

Time To Talk About Stroke - Derek Van Oss

Derek Van Oss suffered from AVM (Arteriovenous malformation) back in 2002. Since then he has struggled with so many challenges but now 18 years down the track, Derek was able to get back on his feet and turn his life around.

Instagram

Website

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Bill 0:00

Nothing is stopping me from making sure that I keep releasing podcast episodes so that other stroke survivors don't go through such a hard time as I went through. I don't want them to do that. I want them to find us a lot earlier in their journey, and be healed a lot earlier in their journey so that they can pass it forward to other people and heal them as well.

Bill 0:24

What I've done as a result of that is because I've met so many stroke survivors, I

coach a few stroke survivors. And then that's amazing because coaching people is not telling them how to fix things or what to do things. It's just to be there for them to have somebody back all the time. And just to help guide them to the next milestone.

Intro 0:49

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

Introduction



Bill 0:56

Bill from recoveryafterstroke.com. This is Episode 94 My guest today is Derek Van Oss. Derek had a hemorrhagic stroke 18 years ago, and this is the first time he has put himself out there to talk about his stroke to such a large audience. Over the years, Derek has overcome so much and reflects fondly on the lessons and growth he has had.

Bill 1:19

Now just before we get started, I wanted to let you know that you can now download all the words of this episode as a PDF. It's perfect if you prefer to read and take notes or highlight different parts of the interview for future reference. It's a great way to learn and it helps retain new information in memory, just go to recoveryafterstroke.com and click on the image of the episode you've just listened to.

Bill 1:43

At the very beginning of the page, you will see a button that says Download transcript. Click the button. Enter the email address and the PDF will begin

downloading. Also, if you love the recovery after stroke podcast and you think it is helpful, please share it and tell others about the podcasts that they may benefit too.

Bill 2:03

If you're watching on YouTube, please give us a thumbs up and leave a comment. I love to hear from other stroke survivors and answer all questions personally. Go to iTunes or your favorite podcast app and leave a five-star review. Finally, if you think you would make a great guest and have an inspiring recovery story to tell with our community, please get in touch.

Bill 2:26

Just email me bill@recoveryafterstroke.com and I will make it happen. Also, come along and follow me on Instagram by going to [instagram.com/recoveryafterstroke](https://www.instagram.com/recoveryafterstroke) and visit the Facebook page at [Facebook.com/recoveryafterstroke](https://www.facebook.com/recoveryafterstroke). Now it's on with the show.

Bill 2:49

Derek van OS Welcome to the podcast.

Derek 2:52

Thank you. Good to be here. It's been a long time coming when we first talked about this probably over a year ago.

Bill 2:59

Yeah, it has been a while I imagine that you've been through some of your things. So I completely understand I have a total understanding of what it is that you might have been through. Tell me a little bit about what happened to you, Derek.

Derek 3:14

Oh, man, it's a it's a long story. But yeah, I'm a stroke survivor. Let's see, I had my stroke in 2002. So I'm pretty far out from the point of impact, I guess, which seems to me in the kind of the community the online community of stroke support and stuff like that kind of where I found you on Instagram and things of that nature that the majority of survivors and seeing kind of getting involved are fairly closer to their point of impact, more in recent years than the last five years or so.

Derek Van Oss had an Arteriovenous Malformation

Derek 3:56

So it makes me feel a little awkward being so far out. Because I just passed my, I guess it was my 18th anniversary of when I had my stroke on March 7, 2002. I think today's the 26th of 2020 Um, so yeah, I had an AVM so I was 19 years old at the time. I'm now 38 I just turned 38 so this happened five days before my 20th birthday.

Derek 4:37

Just kind of bizarre to spend your 20th birthday in the hospital but necessary. I didn't know I was having a stroke, which also seems kind of unique. I didn't have any kind of major headache or a real moment Oh my god like what's happening to me? Where I've heard a lot of other people's stories of them having a real like sudden something's happening now I need to get to the hospital.

Derek 5:09

For me, I had a vision problem I just started to have vision problems. I was driving to work one day and almost got in a wreck and I was a very cautious driver and always checking over my shoulder and just making sure that I was driving safely and you know, using my turn signals and all that stuff. One day on the way to work I almost got into a wreck I looked over my shoulder to merge into traffic and on the freeway and to me, there was no car there.

Derek 5:44

But there was a car there and they honked their horn at me like you know, and I'm like, That's weird. I swore I checked well. I didn't see anything. So that was strange. And then I got to work and I'd noticed that I was having trouble reading my emails, like just, I was a computer programmer, kind of right out of high school. I started working on the internet as a programmer.

Derek 6:10

So I happen to be fortunate time and place to have learned how to program HTML for the internet when it was still in its infancy. And I ended up working at Verizon and that's working on Verizon.com, and that's where this all happened. And so I went to work that day and had trouble reading my emails. It was just strange. And I couldn't figure out why. I just noticed that I, you know, get to the end of a

sentence and then end up in the middle of the next line. Like I just couldn't figure it out. I did. There was no real. In my field of vision, there was no real like, I couldn't tell it's really hard to explain.

Derek 6:55

And so I didn't know what was going on. And then I went to lunch and I had trouble reading like the menu and I had trouble, you know, reading the signage behind the register. I think we went to like check later or something for lunch and I say I having trouble figuring out where things were, and it was just kind of more strange.

Derek 7:18

And I felt fine. I felt normal. I didn't think anything of it. I thought, Well, my parents and my brother have glasses. Maybe I just need glasses now. No real other thought then then. I guess I'm having a vision problem, you know, like, but I felt fine. So you know, there was no real, immediate urgency to me. And so that went on for a couple of days, two or three days.

Derek 7:50

I probably just was like, it's just weird here. And I ended up you know, just talking to some co-workers about it. And you know, I was having trouble and told my boss, you know, I'm having some trouble. But that may be why I'm not responding to emails as quickly or why some of the programming code that I was writing might be a little off and I just had trouble seeing the screen.

There's nothing wrong with your eyes

Derek 8:19

After a few days of that, a couple of my coworkers were like, you should probably go to like an eye doctor. Like yeah, I guess probably. I might as well you know, like, maybe it's my time to get glasses, you know. So I just scheduled an appointment with a local optometrist and went to see this guy in the middle of the day, you know, I'd gone to work that day and got permission to take a long lunch and got to see this doctor and that's when things got real crazy.

Derek 9:00

He did every test in the book and he seemed concerned like he wasn't saying it but it was taking a lot longer than everything and then I would have thought it

would you know, all these tests I wouldn't have thought I would have had to do and he went away into you know, left me in the room for a little bit and came back and it was one of those like movie moments of just like, well Derek, I'll never forget it. He likes verbatim like what he said he's like, I think you're old enough and mature enough to handle what I'm about to tell you.

Derek 9:42

Like, I need glasses but that's fine. It's not a big deal. Just make the glasses. Like it's like, why is it so dramatic? And he said well, you know, I did all these tests, this test, and that test and your eyes are fine. You know, there's no nothing wrong with your eyes and I'm like dude, yes there is like I'm telling you I have trouble reading. Can't see this. I almost got in a wreck like, I need help there's something wrong and he's like, well, I didn't say there's nothing wrong I said there's nothing wrong with your eyes.

Derek 10:15

You know, you see there's no disconnected retinas. There are no tumors, there are no scratches on whatever, like your eyes are fine. Like so what is that? What are you trying to say? And he's like, I think there's something wrong with your brain. I don't know what it is. I couldn't tell you. But I think you need to go to the hospital like, now like, an emergency like, do you have family nearby I was living on my own at the time I'd moved out of my parent's house when I was 17.

Derek 10:53

I started working and got my place moving with some friends then I ended up moving on my own and so yeah, my mom, my dad, and my brother are all in town, and it's like you need to call them they need to meet you at the hospital you need to go now. And like, This is crazy. Like, what's the big deal? Like what do you mean something wrong with my brain like, I don't understand what like, I mean I was 19 years old I was a kid, right?

Derek 11:19

So like, none of this ever registered. I'd never been in a hospital in my life except for when I was born. But you know, I never had a broken bone. Like I never needed any kind of emergency treatment of any kind ever. And I ended up calling my dad and well, I called my mom first Southern Texas mama's boy here. I'm originally from Texas, so she didn't answer. So I called my dad and I said, You need to come to the hospital.

Derek 12:01

He was sending me to Baylor Medical Hospital in the Dallas area. And dad's like, what happened? I'm like, I don't know. I don't know what happened. I just had some trouble seeing and almost had a wreck I went to an eye doctor and he's telling me this is like something serious I need to go to a hospital.

Derek 12:23

So I drove myself to the hospital. I was still feeling fine, like no big issue. And they, you know, on my way out of the optometrist's office, I'd heard him calling over there. And he was calling the radiology lab at at Baylor saying, It was later in the day saying, I'm sending someone over to you. I have a patient coming and he needs to be seen now it's an emergency don't close down for the day somebody needs to be there to see him and get him an MRI and, I heard him say this is life or death. And I was like, What are you? What is going on? I felt like I was in a dream.

Bill 13:14

And had let you drive?

Derek 13:16

And yeah, I mean, I had my car. I mean looking back on it now I'm like, why didn't he like call an ambulance? I don't know. But, I mean, I am blessed that this guy this optometrist it was a real small little operation not like some, you know, not like I didn't go to the best guy in town or anything. Maybe he is but it was just a tiny little place of an optometrist like in a strip mall.

Derek 13:40

And I'm so blessed and fortunate that he was smart enough and, you know, took the time to do the tests and realize something critical was going on, you know, he didn't just like send me on my way. So I went to the hospital right away and I got an MRI and came out my parents were waiting for me and what happened? What happened? And I'm like, I don't know, nothing we don't know. I just waited for the MRI results and the doctor came out and said, well sit tight.

Derek 14:15

Your, brain is bleeding. So we might have to do emergency brain surgery, you know? But we're not sure yet. So just kind of hang out. And it's the most bizarre thing in the world to me, you know, like, and the doctor came out and thought

that it was my dad, that was the patient because he didn't look at the age of the patient.

Derek 14:40

And so I think he thought brain bleed AVM whatever. I mean, I don't know if he knew it was an AVM yet. But all the doctors that I saw that day like they come in and they address my dad, like, because he was the older gentleman in the room and I was a kid so they didn't think it was me and then they start talking to him. Well, it's my son.

Bill 15:06

Did you end up having surgery to remove the AVM?

Derek Van Oss had Cerebral Arteriogram on his birthday



Derek 15:10

Not then not right away no. So what ended up happening was, you know, I spent the next, you know, month in and out of other hospitals seeing other doctors tried to figure out exactly what was going on all kinds of tests and you know, I had a cerebral arteriogram on my birthday. Like, that was like my birthday present, I don't know if you were, any of the people that may see this have had one but it's, it's a cringe-worthy process of having a line put up your femoral artery, which is the big artery in your crotch area.

Derek 15:49

And they send that all the way up into your neck and release dye into your brain to take a 3D image of your brain. And you're awake during this and it's just really they were telling me I was gonna have to do that on my birthday. I was just like, this is just creepy. And I don't know, I don't want to do that.

Bill 16:09

I had that same procedure. I relate to a lot of what you said because I had a bleed in the brain. It was an AVM that happened when I was 37. I ignored it for about seven days, I had numbness on my left side. So I didn't realize that it was a brain bleed. I went to the chiropractor and the chiropractor told me that something was going on with my brain, and I needed to go to the hospital.

Derek 16:33

Did you have to drive?

Bill 16:34

I also had to drive. Yeah, because I argued with him for quite a while I said to him, I can't go to the hospital. Because I've got to go to work tomorrow. If I go to the hospital, are they gonna have me there the whole weekend? I'm not going to be able to get to work you know, inconvenient. So then one of the tests that they did sit around seven days later was that procedure.

Bill 16:57

They ran the catheter or whatever it was they ran the pretty sure some kind of a catheter some kind of a cable into the artery and the brain and they released this whole couple of different things in my brain and one of them was the dye. And when they released the dye, I had this massive internal experience of like, inside my brain. I would like to see neurons firing off. It was like, fireworks going off in my head.

Derek 17:33

Yeah, they said your brain going to feel like it was put in the oven or like a microwave because it gets really warm for some reason. And then you'll probably see like a star field or like you mentioned kind of fireworks kind of explosion sensation and yes, really bizarre. So leading up to that, you know, I'm just thinking squeamish about all this, you know, going like, what are you trying to do to me? Like what? Like, just give me the glasses.

Derek 18:08

Like there's nothing on my brain I don't believe you like I mean I believe them because they showed me the MRIs and it shows a big splash of you know, white blood in my brain on the MRIs, but it was about the size of my eyeball. You know, it's the same size as the blood patch. Right? And yeah, so over the next month, I just was in and out of hospitals and doctors' offices trying to figure out exactly what was going on and where it was and how it happened. And is it stable? Is it not like how much of an emergency is this right now?

Derek 18:49

And ultimately, it was kind of decided that well, apparently it had been bleeding for a while. Maybe Weeks could be months, they could tell by the kind of the the color, the shade of the blood on the MRI how old the blood is, and how fresh It is based on how dark it is and how bright it is. And so that there was a lot of darker blood, which is I guess, the way they described it was like that was more like dried older blood in the brain matter.

Derek 19:28

So they could tell that it had been there for a while. And bleeding and bleeding little by little over time, it eventually bled into my optic tracts and caused vision impairment. And for whatever reason, it never caused any other symptoms. Up until that point, like every time the doctor came in, they're like, are you sure you feel okay? You should be having the worst headache of your life like you should be on the ground in a fetal position crying in pain and I felt normal.

Bill 20:04

So do have any, any feelings of pain or anything like that just numbness just numbness. big toe.

Derek 20:11

That seems pretty uncommon. In most of the other stories I hear people have massive headaches and real just or they have the onset of weakness, and numbness right away immediately. And that's what so I don't know I guess I feel fortunate that it was just my vision problem thing.

Bill 20:31

So then did you go through several months before surgery, it took me nearly three years to get to surgery. How long did it take you?

Intro 20:41

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. How long will it take to recover? Will I recover? What things should I avoid in case I make matters worse, doctors will explain things but, because you've never had a stroke before, you probably don't know what questions to ask.

Intro 21:05

If this is you, you may miss 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

Derek 21:53

Three years. No, so this all happened in March of 2002 and I didn't know I was having surgery till October of 02. So it did happen pretty quickly. But I mean the doctor's plan was when, because it's been bleeding for a while, and you're not having any major, like debilitating symptoms other than your vision loss.

Derek 22:20

You know, still able to kind of, you know, function and get up and I mean, I went to work or, like, it just wasn't safe for me to drive at that point. So they said, Let's monitor this, you know, I was going to the doctor every, few days, you know, not getting scanned every time but, you know, like, just for checkups, you know, like, how are you feeling, you know, on the scale of one to 10 and all that kind of stuff.

Derek 22:49

And I did that for a few months. They also said, You know, I was young enough that they didn't want to just want to crack my head open and start messing with me. Like you're pretty young. And when you're that young, your brain and all your other vital organs and everything has a much higher propensity for healing.

Derek 23:11

Not that the brain matter heals, once it's been bled into, I don't think that it does. But it can, you know, find new neural pathways to do those things. But the optic

tract is one of those pieces of the brain that just once it's been damaged, doesn't prepare itself. It can't or, I don't know, this was 18 years ago, maybe that's changed since then.

Homonymous hemianopsia caused by stroke

Derek 23:39

It's still the same. So I have a full left-sided Homonymous hemianopsia is the technical term. A lot of people just call hemianopsia the entire left side of both above my eyes from the very center all the way left. Um, yeah, I guess it's more of a curve that is completely blind, so it's completely gone. So anything I look at straight on, I only see half of it.

Derek 24:06

Like I'm looking at the screen right now. And, you're in the middle, I only see, which I guess is the right side of you. So I scan around a lot, as long as I'm looking around a lot, I can take everything in. But it makes everything extremely difficult to read to see, you know, I'm always kind of looking around people think I look kind of paranoid, because I'm, I have to check things out, you know, to make sure I'm seeing everything.

Derek 24:36

I'm always looking as far left as I can. So basically, like where your peripheral vision ends on a normal person. Mine just ends right in the middle of my eyes. So it's not like, you know, one of them's good, and one of them's bad. They're both 50%

Bill 25:00

So you have a narrow vision of the field.

Derek 25:04

Yeah, it's a visual field cut as they call it. I guess. So it's pretty crazy to think about. That's how it is. And I mean, I've adapted to it well. It's been 18 years. So I'm pretty good with it. But I guess yeah and I ended up going through all that monitoring. And then one day at work, I'm still going to work I just had a coworker picking me up and driving me to work that live nearby.

Derek 25:34

And I didn't feel safe driving and so I had a co-worker taking me to work and I

was still going and one day I had trouble typing with my hands, you know, and it was my left hand and a little bit of a foot kind of weirdness. It was subtle, but on my hand, it was noticeable. And I was having trouble typing. And this was, I think, in August, so then a few months from March when all this first happened, and, I guess it had been long enough that I didn't even really think anything of it again.

Derek 26:16

And I thought maybe I was getting carpal tunnel syndrome or, like, stressed out or, you know, it's just like, I had just been to my uncle passed away, and I'd been to the Boston area to go to his funeral. And so I'd flown out there and flown back and work and, you know, like, had dealt with the stroke stuff and I just, I didn't think much of it again, thought I'd it'll go away. And I went to lunch with a co-worker and was telling her about it.

Derek 26:55

She goes do you think that this can have something to do with that stroke stuff that happened to you a while back? You know, it's August now so, I'm like, oh wow, um, I guess they did tell me if anything happened, it would be weakness or numbness on my left side. And it was my left hand that I was having a problem with so I'm like, wow you know, like, we're so naive to, you know, like to think that anything could ever be wrong with us.

Derek 27:30

And I think especially more so when we're kids. You know, I was, I mean, I was 20 at that point, but I was still a kid. So I called the doctor right away and was like, I think something's going on and they said, you need to come get an MRI now like leave work. Don't even bother telling them they'll try and get you to stay or tell you it's nothing like just leave and come now.

Derek 27:54

So I went and got another, you know, rush MRI. I told my family Come meet me and they kind of came out like they did the first time and said, well, you know, it's bleeding, some more bleeding again, you know. So now this is serious it's like DEF CON five or whatever. So like, what do we do, you know, and the doctors say, you know, some people have AVMs and had these bleeds that go their whole lives and never even knew they had a bleed, you know, like, until an autopsy happens and, you know, like, the family finds out or, I had I was living with an AVM for probably months and didn't know it was bleeding.

Derek 28:43

And sometimes these things stabilize and people can go and live the rest of their lives with no intervention and you know, no kind of other additional problems. So it seems like at the first incident, most doctors say let's monitor this, let's get you on a plan to see regularly and make sure unless it's already wrecked some kind of function pretty badly.

The 2nd incident led to Derek's surgery

Derek 29:09

And at two incidents, it's probably time to do surgery, it's probably time to intervene. Because the third one's most likely going to kill you. Was basically what they were telling me, you know, like three strikes and you're out kind of thing. And it was really deep in my brain, like if you cross-section like over the ear from the center like it was really deep inside their basal ganglia area.

Derek 29:38

I think they were saying I had to look back to my notes I had them on file, but I was really deep in there. So it was bleeding towards my brainstem. And they said, if you bleed into your brainstem, your death kills you instantly. Right? So they're like, they bled a little more into something that was, you know, affecting my hand and partially my ankle, it felt like at some foot drop.

Derek 30:10

Real, subtle at that point. And so they said, you need to think about it. We're recommending surgery, I remember my dad asking. There was a neurosurgeon. I think he was there at the time and asking him if this were your son, well, what would you do? You know, and he said that he would do the surgery, you know?

Derek 30:40

So I spent the next few months doing a lot of soul searching and deciding, you know, they said, like, you need to probably figure out what you want to do as quick as you can. And we wouldn't recommend, you know, taking too much longer to make the decision. But surreal, complicated surgery. It's really deep in the brain there are not a lot of people that could do this. I guess, and you're gonna get me all choked up just thinking about this.

Derek 31:22

It was time to explore the idea of surgery and well who's going to do it and you know, where is it going to happen and what are the odds? And you know, like, is this going to make things worse? You know, could I die? You know, and that was one of those that they answered pretty quickly was you know, it's not a matter of if more a matter of when this could kill you. Tomorrow, it could kill you. a month from now it could kill you 10 years from now, but if it continues to bleed in the direction that we see it's bleeding, it's going to kill you. So the surgery could also kill you.

Derek 32:05

Very, very risky surgery. And I started meeting with neurosurgeons or you know, the, the guy, some of the doctors would send, notes out to their colleagues and say, you know, I have a patient, you know who amongst you feels like they could do the surgery. And some surgeons said, no, I don't feel confident that could be done safely and that he would survive or you know, and I was kind of going all back to, you know, I was 20 years old. I like to make that kind of decision was the scariest kind of moment in my life.

Derek 32:52

And like I said, I did a lot of soul-searching and spent a lot of time with family and friends. went on a leave of absence from work so I could focus on you know, taking long walks and drives and listening to a lot of music and spending time at my church and ultimately ended up deciding to do it and felt confident and ready, and that I'd found the right doctor and there's a whole like story about you know, finding talking to some of the wrong doctors or doctors that that seemed just like totally in Fantasyland about. It was really strange and kind of a random series of events.

Derek 33:43

Through like, my aunt, I knew a guy in Chicago or somewhere that from like 30 years ago that's a brain surgeon, and like he referred this to that, like this random series of events ended up getting referred to a surgeon in Dallas at a hospital near there, where I was that felt ultra confident about it. And I felt confident in him. And so I had the surgery on October 16, 2002.

Bill 34:17

Wow, that's a massive story. I relate to a lot of it because I had a similar issue with my doctor as well. I sacked my first load of doctors and I went to a different

hospital. And one of the reasons I did that is because they didn't have confidence in what they were telling me. And I'm not saying that my surgery wasn't risky. Opening anyone's head is risky, regardless, but again, was deep in my brain as well.

Bill 34:45

And I remember the first surgeon going, No, we're not going to touch it because we don't know what's there and we don't want to cause any further problems, which I understand. I'm very happy that they said that but then I was thinking about what happens if, you know we do need to operate later and you're not confident, I don't like going into surgery with somebody who's not confident I'd rather go into surgery is somebody confident.

Bill 35:12

And I know the risks. So I found another doctor who we flat. We just bluntly asked her the question, you know, we just said to her, listen, this is something that you can do. Are you confident in doing this surgery? And she just looked at us and said, I'm a brain surgeon. That's what I do. I do these things every day. So yeah, you can do this.

Bill 35:33

And I think we'll get a really good outcome, but there could be some issues. So you need to be aware that we'll have some issues, but we'll get rid of that blood vessel out of your head, you know. And that was it. And I said, Well, okay, so what's the plan forward? And then she said, Well, we'll just take our time. We'll do some regular scans.

Bill 35:51

We'll monitor it and we'll see what happens. And then my blood mine bled a third time nearly three years later, and she said the same thing to me. She goes, we've got to go in and get this out now because the risks of it staying in there are far greater than the risks of surgery. And you want to avoid this happening when you're driving or when you're with the kids or any of that kind of thing. I said, Well, I agree with you, I trust you, I've got confidence in you. And let's book it in so we did you know, what did you wake up with? Other than the vision issues? Did you wake up with any other issues?

Derek 36:27

Yeah. It's funny, like, cuz that common phrase, you know, it's not brain surgery. Like, man, when you're dealing with all this, it's like, it is brain surgery. Which, you know, it's like funny I have a friend from a friend of mine from high school who you know, he like he's a rocket scientist now like, literally works for Virgin Galactic. It is like, it is rocket science. It's weird when you get to these places And those phrases come up and like, whenever somebody says that I always have this brain surgery,

Bill 37:08

Brain surgery, which means it shouldn't be that hard, but now it is brain surgery. It's bloody hard.

Derek after the surgery

Derek 37:15

Yeah, I so going into the surgery that like I mentioned, you know, one of the risks, you know, I remember the day, the morning, you know, super early in the morning like 4 or 5:30 something like that in the morning, I had to show up and sign a waiver saying, you know, that I understood that I could die and you know, and I had to sign it. I want to do a DNR Do Not Resuscitate. You know, if I end up a vegetable or whatever, like, in a coma, you know, like it's bizarre, and you know, they told me that the risks of going into the surgery were that it could kill me or that if it didn't do that. that it could cause worse troubles on my left side probably bleeding on the right side of the brain causes problems in the left side of your body.

Derek 38:10

But they felt confident that they could get it all out. And that I would be fine. There was a lot of confidence in the room and I felt confident and relatively comfortable for 20 20-year-old going into brain surgery. But yeah, I ended up waking up. You know, it's like, all day surgery, eight hours, whatever, 10 hours I don't remember my mom she was there the whole time. And I remember waking up and there was just a bunch of people around in white coats and all that and they started testing me.

Derek 38:54

About, like, do I know what day it is what month, or what year you know, is it Day or night outside right now, if you look out the window kind of thing, who's the

president? Which I guess at the time was bush. Like, and then they started testing my limbs, you know? And so, can you squeeze my finger and the finger in your hand if you squeeze my finger, that kind of thing, and I remember them doing it on my left hand and I couldn't do it.

Derek 39:28

And I didn't get it. I'm still coming out of anesthesia, I guess, and groggy and all that but then they did my right leg. You know, I'm laid out flat in a bed and lift, can you they put their hand over my toes and say, Can you lift your leg and touch my hand with your toes and did that with my right leg and then they did my left leg and in my head, I was trying to move it and I couldn't move it to touch their hand above it. So I put my right leg under my left leg and lifted my left leg with my right.

Derek 40:06

To touch their hand and, and she said, I remember she's just like, Oh, we got a wild one here. Something like that, to that effect, they all laughed and thought it was a funny thing. I mean, I didn't even really know I was doing that. But I guess I just had kind of a problem-solver mentality or something like it hadn't hit me yet that anything had happened. But essentially, I woke up with the left side of my body completely paralyzed. Zero function from head to toe, my face.

Derek 40:45

The you know, the side of my eye. Total split just like my vision 50% split in the middle like 50% split down my body. The left side had zero function. I couldn't move anything. And so I guess that's when my journey started, you know, was like I stayed in the hospital for a month. They said I could leave when I could walk out. And so I you know, and then on October 16 and left on November 16 I could walk with like a cane or walker a few steps, but I could walk you know, I wasn't walking like but I can hold and support my weight with a cane or you know, the device and I was able to get a few steps outside of the threshold of the main doors of the hospital.

Derek 41:41

That was like the goal. Their whole thing was we need to get you walking in. That's the most important thing right away: trying to avoid letting my leg atrophy and never end up being able to be used properly again. And so I spent, you know, all day every day, for that month in therapy you know, occupational, physical,

psychological, cognitive, just began this huge program for the next several years of therapy was really how it went.

Bill 42:25

You're quite a long time out you're 18 years out. What was support like then as a young guy who was experiencing stroke and recovery? Did you have any support networks on the internet that didn't exist like it does now?

Derek 42:42

No. There were support groups within the hospital community, like so. You know, I was an inpatient in the hospital in a therapy program. And so I had there were other patients around going through it. Most of them were, you know, two or three times my age. So even though I had people around, I didn't have a lot of people I identify with, I guess, I made friends quickly with the older people and it was great. I still remember some of them very well. And yeah, the internet, Instagram, YouTube, Facebook, none of that existed yet Twitter and like, nothing like that. And so it was kind of guerilla-style, support and you know, I said to kind of lean on my friends and family.

Bill 43:44

As a young guy. Did you feel isolated?

Bill 43:46

Yeah, I mean, I was pretty involved in my church at the time. Do all this and they were ultra-supportive. Fellowship Church in Grapevine, Texas. amazing group of people. We're there kind of with me the whole time and, it was, it was but it was difficult you know, I felt isolated in like I didn't have anybody to relate to with it others there's a side story with a real dear friend of mine that I met through this that and she went through a brain surgery the same day the same place and like and we didn't know each other and we ended up meeting we had a mutual friend.

Derek 44:36

It's so strange. And yeah, we ended up getting to me and she had a rare disease moyamoya disease, which is super rare and she was 17 at the time and I you know, I was 19, 20 and you know, I got out of the hospital we were able to meet and we ended up dating. It was a really special thing, but it was also a complicated time and complex for both of us.

Life will never be the same



Derek 45:13

And I think especially me, kind of feeling like, my life would never be the same. Will I ever get any function back in my hand, my, you know, will my leg ever be able to run or you know, whatever, will my vision get better will I ever be able to drive again? And I kind of felt like life was kind of over as I ever knew it. You know, and I had been on such a kind of accelerated path into my career, having kind of locked in and I mean, worked hard to get into the internet industry right when it was taking off. Then all of a sudden had to put the brakes on because I almost died.

Derek 46:01

And I was able to move out on my own and I had to move back in with my parents. It was real dark times, you know, it was real difficult to get through that. And the support groups that I see now, are just so amazing to people like what you're doing with your podcast and your outreach all over the world to people like this is amazing to me because now I see people like that you've had on your show like that, you know, like I mentioned are still fairly close to the point of impact, you know, within the last few years that have just made so much progress and just seems so positive and ready to seize the day and that they know that there's thousands of other people out there that have gone through this and that can go on YouTube and see people you know who have hemiparesis and see how they do things with one hand.

Derek 47:03

You know, like seeing this guy, Jason Lester, who only has functional use of one of his arms, run Ultraman contests all over the world and be able to swim, you know, dozens of miles to open water with one arm like, yeah, like, I never would have,

you know, like to find those kinds of stories, I would have been into that kind of stuff. And to meet people like 18 years now and I still haven't met like, or randomly run into people like have gone through a lot of the similar same kind of stuff.

Bill 47:40

Yeah, where do those people hang out? It's interesting because I haven't found anyone, unless I go to a stroke event or some kind of an event where stroke survivors are, you very rarely run across somebody who's had a stroke and is happy to have a chat or is, looking out for you, and I think for me, one of the issues might be that I don't appear like I've had a stroke.

Bill 48:08

Yeah, I have the same problem. I've gone to work at places where people I've worked with for a year never knew. And like what happened to you? Like, I don't believe you, They never noticed that I only type with one hand. And it and that's kind of a blessing and a curse, right? You know, like, cuz sometimes it's nice for people, it'd be nice if they recognized like, the reason I'm acting the way I am or I'm doing something differently is because I had this issue, but I've managed to make it so. not noticeable, you know, and that's not necessarily on purpose. I mean, to a degree, yeah, I mean, but that's a double-edged sword, right?

Bill 48:57

Is It is and it an invisible disability you know people talk about invisible disabilities and as a result helps me relate better to people who have mental health issues and understand you know that one of the biggest issues is discussing this and talking to people about it and making them understand that appreciate what's going on. Did you experience some mental health issues with depression or anything like that as a young guy?

Derek 49:28

Oh, yeah. As I said, it was a dark time. And I mean, to be honest, like, me talking to you right now. This is like the first time I've ever talked with anybody on a like over the internet kind of in a video chat thing about this thing. I mean, I talk to people in regular day-to-day life about it quite frequently. People ask and are curious when they notice and I'm an open book and happy to answer questions or tell them the story. You know, it's something I'm proud that I'm alive to be able to tell the story.

Bill 50:10

Hi there everyone. I just wanted to jump in here and let you know that for the next 10 minutes of this episode, Derek and I will begin a discussion that is about self-harm. If this is something that you would rather not listen to, you can just stop this episode right here and not continue or skip to the 60-minute mark.

Bill 50:30

More importantly, if in the past, you have had thoughts of self-harm, I'd like to encourage you to seek out somebody that can support you with this in your local area, be it a friend or a personal. More importantly, if in the past, you have had thoughts of self-harm. I would like to encourage you to seek out somebody who can support you with this in your local area. Be it a friend or professional counselor, your doctor, or any other person that may be able to assist.

Bill 51:03

If you can't get out and about due to Coronavirus restrictions, seek out a professional who can help you online or over the phone. Please remember that it's okay to ask for help, and you can get through this.

Derek wanted to end his life



Derek 51:17

But yeah, for the first few years, it was a real, real dark time and there was a day, I guess, yeah, one day where it had gotten so bad that I almost attempted suicide. And it was kind of a real divine intervention kind of thing that I didn't because I it was like sitting on the side of my bed in my parent's house, like you know, I'd had to move back in. I had been in therapy all day and I went to bed at night saying, well, like, I'm going to go to bed. And if I still feel the same way in the morning, then I'll wake up and I'll just be done with it.

Derek 52:09

I woke up that morning, and I still felt the same way. And I felt like I'm kind of

done with this. Like, who cares? What's the point, there's no real it's not going to get better. You know, or it'll only get a little better, you know, and it's still just, it's just gonna, I'm never gonna get to go back to work and be independent again, at my parent's house.

Derek 52:34

You know, nobody's ever gonna love me. All the every thought that you know, I'm sure you and other people have been through facing this kind of adversity or coming up against a wall like this. And it's a wild thing to think I sat on the side of my bed and I thought, well, I don't want to do anything messy. I don't want my mom to have to clean up any blood.

Bill 53:04

You're very kind and caring like that man, you're thinking of ending your life, but you don't want to make it bad for somebody else. I'm adding some humor into that but I understand what makes people think in that strange way, you know, it's about relieving the pain and suffering that they're in. But obviously, somehow also do not want to create too much pain and suffering for anybody else.

Bill 53:34

If somebody's listening to this, and they are going through a tough time right now, I've just got to say, reach out to somebody that can talk to you that understands you, that relates to you. I'm more than happy for people to get in touch with me, Bill@recoveryafterstroke.com if you're listening to this podcast episode, and you're feeling that way, please just reach out and ring your local support organization.

Bill 54:00

Whoever they are, because there is a way through that. And Derek is a perfect example of somebody who's been able to get through that. And I have a lot of those issues and be independent. So I understand you, I know why you might have been thinking like that. And I made light of Derek's process of thinking at the time. But I know it's a serious thing. And I truly understand and believe why you might be feeling that way. So I'm glad that you didn't make that decision Derek.

Bill 54:17

I want to make sure that like, you said, If anybody's watching this, the thing that

struck me that day as I was about to do it is kind of a become a mantra. And it stuck with me for the last 18 years. You know, like I said, I don't want to do anything messy. So I decided I would just swallow a bottle of all the medications that I was on, you know, I mean, I was done like six or seven medications that had all the bottles next to my bedside, and like, I bet if I took all those would probably kill me, you know, and it probably wouldn't be too painful.

Derek 55:11

And it probably wouldn't make too much of a mess, you know, like so that's what I decided I was going to do. And it's really strange, really bizarre, but it was so quiet in the house and I knew my parents were home and it was it was early in the morning. But it was so quiet and it just was too quiet for me. And I just needed a little bit like because I'm thinking through this and like, Am I about to do this and I like think I'm going to do this.

Derek 55:43

I've got the pills in my hand and like, but it's too damn quiet. So I turned on the TV in my room. And it's really strange, but I turned on just whatever channel was on was on And, and the movie Good Will Hunting was on. And I don't know if you've ever seen it. But it's an amazing movie, one of my favorites, if not my favorite for more than what ended up happening but towards the end of the movie Robin Williams's character and Matt Damon's character are in a therapy session and Robin Williams kind of comes at Matt Damon and in the time of kind of talking about what he'd gone through its life of being an orphan and being attacked and abused and kind of why he is the way is and why things are the way that they are.

Derek 56:40

And Robin Williams his character reaches out to him and just says it's not your fault. And, he just kind of keeps going, it's not your fault. It's not your fault. And you know, he's like, Okay, I get it just leave me alone. Like No, it's not your fault, it's not your fault. And you know they hugged and he has a breakdown, he just cries and just is destroyed by realizing like this, all this stuff that's happening and happening and the reason that he is the way that he is, and it's not his fault, there was nothing he could have done about any of that stuff that happened to him.

Derek 57:19

And, and, for me, that's how I felt, you know, was like, I just felt so helpless and

destroyed by this thing that I had no control over, you know, like, this just happened to me. And I was blaming myself, you know, and my parents are blaming themselves. And, you know, like that it's my fault for that I'm not going to get to have a normal life again, or go back to work or be independent again, and I was blaming myself and it's just, it's just tearing you apart. And you know, it did and it got me to a point where I wanted to kill myself, and for whatever reason this movie was on when I turned on the TV at that exact spot.

Derek 58:03

And it was exactly what I needed to hear, and I don't know about you, but to me, that's divine intervention if there ever was a point of divine intervention in the world, I, that's not a coincidence too, like no like that was meant to happen at that day at that time. Does that scene that movie, whatever, like it was made for that? And I mean, I know people have those kinds of experiences all the time. And I don't think that is a coincidence.

Derek 58:35

Like, that seemed that those words that were written and that was filmed and it was acted like it was made to save my life. It's just incredible. And it lights which just went off in my head, like, what could I have done about this? Like, there's nothing I had, like I had from that point right there. That's when I decided like, it's not my fault. I have to get through this. Like, I have to figure out how to get through this like There's gotta be a way.

Bill 59:01

Yeah, an easier way for everybody to get through what they're going through. They've just got to be brave, to seek out their path. And then, and then get people to help them on that path. And on that journey, because everybody's different, and everybody needs something different. You know, when we connected the first time we connected on the third of April 2019. And you wrote, you would love to chat with me and share to reach people through the work that I'm doing. Your stroke recovery journey, you're talking about yourself was a positive one that you're blessed to have. Tell me about that. Tell me how has this experience become a blessing?

Derek 59:48

Well, I mean, it's one of those things you've learned through the process and through talking with other people that have experienced it and through talking to

with like, staff and the care facilities and that, in particular, as somebody so young when it happened, a lot of the most of these things happen to people later in life, you know. And so the recovery process and kind of the outlook and it's different when you're when you're young versus when you're old when this happens. I mean, there's not a real line in the sand, right? Like, like, here's where it becomes different.

Derek 1:00:33

But as it is somebody who has their entire lives ahead of them before they even fully matured or able even able to legally drink or any stuff. It's pretty different. And I learned so much about myself and about life and about people and about strength and perseverance and attitude and, like what I'm capable of and how to solve problems and how to connect with other people and recognize that we're all kind of dealing with our issues.

Derek 1:01:18

We're all broken in some way. We all have adversity in some way or another. And there's a lot of the stuff that I've learned I've been able to kind of help others with that knowledge or that kind of understanding, or maybe just the way that I've thought about things and how to work through some of the stuff hey, here's what worked for me. Maybe try this or here's how I do it or you know, I've been able to go into volunteerism and work in hospitals and with other stroke patients and physical therapy units and or just random families that, a coworker of mine.

Derek 1:02:05

One time, I met a family who had a child that had. I don't remember exactly. He had a stroke I think he was nine or 10, or something very young. And this was one of my co-workers who never knew anything had happened to me, like you're saying, like, never notice. And then one day, he noticed, we talked about a little bit and then he ended up at like a party with some people and they were talking about their childhood and had something similar and he's like, I know this guy you guys should connect.

Derek 1:02:46

Like, maybe. He asked me, Hey, can I give them your information and like that kind of stuff and can be with them and, you know, they had questions about you know, how, how should we approach this? How do you do this? Or, you know, like, how do you put a jacket on with one hand or, you know, brush your teeth? Very,

very trivial stuff to very complex stuff about like, dating and you know, sexuality and there's just so much that I've kind of had to work through that.

Derek 1:03:22

So, it just feels like a blessing that I've had the experience and then I get to know I've been able to go through the last 18 years kind of felt like a project, you know, like, rebuilding my life, you know, rebuilding my career and being able to go back to work rebuilding my independence and being able to live on my own.

Derek 1:03:46

And, this all happened in Dallas, and, you know, I moved to New York City in 2004. That was, one thing I did for me was to get away from where all this happened. And move on with life in this I chose to move to New York City and throw myself into the deep end of figuring out how to live an independent life and you know, in a place where you didn't need to drive. Because I couldn't. And that was one of the best things I've ever done in terms of therapy as I moved away and moved to the most, quote-unquote difficult place to live in New York City, for a disabled person.

Bill 1:03:48

Is it? I've been to New York City. It didn't seem that it was a difficult place to live to look. It looks like there's plenty of access, but maybe.

Bill 1:04:45

Yes and no. I mean, to me my experience, and again, this is in 2004. And I was there from, 04, to 07 and a lot of things have changed and there's been a lot of progress made in terms of accessibility. In recent years, there have been a lot of groups that have advocated for fixing sidewalks and making sure that the elevators and subway stations are operable even now with Uber and Lyft and everything in the city there's a certain number of accessible vehicles in the fleet that people are driving.

Derek 1:05:17

That's a thing that has been worked on, which is amazing. But back then, you know, no, not considered. You know, elevators were very often not operable, and the subway stations for weeks or months at a time. So I knew that I'd have to get off at the station before and take a cab because I couldn't walk 10 blocks, you know, that kind of stuff.

Derek 1:05:46

One of the most difficult things in regards to living in a city like that or anywhere really, because I don't appear that I have a visual impairment I run into things a lot you know, even though I've adapted to it real well I still run into people I still run into polls I still tripping hit a fire hydrant with my chin the other day, like, really hurt.

Derek 1:06:18

Big old bruise and like I was on the ground. Just didn't see it, you know, like, because I wasn't scanning well enough, sometimes I'm off my game but in New York City when you're crammed down in the subway station and people at rush hour and Manhattan, like there's, you run into things you run into people and one day, you know, I ran into a guy, I'm a pretty big guy. I'm six foot four and 200 pounds, right? Like most probably a bigger time, but I'm a big guy and I ran into an even bigger guy. Like, a bodybuilder type guy on the subway and I ran into him pretty hard, and he got upset about it.

Derek 1:07:05

Like, you know, you need to watch it, you know, watch yourself, bro. Like, it was like in my face You know, like, I'm sorry I've got a vision thing I didn't see you there like, yeah whatever bro like, you better watch it you know like, and it was scary you know like I'm real sorry and so for that reason when I went through now I have a white cane like you'd see it traditionally a blind person, low vision person using on the street. I went through cane training in case anything got worse with my vision because now half of my vision is missing. If anything happens to the good half. I'm in real trouble.

Derek 1:07:55

So I got cane training in early in case anything like that happens, you know if the good part of my vision starts to go, then I've already got the training. But they recommended that I always bring my white cane with me just so people recognize that I have an impairment, you know, and that there may be a reason that I am running into things or that I accidentally bumped into you on the subway.

Bill 1:08:25

I'm not looking for a man.

Bill 1:08:27

Yeah, you know. And that's been interesting to do that too. You know, sometimes I do. I don't bring it with me. I bring it with me everywhere. Pretty much I always kind of have a backpack with me with stuff like that in it. And in case I get into a situation where, but it's usually when I go to like an event where there's going to be a lot of people like a concert or something.

It took a long time to be ready



Bill 1:08:51

Tell me, Derek, why did it take you a year to get back in touch with me and say, I think I'm ready.

Bill 1:09:00

Are you offended?

Bill 1:09:03

Not at all. But I'm curious to know because I think a lot of other stroke survivors need to hear. Maybe, they need to hear maybe they don't if you don't want to share, that's fine. But I think they just need to feel okay that things take time. And when we get there, we finally get there. Then that's okay. Because stroke survivors put timelines and pressure on themselves to achieve things. And when they don't achieve those things by the timeline, they feel bad about it, So I'm just curious about what your reason was, and it doesn't matter what it was to me.

Bill 1:09:44

Well, there are several things and I think one of them just has to do with the nature of having a community online like this because this happened to me so

early on so long ago. Before all this existed, it was still kind of foreign to me, and the idea, and I only in the past, what three or four years even really got in touch with anybody online about any of this and started trying to connect with people about it outside of the people I'd met in person. And I start I was one of the things that I started doing was rock climbing. So I started doing I joined an adaptive rock climbing group in LA.

Derek 1:10:33

Amazing group of people. I never thought I would rock climb again with one hand and then I started searching, you know, and found some people on YouTube that you know, like we're born without an arm, you know, and were rock climbing. Just amazing. The one girl Her name is Shawna and she's is in Ireland I think. Forgive me if I'm wrong, Scotland maybe. Anyway, she's amazing.

Derek 1:11:03

She was born without one of her arms. And she's just the most amazing rock climber. And I was like, if she can do it, I guess I can too. You know, I used to climb when I was younger when my brother worked at a rock climbing gym, and so I used to go annoy him at the rock climbing gym. And, you know, I'd always thought, as I got older, I'd love to be able to do that, but I never thought I would be able to. And so when I saw that she was doing that I went to a local gym.

Derek 1:11:35

Shout out to Rockreation, they're in Los Angeles. I went and I said, Hey, I don't know if I could ever do this. But I saw a girl doing it online. And I'd like to try. And I said, Sure. We'll help you try. And I tried. And it was incredibly difficult. But they said, hey, there's a guy that works here. And He's, uh, had one of his legs amputated. And he's an amazing climber and he works here and he wanted to put together a group for adaptive climbing.

Derek 1:12:16

You should talk to him if you want, you know, like, maybe he can help you with some of this. And his name's Jake Sanchez. I think his Instagram is Jake, assembly required Laurila entity. And he's just amazing. Put together a group of adaptive climbing out of that gym there are people of all different kinds of disabilities and ages and from all different walks of life, and I started climbing with those guys and we were trying to grow the group, you know, spread awareness about that.

Derek 1:12:55

This group exists and where there's a will there's a way to get you on a climbing wall. You know, and so I started posting some videos on Instagram of myself doing it so that I could show people this is possible. And we'd love to have you come join the group because a lot of people just don't know that the groups like that exist.

Derek 1:13:17

And that's one of the problems like you mentioned about isolation and feeling like if you don't put yourself out there, people don't know. And so I wanted the group to be able to grow and so I started posting some videos of myself climbing, you can find them on my Instagram, which is at DVO photo. They're pretty far back there now, but because I haven't climbed in a bit, people started responding to those and I'm like, wow, like I guess there's you know, interest and that was kind of like my first taste of like putting myself out there as a stroke survivor and you know, sharing a bit about what happened in showing, you know, how I move and you know what, my situation is and trying to, you know, get people that might not be aware that that's something that could they could maybe do to be able to try.

Bill 1:14:16

So it was a little bit confronting for you to put yourself out there like that?

Bill 1:14:21

Yeah, it's not something I'm super comfortable with, like being the center of attention, or, you know, I mean, any of this, like talking about this stuff, like one-on-one with people or even in groups, you know, I've spoken to a few groups, small groups of people about this kind of stuff, like, I'm pretty comfortable with, I guess, the idea of on the internet forever, it's just weird to me. You know, like, oh, man, how am I gonna feel about this in 10 years, you know.

Bill 1:14:51

We're not doing anything that you're gonna regret. I'm not gonna see you naked. There's no challenge where you have to show me your butt cheek or anything like that.

Derek 1:15:00

Okay, I was just going to do that anyway. But no, and then I contacted you because I'd seen your, you know, your videos, and I was watching and listening

and enjoyed and thought what you're doing is great and just like, what a great cause, you know, to just to be able to share stories and I've never really kind of gotten involved in anything like that.

Derek 1:15:29

And so, at the time, when I messaged you, I thought I should do that, you know, like, I should try and just, it's uncomfortable. And I was at a time where I was I was climbing because it was uncomfortable and it was challenging and it's just kind of leaning into like I just want to push myself to do things that aren't so comfortable.

Bill 1:15:49

I love it when you said that. You started to explore the possibility of doing uncomfortable things. I mean, that's what stroke survivors need to do they need to do things because that's where the juice comes back into your life.

Bill 1:16:09

Yeah, I took singing lessons just because I wanted to do something creative. I have a background and visual arts and computer programming and nice thing I always wanted to do something musical but playing instruments one-handed is a different exploration. Yeah, so I thought maybe I'll try it with my voice and I just did it because it was so uncomfortable.

Bill 1:16:32

Awesome. I just had a look at Jake's website. It is not a website Instagram. It is Jake_assemblyrequired.

Bill 1:16:39

Underscore Yeah,

Bill 1:16:42

Yeah. And he's got he's got a little quote there that it says that I'm not sure whose it is. It says I hate being bipolar. It's awesome. I love his attitude and the way that he goes about it.

Bill 1:17:00

Oh man, he's an adaptive shaman to me like just the way that in his story and how he's persevered and what he's doing in the community to try and help people and encourage and grow and find strings and like I haven't been able to climb with

them for a long time that's the other reason that I waited so long was that I got ended up getting injured as well on my right side.

Derek suffered from an injury

Derek 1:17:30

So it's kind of a long story but I ride the metro here in Los Angeles and I ended up kind of getting caught in the doors of the train and noticed like my I can't often is just out you can see that but the doors you know, they close like elevator doors on the train, and I ended up getting my right side stuck in the doors.

Derek 1:17:59

And The doors on that train didn't have the safety mechanism installed to reopen if something gets stuck in them so apparently the trains or programs when they don't have the safety mechanism installed to just close harder instead of opening back and so I had my whole right side from my you know, shoulder to my knee stuck in the door and it was just closing on my right side is the most immense amount of pressure I've ever felt in my life it hurt incredibly bad.

Bill 1:18:35

And that sense has put me in a state of chronic pain just on my right side too. So now not only is my left side still partially nonfunctional. Now my right side is in a state of chronic pain, kind of all day every day. My shoulder, elbow hands half my hand are numb and so as somebody whose left side is mostly nonfunctional, I rely on my right side for like so much. And I've learned to do so much with one hand and one leg and my right arm and right leg are extremely strong compared to my left and now it's nothing but extreme amounts of pain and, all that.

Derek 1:19:26

I wanted to work through that before as well. I was hoping I would get better quickly. And it turns out it's not gotten better at all really, over the last year. And so that for that reason, I haven't been able to climb because I rely so much on my right side for climbing and, I've just kind of been in treatment in occupational and physical and cognitive psychological therapy for the last year to try and get my right side better. has been a miserable experience. And I didn't want to, you know, like, after it happened, it happened in March of last year, so just about a year ago. And I messaged you, I think right after that,

Bill 1:20:21

Yeah. Because I was feeling like I'm gonna get through this, you know, and I'm gonna be fine and my doctors were like really pushing you know, like it, you'll probably be a month or two you should be fine. And then I'd be ready and then it just slowly has never gotten any better and it's been miserable and I guess just now passing the year mark. I was like, this is just kind of a new normal for me now. Like, I think you had two recent episodes with younger stroke survivors as well that I listened to.

Derek 1:20:56

And I remember you mentioning on one of them that you felt like It was important to get, you know, to hear from younger people that this happened because it is happening to a lot of young people out there. You don't hear about it a lot. But you know, like I mentioned that, young child that I met with his parents, like he was like nine or 10 years old, you know.

Derek 1:21:18

I've seen some Instagram accounts that parents have made for their younger kids who are going through this just to show their progress and be able to reach out to some of them and say, would it be helpful if I made a video that showed how I do it as somebody older that has, you know, been through it but happened when they were about that age? And just hearing from you that, you know, you felt like it was an important thing to be able to share? I, I felt like, well, maybe I could do that. Now. I don't know.

Bill 1:21:47

That's awesome that you did and look, stroke survivors go through a lot. And often you hear from stroke survivors who experienced another injury or another trauma and it's a bigger issue for them because of the effect of the other issues that they're facing and the last thing they need is to have an additional issue. Yeah. And I get it, you know. So I'm glad that you've done that. And look, what I want to say to you is, you've been brave in your whole recovery. And I hope that this new version of you going forward and putting yourself out there is going to offer you a lot emotionally.

Putting yourself out there after a stroke



Bill 1:22:22

And I think that if you go down that path, emotionally, you'll get a lot of responses. And you'll start to feel better physically. And I got a lot out of being emotionally what's the word like prepared to be emotionally challenged by my situation, and the more I did that, the more I let go of pain and suffering, the mental pain and suffering and I was able to see that on the other side of holding up my emotions back.

Bill 1:22:57

On the other side of that was a relief and then the relief becomes physical relief as well. And I'm not saying that that's going to make your pain go away, it'll probably ease it because it'll give you another avenue of relief like you won't, you won't be experiencing this emotional challenge. And then the physical challenge, and then that won't be combined anymore. It'll be released. And then you'll be able to just focus on where the actual issues are.

Bill 1:23:29

And whether the pain or the suffering lies you'll be able to pinpoint better, the kind of work that you need to do to help release that as well, you know, down the track. So, Eric Henwood was 18 or 19 when he fell, and there's a bleed in the brain, so similar age to you. And, you know, he's done a tough, and as a result of what he's learned he's been able to grow and become a bit of a version of himself.

Bill 1:24:01

And a lot of stroke survivors say that, but it doesn't happen. And I'm telling you this so that you can hear about it so that other people can hear it as well or listen. It doesn't happen by staying isolated staying in your shell, not reaching out to other people by not sharing your experience. And by not talking about it, it happens when all those things are happening, because that's how you do self-

healing. That's how you do self-release.

Bill 1:24:32

And that's how you do all these things. And you take control of your experience instead of waiting for somebody else to fix you and somebody else to have the problem solved and somebody else to have the solution. All those therapists are great. Absolutely. And they're important and they're necessary. But when you go in and you allow yourself to be vulnerable and you allow yourself to express your challenges and your pain and your suffering and your anguish then you're releasing that.

Bill 1:25:03

And it's not being a burden on other people. It's just, you're releasing it. Most people don't know how to take that information on and be burdened by it. They don't even know how to help. So just sharing it, like you do in short amounts or in a podcast or whatever, you're gonna find that the more you do that, the more cathartic, those conversations will be.

Bill 1:25:26

Yeah, I'm not real sure what to do from here, you know, but I know that I'm, I've gotten to a point where I'm more open to the idea of putting something out there, like what we're doing right now. I mean, I was going to ask you about your experience and just like, I mean, you just dove right in and were cool with it, and like, Whatever happens, happens, and I mean, I'm sure it's been a journey for you just doing what you're doing, you know, and a journey of being comfortable with it, and feeling like you're doing it the way that you want and getting feedback and, all that, you know?

Bill 1:26:07

Yeah, I was really, concerned about doing anything that I'm doing right now. And I was concerned about what people would say, of course, I'd never had the experience of people saying that this is a great thing because I've never done it before. I never had growing up. I've only ever had the experience of people telling me that what I was doing was wrong, or was not right, or no one's going to be interested in that.

Bill 1:26:31

So I was extremely apprehensive. I didn't want to be wrong. I didn't want to not

do this. I didn't want to do three episodes and not get to 100 episodes or more. And I was just becoming I just had to bite the bullet, so to speak, and do every step and then experience the discomfort in every step. And I remember, releasing the first episode and then doing three or four and then just getting shit scared again and then going, no one's listening to this.

Bill 1:27:03

It's a waste of time, you know, who cares? Like, I'm not gonna even bloody do anymore. And then what happened was, I met somebody online or something inspired me and I thought we should talk about that on my podcast. And what I realized was I was not doing it for other people. I was doing it for myself.

Bill 1:27:21

Because I didn't have a community I wanted to reach out and learn from other people who would go through stroke. And I wanted to hear from them so I could grow so I could feel better about myself. So it was kind of selfish. But then, once I started to get the ball rolling, the selfishness turned into selflessness, and it started to make a difference to other people and they were telling me that it was making a difference.

Reaching out to other stroke survivors

Bill 1:27:47

And then the fear and the pain of doing it just melted away when somebody like you contacts me and says, Man, I just needed to hear that episode or that episode inspired me to do something. That's it. Nothing is stopping me now from making sure that I keep releasing podcast episodes so that other stroke survivors don't go through such a hard time as I went through.

Bill 1:28:14

I don't want them to do that. I want them to find us a lot earlier in their journey and be healed a lot earlier in their journey so that they can pass it forward to other people and heal them as well. And what I've done as a result of that is because I've met so many stroke survivors, I coach a few stroke survivors. And then that's amazing because coaching people is not dealing with their mental health issues coaching them is not telling them how to fix things or what to do things.

Bill 1:28:48

It's just to be there for them to have somebody's back all the time. And just to help guide them to their next milestone. And that is something that I can do. And I don't have to worry about all the other stuff that I had to worry about that I don't have to worry about all the other stuff that I had to worry about. So one of the things I did do is I got coaches. Again, I did it for myself, I didn't realize that they were going to benefit other people down the track.

Bill 1:29:26

So I got coached profusely, and I stopped seeing a counselor and a therapist who was telling me about who made me talk about my problems. I was rather focusing on solutions and goals and outcomes and getting there and overcoming the little obstacles that I needed to overcome to get there. And every time I achieved something, I looked back and I thought, wow, actually, I achieved that.

Bill 1:29:50

I didn't have the guts to do that before the stroke when I could walk or didn't have the guts to attend this course when I was healthy now on doing that, I'm feeling better about myself, you know, and I'm achieving these things, and I'm inspiring people, and I'm connecting with people that are like me. And for the first time, I feel like I fit somewhere.

Bill 1:30:11

And I've never felt that I've never felt that in my 37 years, I always felt that I didn't fit. So it's been a cool journey. And I had this awareness a little while ago, and I got really curious about it, you know, and I looked back and I said, Man stroke is one of the best things that ever happened to me. Some people lose their shit when they hear me say that, because how can that possibly be you know, and then I asked some time ago, I asked on Instagram, whether other people felt that way. And there were loads of them.

Derek 1:30:48

Yeah. I always say people ask me about it. I say it's the worst thing that ever happened to me. It's pretty tough. the thing to go through, you know, and everybody's journey is different and every the struggle that, you know, everybody in the stroke survivor community face. Everybody's kind of mixture of things that they deal with is it's not all one-to-one, you know? And so, for me it yeah is terrible.

Derek 1:31:23

I wouldn't wish it on anybody. Or I wouldn't say yeah, you shouldn't go have a stroke. Like you'll get to have the best thing happen to you too like, I don't want that like, but it's something that I'm so grateful to have the experience of and to have learned and gotten perspective and like you mentioned, like there are things that you wouldn't have done pre stroke that you're totally up for now, as a challenge.

Derek 1:31:48

It's changed the direction of my life completely. You know that that has happened. I think if it hadn't happened, I'd still be living in Texas, you know, probably working at the same place and I never would have ventured out and gone see the world and rebuild my life and be independent again I might still be living in my parents house you know as a guy who never pushed himself physically and just kind of let my body go to waste and you know, that happens to a lot of people that go through this there's a lot of people out there that are probably have seen your shows and watched all the videos on YouTube and seeing people on Instagram that they feel like it's too late or you know, that they kind of let themselves just kind of have the stroke decimate their lives.

Derek 1:32:41

And they haven't gotten out there and met other people and seen what other people can do and given a shot for themselves. And that's what the rock climbing thing was about for me: I never knew that was a thing that could be done. I'm so glad that I looked it up and went to a gym and gave it a shot and it changed my life physically like with my body and, my physical fitness and wanting to get outside of just doing things in physical therapy and occupational therapy and do things with an actual group of people.

Derek 1:33:10

And something fun and not doctor-prescribed. You know, like it was something that other people look at is difficult to do as a quote-unquote, normie, you know, like, it's difficult for people with fully functional bodies to do like so to go in there and do it with one arm and one leg and half your vision. You know, like, I would have never thought that I'd even attempt that, you know, but I found this group and if there's something that I can do and say and put out there that inspires somebody that never thought that they could do it to go out there and do it, then hell I want to be able to do that.

Derek 1:33:49

You know, I had an Uber driver that was he's how's your day and I was like, oh, man, I'm tired and he's like, Yeah, me too. and he pulled out his prosthetic, he had a prosthetic leg. And it was sitting in the passenger seat of his car, you know? So yeah, I'm having a pretty rough day too, you know, my leg's killing me making a joke he's an older guy, you know, probably in his 50s or 60s, maybe even probably late 50s Uber driver, and as we just started talking about, you know, he had been in a motorcycle accident and lost his leg.

Derek 1:34:29

And that's, that's what had happened to Jake. And so, I'm like, you know what I know a guy had that happen too you know, he's a badass rock climber, like, have you ever tried rock climbing and he's like, Oh, my wife would kill me if I tried to do that. You know, if I told her I was gonna go do that. Maybe I should. And I was able to, you know, connect them and I got his information and that if you want to go climbing like there, I know a guy that can put you on a wall. Like if you're feeling You want to have a physical challenge there's an older lady there that's gone climbing at the gym and she's probably 70s or something, you know, that just wanted to challenge herself, do some physical.

Derek 1:34:32

It's not like they're out there ripping it up, like competitively just you can get on the kiddie wall if you want, you know, and just to get active and get moving. And that's one of the other things as a stroke survivor that you need to do, especially if you have mobility limitations is keep your body moving, you know, use it or lose it they say.

Derek 1:35:20

The more you're keeping active, the better and so if there are people out there that have kind of found themselves feeling like it's not worth it, there's, you know, I'm too far gone, there's nothing I can do or I wouldn't be able to do that or there's nobody to support me through that. A little research especially now goes a long way.

Derek 1:35:55

In typing in on hashtags on Instagram, a stroke survivor or adaptive athlete or adaptive sports or there are people doing everything adaptive archery, adaptive rowing, and like adaptive climbing adaptive cycling, there's, I mean, where

there's a will there's a way and it's blown my mind the last few years that now I feel like if there's something I want to try, I'm sure I can find a group of people that are also trying it, you know, and a lot of them are doing it well. You know, so that's kind of where I'm at now, with having gotten back in touch with you and after being in my one-year post-second injury.

Derek 1:36:43

I'm just like, I just got to move forward. Everything's extremely painful now and I you know, I have doctors that are helping me with pain with both like natural healing stuff with like, breathing techniques and you know, engaging the parasympathetic nervous system and that naturally and you know I have a doctor that's given me some painkillers like gabapentin and ketamine and things of that nature that, you know, I've worked through for the last year to try and figure out what helps me not have a ton of pain sitting here as I have with you right now just sitting with my knee bent, like makes it feel like it's going to explode, you know?

Derek 1:37:26

So I've had it kind of stretched out and I'm sitting in a movie theater with my knee bent. I can't make it through Full Movie unless I have, you know, some kind of relief and I know that there are people that have shared stories about you know, and I went to a stroke, or chronic pain support group and people were talking, just sharing. Here was my experience with this medication and that medication and you should talk to your doctor about CBD or, you know, like, all these different things that if people aren't putting themselves out there, you know, then it's just like, it's just like, I'm back where I was in 2002.

Derek 1:38:04

And this happened and none of this stuff even existed. So, um, it's a great time for, you know, people who are going through it just now or just recently to find a way and find support, you know, I'm excited. It's just gonna make people heal faster and, have a better community around them. So I want to be a part of it. I just still trying to figure out like, where do I fit? I guess.

Bill 1:38:32

Yeah, you'll find your place man. Just give it time. We've come to the end of the podcast episode. If people want to get in touch with you, what's the best way for them to reach out to you?

Derek 1:38:46

I'm not sure. I guess. I haven't been as active on Instagram since I got injured a year ago. That's probably generally the best place and I've thought about creating a separate one. Just stroke-related, because my climbing videos and all that stuff got kind of pushed down by pictures of my cats. But, probably still Instagram. My thing there is @dvophoto, like my initials Derek Van Oss.

Derek 1:39:24

I have a background in photography, which is another weird part of my story. Being a half-blind, one-handed photographer, I've done a lot of work in the photography world as well. And, like, that's something that people I don't, you know, very rarely met very few people that have ever had the visual field cut like I do, but I've read about people online and forums and stuff and discussing it, and how debilitating it is.

Derek 1:39:48

I've been able to show that I was still able to work at a professional level as a photographer with half of my vision is kind of weird. To me, it makes me a better photographer. And then also driving, I can drive now I'm legally licensed. And that's something that most people with the visual field cut is the most scary thing is that they get told that they'll never be able to drive again.

Derek 1:40:13

And I was able to make it happen. And I and I don't think that that's very common and I think it's something that is very suppressed in the medical community that I, you know, I was told I'd never drive again and I have a license, you know, like, and I think that it's something that doctors kind of, because it's so unsure and it can be you could hurt someone or hurt yourself doing it wrong.

Derek 1:40:39

Doctors are quick to say you'll never drive again. And then it just discourages people that have had this kind of visual impairment happen, but I can be a living testament to saying it's possible, you know like I have half of my vision in both eyes and I'm legally licensed in the state of California. I don't have a car Right now anymore, um, but I just use the metro, but I want to drive I want to rent a car if I want to whatever, right? I'm licensed.

Derek 1:41:08

You can do it, you know, I mean, you gotta be safe, and you got to do it the right way. And that's something that I'd love to if there was somebody out there if they wanted to get in touch with me about like, how did you go about being able to drive again? Like this? What are the steps you went through? And is it possible and how I'd love to show them how to do it or, you know, like, if they're in California, I could go to them. Like, because I also do it with one hand and a bad leg. You know, so it's, it's not just my vision is gone. I you know, there's a lot of it's complex. For somebody that's done it. I'd be happy to be that kind of a person for somebody if they're out there.

Bill 1:41:53

Awesome, man. Look, I appreciate you coming on the podcast. Thank you so much for your time. Thanks for finding the courage to reach out. And I wish you well and as your T-shirt says, stay inspired.

Bill 1:42:08

Yeah, that's a good one right is a company called Into the AM. They have these shirts and this is one of my favorites when I want to go do a workout or whatever keeps me motivated. It's also kind of perfect timing, considering we're all stuck inside and we're all conferencing with people and supposed to be distance. This felt like a good time as well. But if I was going to sit and talk with somebody, this would be the way to do it. So now I can feel like I'm primed and ready to call like 10 people after this, to be able to say that I feel comfortable being on a video conference.

Bill 1:42:50

Good man. I'm glad to hear it. Derek, thank you so much for being on the podcast

Derek 1:42:55

Thank you for doing what you're doing and putting all this out there and want to help people because Like with the virus going around we got to get through all this together and I think the same with the stroke support we got to get through this together it's a small group of people going through all this that have experienced anything remotely like what other you know you're you might be experiencing out there so what you're putting together and doing I think is amazing and I'm honored to be able to be a part of it you know, like keep at it and looking forward to the next episodes.

Intro 1:43:34

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