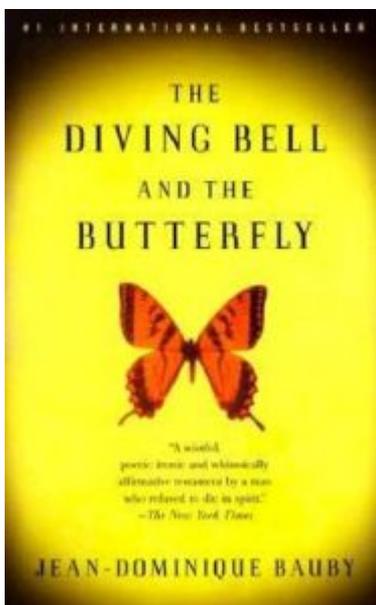


The Great Now What? - Maggie Whittum

Maggie Whittum suffered a massive brain stem stroke at age 33, which was caused a Cavernous Angioma also known as an AVM (ArterioVenous Malformation) Maggie is creating an empowering & life-affirming film illuminating her experience with stroke, disability, chronic pain & resilience. She is a stroke SURVIVOR, not a stroke victim. Let's find meaning & beauty in what is an otherwise ugly experience.



The Diving Bell and The Butterfly

The Crash Reel

Phamaly Theatre Company www.phamaly.org

The Great Now What - documentary on stroke, disability & resilience

[The Great Now What](#) - on Facebook

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Maggie 0:00

I would go to these doctors appointments over and over and over again for, you know, a year and a half and explain to them what my body felt like. And I just felt like no one was really understanding me. And so then I thought, as opposed to drawing something, if you take something that is a human form already, like a Barbie doll, and then make it look like you feel, then that will communicate to people more effectively. So I've done several different ones. And they're all about the nerve pain that I feel. And one of them is encased in gray Clay So it looks like concrete. That one's about the numbness and the lack of proprioception.

Intro 0:53

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

Bill 1:02

G'day, and welcome to the podcast.

Maggie 1:05

Thank you so much for having me.

Bill 1:08

Thank you, I came across your Instagram and your Facebook. The great now what?

Maggie 1:17

Thank You

Bill 1:17

it was was, it was the most the most I've been curious about somebody's Instagram or Facebook page, because the great now what creates a whole bunch of uncertainty about what I'm about to discover when I go into that particular person's profile or page or whatever it is or Instagram. And I thought I have to get in touch with you and find out exactly what the great now what is about before we get started in chatting about that. Can you tell me a little bit about what happened to you?

Maggie had Cavernous Angioma

Maggie 1:53

Sure. So I was 33 and I was quite healthy and fit, I didn't smoke or have high blood pressure. I didn't, I wasn't overweight. I didn't have any of the warning signs for stroke. But then on Christmas Day, about four years ago, I had a major stroke it, massive stroke in my brain stem, and it was caused by a cavernous angioma, which is a vascular malformation, that one in 500 people has. And you know, is totally out of the blue and really, I really changed my life.

And I was in ICU for a while I a nine hour brain surgery, to remove the hemorrhage and I spent a while more in an acute care hospital and then five weeks in a rehab hospital and then I've done months and months and months. years now of outpatient therapy.

Bill 3:02

Yeah. Where were you when you started to notice something going wrong? Or did you even notice something was going wrong?

Maggie 3:09

Yeah, so I actually had my first symptom 48 hours before I checked myself into the hospital, because I was having a hemorrhagic stroke. You know, in retrospect, I've learned you gotta get to the hospital, so important to get to the hospital. But because I was having a hemorrhagic stroke, there really wasn't anything that could have been done to change it in any way.

That my first symptom with a headache. And that was on a Sunday morning and I thought, maybe I'm just dehydrated or I drank too much last night or, you know, stress because at the time, I was in a very rigorous MFA program, Master of Fine Arts program in the US. in Washington DC at George Washington University. And I just finished my first semester two days prior. And so, you know, when the doctors were like, when was your high stress or high blood pressure event? I was like, well, I just finished a semesters worth of school.

But really, this is arbitrary. My stroke was arbitrary. Nothing caused it. Nothing necessarily made it any worse than it might have been. But my first symptom was a headache. And then by 24 hours after that, I had a minor balance problem. And, or, but it was, it was major, but it was just for an instant and I was like, thought I

would fall over but I didn't fall over and that was strange, but it disappeared immediately and then it happened again.

Very late that night, you know, I went to bed thinking if I just go to bed, maybe I have the flu, I just need to get enough rest and I'll be okay. And I went to bed that night and got up to use the restroom in the middle of the night and I had another balance problem. So I thought, Oh, geez, by tomorrow morning, I should go see someone. So I checked myself into the hospital actually walked to the hospital because I could still walk at that point. And it was only a couple blocks from my apartment 48 hours after my first symptom, and then 48 hours after my I checked in the hospital, I had to be put on a ventilator. Because my hemorrhage it worsened and I was totally paralyzed on the right side of my face and the left side of my body. And I couldn't speak I couldn't move. It was real crisis situation.

Bill 6:00

Yeah, it's a it's interesting how you said you should have done something about it. And I left, I left the symptoms. I didn't attend to my symptoms for seven days. Before I did something about it, and I had a similar arteriovenous malformation wasn't in the brainstem mine was near the cerebellum. And as it was bleeding, it started to impact more and more of my left side until the entire left side was numb and I couldn't feel my balance was a little bit off. I was dragging my leg.

I know I know that you said I should have done something about it sooner but you've got no idea really do we? How could we possibly know that you at 33, me at 37 you've got something, is about to happen that's going to dramatically impact your well being and potentially kill you. How do, you know you're not a doctor.

Maggie 6:58

I had no idea and You know, I've gone over this in my head a lot, you know, could I have done something differently? Could I not? And, and several of the doctors told me, you know, if you had shown up earlier in the ER, we probably would have sent you home, you know, because, because the issues were not that significant at that moment. So, um, but time is brain when it comes to stroke and 87% of strokes are ischemic strokes, the blood clot kind, and you can you can do something about those. So I would encourage everyone to get to the hospital ASAP, if they're having any of the stroke.

Bill 7:41

Yes. So the message really here is anyone listening who is not certain. If they know enough about stroke, just also trust your gut instinct. If your gut instinct is telling you there's something wrong, go to the GP, go to the hospital and persist with them to do a scan do whatever it takes to get a scan and see, you know, just look into that, that concern and that issue that you have, and also listen to your loved ones because my wife was telling me that she could see me working differently. She noticed me being different, and I ignored her.

And unfortunately, you know, I was running around and I was busy. And I had work to do. And I was highly stressed. And I just told her look you know just leave me alone. I've got stuff to do. There's nothing wrong with me.

Maggie 8:28

I'll just walk it off, right?

Bill 8:31

I did say that at one point. Yeah, absolutely. And so bizarre, but

Maggie 8:35

wow

Bill 8:36

yeah. And so you, you were 33 year at college. You're studying? What were you? What were you hoping to achieve with your degree? Was it an arts degree?

Maggie 8:51

It was Yeah, so I was getting a master Fine Arts in classical acting. I had been a professional actor and voiceover artist for a while, and I was going back to this program, which was a lot about Shakespeare and about his contemporaries and how to analyze text and a lot of very physical things like stage combat movement dance, and I was actually in the best shape of my life, because I just finished two semesters worth of this program that was so physical and and then I had a stroke all of a sudden.

But yeah, I had been an actor before that. And I figured that I wanted to get the terminal degree that you can get in acting with your MFA. And then I would be able to teach at the university level if I wanted to, and, you know, continue building my resume as an actor.

Bill 9:49

Yeah. So how was it that you ended up in hospital? Did you have a massive incident where you collapsed somewhere where you with people how did that pan out?

Maggie 10:00

No, I had a headache. And then I had a minor or I had this balance thing at about noon the next day. And then I was engaged at the time. And my fiance told me that by the end of the second day, there, right corner of my mouth had stopped moving. And so my speech was slurred and being an voiceover artists, I was very familiar with how my voice should sound and how I should make my voice be able to sound.

Suddenly there was this thing going wrong, and I couldn't really figure out why. And then, you know, that middle of the night, I have another balance problem. So and the next morning at about 11am I had a balance problem and I thought, oh my god, I have to see a doctor. So I had just been approved for new health insurance. And I call up the health insurance and they give me a list of doctors I can see and I call up a doctor's office. And they say we can see you in two months. And I say I need to see someone today I think and they said, Okay, go to the ER.

The stroke paralysis was complete

Maggie 12:00

So I walked to the ER, which is two and a half blocks from my apartment and I checked myself in because I'm, you know, the age I am and I'm quite fit they don't think I'm having a stroke. It takes six hours for me to get a CAT scan, and then they say you're having some bleeding in your brain stem. And, and they admit me and they put me in the ICU and I get an MRI later that night. And that's when they can really really tell this is, you know, this vascular malformation incident your pons and your top of your brain stem and it's hemorrhaging. And you know, by the end of that day, I couldn't walk anymore. And then it was about day and a half after that, that the paralysis was complete and I couldn't move it on couldn't speak.

Bill 12:18

But you consciously aware of what was going on to you.

Maggie 12:24

Exactly yeah, I'm your brainstem is where you have a lot of basic life functions, like your heart rate and your respiration and your body temperature. So if you have a hemorrhage there, it's quite likely you're going to die, but it doesn't impact things like your ability to think, to process. And, you know, I was able to form the words in my head, but I wasn't able to get them out before the ventilator went in because my tongue and my lips just weren't working.

And then I lost my gag reflex. So that's why they had to intubate me. And I was totally conscious. But they had sedated me because being on a ventilators very stressful for your body, your body wants to pull it out. And they also put me on a steroids to try and lessen the swelling in my brain. But it also gave me these wild hallucinations. So I was totally there I was cognitively intact and I was trying to communicate with the outside world through my hand basically, I would do a thumbs up for yes ah pointer finger for no. That's how they would do the neuro checks on me because you know, checking me quite often to see if the hemorrhage was worsening. With the Yes or no questions.

And then, you know, my sister thankfully flew in from Colorado to Washington DC, when things got really bad when I got on the ventilator, and she would hold my hand and she would say the alphabet, and I would squeeze her hand on the letter, and I would spell out words very, very, very slowly. So I was very, I was aware of everything that was happening to me. And it was completely terrifying. But I also couldn't move and I couldn't vocalize at all, and it was an experience.

Bill 14:37

Yeah. It's a common thing. I never went through the ability not to vocalize or talk but I, at one point realized that other people had so I sought out to speak with people who were locked in. And then a couple of episodes prior, I've had some interviews with some people who are locked in and just to get people to understand what it's like to be Locked in or not be able to communicate by voice? And how scary that is, and therefore, how to potentially be better at supporting people in that situation. So I think it's really important for us to talk about it. And although doctors and nurses would come across it a lot, I don't know if there's many doctors and nurses have had the opportunity after to speak to the patient to find out what could we have done better? or What was it like for you? How could we have these your concerns better? Or, you know, how could we treated you nicer or I don't know what. So I think it's really important to have those

conversations.

But I don't want to make this podcast all about crazy stuff that stroke does because we know that's a whole bunch of crazy, crazy stuff.

Maggie 15:50

I would I would recommend to everyone. I was not locked in myself, but I was very close to being locked in. And I read a book called the Diving Bell and the butterfly, written by Jean-Dominique Bauby, he was locked in and he dictated this entire book, letter by letter, blink by blink. And I've read it a couple of times. I think it's magnificent. Wow. And I would recommend it to everyone.

Bill 16:18

What is it called? Can we repeat that so I can make a note of it?

Maggie 16:22

It's called the diving bell and the butterfly. And they also made a film in 2004. It's a French film of the same title that diving bell and the butterfly and the film is also gorgeous and so well done.

Bill 16:42

Wow, thanks for that will definitely put that on the links and then I'm definitely going to go sort that, seek it out and find it and watch it. So at 33 you're at the prime of your life is your family nearby. I know you said your sister flowing. But are you living in a state where you're quite far away from your loved ones?

Maggie 17:08

I was pretty far away. I was living with my fiance at the time and we had moved away from our network of friends and family to Washington DC so that I could go to graduate school. Thankfully, I had an uncle nearby who happened to be a doctor, not a brain doctor, he is an endocrinologist, but he, he came and saw me a couple of times and a cousin nearby. But basically everyone was in Colorado, which is a solid like three and a half hour flight from Washington DC. And my sister lived in the mountains. So she had to drive in a snowstorm, a couple of hours down from the mountains to get to Denver to get to the airport to fly to Washington to help me and eventually, my mom team about six days later when I had to have brain surgery, and my brother in law and my fiance's father. So I did have a lot of people around me at this crucial time, which was a blessing.

Bill 18:16

Yeah. Beautiful. When you had surgery after I suspect you went through the initial rehabilitation stage, how long were you in hospital for?

Maggie 18:28

So after the surgery, I was in ICU for another five days in the acute care hospital for another two weeks? And then and then inpatient rehab hospital for another five weeks. So all total I spent two months in different hospitals.

Bill 18:49

And then you got home. You got high right. Back to the place you are living with your fiance is that where you ended up?

Maggie 18:59

Yeah, we had an apartment. And thankfully, it was not too difficult to get around. There was an elevator and I had the building people install a grab bar in the in the bathroom. But thankfully, there weren't like stairs in my home or anything like that, that I had to deal with. It was it was hard enough just going back to that apartment and being so changed.

Bill 19:30

Yeah. And how, how was that transition? I imagine, it was difficult, but what some of the things that started to go wrong, or you couldn't cope with while while you were back what was happening?

Maggie will be back soon

Maggie 19:43

Well, I just I heard some people say to me, that only 10% of stroke survivors made a full recovery. And basically, I thought to myself, okay, I'm going to be in that 10% I'm just going to work really hard. That's how I've achieved everything before in my life is just through hard work and determination. So I, I'm throwing all of my mental and physical energy into my recovery. And I it is it's incomprehensible to me that anything is permanent. Any of these problems, you know, and I think they must just go away at some point. I'll get my feeling back at some point, my face will move again, at some point and, and I think I'm going to be able, I withdrew from my graduate program for that semester, but I thought I'm going to rejoin in the fall. And, you know, no problem. I'll, I'll be back soon.

And, and that was very hard for me. You know, as the as the months went by, and I hit six months and hit seven months and I hit eight months to nine months and and I was like geez im permanently disabled now. And that is a hard, tough pill to swallow. That was hard for me because I was you know, I had this incredible body that did everything I wanted it to you know, and, and I was conventionally very pretty. And I had a paralyzed face now, so you know, half my smile, doesn't smile anymore. And my vision was all messed up. And you know, the brain surgery was a big deal, of course, but then I had to get a couple more surgeries. After that.

I got a surgery to try and help my face regain symmetry. Six months after my stroke, I had eventually two surgeries on my eyes, because my eyeballs were misaligned. They were pointing in the wrong direction. And that was another thing that I thought would heal of course, it's going to heal. Definitely temporary. Well, no, it's not.

And so they had to, I waited 10 months after they did this, but um, they basically cut the muscles on the sides of my eyes and realigned my eyeball. And sewed the muscles back together, they did this I my right eye, 10 months after my stroke, and they did my left eye 13 months after my stroke. So that was four surgeries above the neck and 13 months and, and that's a lot of medical trauma go through.

Bill 22:56

Yeah, that's more surgeries than you ever plan for ever imagine happening, even think about ever do anything about you know, and then all of a sudden you're in the situation and you know, what is occurring to me as when I when I reflect on who I was before, all of the stuff that I went through. So I had three surgeries, I had surgery, I had brain surgery, and I had thyroid surgery all in the space of three years. And I was over if I did, but what occurs to me is that the previous may would have looked at somebody who appeared physically disabled. And I would have never connected the trauma that had occurred physically mentally, emotionally, to that person before the physical disability. So I just assumed that there were a normal happy go, go lucky person, the same as they've always been, for some reason, have this physical inability.

And that is what I think most normal in inverted commas people have never has been, it's never occurred to them. It's never occurred to them that they're not only dealing with when I come across somebody who's struggling for whatever reason, they're not only dealing with the the person not being able to get out of

their wheelchair or walk or drive or do those things. You're also dealing with somebody who's emotionally been really challenged. And they need to be more aware of that. And people need to be more. What's the word? I'm not sure if it's compassionate, or anything like that. I think they just need to be more curious about what else is happening that I'm not seeing actually, that's what they need to be.

Hypertrophic Olivary Degeneration caused by stroke

Maggie 24:46

Hmm. Yeah, I mean, I am visibly disabled. You can tell, you know, quote, unquote, tell immediately that something has happened to me. But the biggest challenges that I face are invisible challenges. I have major vision problems. So I can't drive I have double vision, it's hard for me to read, I have this constant bouncing in my eyeballs called hypertrophic olivary degeneration, which means my eyeballs are constantly moving up and down. So my entire life is like on a shaky camcorder. And you can't see that unless you're six inches from my face and looking very closely at my eyeballs. And the other thing that's invisible is my chronic pain. I have an enormous amount of nerve pain and the left side of my body where it's completely numb, but somehow also on fire, and somehow also freezing. And like the worst pins and needles you've ever experienced.

Bill 26:06

I know that I know that feeling, because I have that every day on my left side. And I get really edgy when people sit on my left side. And then my wife goes to touch me on the hand. unless she's been rough, it hurts. And I don't want to, I don't want to touch I sleep on my left side now in bed. Because when I sleep on my right side, my left side feels like it's colder, even though I'm covered, it just feels like I'm cold and I can't get comfortable. So I sleep on my left side. Because if I said on my left side, the mattress masks some of those weird sensations that my skin is creating because of the weight. So that's one way that I try and combat that.

And then and then in summer, I don't know whether I should put my jacket on, I'll take it off, because half of me is way too hot. And the other half might not be yet, that's even in winter, like any time of the year, there's this constant forever, two

different sides of may two parts of me. It's like they got two bodies, and attached one and forgot the wiring of the other one. And it's constantly on my mind. But then sometimes I forget. Do you ever find yourself forgetting and, and somehow just going unaware of all of the challenges that you go through? Is it something that's constantly there.

Maggie 27:41

I mean, if it feels quite constant, you know, if I, if I take some time to rest, which I do quite often during the day, and I lie down and I close my eyes, and I have very little stimulation. And I'm not like talking to anybody you're listening to anything, then you know, I can sort of forget for a little while. But really, it's it's so there, it's so present to me at every moment of my life, especially if doing anything.

Bill 28:17

Yeah. So tell me briefly, how was your relationship affected?

Maggie 28:25

Well, I you know, this sort of thing happens, lots and lots and lots and lots of relationships end. I don't know what the statistics are like in Australia, but I've been reading up in on it in the United States, and up to 75% of marriages end in separation or divorce, when one person is diagnosed with a chronic illness. And, you know, I've gotten to know a ton of stroke survivors in the past four years, and so many of them have, you know, stories of heartbreak and, you know, breaking up with their significant other, so we were not an anomaly. And it's not his fault, and it's not my fault. But we just didn't last we made it another 10 months after, after my stroke, but then it ended.

Bill 29:26

Yeah. And I know some people you know, have your approach. It wasn't my fault wasn't his fault just ended. So that's interesting. But, you know, some people's, spouses decide they are not going to hang around and help this bitch or bastard at all, because they were potentially going through a tough time beforehand, or something else went wrong. So you know, it's a good opportunity for somebody to say, you know, what, I'm out of here, I'm not gonna hang around,

Maggie 29:56

yeah,

Bill 29:56

to sort of sort you out. But then I also understand what why people would feel a need to get distance from the disability, because it could potentially bring up emotions for, you know, the significant other, that are really difficult to deal with, like, their own mortality, their, you know, what's my life? You know, how am I supposed to help this person, you know, feeling trapped or inadequate. You imagine that, you know, the other person on the other side is also going through a rough time and I'm trying to make light of why with and I'm not trying to take sides, whether somebody should have might hang around, or whatever, I was fortunate, my partner, she was amazing and she hung around, she was never gonna leave.

We never had difficult times before that. So it was all good. But also, I'm not physically disabled, in that way where she needed to care for me 24 hours a day, seven days a week. So, you know, thankfully, that didn't happen. So it's such a complex situation, because, you know, people also dealing with their own emotional trauma, and now they're dealing with the breakup. Was it?

Maggie 31:10

Right,

Bill 31:11

okay, for him to go at the time? Was it easy for him? For you to let him go? Or was that difficult?

Maggie 31:19

No, no, I mean, I was completely devastated at the time. But I've had a lot of time to process it by this point. And now I think he made the right decision. I think that something like this is gonna take every single weakness you may have in your relationship, and really exacerbate it. And, you know, touch it, like a hot nerve. So, it doesn't surprise me that so many relationships, and, and I think that, you know, if you haven't had any sort of exposure to people with disabilities beforehand, it can be, it can blow your mind, you know, in, in not a good way, in a, in a way where you feel totally overwhelmed. And, and, like, you just want to escape.

And, you know, I had had some experience with a friend of mine with cerebral palsy earlier in my life, but, um, my fiance, really hadn't had much exposure to people with disabilities. So I think, you know, that's part of it, too. I mean, it's, it's

hard, because it's like, you know, that idea of I didn't sign up for this. But I feel like that is, you know, when you're not actually married yet, It's, it's a legitimate thing to, to consider. So

Bill 32:57

yeah, fair enough. Hey tell me? Now, your art, I've had a little bit some of the stuff that you do. And I had a look at that trailer, which is on your website, at the greatnowwhat.com. Tell me about when you started to find a way to start expressing yourself with your art. How did that evolve?

The Crash Reel

Maggie 33:22

Well, um, my relationship had ended and I had moved back to Colorado because I felt like I can't rejoin my graduate school program. And I was just at, you know, a very low point. And I watched a documentary called the crash reel, spelled r e e l. And it's about a snowboarder named Kevin Pierce, who is quite talented and he's um, so exceptional that people think he's going to go to the Vancouver Olympics, and just win everything. And he gets a massive traumatic brain injury seven weeks before the Olympics. And the documentary follows him for the next two years of his life. And he really wants to be a professional snowboarder again, but he can't.

And he has to reconcile himself with that fact. And, you know, there are other aspects to the film to about extreme sports, and what we ask of athletes when we keep on upping the risks in extreme sports. And also, there's a section about his family. His family super supportive. And he's one of five brothers and one of his brothers has Downs Syndrome. And so there's a section in the phone about disability and, you know, quote, unquote, a acceptance.

I don't think acceptance is a very useful word. I think that reconciliation carries more gravity to it. I think acceptance is kind of a nothing word. But I've watched that film, and I had a eureka moment myself. And I thought, Oh, my God, I have to make a film right now, about stroke. This film is amazing, but it's about TBI. And there's a lot of similarities. But there's also some differences. And I think I could make an incredible film about stroke, a documentary film.

So I, you know, kind of reached out to my network of creators because I knew

some people in the industry and ended up meeting up with an extremely talented woman named Lisa Donato, who is directing the film. And she's just been amazing. And like, as the film has sort of been formulating, I also have been creating the art pieces, which are a way for me to deal with this feeling of having a shattered sense of identity, and also a way to communicate to people what my mind and my body feel like now, or felt like, in the first two years of my stroke, recovery,

Bill 36:39

it's um, I love that I love the visual side of it. So when I saw your picture your before picture, and then you have a good version of that on the desk, and then you get the copy of the before picture and you tear it up.

Maggie 36:59

Mm hmm.

Bill 36:59

And then you glue it back. But now all teared up, back on to the good picture. It really throws your mind to another place of what you're expressing about your emotions and what you're feeling. You look at that, and you go, Okay, this is somebody who is expressing that, that picture of seemingly perfection or whatever it was, or normal life or everything was great. Now feels torn, now feels, you know, disjointed now feels, all these things, when you're creating.

Maggie 37:32

yeah

Bill 37:33

Sorry you were going to say go.

Maggie 37:36

Oh, well, you know, I had been an actor beforehand. And so I had this headshot, this very flattering picture of me right of my face. And I'm smiling, this big, beautiful smile. And a year and a half after my stroke, I'm looking at this stack of headshots, it's a couple inches tall, and thinking these are useless now. And I hate them! And I, I feel so different than this person in the picture. And there's no possible way for me to look like that ever again.

So I just started to, like, disassemble them, and, you know, like, give them flaws

in certain ways. Like, I would cut them and rip them and burn holes in them and, you know, slice them up and put them back together as a way to try and show people how I how I felt about my, myself, you know, because your face is yourself is the thing that you know, people see, you can tell you're Bill from a picture of your face, not from picture of your hand. So it's like the thing that is emblematic of you and especially for an actor, your face is terribly important. And for a woman in your face is very important. So I just I felt the need to disassemble them and reassemble them and in different ways.

Bill 39:17

Yeah, for the very powerful the one that was the most powerful was when you were cutting it with the with the blade, and just sort of tearing little holes and and slits in it until it was gone. And then by burning it, i don't know it just spoke to me, it was just something about and I could I could sense your, your emotional state at time. As the trailer changes, I'm not sure if it's before that that picture scene or after that picture scene we see a Barbie doll. Tell me a little bit about your thinking about Barbie doll. What went into that

Maggie 40:02

Well, So you know, I used to be so in tune with my body and I would dance and do yoga and stuff. So I was so familiar with it. And and and I loved it. And after a stroke, it just feels completely different. And so bizarre, the things that are going on in your, in your, in your body, like you ask your hand to do something, and maybe it doesn't do it at all, or maybe your foot starts doing something instead. And it's just so strange.

And I would go to these doctors appointments over and over and over again for, you know, a year and a half and explain to them what my body felt like. And I just felt like, no one was really understanding me. And so then I thought, as opposed to just drawing something, if you take something that is a human form already, like a Barbie doll, and then make it look like you feel, then that will communicate to people more effectively. So I've done several different ones. And they're all about the nerve pain that I feel. And one of them is encased in gray clay. So it looks like concrete. That one's about the numbness and the lack of proprioception and the heaviness. And then I've done one with rubber bands that is trying to show the tightness that I feel and one with a vise grips. And there's a couple others one with nails. Yeah, so I'm making a whole series and I want to have an art show with this stuff.

Bill 41:49

Yeah, that every one of those things that you did, the elastic band that covers all of them that is so you've nailed it with regards to not only how you feel, but also how it feels for me, it does, it feels like my muscles are all tight. And then it feels and then it feels heavy and bound or, or restricted. So I can see that the concrete, you know, thinking behind it, everything you've done, is really well expressing how it is and what I'd love to do.

Now every time I see them and think about our discussion in it right now what I'm thinking is one, wouldn't it be great to get some, some people who turn up to a location be it an exhibition or something, and incase them in something that's not the amount of rubber bands that they wouldn't know, but a few or put on a heavy suit on one side of the body for them and tell me to walk or do something that's a physical, disable them temporarily in in a physical way, so that they can sort of try and get a bit of an idea of what it is that people go through. It'll take it to the next level. So

Maggie 43:11

I did that once Actually, I made because you know, I'm always trying to find out ways to communicate to people with this experiences like so I made a fake arm. And I like made it about the weight of human arm, and or about the weight of my arm. And I like sewed it into a shirt. So that you could actually have this arm kind of dangling next to you. And it would like balance against the side of you when you walk. And if you were sitting down, you know, and you could put it on your lap and you would feel the weight of it on your lap on time. And I think that that was a good thing to do.

Bill 43:59

Yeah, it would give people an insight. And I know there's a lot of people that are curious that wants to know what it's like because they want to be more supportive or, or they want to be more interested in topics of ability and inability or disability. So I think the more we do that, the better. And what's great about what you're doing is you're going to turn it into a movie. How did you possibly come up with the idea to create a movie about this? And where are we at with it now? How long ago was that?

Maggie 44:31

Well, the initial inspiration was watching the crash reel. And then I've watched a

ton of documentaries since then, with the idea of, you know, how do I how do I construct something that is the film that I wanted it to be. And we've been working on it now for a couple of years, Lisa and I and the more we work on it, the more we refine it, and I think it's going to be so good when it comes out.

In terms of our status, basically, we've pulled a little bit of money together here and there to do a couple of days of shooting, because we want it to look nice and professional and gotta pay the cinematographer and the sound guy and the gaffer and that kind of stuff. So, you know, we've just done it kind of nibble by nibble here and there and gotten some really solid material. And last fall, we did a crowdfunding campaign, we raised 43,000 American dollars for the film, which is so great, because it shows the world. You know, it's not just me and Lisa, that want I see this film, it's a lot of other people do.

So that was great to have so many supporters from all over the world, pitching in, you know, five, or \$10, or whatever. And people are welcome to donate at any time if they would like because we're always, you know, trying to gather a little bit more and a little bit more money to make the film as high quality as we want it to be, you can donate on the website, there's a link to go to, you can use a credit card.

And then, in terms of finishing it, I really hope it's going to be done by the end of 2019. But it's a it's a very long process as I am learning. I was not a filmmaker before this, but it is a years long process to make a feature length film. And I didn't quite realize that getting into it, but it is and it is so worth it. And you know the the material that we have out there right now, the teaser video that you can see on the website. If you also go to the bottom of the website, you can click on a link and see our crowdfunding video from last fall. I think those are both such solid pieces, you know, and they're just two minutes and three minutes. But we want to make a film that's 90 minutes, and is that good. So it takes a while but i am i'm really enthused about it. And I want to reach people, I want to reach people with disabilities, people who can't leave their houses easily. So we're going to have it on a streaming platform of some sort, when it's finished.

Bill 47:37

Beautiful, I'm looking forward to it. The teaser was what made me send the email to you to see if I can get you on for an interview. Because I was so impressed by it. And I wanted to find out more. And then also impressed by your art, I wanted

to find out more. And my, the thing that I did to raise awareness was I don't consider myself arty, although I enjoy when I'm doing artful types of things.

The thing that I could contribute was this podcast and creating awareness in this way, because it's the easiest for me or get in front of a computer press record. And then I upload that to the internet. And I'm basically done. And it's not hours, or it's sorry, it's not years and years of production work and all that kind of stuff to get it done. It's only hours. It fills me with a tremendous amount of joy. It gives me purpose. It it I get more out of it than I thought I would. I'm wondering about now that you're at this stage in there for years post stroke, overcoming the challenges, certainly still dealing with a lot of them. What does it mean to you to have this project to work on? And how does that help you moving forward?

Maggie 49:03

Well, it's, it's great to have some purpose, and some reason to want to get up in the morning, because there are definitely some mornings early on where I did not want to get up. And you know, I couldn't work for a long time. And then I started to work, some doing some administrative stuff from home very part time for a friend of mine. And I'm so grateful that I that I can work a little bit but it wasn't like creatively fulfilling.

And I, I was an actor and a creator for a long time. And I would also produce and direct a lot of live theater and live improv comedy. And suddenly, I'm feeling like that sort of creative element of my life is gone, because I can't move around the way I used to. And you know, live theater necessitates getting somewhere in person.

So this film comes into my life, and it and it is the place where I'm putting all of my creative energy right now. And it's very satisfying. And I just want to reach people, I want to reach people who were in the same place that I was, you know, a year after my stroke in this place of real desolation and, and talk about now what? you know, that's the title of the film. Because as I had all these plans, and I thought I had my life figured out in terms of I'm going to do a, b, c, d, and, and then everything radically changes. And that is sad. It is tragedy. And I don't want to you know, negate the strategy or underplay the tragedy, because it is really, really, really hard. But then the question is, what happens after the tragedy? And I want to, I want to answer that question with this film.

Bill 51:22

Yeah, that's a great thing to answer, it's a great thing to give back to the world at large and the community of people who are recovering from some kind of a traumatic life, health challenge, and now are disabled. It was, I from time to time, and I'm not sure if you've already started to get people contacting you and saying that amazing thing to doing that. But I, I get that type of feedback from people. Thanks for that episode. That's the episode I just needed.

And I was going to stop doing this at one point, because I didn't think it was going to get traction, and started to question my ability to interview, you know, all the crazy stuff that people do about feeling unable or incapable or afraid to put your voice out there to be judged to be all these things, you know, that was all going through my mind and it and it took me it took me about a year to find the courage to release my first episode. And then I did that for some time. And then I stopped doing them. And I didn't put out an episode for maybe 9 or 10 months. And you know, that the listeners fell away as they do, and all those things change.

And it was mainly dealing with my issues and my concerns, again, I was going through emotionally hard time, physically tough time I was working the place of didn't want to work. And it's the one thing that got me going and feeling that I have purpose again and feeling better about myself again, and exploring this art of mine, which is talking to people and getting their stories out of them. And and what motivates me the most. And what makes it impossible for me to stop now is the feedback from the people who need it the most to I didn't know we're out there.

How has, how has the trailer been received so far? And what is some of the feedback from the people that have supported you through the GoFundMe campaign?

Maggie 53:37

Well, the the teaser video has been very popular, and you can find it on the website. And on Vimeo where we have over 4000 views. And, you know, it's just two minutes, which is very effective. And it also teaches you some things that you may be didn't know, like, in the United States, that person has a stroke every 40 seconds, and only 10% of stroke survivors make full recovery. And in that way, you know, people who had absolutely no experience with stroke, felt like they learned something, which is great.

But also just in general, people It has an emotional impact. And many people have told me that they were very powerfully affected by it. And then, you know, stroke survivors like yourself, and others have, have talked to me about this idea of identity and seeing yourself you know, and your picture of your face being ripped up and reassembled or your body being persecuted in this way. And and and this idea of living with chronic pain and chronic pain, being invisible and that being such a struggle for some people, because other people don't understand it.

A lot of people have gotten back to me with positive feedback about that stuff in the in the teaser. So it's it has a lot to offer people in a lot of different ways.

Bill 55:20

Did you ever

Maggie 55:20

So if you like it, you should share it online. Yeah. And may is going to be stroke Awareness Month in the United States. So we're going to make an extra effort to, you know, get it out there even more in the month of May.

Bill 55:36

Awesome. Well, I'll support that. And I'll definitely do my bit. Did you ever get to the point during this last couple of years of developing the movie, filming for this type thing where you said, it's not worth it? I'm not doing this anymore? I've had enough?

Maggie dealing with frustration

Maggie 55:54

Well, I mean, let's talk about frustration for a second. If, if you could die of frustration, I would be dead years ago, right? Being a stroke survivor is so immensely frustrating. And, you know, there are plenty of times where I've just wanted to give up on life in general. So, so yes, it's, it's tough to put one foot in front of the other metaphorically or literally, every day. And sometimes I congratulate myself just on getting through today. Tomorrow will be its own challenge. But yeah, I mean, I I thought I had experienced challenges earlier in my life. But this one is certainly makes all of them sound tiny in comparison.

Bill 56:55

Yeah. But you know, the old you know, the ones that you taugt up and said is no

longer you, she's gone in one of your pieces, do you still though draw on her way of overcoming things? and use some of what she has taught you in the past? And helped you over come in the past, even though there were a lot smaller challenges, you still draw on her to help you overcome some of the things that you're going through now?

Maggie 57:26

Well, yeah, I mean, in some ways, I feel like a brand new person, but I am the person I have been for the past 37 years of my life. And I think that I had a certain amount of determination and force of will, in my previous life that I tried to use on my stroke recovery to make my stroke vanish, you know, i thought, this thing that's happened to me, it's going to be a secret. And I'm going to be able to hide it away and pretend like never happened.

And then I realized that Brain, Brain Damage cannot be fixed through force of will. But now I feel like I'm trying to use that determination and force of will to get the film complete. Because it is so important to me. I've never felt this much desire to complete one specific thing as I felt to get this film done.

Bill 58:30

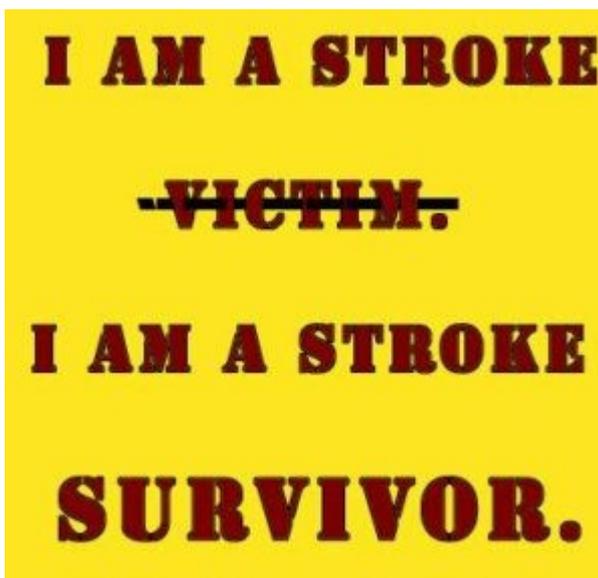
Yeah, I can relate to that, Hey, tell me about the mood of the film. So my sense about this podcast is it's really difficult to make it light and airy, and make it less doom and gloomy now. But, of course, I'm always interviewing survivors, which is great can't interview people that are not here. I'm also always interviewing people that have overcome different levels of disability and still dealing with different levels of emotional trauma challenge, you know, mental issues, a lot of the invisible stuff. How do you? How do you feel the mood of the documentary is? But what's that, like?

Maggie 59:21

Well, you know, initially, I wanted to make a project about, quote, unquote, overcoming, right. But as the film has evolved, and as I have evolved, I don't think that's very useful. And I also think that the way that disabled people are often portrayed in film is that they're either overcoming and happy, go lucky, and they are disabled anymore, because they're cured, or they kill themselves, or they die of their disability. And I'm like, that is a crappy way to have me and my community portrayed.

And there happens to be a theater company here in Denver, that only casts actors with disabilities, and you have to have a disability under the Americans with Disabilities Act in order to audition. So that's a physical, cognitive, emotional, or intellectual disability. And they've been in Denver for 30 years. And I feel so blessed and lucky to be a part of this company. Because the idea is not to overcome your disability, the idea is not to hide your disability, the company elevates people with disabilities and celebrates them.

Living with your disability after stroke



Maggie 1:01:30

And, you know, does an amazing production every summer that shows the world, that they're just as talented and capable as anyone else. And I think that, you know, I, I resist, I'm trying to resist the overcoming something, idea. Because, you know, you got to live with it, you got to live with your disabilities, and, and, and, and reckon with them and figure out how to deal with your life after they arrive?

Bill 1:01:30

I'm glad I asked you that question really I am! Because you've answered a question. That was something that was puzzling me for a little bit. And I think each episode of mine will be different as each individual is different. And as each challenge that they face is different. So I think it's great that I don't have to worry about making it airy, and fluffy and feel good. All the time.

Maggie 1:01:54

Right.

Bill 1:01:54

Make it what it is,

Maggie 1:01:56

Life, life is not, you know, all airy and fluffy and good but it's not all terrible bad it is what it is.

Bill 1:02:04

Yeah. Good. I have to think about that list now and they will take up less of my brain power to work it out. We'll just go with the flow is basically what we'll do. And I suppose that's a lot of what happens in stroke recovery and disability in dealing with disabilities you go with the flow, and for me the flow the flow is different every day sometimes the river runs fast, sometimes it's still. Sometimes it runs cold, sometimes it runs warmer. You know, sometimes you can see through the water right to the bottom, sometimes you can't see through because it's murky for some reason. And you just got to go with it the way that it is on that particular day. And like you said, look, you know, if you're going through a tough one, just think about tomorrow, could be a better one could be easier to deal with.

Now, There's a lot of people talk about can I do to be talked about, We talk about, we talk about? mind?hang on a sec whats the word? we talk about? Mindset, golly, gosh, that was hard to get set out. We talk about mindset. What's your take on mindset, because everyone kind of in the in the self help world in the you're going to be amazing, making millions of dollars world, it's all about mindset, mindset mindset.

And part of what I'd like to do is support people so that they understand that mindset is important. And that if your mindset is a negative one, or you focus your mindset in a way, which is negative, perhaps your challenges are harder or more difficult to deal with. Tell me about what you think about mindset.

Maggie 1:03:58

Well, I I think you're mindset is incredibly important. And you know, this is such a mental challenge. There are certainly plenty of physical challenges, but I have felt most most challenged by the psychological element of this illness. And, you know, I used to be such a happy go lucky person, and very positive and upbeat. And I think that and perky. You know, and I think part of that was because, in general, I

think women are sort of trained to be that kind of person in life, you want to be agreeable and pers, pleasing and, and not cause problems, not be angry.

So I couldn't be that anymore. I had no capacity to be that person anymore, and no energy to be that person anymore. Because it takes a lot of energy I found out to be like. So now I'm in a different mindset entirely. But it's all about, like, what is what is next? And I certainly had a long period of feeling exceptionally pathetic, and very sorry for myself and i, and I wouldn't go outside and I didn't want to do anything social. And I didn't want to see anybody, especially anybody who hadn't seen me yet. You know, it was very hard to see people for the first time after my stroke. And there were people that I resisted seeing for years after my stroke, um,

but actually just a couple months ago, and when to my 15 year college reunion. And so I saw a ton of people who knew me in college when I was perfectly healthy. And I thought that was a major step forward to be able to do that and see those people. And that is a question of mindset that I'm just going to go forward. You know, you how you talk to yourself, in your own mind is such a big part of this. And I have actually a sign on my refrigerator over there that says "Be kind to yourself". Because, boy, have I been unkind to myself and mean and frustrated and so like disparaging to myself.

And you know, that's cruel, you shouldn't be unkind to yourself because the world is plenty unkind on its own and, and, you know, the way you talk about yourself, you can say, Oh, I'm, you know, dis, I'm permanently disabled, and I'm, you know, my partner left me and I have no job but blah blah blah or you can talk about yourself in a more positive light. Like, you know, I'm an actor with a disability, I'm a person with a disability, I you know,

I perform with a theater company for people with disabilities and I, I work on a film that is going to help expose stroke and disability and chronic pain to the wider world in a way that will build a compassionate understanding. So that is a Jedi mind trick, you got to play on yourself, to talk to yourself in a in a compassionate way. Because it's very easy to talk to yourself, like you hate yourself. And I certainly have hated myself for long periods of this, but I'm trying not to anymore.

Bill 1:08:06

Yeah, there's no point doesn't achieve anything. I do love your insight, though.

The Jedi mind trick is it really good one. Because that's what it is. It is just literally using the same energy or even less energy to have better thoughts and better descriptions of yourself. And this was a topic yesterday's podcast episode, which hasn't been released yet. Which was similar with Jenny McAllister, who talks about, you know that she was hard on herself. And I've been hard on myself. I think what motivates me now the most, and I'm not sure about you and other people. But what motivates me the most now is missing out. So now I don't want to miss out.

So I think about my mortality, because I've already experienced that possibility. And I think about if I went out in a little while, whenever it is, and I had the opportunity to just think about my regrets what my regrets, well, I don't have that many. But the podcast, if I don't do that, and I don't take it to the level where I want to, I'm going to have that is going to be a regret. And that is going to be something that I'm going to feel like I missed out on and I don't want to go out that way. I don't want to go out thinking I missed out on something that I was afraid to do or try or learn about for miss out on. With regards to other things. My health didn't allow me at the time or my condition or whatever. That's ok I'm ok with that. But missing out because I didn't try is not not going to happen.

Maggie 1:09:45

Mm hmm.

Bill 1:09:48

Do you feel like you're missing out on anything?

Maggie 1:09:51

You know, honestly, I don't, I was very adventurous in my life. And I traveled a lot before I got sick. And I did a lot of bold experimental projects. And I feel like I really did so much in my life already, before I turned 33 and had this stroke, I, that I lived an entire lifetime already. And then when I was sick, I spent nine full days, unable to move, I'm able to speak, communicating through my hand, I'm unable to breathe on my own. And I was suspended in this place between life and death.

And death was so so near for so long, that I really came to terms with it. I feel like I am not afraid of my own death anymore. And I could die in 10 minutes, I could die in 10 years, I could die in 50 years. It doesn't really matter to me. I just I want

to reach as many people as I can. In the meantime,

Bill 1:11:19

Beautiful. On that note, we'll wrap up. This has been an amazing opportunity to learn from somebody else. Thank you so much for that.

Maggie 1:11:32

Thank you Bill.

Bill 1:11:33

Yeah, my pleasure. I'm going to look forward to the release of the documentary, I'm going to look forward to following your work. I'm going to look forward to your art exhibition.

I'm so far away from you. But somehow I'm going to keep on top of things and and focus on seeing that, that piece of work, my

Maggie 1:11:56

And maybe the film, maybe the film will be at the Melbourne festival and we can meet in person.

Bill 1:12:02

Wouldn't that be amazing? I plan on coming to the states at some point. So wouldn't it be good if I could come to the states and see the film while it was being launched or first shown or something like that, my wife would jump at the chance of saying we're going to the United States should be straight on the plane with me. So let's see if we can make that happen somehow.

As we wrap up, you know what I've become aware of and remember, at the beginning of the video of our interview, before I started recording, I said you can use sit in the middle. Because we're miss, we're potentially going to not be able to see some of you? As the interview has progressed and you're moved closer and closer to the edge of the frame. And I was gonna, it doesn't matter doesn't matter, it really doesn't matter, I was going to remind you to come to the middle of the frame, but then I think is not just let it go.

Because naturally, what's happened is your body has moved to that position. And you haven't noticed that, I think it's important to emphasize that and to show that as well in that we have those are involuntary things that occur and our body does

things that we don't really know or want it to do, and we can't do anything about it. So it's been a really slow and gradual movement to the other side. And it's kind of been perfect because it helps to illustrate all those things that you're trying to illustrate.

So I'm okay with it. Can you tell the people watching and listening where they can find out more about your documentary movie, yourself and your art?

Maggie 1:13:53

Yes, so we have a website for the film. It's the title of the film, The greatnowwhat.com and you can go on the website and watch the teaser there. And if you like it, please share it online. And you can learn a little bit more about the film who the people are, who are working on it. And go and donate if you would like to donate. Also, we have a Facebook page for the film. And I try and put something on it every day. That is a positive quote or something about stroke, something about disability, something about cavernous angioma, which is what caused my stroke or something newsworthy about the film.

So join the Facebook page, if you would like and also on the website, you can join our email list. And I send out an email every couple of weeks with some really beautiful production stills and info on what is happening next.

Bill 1:14:57

Awesome. And I hope that you send out this the link to the podcast that we've just recorded in one of your emails. That'd be great.

Maggie 1:15:04

Oh, for sure. For sure. Oh, and I don't know if I mentioned on Facebook, just search for the great now what? And there's a page.

Bill 1:15:12

Yeah, I'll have all the links there. And would you accept a very small donation as much as a cup of coffee, the cost of a cup of coffee that they have to be massive donations?

Maggie 1:15:24

Exactly. Yeah. Anything, anything would be much appreciated.

Bill 1:15:28

Yeah. Awesome. Well, thank you so much for joining me on the podcast. I look forward to keeping in touch with you and learning more about what it is that you're doing and seeing how everything evolves.

Maggie 1:15:38

Thank you so much for the opportunity and thank you to everyone listening.

Intro 1:15:42

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