identity shift, do you move from this clear different person, say at 19 prior to this accident to this new version different person afterwards and you decided to do the right thing by the other guy and help that guy fulfill his dreams?

Eric 23:37

Kind of Yeah, that was kind of the first maybe two and a half years was very much reactionary. And how would I have done this before? Let me try to recreate you know who this person was until the mental clarity started to come back. Like I said around like 2016 2017 I started to think, well, what would I want? Now, you know, now that I do have the ability to process this mentally to think about this and come to my own conclusions and to trust my conclusions a little bit more than I did, you know, within the first year of the accident, it allowed me to kind of expand and begin to grow in a way that I don't think I had been before.

Bill 24:25

Yeah. So the trip then would have taken that growth and that expansion to the next level. You're overseas now you have, you know, some time beyond your injury and your recovery is on the way, and now you're in this completely new place that you've never experienced before. What was it like having that new experience while you were there?

Eric 24:51

Well, it was pretty incredible. Because one of the things that had really been an everyday situation while I In the US, was working out. Before I left the hospital, they had given me a very, very intense workout regimen. And they had me two hours a day, six days a week in the gym, and three days a week, running 15 minutes each day, but every week, I had to add 15 minutes to the total time.

Eric 25:27

So the second week would be 30 minutes, three days a week and then 45 minutes, three days a week until I reached four and a half hours. So I was basically running like a half marathon three days a week at that point because they had said that marathon runners have the highest chance of surviving my type of stroke type of

injury.

Eric 25:49

So they had put me on a real difficult workout routine for the first six months but going overseas, you know that time was over the workout routine. was over, I was able to kind of, and then have more of a exploratory lifestyle than I had before. And it was very routine before that

Bill 26:12

Was running hot up, because you mentioned that you had a difference in the length of the legs.

Eric 26:18

Right? So I was in a walker for about the first month, transition to a cane and then eventually walking on my own after that. And I do think running was one of the one of the most helpful things and allowing me to walk without a limp and to walk more normally.

Eric 26:37

Because even if there had been muscles that were greatly weakened or atrophied by the weight loss, different things, I was able to help regrow and to and to feel more normal, even if, you know, like my hips are, you know, one's higher than the other things like that. I was able to, I guess to figure out how does this body run over time.

Bill 27:02

Yeah, right, cool I'm listening to all this stuff. And I'm just to me, it seems to me like you were in really good hands medically. And a lot of how far you've come. It's got a lot to do with you. It's got a lot to do with your need to solve problems, and overcome things and find new ways, which is, I think, is really amazing. If a stroke survivor can have a problem solving attitude, they're going to be able to overcome more things than by waiting around for other people to solve their problems for them. Do you relate to that? Would you call yourself a curious problem solver?

Eric 27:48

Definitely, yeah. I spent a lot of time just googling and researching and finding out more about the situation. That's, you know, how I learned about the the marathon runners thing. That's how I found out about, you know, avoiding things

like alcohol, tobacco, high amounts of caffeine, you know, things that I didn't realize could be things that could cause a stroke or that could you know, because at 19, I wasn't prepared.

Eric 28:18

I wasn't looking out for like, Oh, I gotta prevent a stroke. But I will say because after I left the hospital, I had a couple of appointments. But I only saw a neurologist one time. I had the accident, December 27 2013. I saw one other neurologist in January, and that was the last neurologist I saw before leaving to go overseas.

Intro 28:47

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

Intro 29:12

If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com, where you can download a guide that will help you. It's called seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke. They'll not only help you better understand your condition. They'll help you take a more active role in your recovery. Head to the website now, recoveryafterstroke.com and download the guide it's free.

Eric 30:00

So that whole six month period, I was doing the physical therapy workouts. I'm doing that on my own. You know, unassisted, I was they had told me that they had wanted to do MRIs every two weeks to see whether my brain was filling with blood or whether it was decreasing, but we couldn't afford that. So it really was after a certain point, just figure it out.

Eric 30:25

And just, can you Google it? Can you find the answers? Is there someone you can

call that might be able to give you the answers? No, then good luck. So it definitely was that type of lifestyle.

Bill 30:39

I'm, I live in a bit of a bubble. In Australia, we have an amazing healthcare system. If you don't have insurance, the public system provides everything. And by here, things like we couldn't afford an MRI. And that just, that just throws me off.

Bill 30:58

I don't know how to respond to that. It's so bizarre to hear that from, you know, the part of the world that we live in, there's no such thing as you can afford an MRI. It just somebody just orders an MRI and it's done and the public system pays for that. What other things couldn't you afford that you had to go without that were potentially critical to your recovery?

Couldn't afford physical therapy and other stroke aid

Eric 31:22

Well, since leaving the hospital, I've never been to a physical therapy appointment and occupational therapy appointment. And it was six years before a neurologist looked at my previous records and talk to me, you know, today. So it was a lot of things. I mean, I couldn't afford a hearing aid.

Eric 31:58

I think I didn't get my first hearing aid until believe it was late 2018, early 2019. So you know, like five years after the accident. So as it was, it was around \$300,000. For the time I spent in the hospital on the associated fees. I did have medical insurance at the time, and that's still left me with \$67,000 that I was unable to pay.

Eric 32:30

I ended up applying for a need base, I guess, medical aid program and was able to I got accepted for that due to I believe it's just future income. So I was able to get some of that taken care of, but yeah, if I hadn't had insurance if I hadn't been able to receive that help from the program that I applied to. It really would have ruined my life financially, as well as medical, it was quite difficult.

Bill 33:05

They help somebody survive a stroke, and then they give them a \$300,000 bill. What's the point in helping him survive? Just let him go forget about it.

Eric 33:18

You know, I had that thought myself, but

Bill 33:22

I know I would too. I mean, that's so cruel to do that to people. And I know that you guys in the states don't have another solution for that. And there's often many people that are going through that I know I speak to a lot of people that go through that it's just seems so such a stupid system to heal people. And then we'll try and heal people and then hit him with a \$300,000 bill. You're undoing all the good work that you just did in healing them.

Eric 33:51

Right. Yeah. Because if it had been like if I had been in a country that had, you know, coverage like you did or like a lot of the Western European countries or, you know, Scandinavian countries since I know I would have had continued care for the next you know, maybe three months afterwards to get me to a more stable place and position but now that this wasn't you know in the US as things are currently not the political hopefully change you know, that won't be the case forever. But currently Yeah, that's that's how things are unfortunately,

Bill 34:27

I had a choice I still have a choice whether I take out insurance or whether I just go via the public system. I choose the public system. I pay taxes that cover that and you know, our taxes are quite high and I'm, you know, we pay it goods and services, tax and all sorts of taxes and I whinge about the taxes but when I needed to be a health and I needed brain surgery, when I went to hospital, no one ever said to me, where are your insurance papers? Do you have a credit card? Nobody ever said anything.

Bill 35:03

They just said, this is the problem. We need surgery, it's booked in two weeks time. And that's it. You never heard from anybody about money ever again. And then physical therapy lasted for a month. And then physical therapy at home, lasted for six months, couple of days a week. And then physical therapy out of

home where I was going to physical therapy that was costing me like \$3 a session or \$4 a session.

Bill 35:35

You know what I mean? So I live in a really privileged part of the world and I and I live in this bubble of you know, stroke, something that we can, go to hospital for and get fixed for etc. But it's not the case for everybody. And I suppose why I'm going on about this a little bit is because I just want to bring attention to it, and I think it's wrong.

Bill 35:57

And I'm not sure what the solution is it's definitely beyond my influence, you know, being able to change the way that things happen in a country like the United States, but definitely needs to be more spoken about it because I'm talking about stroke. But this is happening to people that are recovering from all sorts of issues all over the place, and everyone who has to recover from something has to stop working. So their ability to actually come up with money decreases because of the fact that they're unwell.

Eric 36:31

Yeah, that was also an issue for me is that, uh, so I had been, you know, paying for school myself and just working to pay for it. And that was definitely made quite a bit more difficult by the fact that I also had to, you know, figure out what was going on with me medically and handle all that on top of work in school.

Bill 36:52

The man I get inspired more and more when I listen to stroke survivors who, you know, tell a story Like you do, and many of them that I've interviewed tell a similar story that they've overcome so much, they found ways to resolve their problems. They're being creative in coming up with solutions. And I think that more stroke survivors need to hear from people like you so that they know that there is a way and they can reach out to other people about how to find the way to overcome some of these problems.

Bill 37:29

The other thing that people struggle with is relationships. Tell me about how does a 19 year old deal with relationships of intimate kind but also friends, you know, how did that all change for you? And how is it now different to what it was like

then?

Mental and emotional challenges

Eric 37:48

So it was very difficult. I'll just say that right off the bat. My experience was here's the unfortunate bit I don't remember this. But during the time, after I had left the hospital before returning to school, there's about a month time period that an ex girlfriend had come to see me. And we had gotten back together. I I guess i'm one of those, like all those, you almost lost this person, this person means more to me than I thought they did kind of idea.

Eric 38:25

I assume. Unfortunately, I was unaware of that, that I was with this person and living as much of a reactionary lifestyle as I did, um, you know, if someone wanted to, you know, make out with me at a party or, you know, something like that, I would just do it, because that was what they wanted. And I was just kind of, you know, responding to stimuli not really making decisions for myself.

Eric 38:53

So there was definitely this sense of like, I may not remember the last interaction I had with this person. If I did I may not realize how that fits into the overarching, like broad picture of things. And even later on in future relationships, I did have someone who said, Hey, the symptoms that you go through are too difficult for me to handle. Like, I don't think I can be with someone that is a stroke survivor.

Eric 39:25

And that was real hard. You know, I didn't date for about maybe two years after that of like, All right, I'm just going to focus on me and try to get these symptoms down. And maybe it's something that maybe it was just that individual, but maybe it wasn't, you know, so. Definitely, definitely changed things quite a bit.

Bill 39:46

So you're now questioning, you know, like, What's wrong with me? Like, why why wouldn't you date me? That's an interesting thing, because I've also met and spoken to stroke survivors whose partners left them after stroke some of them because they will already about to leave or things were just rocky and, and it was no reason to continue a relationship that was no good.

Bill 40:11

Others were because they just couldn't handle it. And they didn't understand what that meant for them because people in the caring capacity often also struggle a lot. So you can understand it. And I think when it's a reserve judgment, but there's no doubt about it. It's traumatizing to the other person as well.

Bill 40:36

And at 19 a 19 year old partner, you can kind of understand it really kinda is this like, just met each other. This is probably not the deepest love ever. And maybe, I need to just move on with my life and let that person move on with their life does that kind of ring any bells? Does that sound like it could have potentially been the case there?

Eric 41:06

But we were close. We've been dating since I guess would have been my junior year of high school. So it was like a two year relationship that we did try to make work with that. But yeah, that was kind of the end of things because it became an issue of well, even if we had worked past, you know, like now I remember things better and that sort of stuff, the trust was broken.

Eric 41:28

But I think one of the hardest things is getting someone who hasn't experienced traumatic brain injury of some sort or another, trying to get the idea that not remembering something doesn't have to do with how important that is, to me. The way that it does for a lot of people. A lot of people have this sense of well, if you forgot about it, then it really wasn't that important. And that is not the case with me in any way, shape, or form. And it's so difficult to convince other people that I actually forgot something I really cared about, because I don't get to decide what I forget.

Bill 42:07

That is very interesting. I reflect on the conversations that I had with my wife about who came to visit me. And often I would say to her, did such and such come and see me and I don't think that came in saw me she said they did. Everyone came and saw you. People traveled interstate to come and see you and I said, like who? And she would say a name and I'm like, Oh, really? Oh, I had no idea.

Bill 42:31

Yeah, it's really important for us, to somehow get the message across that forgetfulness is common for regular folk. And for stroke survivors. It's even like its even, it just comes with the territory of being a stroke survivor, you're going to forget things. And I have a friend of mine who is probably 25 years post stroke. She had a stroke when she was 21.

Bill 42:59

That was caused by an aneurysm that burst in her head. And one of the things that she does before she goes to bed every night. She has a little whiteboard next to her bed. And she writes things like tomorrow is Monday. Monday is a work day, go to work. And we, laugh and smile about it. But she's been doing that from day one. Like she's been doing that for 25 years, she has to say, make notes like that. Otherwise, she won't remember in the morning or she won't have the processing capacity in the morning to remember that she's got to get ready and go to work.

Eric 43:46

I kind of do something similar. I guess I think about it. It's like setting my intentions for the next day. I'll set reminders on my phone like set one for noon, and it'll be eat. I'll set one for 2pm it'll be do push ups set one for, you know, just little things that it's like, well, these are things that I would want to have happen tomorrow. And if I set reminders for myself now, then I can make that happen kind of thing. But yeah, it is interesting.

Bill 44:19

It is so fascinating. You've come a long way you've overcome a heap of things. I imagine that stroke recovery is still ongoing. What else do you do these days? What have you been able to achieve in your in other parts of your life?

Breaking my own record after stroke



Eric 44:39

But I'd say some of the biggest achievements or things that I'm proud of is I had run a Spartan Race before having the stroke. And if you're unfamiliar with it, it's a think of it like an obstacle course race that takes place over like 1015 miles. It's difficult, it's intense. And it was something that I had done after graduating high school.

Eric 45:08

And I decided that I needed to beat my time on that race after the stroke. And, and I was able to do it. It was 15 mile race was about 30 35 obstacles. And I was able to beat my time by I think it was like 5 or 10 minutes. So that was a big one for me. That was a can I get to a better physical level than I was at before the stroke and being able to say that, yes, I can and have been able to do that. That was big for me, that meant okay, my body can, you know, recover.

Eric 45:47

Another big thing was my first feature film, I had, you know, written, directed and starred in it. And, you know, got that onto Amazon Prime. That was a big one. It's called Carpe Diem, European Escapade. And it was. I went to film school film trade school for two years when I was in high school. So when I graduated high school, I had a trade school degree and a high school diploma.

Eric 46:14

And my friends that I've been in film school with, we decided to do a trip that we've been saving up for for a few years, take a camera and make a movie. And we did so it was cool to finally see that, you know, be completed be released. I

guess the film stuff has been, you know, some big moments of art. I'm proud of this. I'm glad I was able to accomplish this.

Eric 46:43

Another thing that was actually a suggestion from a doctor was writing an autobiography. And they thought that it could be really helpful for me to have my memories in order to have a book that I could look back at and be like, what did I do in this year like, do I remember this? And to actually be able to say like, Oh, yeah, I did this.

Eric 47:06

And the side effect of that that's been positive is I've had a number of people that have also had strokes asked me like, well, when are you going to release that book? Like, I'd love to read it, which is something I didn't think would be. I never considered that when I was writing it that people would actually want to read it. I'll do the me. But, yeah, there's been some things that I've been proud of.

Bill 47:30

So is the book available?

Eric 47:33

Now at this point, still writing it? It's hard to know when to stop it. When it's like, well, you know, I'm young. How how do you put out an autobiography when you're only 25?

Bill 47:45

Yeah, that's a good question but you just do it. And then in another 25 years, you write the.

Eric 47:52

The sequel? Yeah, that's true. Yeah.

Bill 47:57

And then when you're about 85, like Some of our action hero actors, you know, like Sylvester Stallone and, and Schwarzenegger, you release, you know, 10 more versions of every other thing you've ever done just so that you can retire with another pocket full of cash just because you might not be acting for too much longer.

Bill 48:24

So, good thing to look forward to man, that'd be awesome to see that book happen. Because Yeah, it's it is important because there's not a lot of 19 year old stroke survivors, you get to write a book about their experience. Therefore, there's a whole demographic of people that would relate to you more, than that would relate to a 45 year old person who wrote a book about stroke.

Eric 48:52

Something that I noticed, because I go to like the stroke support meetings in Los Angeles County and stuff, and I find that I'm easily The youngest person there by two decades, I've never met anyone my age or close to it that's had a stroke. I know that they're out there, but I've never met one myself. So it definitely is something that I would like to get that out there more.

Eric 49:19

And eventually, because I've done it with a short film, but I love to make a feature film as well, that can, you know, spread awareness and be in some way related to the idea of, you know, brain injuries and that sort of thing.

Bill 49:36

Yeah, there's a couple of beautiful movies out there. I think they're both on Netflix. One of them is called the butterfly effect, I'm pretty sure. And the other one is called my beautiful broken brain. And, you know, they talk to people. The butterfly effect was written by somebody who I think experienced some really traumatic brain issue and I think it was stroke, and they talk about that process that that person went through. So it's done by somebody else.

Bill 50:06

I feel like it's done by somebody else about this person's experience. And it's quite an older movie. And my beautiful broken brain is in is a documentary type of movie, which follows this young lady who has experienced some neurological challenge, and she talks about attempts to talk about the stuff that's going on inside her head, and tries to bring that out so people can understand what the experience is like.

Bill 50:36

And there's definitely not enough of that material out there. You only hear about the two or three things often repeated that are out there. So, you know, the more

people that put out that type of content. I think the better for being able to bridge that gap between this unknown thing that we all go through after experiencing a stroke and bring it into the mainstream so that people have a better understanding and more tools to be able to communicate and understand and support people that have had a neurological condition from any trauma.

Bill 51:17

As well as, for the first time and I don't know about you, but for the first time, after experiencing my brain bleeds and brain surgery, I got to understand what it was like to have a mental illness. Because I experienced isolation, I experienced depression for a small amount of time. I experienced that thing that people do when they mean well and say, Oh, well, you look great, actually, man. And then not knowing that actually, I am not great.

Bill 51:56

Did you have that experience as well? Did you start to be able to relate to people who had you know, previously you had previously not taken notice of like people in wheelchairs and people with other challenges.

Suffering from PTSD caused by stroke

Eric 52:11

Yeah, definitely one of the biggest things that I didn't expect and didn't know what's coming was late onset PTSD, which when I googled the type of stroke and had I saw that it was, you know, listed as one of the symptoms like, Oh, this is a, something people are aware of, but I, I wasn't, you know, what wasn't ever told. I don't know. I guess it was just that I didn't see a doctor for so long afterwards, that I just wasn't aware.

Eric 52:39

But I ended up enrolling in a PTSD clinical trial. For us. It was a new medication, they were testing for it. Because I couldn't afford to see a normal doctor. I couldn't, you know, go that route. So I had to become part of this clinical trial. And that was actually how I got the diagnosis that hey, you You have PTSD, and depression and anxiety and different things are, you know, symptoms of that, which is itself a symptom of strokes.

Eric 53:10

So I definitely experienced like, you know, fear of leaving my room or house that I didn't know that people with anxiety can sometimes experience I didn't know that, like happiness and motivation are so interwoven and connected. Like I didn't realize that it would affect my motivation when depression hits, things like that. So definitely gave me a new view on mental health, how we look at it, how we treat it, and how we treat people that are trying to better their mental health or struggling with it.

Bill 53:48

You know, when you were told that if, by the way, you know, when you experience stroke, posttraumatic stress disorder might kick in and when you have Post Traumatic Stress Disorder, that might be anxiety. And when you feel anxiety it is as a result of this. Did having those dots connected for you make it better and make it possible for you to be in anxiety and go. Oh, okay, that's what this is. I'll just ride this out and this will pass and then I'll be able to get that next thing that I need to do done. Did it help?

Eric 54:26

It definitely did. Because it then I could come up with tools that I can use to help myself. You know, I'm when I didn't know what it was it was this is a scary thing that I'm experiencing and I don't know how to stop it. I don't know what it is. Am I just going crazy like what's going on here? And then to sit down and be like, okay, when PTSD causes depression symptoms, you need to get yourself out side and get into sunlight. You need to listen to music. You need to surround yourself with people you need to do certain things.

Eric 54:56

When it's anxiety. You need to you know, Call a person you need to open a window instead of locking all the doors in the house and, you know, containing yourself, you know, different. It gave me steps to take to get through these things rather than just wondering what these things are. So instead that was incredibly helpful.

Bill 55:19

Yeah, one of the every once in a while, well, quite often, I posted in Instagram at my Instagram page recovery after stroke. And I asked the stroke survivors what their three main challenges were when they were recovering from stroke. And like I've often those many stroke survivors, gave many things. So I ended up

making a list of about, I think it was about 15 challenges that people regularly face.

Bill 55:47

But one of the main things that came up more and more was fatigue, headache and anxiety were the three key things that people were talking about regularly. Experiencing after their stroke, and I had a little bit of anxiety that was based around noises when I heard a lot of noise. When I was in a crowded place, overwhelm would cause anxiety and I would want to avoid that situation.

Bill 56:18

And if somebody's listening and watching this is thinking that that's an issue for them. It's actually not an issue your body's telling you like at the moment for your brain that is way too overwhelming. Get out of there. And it's really a great defense mechanism to get out of there and be not in a space where noise is overwhelming your brain and it's starting to hurt.

Bill 56:45

And one of the other things that was an issue was light and sensitivity to light, and that used to cause trouble at night, when it was time to wind down and go to bed. And light would affect me kept me stimulated or more awake. And as a result of that, what that would do is that would mean that I would had a bad night's sleep and then the cycle of distress and anxiety and all those things would be easier to fall into.

Bill 57:19

Because I was tired noise would make it worse and light would make it worse quicker. So there was a whole host of things that if I intervened in one place at the right time, it would stop that cycle from taking off and occurring again. What did you do to get out of those situations that you found were really difficult to deal with?

Eric 57:47

You know, I'm always surprised by how similar certain experiences are between people that have had issues like we have because I also had the same thing of like, it seemed like my eyes just took forever to adjust the lights. You know I walk outside put sunglasses on and have them on the whole time or outside my friends like it's not that bright out like but it is.

Eric 58:10

And so one of my issues for that in regard to sleep was I sleep with blackout curtains. So I can have almost total absolute inky pure black darkness when I sleep. And that's the only way I can do it. And and I put a fan on loud because I have tinnitus and it's actually pretty bad. And that also helps with not hearing outside noises.

Eric 58:35

You know it helps mask is the term they use for mask the tinnitus and helps me not hear anything outside or you know outside of the room I'm in. So I find I close the door I lock the door I turn the fan on, I put the blackout curtains over the windows, and it gives me like a almost like a sensory deprivation chamber kind of idea of like This is how I can get to sleep. But it's interesting to hear you go through some of the similar thing.

Bill 59:07

Yeah, sensory deprivation is a thing like you know, people have going into sensory deprivation chambers, floating chambers and all that kind of thing to experience sensory deprivation because there's so much sensory input. A lot of our autonomic nervous system is overwhelmed. And when you're struggling with the stroke, injury and recovering from that, it's overwhelmed to the next level.

Bill 59:29

So, you know, being able to give yourself some time and deprive yourself of some external influences is a really good thing. It helps the body to just calm down and heal. So it's great now, were you drawn to get blackout blinds or like, was it instinctive or how did you get to that point where you felt like well, this is the right thing for me.

Eric 1:00:00

I guess it started when I realized that I could walk from outdoors to indoors without taking sunglasses off. I would be totally comfortable wearing sunglasses indoors. And something that I realized was unusual. And so I slowly started to come to this realization that I am more sensitive to light than I used to be. Or not even that just I'm sensitive to light.

Eric 1:00:27

You know, I don't know if I was that sensitive to light before. And, you know, I

don't really remember. Because I have good knowledge of like events and memories, but very little knowledge of like, how did I react to light in the past and I'll know but I started realizing that I liked things darker if there were if someone kept night lights on, I wouldn't be able to sleep. Like I would be the kind of person that was looking for more darkness and so it just kind of led to well, why don't I get thicker blinds that will help need to not have, you know, things shining in the window late at night or something.

Light as a stimuli

Bill 1:01:08

That is just amazing to hear them and I had. I had an interview early on in the podcast series before it was called recovery after stroke with a guy called Alex Ferguson we spoke about light and how light interferes with the body and sleep. And specifically, we spoke about things like artificial light at night, as the sun goes down.

Bill 1:01:35

Most of us switch on our lights so that we can get things done inside the home. But that's not what we did until just about 100 years ago when electricity was invented, you know, and, the Light was invented. So what that's done is that shifts a whole bunch of things and he talked about, you know, the different spectrums of blue light being the most stimulating at night and needing to minimize the amount of blue light, and then increasing the amount of warm colored lights.

Bill 1:02:08

And then the best colored light at night was the light that you see in fires like red light and orange light. And this guy him and his he kind of made his girlfriend sort of come along for the ride, he decided that they would do at night there would be no lights on in the house. As soon as he went dark for a period of time, and he ended up using red lights inside the house.

Bill 1:02:38

Red Light inside the house, just as nightlight if necessary to get up and go to the loo or, you know, get up for any reason. And that was a real fascinating conversation because he talked about exactly what you did about blackout blinds, and he took it to the next level when he traveled into state or two another country and went to a hotel room, he would take sticky tape and stick sticky tape on the

little lights from the alarm clock, or from the air conditioning, or from anywhere where there was a little light.

Bill 1:03:13

And what he said which was fascinating and I've read into this a lot further since then. And the the research, there's a there's an abundance of research about it is that the skin is what detects light before anything else. And you can influence the way a person's nervous system responds just by changing the color of light that you're pointing to the skin. So the eyes play a massive role in you know, providing input from light, but then the skin also provides a massive amount of feedback to the body.

Eric 1:03:58

So that's interesting because I wasn't really aware of most of that. But I, realized that I do like I put both my computer and my phone into like night mode in or there's more of an orange than a blue light tone. And I keep that on almost constantly. And when I go to bed, I'll light a candle and have that be the last thing that's all in the room before I go to bed.

Eric 1:04:24

So turning off the light switch, it's blowing out the candle. Because that does this help me seem to like wind down to get closer to the ability to sleep because I have trouble sleeping. I think for me, the thing that brought me to the point of using the candle and being able to do that was one of my issues was figuring out what do I want? Like what do I like? What do I enjoy, like what makes me happy in life. And so I started meditating.

Eric 1:04:53

And I tried to meditate, you know, consistently every day if I can. And that was how the the candle thing came about. It was a, just a, you know, one of those moments of what do I want out of life? What do I enjoy? What do I like? And something that I realized I liked was the sense of relief that I got and turning off an overhead light and putting on something smaller. And so that was my way to experience that. So I guess what it could mean for other stroke survivors is pay attention to what you like because your body might be trying to tell you things about what you need.

Bill 1:05:32

But it just seems to come hand in hand I'm not sure why exactly. When we sit and watch TV in the evening for a couple of hours perhaps. And it's gone dark you know, we've got lots of top of our head and I'll, every single day I'll have to ask my wife to switch that off because I can't deal with the light on top of my head. It just feels too overwhelming. And my screens all set tonight mode. That really does help.

Bill 1:06:02

And at one point after my stroke recovery, I probably spent a few months in orange glasses in blue blocking glasses. And I found that that really helped me in my recovery. And also, it helped me calm myself down and my brain down on the way to bed for a couple of hours before bed. So they cost \$20 or something to buy. And basically, they're just a tinge of orange. They're really bright kind of orange looking.

Bill 1:06:32

And when you pop them on, it just filters out that blue light and starts to allow you to get into your circadian rhythm and change the cycle back into it's getting dark. Now let's stop decreasing the amount of cortisol and increasing melatonin and then moving towards sleep. So it's a fascinating conversation. Your story has been pretty much amazing for me to hear. I haven't spoken to a lot of young stroke survivors, especially, you know, people that experienced a stroke at 19, two strokes like you did. What else is coming up for you? projects that you're working on? And with regards to the work that you do.

Eric 1:07:17

Let's see next things. So I have a feature film that I directed, that I'm currently editing. We're hoping to have that completed by this summer. It's about the Syrian refugee crisis. It's kind of a Syrian refugee teenager gets brought into the US illegally. What do you do with that? You know, where's the moral? What's the moral answer for this kind of idea? There's a lot of compare and contrast between what we see who we see as refugees and who we see as immigrants and that sort of idea.

Eric 1:07:55

So I'm, I'm passionate about that really hope that that does well. And then I was the director of photography for a horror movie called The Butcher that's on Amazon Prime now. And we're doing a sequel for that one coming up this

summer. Those are maybe the next projects coming out. I'll be looking forward to many I have a couple short films, small projects, other things that were, you know, hoping we'll get places but we still got, you know, a good amount of time left to go.

Eric 1:08:29

A lot of filmmaking juggling, you know, juggling different projects and different aspects. You know, one of them is post production, ones in production, ones in pre production, and you're just trying to make sure everything's still running.

Bill 1:08:43

Seems like you need to be able to do many things at once.

Eric 1:08:47

Unfortunately, yeah.

Bill 1:08:50

Eric man, it's been a real pleasure getting to know you and getting to hear your story of recovery and survival and It's just great that you went through something so traumatic and you're coming out the other side. And I'm really excited to know that, you're 60 years out, and you've got your whole life ahead of you and your past the milestone that the doctor said, If you pass that, that'll be great. They're looking like you're gonna pass quite a few more milestones, man and really appreciate you being on the podcast. If anyone wanted to get in touch with you, where would they go?

Eric 1:09:32

Well, also, thank you for having me on the podcast notes. Always happy to be a part of things like this and to try to spread awareness about you know, what it is and how it affects people. If people want to get in contact with me, you know, Facebook, Instagram, Email.

Eric 1:09:53

Really, the easiest way is just it's my name. Eric Kenwood, That's my handle for Instagram. That's my name on Facebook. That's my email address @gmail.com. Just use that name, put whatever you want after it, and then it will get to me.

Bill 1:10:12

Awesome. thank you so much for being on the podcast.

Eric 1:10:16

Thank you for having me. All right, And thank you for helping me learned some new things, because I learned quite a bit as well.

Bill 1:10:24

Yeah, my pleasure. I mean, that's the reason why I do the podcast. I do it so that hopefully, we can bring ideas and information from people from all around the world and we can share some information that will make a difference. I mean, I needed the help so bad, you know, when I experienced a stroke, and in 2012, there was not much of this stuff happening yet online and it seems to have taken off really amazingly now.

Bill 1:10:53

And I can't do it without people like you. So if anyone watching out there or listening out there wants to be on the podcast. please get in touch bill@recoveryafterstroke.com, send me an email asked me to be on the show. And I'd love to have you on there, just so that we can create our own community. You know, we don't have to all be over active in the community.

Bill 1:11:12

But I feel like you know, if anyone wants to spend an hour on the podcast with me, that is going to make a massive difference because people are going to be able to get to that episode forever, man. So I just appreciate it when people do that. And I really appreciate you for doing that and taking your time out for me, man.

Eric 1:11:28

I'm happy to you know, and hopefully, people learn a little more we can help them as well.

Intro 1:11:33

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