

114. Vertebral Artery Dissection & recovery - Amy Wells

A vertebral artery dissection is not what you'd expect at 35 years young. In this interview, Amy Wells talks candidly about her stroke and how life has changed for the better in the last 12 months

Socials: <https://www.instagram.com/aimzwells/>

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Transcription:

Amy 0:01

I'm in, the hospital had a bit of a tear in artery. They're saying I'll be a bit slow for a few days, but you know, I should be back at it pretty soon. Which I guess it's a blessing to think to be like that, at that point in time.

Amy 0:16

You don't want to know what's necessarily ahead and what challenges you're going to run into. And you know, where that would be awful to sit in a hospital bed and be like, okay, you're going to come up against this, this, this, this and this, and the next 12 months you'd have a meltdown so that ignorance is bliss is

probably a good place to be and you just have to take it day by day.

Intro 0:40

This is the recovery after stroke podcast. with Bill Gasiamis, helping you navigate recovery after stroke.

Introduction



Bill 0:52

Bill from recoveryafterstroke.com This is Episode 114. And my guest today is Amy wells. At 35 Amy experienced an ischemic stroke caused by vertebral artery dissection. Before the stroke, almost every waking hour of Amy's life was scheduled and jam-packed with things that needed to be done, and events to participate in.

Bill 1:16

In our chat, we talked about what it's like for her and the family almost a year post-stroke, and how life has changed for the better. Now before we get started, if stroke has made you feel isolated and lacking purpose, you're not alone.

Bill 1:30

If you're fed up with the lack of progress during your stroke recovery, I want you to know that there is help available. Most stroke survivors have been where you are now and you should know that it is possible to get to the other side with a little support.

Bill 1:45

For years now, I've been helping stroke survivors beat fatigue, reduce anxiety, and get their confidence back from stroke. As someone who considers themselves fully healed after three brain hemorrhages and brain surgery, I will spend time with you, help you get clarity, on what the first thing is that you need to do to help you get past the roadblocks that are stopping you from getting back to your life before stroke.

Bill 2:08

When you sign up to one of the recovery after stroke support packages, you will get help from someone who was where you are now and has turned the corner to being healthy again.

Bill 2:18

There are different levels of support with packages offering private one on one coaching with myself. instant access to online training materials, access to courses, monthly trainings and challenges made by stroke survivors for stroke survivors.

Bill 2:32

All trainings are transcribed to PDF for people that prefer to read and take notes or highlight important bits for reviewing at a later time. You can access the training area 24 hours a day, seven days a week and complete training at your own pace without needing to leave the comfort of your own home.

Bill 2:49

People that have already taken action and done what you are still thinking of doing have described recovery after stroke coaching as leaving them feeling much more positive about themselves.

Bill 2:59

And this has a clearer understanding of what they can do to take responsibility for their own recovery. If you have tried another program and is still feeling the same or not much better off than when you were when you started, then you might want to consider a more tailored approach where support is designed specifically for you.

Bill 3:16

All support packages are free for the first seven days so you can see if you have chosen the right solution for you. To find out more simply go to

recoveryafterstroke.com or send an email to bill@recoveryafterstroke.com I answer all my emails personally. And now it's on the show.

Bill 3:35

Amy wells, welcome to the podcast.

Amy 3:37

Thanks for having me, Bill.

Bill 3:39

It's a pleasure having you here. Tell me a little bit about what happened to you.

Life before the stroke

Amy 3:45

Okay, on October 2019 life was babbling along as normal. Normal probably is a bit questionable now. I was you know, trying to do it all thought I was invincible. I had a job, which was quite stressful but demanding. I have two young children who I like to over commit to extracurricular activities.

Amy 4:15

I like to then take on their extracurricular activities. I'm not good at saying no like to jam-pack, the days and the weekends. I also exercise full-on pretty much every morning, every second morning of the week 6am before everybody woke up, and I socialized a lot.

Amy 4:37

So that's how I thought life was supposed to be until I had the shock of my life. I had a great day at the races on a Saturday last October and went to work that following Monday and just felt a bit off during the day. I thought maybe one of the kids might have passed on a virus and I was coming down with a bit of a cold or something.

Amy 5:07

As the day went on, I just sort of, you know, had a bit of a sore neck. And, you know, I couldn't really look over my left shoulder, I was like what is this? Must have been gone too hard in my workout last night.

Amy 5:20

Anyway, it was about three o'clock in the afternoon, and I'd walked out of the office with one of my colleagues and as we were walking back in with cups of tea. I looked at my feet, and they sort of went blurry.

Amy 5:32

And then I looked up and the room did a spin. And I felt Oh, that was a bit strange. So I kept on walking and as I sat down at the office desk, I felt my left ear being pulled towards the ground, almost like a force. Something I've never experienced before in my life.

Bill 5:52

Like physically pulled.

Amy 5:55

Like someone was pulling a string sort of out of my ear towards the ground, my whole left side. And I tried to sit up and I was able to sort of fight it. And I said to the guy in the office with me, I don't feel so good.

Amy 6:11

And you know, just getting a little bit sick or I don't know about this spinning and this force, and I said, I'll just lay down on the floor and put my feet up on a chair. This guy must have thought I was a bit crazy, but no, that didn't seem to fix the problem either.

Amy 6:29

And then a half an hour later, I said, I might just go home, so my colleague drove my car, drove me home in my car, and I got home and basically went to bed, my husband fed the kids and I think I must have fallen asleep because about nine o'clock pm, I woke up and tried to lift my head off the pillow, and it was that same force that didn't want to come off the pillow.

Amy 6:29

And then I sort of opened my eyes and I felt like I was on a roller coaster. So imagine doing like the loop at a theme park. I thought oh yeah, this dizziness is back. And when I did get home from work, I was self-diagnosing on Google, okay, dizziness, head spinning, what does this mean?

Amy 7:18

And obviously, that's not a good idea at the best of times. So yeah, I sort of caught

out to my husband. And luckily the kids were in bed and I said, yeah, I'm not good. I think it's hospital time. I think something's wrong here.

Amy 7:32

And he said, Okay, get out of bed and call your mom and get in the car. I said I don't think I can walk. And then I started becoming nauseous. And luckily, my mom lives around the block just around the block.

Amy 7:45

So she'd started walking over. And my husband got me a bucket and I sort of started growing up. And I said, Yeah, I think it's ambulance. I think, you know, I could hardly speak and, but we knew that we started to look a bit more serious than just a virus or food poisoning from the races on the weekend.

Amy 8:05

Yep, so an ambulance took me into the a&e. I spent the night you know, in a very bright emergency department laying on a bed, throwing up anything I had to throw up and my husband sitting on his chair and I remember if I had my eyes open and it looked like he was coming off the wall, so it looked like he was turned 90 degrees.

Amy 8:28

But if I had my eyes closed, it was like bright yellow strobing like hallucinations, memories I couldn't recall couldn't tell you about now because I didn't even know I had them in my mind. So it's obviously that subconscious. So really bizarre experience, which sort of didn't let up till about eight o'clock the next morning.

Amy 8:52

Funny enough, I could hear everything everyone was saying I was very much with it and even my mind wasn't a good hear exactly what the doctors were saying I could hear the cleaners talking I could hear what was going on in that emergency department and when they were talking about me I heard certain words thrown around like meningitis.

Amy 9:15

So you know she's got vertigo should be going home at nine o'clock in the morning me thinking to myself there's no way I can go home feeling like this. Yep, so the next morning, the physician came up and said, we're going to do two scans a CT and MRI.

Amy 9:34

So they got me to complete those and they were interesting because every time I moved my neck even slightly I threw up. So yeah, just looking back on that what an awful experience. And also embarrassed and I can't move my neck without throwing up these four nurses that had to get me in position.

Vertebral Artery Dissection

Amy 9:54

But yeah, once the MRI and the CT were done, they were able to conclude that I had a vertebral artery dissection on the right side of my neck. And following that, after a few days in the hospital, we did a die angiogram of my renal arteries and also of my brain.

Amy 10:22

And they sort of thought I had a condition called FMD, which I think that inside of your arteries, looks like a spring of pills. So it can look a little bit rougher than it's supposed to I guess that's how I interpret it.

Amy 10:38

And that condition perhaps was responsible for this more tear that formed and then the blood clot moved around to the tear and then broke off. So the stroke itself was in the cerebellum.

Amy 10:56

So as the blood clotted around the tear broke off, traveled up landed on my cerebellum. So essentially, that's what happened. Nine days I think in hospital. I didn't actually hear the word stroke for, I think about three days. You know like these doctors are talking, in their language they talk in and I remember the neurologist came in on a particular morning, my mom was in the room, and he came in he is bouncing around and he's saying, oh, yep, so yeah, these strokes are, you know, not so bad.

Amy 11:36

You'll be back to work. You'll be back doing what you're doing before like he seems very, very positive. And I just said to him, hang on did you just say stroke? He said, yeah, small stroke on your cerebellum.

Amy 11:48

I was sort of wind up back a bit. Hang on, hang on. I thought we're talking about a dissection. What's the dissection so to get it really spelled out at that basic level, I guess didn't really happen until I sort of got wind of what was going on and yeah a bit of a challenge because then when you hear the word stroke, that sort of alarm bells.

Bill 12:10

I'm too young to have a stroke.

Amy 12:12

Well, yeah, I just thought I had to be at work that day. I was like a stroke. How did this happen?

Fibromuscular Dysplasia

Bill 12:20

That condition you mentioned FMD fibromuscular dysplasia? And when you look at the images, the images it does look like the blood vessels look like a string of pills that have been put together and what it seems to do is therefore create the incorrect blood flow.

Bill 12:46

And because of the different places the Bloods got to go to flow instead of flowing straight across, bits gets stuck on the inside of the blood vessel and then slightly they just collect them together and together bits of blood.

Bill 13:01

And then when they get big enough, they just let go. And then they just move. So that seems to be what it looks like that might have happened then it's similar to what happens to people who have a hole in the heart.

Bill 13:12

And then the heart pumps the blood as per normal, but because of that little hole, the blood flow changes and the direction of it changes and then it gets stuck in a little bit of spot, and then it just increases in size and then it lets go.

Bill 13:27

And the first time they realize they had a hole in the heart was when they end up in hospital and they've been told the same thing that you were told. But yeah,

doctors. They're so good at what they do in order to be good at that. I think they've got to be bad at communication or something because most of them can't communicate if they like.

Amy 13:50

Yes, or they're just on a different level. Aren't they? And if it's not a crisis, which they obviously thought, you know, the crisis was over. You're okay, now it sort of gets downplayed.

Bill 14:06

So you're in hospital and then you're thinking you're going to go to work because that was my whole routine. That was why I didn't go to hospital for seven days. Because I had all these jobs to do. That's why I argued with my chiropractor who told me to go to the hospital with my wife, with everybody.

Bill 14:22

So then, the next day I rang one of my clients and I said to him, listen, I'm in hospital, and they reckon that I've had a bleed in the brain or something and I can't come to work today.

Bill 14:34

I know we've got to do this job. And I started balling my eyes out to my client thinking the world's gonna come to an end and fair enough right. Did you end up going to work like what happened that next phase how did you get your head around "I'm actually not going to be going to work today"?

Amy 14:54

Yeah, I think I was a bit delirious to be honest. Um, ah, the first thing I said to the irreligious was when will I be back at work? Work was my identity. You know, I'm a finance manager of a large hospital. And that's all I know is finance, accounting and deadlines.

Amy 15:17

You worked on a monthly cycle. So everything's so structured. You've got deadlines throughout the month and people that need certain reports and forecasts each week and what do I do my stroke happened on a Monday night so on Tuesday afternoons, we had a weekly video call with all the different hospitals in the state.

Amy 15:36

And I was thinking well, I'm probably not going to do that from the hospital bed at three o'clock today. So I had my mom call my boss and explain that, you know, there was no word stroke at that point. It was Amy's in hospital with the symptoms etc.

Amy 15:54

And finally, because my bosses are all ex nurses or ex-medical professionals, You know they have known ahead of time I guess what is ahead of me? And you know, I'm still a little bit delirious too and a little bit I'm invincible.

Amy 16:13

You know, this isn't that big a deal. Things will go back to normal. And I guess, resistance to accept. I'm much better at it now but yes straightaway I look at text messages that I sent people during that hospital stay.

Taking stroke recovery day by day



Amy 16:30

I was doing a cleanout last week and I found some text messages from October. And yeah, it was like gee I'm in, hospital had a bit of a tear in an artery. They're saying I'll be a bit slow for a few days, but you know, I should be back at it pretty soon. Which I guess it's a blessing to think to be like that, at that point in time.

Amy 16:51

You don't want to know what's necessarily ahead and what challenges you're

gonna run into and you know, that would be awful to sit in a hospital bed and be like, okay, you're going to come up against this, this, this, this and this and the next 12 months you'd have a meltdown. So that ignorance is bliss is probably a good place to be, and you just have to take it day by day.

Intro 17:13

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like now long will it take to recover? Will I actually recover? What things should I avoid In case I'll make matters worse?

Intro 17:30

Doctors will explain things that obviously, you've never had a stroke before. You probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation. Stop worrying, and head to [recovery after stroke.com](http://recoveryafterstroke.com) where you can download a guide that will help you.

Intro 17:52

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 there. 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.

Bill 18:16

I agree with you, I was probably oblivious to everything that happened for around six weeks. And then it happened again to me because the issue wasn't rectified immediately, and it couldn't be rectified for turned out up to almost three years.

Bill 18:31

But yeah, my identity was work. Running my business, my identity was telling myself that I needed to be doing that seven days a week, 12 hours to 16 hours a day, you know, from waking up in the morning being at the job to coming home and doing the quotes and then doing the paperwork and then doing the emails and then doing all that junk.

Bill 18:55

That my identity was I was going to be that guy. That's the only thing I knew a

dad yeah, sure that kind of stuff, but there was nothing else. Take that away. And then it's like, what I'm a guy in a hospital? Like I don't know what that means.

Bill 19:12

And it's one of the things that helped me. Eight years down the track go, okay, when somebody asks me, what do you do for a living? I'm like, I can't answer that question anymore. Because I don't say that I'm this or I'm that what I talk about is the things that I do on a daily basis. Some days I do this, and other days I do that.

Bill 19:32

And the things that I have, and I involve myself with, so that my identity can't be questioned by an event or by somebody. And therefore what it also does, it opens up possibilities so that when somebody says, do you want to do this, or would you do that? I don't say no, I don't do that. Because I'm this guy. I have a label. And I don't do those other things because I have a label.

Bill 19:39

I never used to travel, I never used to do all these things, and my wife started to bring in these little experiences to take me out of this very narrow-minded view of what, of who I was. And then I became somebody who loved traveling. And then I became somebody who loved trying a different food than I loved somebody to either become somebody who could handle eating a vegetarian diet, and it didn't mean that I was the worst person for not eating meat and all this kind of junk.

Bill 20:31

And it's a real lovely evolution because for the first time ever my identity came into question, and not by the usual methods, not by mom and dad going "we don't behave that way, Bill" or anything came in from idiot, you're in bed in a hospital. And it's a second time you've been here in six weeks for the same issue.

Bill 20:54

Maybe you're not a guy who works 16 hours a day, seven days a week, maybe you need to be a different guy, you know? And then the world opens up. And then I noticed myself while I was in hospital, making, more money, my turnover, increasing my days decreasing, my time on the job site decreasing everything going down except my turnover.

Bill 21:24

And I was like, What the hell have I been doing all this time? How did I have to

get to this where I was in hospital to achieve these amazing things without even trying? It's nuts. So how do you found yourself transitioning back into life? And what does that look like? Now, October wasn't that long ago. So you're pretty early on in your recovery? Where are you at?

Stroke recovery expectations

Amy 21:56

So it's almost 11 months so approaching the 12-month mark? Look, it's been really difficult. Take the hospital experience out of it. And I kind of just expected that within three to six months, I would be normal again, I'd be myself and when that doesn't happen, you know, it's really hard to handle and this recovery is not like getting a cold.

Amy 22:29

It's not like, I've got a cold, but tomorrow, I'll wake up and I'll be okay. Because that's generally what happens you have a cold and the next week, you're fine. It's not really the case. I've explained it to people as it's more of a quarter by quarter comparison. So, for example, the start of this year, I take my son to school and we'd cross this busy road and I'd have to hold on to whatever was on the footpath so like a phone box.

Amy 22:58

I put my hand on it to locate way and that would be how we get across the road. But, you know, I often think now when I'm crossing the road, it's now September, three quarters on, I don't have to touch that phone box. So that to me is progress. But that's nine months.

Amy 23:17

You know, that's, insane when you are someone that used to being results-driven. If I do this, this will happen. You know, I've done nothing wrong. I've done everything people have told me to do in this recovery. So stroke, you know, stroke survivors, get psychology, get into the nature exercise, eat well, I've done it all.

Amy 23:40

And nothing you do speeds this up. So except probably rest and rest isn't my strong point. So, where I am now, I guess is I'm a lot more accepting of what's happened. I'm not resisting it. Like you say, opens the doors to other things, and

I'm probably enjoying life more than I was before because I've slowed down and I can take things in.

Amy 24:10

You know, I've had so much time with my kids. My son started new school this year. So I've pretty much been there for every drop off and pick up. And prior to that, when I was working, I think I would probably be at school maybe twice a term. So I guess, you know, just little things like that and, my prior life I wouldn't have wanted to be at school, but now I find enjoyment in that and you know, you make friends with people and you make stronger relationships because obviously I'm quite open.

Amy 24:48

For the first half of this year, I thought I had stroke written all over my face. So anyone I meet anyone I met you know, almost use it as a disclaimer and say I had a stroke in October. So if I I'm looking at you funny. Or if I look like I'm off balance, you know, that's why there's something wrong with me.

Amy 25:06

And that's so silly, because physically, I wasn't really affected. And you can't tell by looking at me that where my head is at and how my foggy brain operates. But yeah, yeah, so I've got to the point where I'm not having to really throw that disclaimer out there in the first sentence of meeting someone, but you know, when you are vulnerable people will tell you about their vulnerabilities.

Amy 25:29

And I've had so many conversations this year that I wouldn't have had in my previous life. And it's just opened up my eyes to how rushed and stressed and perhaps how I was doing it wrong before because, yeah, I don't know how I'd go over that and talking to all these different people on a weekly basis. And it's kind of nicer,

Bill 25:55

I completely relate to you. I was 37 How old were you?

Amy 25:59

35.

Post-stroke realization

Bill 26:00

Yeah, I was 37. My kids were one of them was a teenager, one of them was in grade six. So I was going through the whole what are my kids thinking and worrying about and all that kind of stuff. And while they were thinking or worrying all those things, I was able to be with them.

Bill 26:20

And therefore, they were able to be less worried and less concerned. Of course, they were worried when they saw me in hospital twice in six weeks. For you know, all up for about, I don't know, 10 or 11 days. But then I had a good opportunity to start pulling my head in and going and doing things like, you know, when dad was an idiot, you know, a couple weeks ago? I'm sorry, you know, when I did that stupid thing two years ago, like, I know, now that was stupid.

Bill 26:54

And I started to build this connection with them. That was Like you did with the people that you've met, I've done it with heaps of people, right? Or that I didn't know that I also got to deal with my kids.

Bill 26:55

And then that next thing that it allowed me to do was go, if this ends badly, and I go to wherever I'm good, I've done what I needed to do. Now had three years before surgery nearly almost three years. And therefore, I just ramped that up, ramped up hugging and apologizing and telling everybody what a dickhead I had been and how I apologize for the stupid things that I had done.

Bill 27:35

And then that brought me closer to my circle of people that I was around all day, every day that I was mistreating because I was stressed, tired, short of time and running these stories that were created in my head.

Bill 27:50

When my head switched off, it completely switched off like I couldn't connect to it and makeup bullshit stories like that anymore. And I started to notice my heart actually in my chest. I Physically, I noticed something in my chest for the first time. And I wondered, What the hell is this? Like? What am I feeling in my chest,

it was my heart.

Bill 28:09

And those conversations that were pouring out, were waiting there. They're sitting in the background, while my head's doing all this bullshit, for 37 years, and then eventually they got a chance to come out and talk and say what they had to say. And then, I felt at ease with everything.

Bill 28:25

And I knew that my kids, if I croaked, it would not say, you know, we had my dad, he was a good bloke but he was always kind of pissed off and angry. And I was then highly motivated to be the guy that I know parents screw up their kids, that's just their job. That's part of what we do. But I was going to be the guy that was going to minimize the amount of damage that I was going to do to my kids as much as I possibly can.

Bill 28:53

Knowing that I can't control anything other than my behavior, how I behave. Pick-ups, Drop-offs, schools cooking. When I got the energy, my wife would go to work in the morning I'd go out and pick up a few things from the shopping center and prepare the meal so that when they all came home at around 6:00, 6:30 food was ready to go.

Bill 29:16

You know, everyone got to eat. I'd be exhausted most days that I did that. But if I broke it up and planned it properly, it meant that we could eat together as a family not rushed. And not sitting down for cook dinner prepared, you know, at seven o'clock. Oh my god. It was I had never experienced that life in all our married years and with the kids, I'd never experienced that type of old school, old style family life, you know?

Bill 29:45

And I would have traded my job for being able to just stay at home and be a stay at home dad. If my awesome clients didn't keep calling me but also if we were financially better off right. I would have just gone. I'm done. You know, like 180 degree turn is just completely improved my life so many ways, and I had all these issues that I never had before, you know, stroke issues like, most people wouldn't think that that's a an improvement on your life.

Amy 30:20

Yeah. Like a new-found harmony.

Bill 30:24

Yeah. And it came from this massive amount of what we call it like, chaos like it came from chaos and disaster. Just such a beautiful place to be. And I'm kind of still there. You know, like, I'm not really, I haven't really adjusted back. I haven't really gone back to my old ways too much. Of course, sometimes I'll work too many hours. But sometimes I have to but I'm aware that I'm doing that because I've just got to get by for that particular time. And then I'm going to go back to the new way of doing things.

Amy 31:01

Yeah. It's so great to have that perspective, which I don't think anyone can truly understand. I can't put it into words. And the old me wouldn't have understood it. Like it was all about status and how high you can get on the corporate ladder. And you know how many sports you can have your kids down for? Every night of the week, you know, are we doing all the extracurricular we need to and you wear everybody out, you wear the kids out you wear yourself out?

Bill 31:33

Yeah. And then you wonder why kids become hyper-vigilant and why they come always obsessed to put their head in a device or whatever, because they've had enough of you that don't want to bloody listen to your bullshit anymore.

Bill 31:48

They want a distraction, and they'll take it wherever they can get it. You know, and my kids stopped playing sport. I was devastated when they stopped playing sport what do you mean you're not gonna play sport? And really made them feel bad about not playing sport anymore. It was terrible that I did that to them because it started off as something that we're going to do for fun. And then I made it about me and I clued on that as soon as I made about me, they were like, no, I'm out of here.

Amy 32:15

Yeah. And also having the time to understand what your kids are into. So, you know, I've had extra time to watch my children and go, you really like making comics? And it's, you know, if you're stressed all the time and busy, you don't

have the time to sit down and really understand. What is it that these kids like to do? You just assume that they like what they're supposed to like or what society says.

Bill 32:44

Yeah. And you impose your model of the world on them. You then get kids to resent you because like, I like doing that stuff that you like doing, you know, Why should I do that? And it's a strange gift. Stroke can be a strange gift, you know, and I'm not saying that it's easy. And I'm not saying that it's pleasant.

Bill 33:02

And I'm not saying that you should like it especially early on Absolutely not. You know, you should feel every emotion and go through all the trauma and all the troubles and all the anger and everything, you should do it all.

Bill 33:15

And then when dust settles, reflect back and look at how you've changed and how you've evolved, and become a better version of yourself because of these lessons that didn't take your life that just came as a reminder that she has to change.

Amy 33:36

Yeah I agree.

Bill 33:39

How do the kids deal with that?

Amy 33:44

Yeah, obviously, like you the hospital stay. It's not great to see a mom in a hospital bed. But at the same time, I don't look any different. So from that perspective, I guess it's been lucky, if I was struggling physically, then I think that would have impacted on them a little bit more.

Amy 34:07

However, in saying that old mom has gone and there's this new mom that gets really tired and you know, I have only recently just being able to start kicking the football with my son or, you know, any sort of neck movement up until about nine months ago, up until about the nine-month mark just made me dizzy and made me feel sick instead of vertigo.

Amy 34:31

So I am different, but I think it's a blessing that they don't see it and I like to think I'm pretty tough and deal with it internally. And yes, I've might go to bed at eight o'clock every night. But you know, that's not impacting on them. I'm home and I can help with their homework, I can help with a research project.

Amy 34:55

I can take them to the school and pick up and drop off and so I think the loss probably got better. But yeah, there's definitely times where I mean my daughter, she's five, she probably feels a bit more than my son who's eight. Whether that's a female intuition type thing.

Amy 35:16

She, I think is struggling with it a bit more. She doesn't like seeing mommy tired. And I think it's sort of just worn off a bit more on her. So she senses that I'm struggling some days and yeah, she's regressed a little bit in some areas. But I think she starts school in January. So hopefully, when she's got a full structured day, that's full week where she's busy and you know, wearing myself out and that might improve. But yeah, on the whole, I've been quite lucky.

Bill 35:53

Interesting, isn't it like five year old child dials straight in knows exactly what's going on. And can feel what you're feeling and has enough awareness and consciousness to say no I don't like it when mom's tired.

Amy 36:10

She, yeah, I was talking to a neighbor the other day and explaining obviously what had happened to me and why I'm not working at the moment. I said, I had a stroke last year, and my daughter was standing next to me. And she looked up and she said, it was in October. And I thought, oh, okay. Yep, it was they, listened to everything. And maybe I need to be a bit more aware of that, because she's probably heard the story multiple times.

Bill 36:39

Yeah. My kids probably got sick of me talking about it and basically do the same thing to you. That as you I have to tell people that I had a stroke because sometimes I would just fade out like while I was talking, or I couldn't get the word out, I would get stuck when I speak or whatever, you know?

Bill 36:57

And I would tell people and often it would come up when I was eating because I really changed my diet a lot. So to decrease inflammation, I really changed my diet. So part of what happens in the brain is the stroke happens. And then there's an area around it there's a technical term for I don't know what it is, where, where the deficit is happening from, as well as the area that's actually physically died.

Bill 37:22

And that area is the area that's going to come back over time. As things get better inflammation goes away, the healing happens, it comes better, right? So I wanted to take control of something that I could, and what I could take a job was what I used to eat, and my diet wasn't the best before Coke, two or three days, two or three cans a day.

Bill 37:42

Smoking, alcohol, all that kind of stuff. And I'm not saying that somebody should never indulge in one of those things, but really sugars like that. They don't really help they increase the fatigue. So we would go to places and I would have a salad and Grilled Chicken and a mineral water with a little bit of lemon in it.

Bill 38:04

And people would go to me, are we going to have dessert again? I'm good. Don't you have dessert, no I don't eat it. And then I would try and avoid the conversation for as long as I could. And then eventually I'd say, look, had a stroke, blah, blah, blah, the kid was sitting there, their eyes be rolling back, because then the conversation goes to the next level.

Bill 38:23

They think oh my god, here we go. And of course, I did that you guys need to stop eating sugar so much and they were like oh my god, this goes on and on and on. And eventually what happened was, I just let them be themselves. And I just stood up, and I lead by example without preaching.

Bill 38:44

And then I just accepted that they'll come to their version of balance in their own way, but at least they've got somebody to refer back to when they have a question to ask about something that's troubling them. That was similar to me when I was

in trouble you know with your daughter I mean what a great example to set to a five-year-old when you're tired you rest when you feel unwell you rest instead of soldier on.

Resting helps heal the brain after stroke

Bill 39:24

Go to work and smash another five hours out you know what a great example. What you know about stroke recovery and how your brain heals you know that it happens when you rest what we want for our daughters and our boys when they're recovering from being unwell is we want them to rest and when they're growing and we want the growing brains to grow as healthfully as possible, we want them to rest as much as possible.

Bill 39:49

Because at night is when the gold happens. It happens when we slip this awesome book called why we sleep I forget the guy's name but I'll bring it up in a second. And he talks about how at night, the cells decrease in size, they kind of shrink, and they separate from each other.

Bill 40:09

And they allow the cerebral fluid to get up into the cells and do this kind of a wash and drain all the toxins out of the brain and get it out into the excretory system. And that only happens at night when you're doing REM sleep. And stroke survivors will tell you that they often struggle to sleep after a stroke.

Bill 40:35

And it's all sorts of reasons why, if they dial that down, if they can get their sleep cycle, kicking in and better. They're doing so much to support their brain in recovering more than they would if they know more than they could ever imagine that it does for them. It is such a fascinating thing that people especially in Australia probably in other Western countries go yeah, I only slept for three hours last night.

Bill 41:04

I mean, I don't need to sleep more than three hours. I'm good to go. Dude like stroke survivors, the more you sleep the better. You're in that really cool phase of knowing how if we transfer what happened in our brain and how to heal the brain

into the how to develop a brain like you're in a really cool space because you're learning about how to get yourself feeling good in that put that into a child's brain and then bang you've got an amazing healthy you know creative child who with a really, really sort of happening brain.

Amy 41:47

Yeah I've seen quiet myself to my five year old in many different ways. Yeah, cuz I basically I'm retraining my brain she's developing her brain and at night. I have this little ritual where I balance on one leg on a piece of foam to help with my cerebellum repair and balance.

Amy 42:08

And she sees me doing it. And last night, she's trying to stand on it with me, and she could probably almost do it better than me. But like, how good's that to teach your five-year-old to balance on a piece of foam? Well, that's difficult. And um, yeah, my son who's eight can't do it. All that well. But it's, you know, I'm doing something that an eight-year-old and a five-year-old can't really do that well. It just yeah. So I try and teach them to do it too. And we can all do it together.

Bill 42:36

And it's really helpful. You people don't realize how powerful that is. But that means that you, if you can balance better, that means you're less likely to fall, that means you're more is activated better, which if your cause activated better, then when you get a dizzy spell, you can, you know, stabilize yourself, you can make sure that you've got a little bit of time to respond and react.

Bill 42:54

So it's amazing and the kids, a lot of them don't have that because they don't exercise enough and I'm not saying Now take them and do 10 times more exercise, but they don't exercise enough because it's sitting down too much. their bellies aren't activated. And they should be able to stand on one leg on a piece of foam. Like their kids. They're the ones that are going to be able to do better than anybody.

Bill 43:14

But look, it's not about that. It's lovely that you're in that stage where you see how this could this thing that you're doing to help yourself is rubbing off. Like it's a beautiful thing. And you do it together, you know? connecting over balancing on

a piece of foam.

Amy 43:33

I know I would have thought hey, um, yeah, stretching on the ground and throwing a tennis ball against the wall trying to catch it on one leg and yeah, I think balance is good for kids too. Their coordination.

Bill 43:50

Who in your family was the worst in a crisis? For me it was my dad like the time I ended up in hospital the first time. He forgot to take his blood pressure tablet or something collapsed at the house and came to hospital in an ambulance.

Amy 44:17

Oh, because you went there?

Bill 44:20

Because he found out that I was unwell in hospital. He went to work and then ended up in hospital and I was in the stroke ward and I had to come down to see my dad come to visit me in hospital in the emergency room, connected to heart machines and all sorts of stuff.

Amy 44:40

That's crazy. Funnily enough, my 84-year-old grandma was in hospital, the same hospital around the corner for me when I was in hospital after having a stroke, but I don't think it's for the reason your dad was it was more so heart fluttering. Yeah, I was walking around with a walking frame to visit her room you know to try and push get moving and get better and get back to work and get life back to normal.

Bill 45:08

That's what I was doing. Who else was terrible in a crisis around you? Or wasn't there anybody?

Amy 45:17

I didn't think there really is anybody I mean, it's been a learning process for everyone. There's no history of stroking our family at all. And I guess people deal with it and dealing with it in different ways. But you know, my husband seen it from the beginning from that night in my bed when I was on a roller coaster to you know, now being out of fill my days with more things, and I think he's

managed the process really well and has been positive for the whole thing.

Amy 45:55

I mean, I guess I found difficult is you know, it's such an invisible problem and people want you to be normal and people want you to be better. So yeah, I think my mom is super positive, optimistic lady that you know, she can't really get it down, go back. It's amazing.

Amy 46:21

And in the early days, you know, we didn't know straight recovery was a one to two-year thing. We thought we thought it's just a small obstacle to get you need to get over and you should be like, okay, so maybe on the weekend, we can do this, this and this, and I'd say yeah, okay.

Amy 46:38

And then we get to the weekend and it would be, you know, one of the bad days of the week and we physically just need to be in a quiet room. And not much fun to anybody. And, you know, I'd have to say, No, I can't do that. And I think that's been the hardest part is me thinking I'm letting people down or I'm having to say no to friends.

Physical limitations during recovery



Amy 47:00

Like, I don't want them to stop inviting me, but you know, come out to dinner at seven o'clock on the weekend and I'll be thinking, but I go to bed at eight o'clock.

And it's really hard to sometimes I kind of wish I had a sign to put on my head to say, you know, it's not normal, or, you know, I was walking down the beach last night and I was thinking maybe I should get a T-shirt printed on the back says I had a stroke, I walk slow or it's that I'm trying to get other people to understand what you're going through.

Amy 47:35

And while everyone's been great in a crisis, like beyond great, it's I think it's they can't understand it and it's only a straight about the cat.

Bill 47:47

My wife's been on that journey now as well. As long as I have in the beginning. It was really difficult. You know, I do remember her saying to me like it's getting old enough. And me getting really offended about that, and thinking that she was telling me, you know, to get over it and just, you know, be better.

Bill 48:09

And she wasn't really saying that she was really saying it's getting old for her that she's struggling through not having me the way that she remembers me being and all that kind of stuff. And not wanting to go out in public because too much noise was affecting me, or on a particular day I'd be wasted or whatever.

Bill 48:30

And I remember traveling overseas one year and Christine's amazing. She's the kind of person who, if you want to go overseas, just give her a buzz and she'll itinerary, the whole thing for you to the nth degree. Yeah, not one thing. There's no one thing that you miss.

Bill 48:48

However, what that means is that I don't get time to just do nothing when I'm overseas because she's overseas and it took us so long to get there and money and all that. So I want to say as much as I can I'm like, man, I can't do that, like I need a day where I'm doing nothing.

Bill 49:05

At least please give me one of those so that I can do those other things The next day, you know? Yeah. So we would go somewhere and I would say to her, listen tomorrow, do not expect me to be up and about all day to do all those things that you've claimed. Don't expect there is no chance. And she'd go all right.

Bill 49:25

And then if I had a good night's sleep and woke up feeling well, I'd say to her, you know those things that you wanted to do today? They're on baby let's go and she's like are you sure? Are you just doing that because you want to make me happy? No I'm feeling really good.

Bill 49:41

I want to do them let's go like strike while the iron is hot you know? And we started, it took some time, but we started to get to that point, just through a lot of conversation about how it made me feel how fatigue made me feel, and me reminding her about how fatigue when she was fatigued a couple of times, for example, in her life how it felt well, but I reminded her of how, when you're fatigued and completely wiped out remember that day?

Bill 50:10

Well, that's how I feel most days, you know. So that was the only way for me to get my to get an understanding across for her to go, I can relate to that. And I'd say to her like, and it happens all the freakin time and I can't stop it from happening and I can't just rest and switch it off, you know?

Amy 50:29

Yeah, you can't predict it.

Bill 50:31

Yeah, which is the worst part, right? And, and then what I would do is go to parties. And I would hang out, like on a stool on my own in the corner. Just try and quietly get out of, you know, the, business of the party and just try and be there so that people could say, ah, he came and then maybe they wouldn't notice me sneak away into the corner and just sit quietly and just chill.

Bill 50:59

That made it easier for me to be there a little bit longer. Yeah. And then not make them feel like, you know, Bill never rocks up anymore because, people who are living outside of the house, are even harder to bring on board and make them understand the ones living in that house are doing it hard enough, but the ones outside the house even worse.

Bill 51:21

And then what I found was that as I sort of stretched my being out time from 8:00

to 8:30 then I realized where my new normal was, and then it started to creep up and creep up. And I don't enjoy being out till one or two o'clock in the morning at all anymore. I can't because then I don't sleep enough hours to feel good in the morning. But if I had to, I can get through it if I had to. But back then we often sort of said it's 11 o'clock. I'm going home.

Amy 52:00

And there's nothing wrong with that.

Bill 52:03

And my friends didn't understand and how could they the only way they're gonna understand is if they had a stroke and bloody hell. We don't want anyone to understand us that way.

Amy 52:13

No, it's kind of like being a baby or like a young child is sometimes how I explain it in, they need their rest, you know, they get to have a playdate and they play for two hours straight and then they all pop all end up piled up on top of each other. It's almost like that they've drunk too much alcohol. It's like that tipping point. And you need that risk to regenerate. And yeah, it's very much like it's being a child. It's like having an immature brain again.

Bill 52:42

Yeah, I I you stole away also then took it upon myself to use it to my advantage a couple of times as well. Yeah, yeah. So it did some stupid I would say, Hey, guys, I've had a stroke.

Amy 52:56

Get away with more.

Bill 52:59

After about five years you kind of got, enough. How are your work colleagues? Being that they're all from hospitals? How are they sort of relating to you now that you haven't been back to work?

Amy 53:19

I couldn't ask for a better response from them. They, right from the beginning. You know, I've got different contacts there that I speak to regularly. And some have said from the beginning, you know, this is a 12 month journey for you. And

I'd laugh and be like, no, it's definitely not how dare you say that I always get offended.

Amy 53:42

But then I had one that straight up said to me, you know, you need to treat this like it's maternity leaves and people take 12 months off to go and have a baby. And obviously, she knew that I'd had children and well while working and sort of listen to that and thought, yeah, okay, I can do that.

Amy 53:59

You don't lose what you know, through maternity leaves, you get back and there's a bit of a transition period to, you know, get that from the folk. But yeah, like we have recently had some chats, and we've got a bit of a plan in place to start up in a couple of weeks.

Amy 54:17

But yeah, with some limitations. So as I approached the 12 month, Mark, there's no way I would have even been considering taking on work, even probably three months ago, that something's turned a corner at some point, which I can't quite identify. Also, just the more people you speak to, they give you those two years, don't they?

Uncertainty

Amy 54:42

And they say you've got two years to technically rebuild the brain cells, or do as much as you can in your recovery. And while physically it's been tough this last 12 months and a lot of the time I don't know if I'm standing up for where I am in space. But as that improves with my phone balancing, you know, I want to start pushing the mental side of it. And intellectually I know I can still do the job. It's whether I have the stamina, the fatigue allows it, whether cognitively can be as quick as I used to be. So all those, you know that all those little challenges are going to be coming up.

Amy 55:29

And yet it's all a bit of the unknown, which is a bit scary. But I won't know unless I try. So I want to use those two years to jam in as much as I can. Because that's my mentality is Go go go. And I don't want to regret anything. So I don't want to

get to two years and mentally say, Oh, well, that's my recovery done.

Amy 55:52

I didn't try hard enough to get my cognitive thinking going. And yeah, I guess you I've got a bit of a challenge, a different phase of the recovery coming up. And I'm expecting it to be very, very tough. And you know, I've been told by you know, the professionals and the people I work with a lawyer on the weekends like this is going to be hard for you don't expect it to be easy. But yeah, it's something I do want to try. I don't want to left it, leave it. I'm not ready to close the door.

Bill 56:28

Yeah. No, I agree. I was never an office kind of guy. Yeah, it was worked outdoors because we had a property maintenance business. I still have it. And that business was it was I was unable to go back to a fully for for many, many years. And at around the six year mark, I was completely wiped out or probably about around the five and a half year mark, which was about a year and a half after brain surgery.

Bill 56:55

I was completely wiped out. But I was wiped out through issue with my thyroid, which creates neurological fatigue the same way as the strokes did, they just happen to one come after the other, right. And I went into an office for the first time in a long time in probably the first time in about 15 years to do an office job.

Bill 57:18

And I remember sitting in front of a screen and trying to get through the first hour or two, and then being wiped out completely, and then struggling to get through the rest of the day and recover and do all those things. And then as time went on, I ended up being employed there for just just less than three years.

Bill 57:39

As time went on, the ability to stay in front of the screen and do those heavy, heavy lifting with my brain, you know, thinking and solving problems on a computer started to increase and it started to get better and better. And it was like it was like a physical recovery of the brain in that the before that cover that part of the brain recovery couldn't have happened if I didn't sit in front of a computer.

Bill 58:05

So I had to do the stuff that I was doing outside of an office, which was happening, you know, through rehab through my nutrition through all those things. But then there was this part that I had to do, which I didn't realize at the time, but reflecting on it now, which was in front of the computer.

Bill 58:21

And that slowly allowed my mind to get more resilient at dealing with bright lights in an office and all that kind of stuff. And I asked them to switch off the two lights though on top of my head. And we put a filter over the screen, and I wore glasses with a filter. And everything that I did, added just a little bit more time to my day, so that by the end of the three year mark, I was no problem.

Bill 58:50

You know, like any other staff member, able to be completely functional for eight hours a day and productive for them and do my job. They were extremely happy. In, in taking me down that path, I didn't have the awareness of having the conversation with them again, at the beginning, sorry, and saying, you know, my brain doesn't do well with lots of light, fluorescent light, and it doesn't do well with lots of noise.

Bill 59:14

So I didn't create the right environment for a healing brain when it when they get back to work. But you're in a situation where you can have a conversation about that. And they already understand that because they're medical people. So you're, really, you're well set up to achieve success in that space. And don't don't put a timeline on it. Yeah, people talk about two years, but it might be three might be four.

Bill 59:43

Others might come back and things might work in six months, other things might not work for a different amount of time. So I found that by not having a deadline on those types of things, but having little goals, and it worked better because my goal was for example, to be able to be present. for eight hours at work, but I didn't put a timeline on when.

Amy 1:00:03

Yeah, sure.

Bill 1:00:05

That takes the pressure off. And then it doesn't make me feel like a failed at the 24 month mark, you know?

Amy 1:00:13

I think it's, um, I was I've listened to a lot of podcasts during this time. And I heard something on one a little while ago. And, you know, you go, Okay, so I want to achieve this. So and that might be a particular row or a particular number of hours a day, whatever it may be, but it may seem daunting, and you know, to me going back to work is a little bit daunting.

Amy 1:00:39

But it's all about breaking it down into steps. So think about where you are. Now, that's step A. Step b is, you know, do your three hours a day in the morning, two days a week. And then once you get to B, you go to C instead of saying, oh, I've got to get from A to Z.

Amy 1:00:58

And that's anything in life, really. Looking at A to E, well, it can be quite overwhelming. And you have to get to B, C and D before you can get to E. So I'm just trying to take that approach in really not looking too far ahead.

Turning corners

Bill 1:01:15

Yeah, absolutely. And I think you continue to recover and turn corners all the time. Like I spoke about it. I think it was just a couple of weeks ago, on one of my posts on Instagram, you know, I spoke about how I had, I've turned another corner, you know, and in COVID, I've been able to actually focus so actually sitting at work and working in a computer is one thing.

Bill 1:01:43

But focusing on for extended periods of time is another thing and for me, that's another layer to the spin able to sit in front of a computer and work being able to sit there and focus without distraction. Like that's another level. So I found I found myself because I'm in Melbourne, we've been in lockdown for 37 years. And I know where I'm still in lockdown.

Bill 1:02:07

And I don't know if we're ever going to get out of bloody lockdown. But I've been

really productive in this last six week block. And, and focused, really focused. And normally I wouldn't be able to do that, you know, where I find myself spending 12 hours a day in front of the computer with breaks and coffee breaks and all that kind of stuff.

Bill 1:02:29

But without even noticing that I did it and not feeling like shit at the end of it. And it's doing work that I love. It's all about the podcasts, right I'm putting courses together, thinking about meditation challenges that I can create for people. I'm thinking about who I'm going to interview next and transcribing it and doing all that kind of stuff.

Bill 1:02:48

But that don't just happen in the last six weeks and I've been doing this podcast since 2015. And it's been a bloody pain in the ass struggle. that entire time, but the value and the joy that I get out of it made it impossible for me to stop. But nonetheless, like, I haven't been able to focus on it, and it was happening episodes would happen intermittently.

Bill 1:03:14

And all the work that I was able to happen just infrequently. And now it's kind of been like, just bang, like on point. So, I'm eight years down, and you still turn corners all the time.

Amy 1:03:27

So it does happen. So you have to you really have to expose yourself to it to train your brain again, which is what I keep getting told by the, you know, the doctors and it's another phase if you don't try, you're not gonna know.

Bill 1:03:42

And you're early on, Amy, I mean, you're so early on. And what they do is, we haven't spoken about it a bit. So maybe we can, like, how did you I'll ask the question, and then I'll explain why I'm asking it. So my question is going to be at the end of this little next section. It's going to be how you dealing with it psychologically?

Bill 1:04:05

And because dealing with it psychologically, for me they do not also offer another level of leveling up and another turning point in how my brain heals, and it

sounds weird, but if I deal with my psychological issues, then the healing in my brain happens differently and better and takes another level. So I how have you experienced the whole did you do the whole? Oh my god, I'm mortal thing?

Amy 1:04:36

Yeah, I think I went through phases. So I know it's kind of like great isn't that I don't know those seven phases off by heart. But yeah, there was denial for sure. That was the hospital phase. And then there was a fear phase and which brought on anxiety so because that day when the stroke happened, I remember how I felt. I felt like I was getting a virus I felt like I was getting a cold.

Amy 1:05:03

And I had a really sore neck like someone was sitting on my shoulders and you know, I had anytime I feel a little twinge in my neck, I would go doing oh my goodness, oh my goodness, I'm gonna have another stroke. And that's kind of passed now, but that was awful.

Amy 1:05:19

That was, you know, that's only just sort of passed in the last two months. And the more people that tell me the physios the GPs and neurologists you know, these dissections are quite rare to happen twice, especially in the same spot and you know, you could have professors telling me that I still wouldn't believe it I'll be I'll be the one that has it twice.

Amy 1:05:38

And so there's that fear. There was frustration there's still frustration you know, I if I exercise for more than 20 minutes I get dizzy. So if I live quite near the beach, I can handle 20 minutes if I went for 30 minutes. Oh, that dizziness would start kicking in. springs on a bit of anxiety, what if I fall over and public?

Amy 1:06:05

So, that's bizarre because I exercise of exercise a lot in my life, I kind of live for it, you know, used to teach aerobics at one point have played different sports. I like long-distance running and to not be able to do that that is also a loss of identity, which has been awfully frustrating.

Amy 1:06:28

And, yeah, I guess with the fear with the frustration with the denial, eventually you have to accept and, you know, move on, and this is how it is now. So I sort of

reconfigure your loss to how it is or keep dwelling on what happened. So psychologically, it's the hardest thing I've ever had to deal with, like hands down. Just Wow. Like you cannot describe it to anybody.

Amy 1:06:59

It's It's just, it's a roller coaster. And like you say, you might wake up one morning, feeling like you blacked out for the day. I can't do anything today. But along with that comes frustration and fear. And I feel really tired today, but I didn't do much yesterday. So does that mean, I'm going backwards.

Amy 1:07:18

And you know, back in January this year, I might have had five bad days and two, good, two semi-good days in the week. But I can say now that those bad days are nowhere near as bad. So I'm not I'm very rarely sort of bed bound. Now, a bad day might be just staying home doing not much and resting and sitting on the couch a bit more.

Amy 1:07:43

But I think I, you know, tend to have maybe four good days a week so it does shift and that helps you psychologically as well when you see those shifts and when you can cross the road without holding on to the phone box. But it's slow. And it's tedious and you have to be very patient and all of these things I'm not I was not so I'm a different person.

Amy 1:08:11

Yeah, it is a complete 180 I now have to be patient I have to become there's nothing I can do that's going to speed this up and I saw a psychologist straight up after the stroke happen because I was told, you know, get some psychology that's what strikes others do so I saw one. And she was good at the time. But now I switch to a new one. He uses the David Schwartz technique at some about internal family systems and labeling your parts of your body and I'm finding it really really effective.

Amy 1:08:52

So it's, yeah, we focus on why have you got that pushy part? You know you've had a stroke you can rest it is okay to respond. sit on the couch and I'll look at the ceiling and I'll say that ceiling, it's really dirty. It needs painting. We're gonna paint the ceiling. So I'll call my dad often you'll come over and we'll paint the

ceiling.

Amy 1:09:09

And the psychologist will say, okay, but we don't want to be painting ceilings, we need to address this pushy part and trying. Yeah, we try and isolate it, talk to it. So we're having a bit of success with that. I've only seen her three times. But um, yeah, I think I think psychologically, your podcasts have been really good.

Amy 1:09:29

Particularly like the ones where you've spoken to other survivors that have had the vertebral artery dissection because it's, you know, I can relate to it and also the young girls that are in their 30s. And I've, you know, I've made friends with Kelly, and we talk a bit on Instagram.

Better after stroke



Amy 1:09:50

But it's Yeah, it's a it's a new life and I'm a much clearer about what, what matters to me now. And I am a better person, and there are silver linings. And there will continue to be silver linings. But where I'm going to go and what I'm going to be you know, I think there's lots of possibilities.

Amy 1:10:13

And as I start to feel better, and my focus gets better and my brains less foggy, I kinda want to use this experience for the better. Like, I want people to know, and kind of like what you've done. You know, there's, people out there you can help and I want to share and I want to I kinda want to show the world that just because something bad happens to you. You can overcome it. And yeah, I'm not sure how that looks right now.

Bill 1:10:49

That looks perfect it looks the way that it needs to look for right now for nearly a year. And what an example you're sitting for your children, you know, you didn't take these things lying down, and then I just fall into a bowl of mess and then just, hope that your life is over and blame things, you know, blame everything on this one experience.

Bill 1:11:12

Like, it's not what you do, you know, it's the seven stages of grief, a shock and denial, pain and guilt, anger and bargaining, depression, the upward turn reconstruction and working through and acceptance and hope. I mean, you've gone through all of those. And now what happens is what I found was that you cycle through them one at a time again, and again and again.

Bill 1:11:34

I went through it shock and denial. Every time I wanted to do that old thing that I used to do, again, frickin Hell, I can't do that still, why can't I do it? And for me, it was bike riding, you know? Yeah, and I still love riding my bike. And I don't ride it like those guys in lycra or anything like that. I just ride it just for just for the sake of riding.

Bill 1:11:55

And I remember getting back on my bike and then my foot falling off. pedal because I couldn't feel my foot and then the pedal scraping my shin and destroying machine, you know, then I got a stirrup, I tied my foot onto the pedal. And then I would go to put my foot down.

Bill 1:12:11

When I stopped the bike, forget that my foot was in the stirrup and not get my foot down, fall over. Oh my god, I can't do that either. And then I discovered, you know, so I went through all those prices. And then I discovered electric bikes, which meant that my left foot didn't get tired, it didn't need to be in a stirrup. And now I can ride because the motor is doing most of the work.

Bill 1:12:34

And I don't have to worry about falling or any of that stuff. And I'm back and that took four years to get to that point, you know. And I wasn't going to like you, I wasn't just going to accept the fact that no, I can't do that. And that's not going to

happen. Because just before I bought the two-wheeled electric bike, I was considering a three-wheeled regular bike because that meant that even if I got tired, I didn't have to worry about resting and stopping myself from falling.

Bill 1:13:04

But what I discovered this electric bike so you know, we get there we go through the cycle over and over again and you'll get there one of the things that I do want to mention and discuss with you is just that idea that when you get to the 30-minute mark of exercising that you can start feeling dizzy again and seeing how much of that is the fact that you're getting there.

Bill 1:13:28

And you're getting sick or the fact that you're expecting yourself to get there and getting sick and therefore making that happen. Now, I could be wrong, right? But there's an expectation and an anxiety level that builds up at 30-minute mark. What makes you think that you're not setting that up at around the 15-minute mark and then creating the environment to trigger you at 30 minutes? Because your body will do what you set it up to doing what you tell it to right. So when your body realizes that 30 minutes are up, it's Go. she's expecting this. Let's give her this.

Amy 1:14:03

Yeah, yeah.

Bill 1:14:04

I could be wrong. But a lot of people have these ideas again, that they create in their brain, in their head about what it means you know what all this stuff means and the meaning they give to it they might live up to. So be careful the meaning that you give to things because if that meaning is not a supportive one, and you're living up to it, and you're not noticing, well, you might be the person who's getting in the way of your own recovery. You know, possibly, yeah.

Bill 1:14:34

And I was that guy, because I used to do that, to do that to my wife. You know, I used to sometimes have those days where I talk about, you know, how I'm never gonna do this again, and I'm never gonna do that again. And I would just devastate her. And I realized that I was never doing those things because I was the one that was saying that she wasn't saying that to me.

Bill 1:14:55

It was me and I was living up to my words and as a result you know, I created one of the one of the presentations that I did for a group, probably a couple years a bit years ago now, maybe three years ago was a presentation that I've labeled words like weapons, you know, they win sometimes.

Bill 1:15:16

And I talk about how one of the people that I was in recovery with was calling his hand a bastard and every time he called it a bastard it didn't do what he wanted to do. As soon as he changed those words to friend, that hand moved and did what it wanted him to do. Like, it was a one-word, the time difference was 30 seconds.

Bill 1:15:37

And the achievement was dramatic improvement in his ability to move his hand just because of that word. So he was setting himself up. Because a bastard hand is not a supportive one it doesn't do what you want it to do. It lives up to what you call it. When he called it his friend man that was a compliant hand. It didn't have a perfect function, but it was just compliant.

Amy 1:16:05

Yeah, I've been told it's a bit similar, but speak to yourself like you're a child or like you're a baby. You know, don't be so aggressive and don't be so angry towards yourself. So, and I've actually got a written on a pink post-it note from psychologists that said, that says, you know, speak to yourself in a kind manner like you would to a little person.

Be kind to yourself

Bill 1:16:33

And don't speak to yourself in a tone of voice that you would never speak to another person in. You wouldn't speak to your friend like that. Why would you speak to yourself like that? It's a really important thing to remember and just catch yourself out when you're doing it.

Bill 1:16:52

That doesn't mean you're always going to be perfect. That just means that you have a bit more awareness and when you do, stop and treat yourself how actually go. You know what? Omar, I forgive myself, I'm sorry for speaking that way. And

you can just get on with it. You know, what I love? About what you said is that you've connected with Kelly.

Bill 1:17:14

And you guys are friends and you talk from time to time, because of my podcasts. I mean, my God, that is amazing to hear. I really loved that you said that, you know, it's the most brilliant thing that I never expected would come out of a podcast that I would connect people and help people find other people that could relate to that were like them.

Bill 1:17:39

And there was another time that that happened to me was when somebody asked me from New York, whether I knew instruct survivors in New York, and I said, Yeah, I do. I know about four. And I was able to connect somebody who's in New York who didn't know any stroke survivors, two stroke survivors. We're in New York and I'm on the other side of the planet.

Amy 1:18:07

no worries a lot. We have a lot in common and um, she's in Hawaii at the moment about to move back to mainland America. And I just recently moved house so it was kind of just going through a lot of the same stuff. Yeah, when her when she turns her neck her eyes make her feel dizzy and it's similar to what I experienced. And she does some really good like, Instagram stuff about physical recovery and different exercises. Yeah, she's quite inspiring, inspiring person.

Bill 1:18:43

Yeah, she's lost a paperweight she realized that maybe she was eating way too much and indulging way too much on you know, those things that that we love, potentially dine support us and she does a lot of awesome assizes she had a stroke at 32. Yeah, she was on episode 99. Kelly. I can never pronounce a surname.

Bill 1:19:09

Something like that. And she was just really, really cool to interview as well, because she was so young and she has so much. She's so inspired, you know, to overcome and get better and achieve and then also help others. And it's just brilliant that everyone's helping everyone. I mean, that is the one thing that struck survivors seem to do heaps off is just that's it. I know something. I learned one thing that helped me, I'm going to tell everybody about it.

Amy 1:19:40

Yeah, and you should because it's hard. It's so hard. I think you're doing a great job. Keep it up. I really love listening to them.

Bill 1:19:51

Thank you so much. Well, do me a favor. When this one comes out. Listen to this, as if you're not the same person just so you can have this third person perspective of your own stories that you're telling yourself about this recovery. Right?

Amy 1:20:09

That's gonna be psychologically hard, because I'll just want to criticize, you know.

Bill 1:20:16

That'll be the next level of learning. And you know what, and then tell your husband when he's on the way to work when they are wherever he goes in the car, to put it on and have a bit of a listen, because that will also help him in this process of understanding you having a conversation to a stroke survivor, which he doesn't ever hear.

Bill 1:20:33

He doesn't ever hear this backwards and forwards between two stroke survivors. It's going to give him a better understanding as well. And hopefully, it'll help him with the things that he's feeling that I imagine. He hasn't really been so upfront in telling you about, you know, carers tend to be stoic, but I reckon they need to be given the permission to be vulnerable as well and to feel like they're freakin over it or whatever.

Amy 1:20:59

Yeah. Yeah, definitely over it.

Bill 1:21:04

Amy, thank you so much for being on the podcast. I really appreciate it.

Amy 1:21:08

Yeah, I've had a great chat. It's been really good Thank you.

Intro 1:21:16

Discover how to heal your brain after stroke go to recoveryafterstroke.com.

Intro 1:21:26

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Intro 1:21:55

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Intro 1:22:11

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Intro 1:22:34

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Intro 1:22:47

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