

46. Young Stroke Survivor - Jenny McAllister

Jenny McAllister a young stroke survivor at 21.

At the age of just 21, Jenny McAllister suffered a massive brain stem haemorrhage and became a young stroke survivor. Jenny was given less than 1% chance of survival. The brain haemorrhage was caused by an abnormal blood vessel (AVM) that was congenital from birth which meant that no one knew it was there.

Jenny went from being a fit, healthy young woman who was living life to the full to being on life support with no mobility, limited communication and a severe physical disability. Jenny experienced Locked in Syndrome which meant she was fully aware of her surroundings but couldn't move or talk.

Jenny's Blog - <https://www.wren2rebuild.com/>

Tableware products - <https://www.ornamin.co.uk/>

Assistive technology facebook group - <https://www.facebook.com/atchatwithus>

<https://www.facebook.com/groups/241407313033708/>

and disability review - <https://www.facebook.com/groups/DisabilityReview/about>

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Jenny 0:01

I didn't go home for, 18 months I lived in hospital

Bill 0:05

wow

Jenny 0:08

yeah so it became home so at 21 my friends were going off to university and I was going off to rehab wards and lived in a hospital for, yeah for 18 months and then I remember actually really looking forward to coming home and i don't think anyone prepares you for that transition and I was so excited and I remember going home and actually being really really upset because it felt like, it just didn't feel like my home anymore and So many things had changed the trees in the street had grown and places looked different and it just felt that home was the hospital I had become so i suppose institutionalised

Intro 1:00

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

Bill 1:07

Jenny Welcome to the podcast

Jenny 1:09

Hi Bill thanks for having me i am really excited to be here.

Bill 1:13

Same here. I get excited about all I've cast that I'm going to do but when I looked into what it is that you do I got excited next level because what you do is you create products that help people and before we go into that tell me a little bit about what happened to you

Jenny 1:36

Yep so just over 15 years ago at the age of just 21 I was like any 21 year old I was living life to the full and I was living in UK at the time and

I was working in the city, so corporate my working really hard and but also partied very hard as well and worked all week lived for the weekends and just a normal 21 year old living life to the full and I was also studying part time and ironically I was studying anatomy and physiology so I'm learning about the body. and and yeah just was really fit healthy was always out and about mountain climbing rock climbing on my bike you know really sort of active. I had migraines probably for about two years before my stroke.

Migraines run in my family so I just put it down to that and also put it down to the fact that I was working all the time and studying part time and I was just really stressed and had a lot going on and then probably a few months before my actual stroke, I just kept getting this really horrible feeling in my gut, almost like a sinking feeling that something wasn't right. I didn't feel unwell but I just knew that something in my life wasn't feeling quite right it didn't know why or what.

So it was the day of my final exam for college and my mom kept saying to me, you look really pale you don't look well. I said I'm just really stressed it's my final day of my exam. Once i get the exam out of the way I'll be fine I'll have a break and mum said I'll come and meet you, when you finish the exam I'll meet you, we'll go have a drink at the pub and celebrate. But I've gone off in the car drives the promise of my car.

And then as soon all I remember is falling over or going to fall over but had no control of my body. I literally went and I just remember wanting to shout and nothing came out. And. and it was almost like slow motion that i was falling over. And that's all I remember. And at that moment I've had a massive brain haemorrhage and collapsed on the floor.

And a guy who was pulling into the car park where I was just parked he had only recently just done his I don't know what they call it in Australia but in the UK. It's like St John's ambulance so it's like a voluntary where you learn voluntary CPR

Bill 4:43

I'm smiling. You know why I'm smiling?

Jenny 4:45

No

Bill 4:46

because in Australia it's called St Johns ambulance

Jenny 4:48

oh, well there you go then. And he's just done that probably about a month before for work and so he drove into the car park, and he has seen me on the floor by my car and he though i had dropped my car keys or that i had dropped something on the floor. And then he noticed that I wasn't moving so he parked his car and

walked over and when he got to me I was blue, my eyes had rolled back and at that moment he believed i had died, but he did CPR on me and managed to get my heart back and called the ambulance and then, ended up being rushed to the hospital had a had two respiratory arrests and a cardiac arrest on the way to hospital and was put on life support and that was the beginning of what has been a really tough 15 years of recovery yeah and learning to get back to being jenny again I suppose

Bill 6:02

Wow, you really went to the next level to you know, be a stroke survivor

Life Support For Young Stroke Survivor Jenny McAllister



Jenny 6:09

I didn't do it by halves i definitely went all out and yeah. So ended up on life support and was told, my family was told to prepare for the worst and they were told that where the haemorrhage was in the brain It was so deep they said that less than 1% chance of people survive. So and they were prepared for the worst. And so yeah i was on life support. And then ended up with locked in syndrome and which somebody has talked about on the podcast before I listened to that one, so yeah ended up with locked in syndrome. And it was about another 6 months before I could actually talk again. So it was a really it has been a really difficult recovery.

Bill 7:08

Yeah, so when you were locked in, were you able to blink a least?

Jenny 7:13

I could blink but I couldn't move or talk and that was the, the first time I moved was probably about eight weeks after the initial haemorrhage. But my but i couldn't actually talk for another six months after that,

Young Stroke Survivor and Locked In Syndrome



Bill 7:27

You know, when you're locked in you're 21 years old. I know with the stroke like there's certain things that weren't able I wasn't able to comprehend because of the damage and you know, you lose a couple of those things. Yeah, but when you're 21 and you're locked in do you recall at all what, and if it's not too traumatic for you to talk about it, what was your thought process?

Jenny 7:57

so for me, um I'd say touch wood but touch wood the stroke didn't affect my memory or my intellect, it was literally all of my motor skills, so and also in the brain stem which affects all of your vital organs, so heart lungs and everything like that. Um a lot of people said to me and friends said to me I just assumed you was in a coma the whole time. But I wasn't I was awake from the moment I was put into resuscitation I was awake the whole time. So locked in syndrome was really hard to describe to other people and it's funny I had no idea what was going on. I just remember my mom sent me afterwards you looked like a rabbit in the headlights you just had that face were you looked so frightened you where aware of everything going on but your eyes said it all all.

I think I was just so scared that I couldn't communicate. I couldn't you know if I was in pain I couldn't say I in pain, if I was scared i could say I was scared, i remember having an itch under the and I couldn't tell anyone that I had this itch for hours, and i think just that mental um, i don't know if its mental trauma but it's almost like a mental nightmare where, you knew exactly what you want to say and exactly what you need to do but you can't do it and then there were days when I actually felt i was going crazy and that scared me more, the thought of going crazy in that in my body um was really quite, quite traumatic for me.

And so I would literally watch the clock from the moment I woke up to the moment I went to bed I would watch that clock and i would just talk to myself I would tell myself stories I would um, imagine I was on a beach somewhere. I was just trying so hard to keep my my head in a good mental space because I knew if I, at any moment if I allowed myself to go there I don't think that would have come out there it was it was pretty dark

Bill 10:26

Were you able to cry and have tears?

Jenny 10:30

I could cry but I couldn't, no tears would come out so I could pull the expression but nothing would actually happen

Bill 10:38

yeah

Jenny 10:39

yeah

Bill 10:40

at the time now looking back now and advice for other loved ones whose whose family member is locked in what do we tell them to tell the person who's locked in? So you're

Jenny 10:59

I have to say my family was fantastic in that my mom said to everyone and this is a kind of a rule in general and that no one was allowed to come into the hospital room or ward feeling unhappy, sad depressed or crying. That just was a role she said "you can't go in there and take your shit in with you because she's trying to

get through this” you’ve got to go in there and it was almost as if we all pretended that everything was all right.

We knew it wasn’t, but mom would say to people, if you’re not coping don’t go in there. Because she sees you not coping, she’s not gonna cope. And i think because and even though I knew they weren’t coping inside i could see it in there face, I think the way they treated me and the way they spoke to me, it just was kind of like they were my safety net. So I would wait from six o’clock in the morning to visiting time I would wait all morning for them to come.

And I knew the minute they were there I could almost calm down because I felt like what ever happened in those two hours I’m okay. My mum and dad are here my brothers are here I’ve got my support. Um for me the biggest issue was actually the doctors. The doctors and the nurses and the way they spoke about me and my situation, while I am laying there and i can hear everything your saying and I can understand everything your saying, It was really really negative.

And really kind of um, there was no bed side manner and no, the language that was used was really quite hard to take in. You know they’re talking about a dire situation and making, making it sound as shit as it possibly can be while your laying there hearing it all and I wanted to put my hand up and say I can hear you and I can hear everything your saying and yeah that’s probably the biggest thing that I’d like to do is go back and tell these people just be aware that when people are locked we will hear what you’re saying

Bill 13:22

Wow. I had my experience with doctors initially when I was diagnosed the first six weeks with the bleed in the brain was talking about me at the end of my bed and not including the conversation. And I was furious and I would sit there and I was half out of it, but I was not locked in and of course are so cranky about it that I decided that I was going to get out of there. I had, I had a friend of mine who was a radiographer at one of the main Melbourne hospitals the Royal Melbourne Hospital and I said to him, get me a doctor who will speak to me get me out of here.

Jenny 14:02

Yeah,

Bill 14:02

And their care was amazing but their bedside manner was terrible. The diag the diagnostics was amazing. Everything was amazing, right? No, no issues there. And then when I left and went to this other hospital, the royal Melbourne and, you know, met up with my surgeon who the person who later became my surgeon, you know, Dr. ah Associate Professor Kate Drummond. at the time, she was an associate professor I'm not sure if she's moved on since then.

She just ,she was just out with it. She told me exactly what I needed to hear answered my questions spoke to me did not, you know, and when she spoke to her team, she spoke to the team after she spoke to me after she informed me. I just loved her for that and I thought that was great no matter what the outcome I was going to be really comfortable so

Jenny Experienced Bad Bedside Manner



Jenny 14:51

isn't it isn't it kind of ironic how you can have a top hospital with the best medical equipment but if you've got staff who don't know how to talk to and treat you, it doesn't matter if I've got the top MRI scanner it's actually about the people who are looking after you day in and day out that is important.

Bill 15:14

Yeah, Most important I feel like if you can manage and it's the same thing it's like managing their state and their shitty day and their 16 hour shift and all that kind of stuff. So I kind of feel for them I get it. It's difficult for them to be on their game so long so often now they're under so much stress and so much duress that you can, you kind of get it but it's still not good enough. I mean if they're not going to be well don't be well elsewhere be well outside of the room ,so I get it but look my heart goes out to them I love them we wouldn't be here without them

so

Jenny 15:53

no we wouldn't,

Bill 15:54

Come on guys. So you were in, it took you six month months to talk?

Jenny 16:02

yeah so um. What happened was because I said the bleed was really deep in the brain stem um no one wanted to touch it no one would operate . Um they actually waited another four weeks after the haemorrhage before they would actually do anything because I just was so unstable and so unwell and so they went in and did this thing called embolisation which is where they're going in through the groin and they super glue that blood vessel

And when they did that unfortunately it cause more irritation which is part of the risk and and but they don't know if that caused the subsequent stroke on top of what already happened so left side then was really affected. So initially it was both. Both arms, both legs, speak couldn't even hold my head up and I was literally like a rag doll but when I went from the embolisation after that the right side decided to come back but the left unfortunately was really affected.

Bill 17:15

And so 6, 6 weeks, 6 months later you got some kind of some kind of ability to talk back or how did that come about?

Jenny 17:27

Yeah, so six months I had a tracheostomy in for six months and then, I was trying to practice every couple of weeks with the speech therapist but just no, no voice would come and I actually remember um, it is just about six months into recovery and my brother came to the hospital with my then boyfriend and the hospital I was I actually had a male nurse a young guy and he was fantastic.

I think because he was my age we just got on really well and even though I couldn't talk and then his name is Jeff and I remember him taken my tracky and changing the tracky devise so that I could try and speak and everyone was really hoping that I would say my first words that came out wasn't my brother's name or boyfriends name but it was Jeff and I just swore this guy Jeff for all the piss taking

he'd done for the last three months in the hospital, that I had to put up with couldn't move couldn't talk but I had racked up all this payback and um i looked at my brother face and he was so excited but then he's like oh she didn't say my name.

So yeah And then yeah just once it came back I found if i could sort of squeeze my mouth in the beginning and then I spoke. But even that I remember, not quite understanding how to talk so I would have to take a massive deep breath. Say a few words really quickly and then take another deep breath. Because I couldn't work out how to talk and breathe It had been so long and once it came back it's like everything it just becomes automatic. And

Bill 19:23

Yeah, so then you're in hospital spent six months you started to talk when do you finally start getting to the point where you're able to move again and start getting your feeling back?

Jenny 19:38

yep so I started moving initially just my right hand so moving fingers and because when I couldn't talk I had the issue of, I could never call for a nurse and I couldn't press the call bell button so I was in a real pickle if I needed help I couldn't do anything. And so just before I started talking I started getting some movement back in my right fingers so that I could at least press the call button and, and then before I started talking the first noise I could make was I used to just go pft pft pft and that was what would come out before I could talk.

that was great if you knew me, but for people who didn't know me and would walk past my bed they would think that I was farting but i was actually calling for help that was my call for that. And the right arm came back first and then it was really a progression of

sitting on the edge of the bed just being in that sitting position holding my head up by myself and learning from sitting to standing and thats just probably about that I would say eight months or nine months in and, and then I moved from that hospital to another hospital that specialized in stroke rehab. So i was still an inpatient. Still had quite a lot of medical issues going on and but it was more around the rehab. because for so long i didn't have that I was just too well and I really miss my initial stage of really intense rehab physio and OT. So for me it can

quite late in my recovery. And so it was a good few months in before I started to get some movement.

Bill 21:40

So then you went home?

Jenny 21:44

I didn't go home for, 18 months I lived in hospital

Bill 21:48

wow

Jenny 21:49

yeah so it became home so at 21 my friends were going off to university and I was going off to rehab wards and lived in a hospital for, yeah for 18 months and then I remember actually really looking forward to coming home and i don't think anyone prepares you for that transition and I was so excited and I remember going home and actually being really really upset because it felt like, it just didn't feel like my home anymore.

And so many things had changed the trees in the street had grown and places looked different and it just felt that home was the hospital I had become so i suppose institutionalised. And that was my safe environment. And now now I was back home and there was no real transition. It was just kind of, alright time to go home, and send off, so yeah

Bill 22:57

Do you ever get used to being cleaned and toileted by other people?

Jenny 23:06

really for me, I found that whole part of _____ um, I need that I couldn't do it myself, I couldn't move I had to have someone do it. But I felt like every shred of dignity I had went out the window the minute that happened, because and I suppose it's similar for other strokes survivors. I was such an independent person very strong minded, very strong willed wouldn't let anyone do anything for me. And now all of a sudden I couldn't even wipe my bum. i was dribbling like a baby. I couldn't roll over in bed.

I had to have someone do everything for me. I don't think you ever get used to it. i

think you learn to live with it. And you have to accept that they're there to help. Even now if I have to go into hospital for procedures, or check up's I always feel, I always feel a sense of being dependent on others. And I really don't like it. I really don't like being back in that environment where you have no control.

Bill 24:33

Yeah, dependence on others is something that I went through, but not so dramatic. You know, I had to have other people drive me take me to my appointments all that kind of stuff. And that was really, really challenging, you know, just for me, of course, I couldn't do without them. I needed it. One of the things I enjoyed the most was being able to get, you know, what I call my independence back. And it took maybe the second time, maybe six or seven months, the third time after brain surgery it took about two or three months, you know, not so long.

And that was always something to look forward to. So that was good as a female you guys do it a bit tougher, even if you're locked in because you've got to be, I remember Clodah when I interviewed Clodah about being locked in, you know, she mentioned know, she was terrified that she would get assaulted, sexually assaulted, and one thing that occurred to me is that there's also you know, menstrual cycles that need to be sorted and that I just can't imagine what that's like, and how, you know, how anyone would be able to what's the word can you or, or, or get you feeling some kind of I don't know calmness or relief about that. I don't think that's even the words I've never know what the word so you know what I mean,

Jenny 26:05

i didn't think that about the sexual assault that was never that was never something that I worried about until I went to the rehab unit. And I was never worried about the medical or nursing point of view, I was actually more worried about the other people people on the ward. And I was on the ward I was an hour an hour and a half from home. I was 21 and I was probably the youngest female on the ward. And it was a ward that was for all neurological injuries. And there was a lot of guys, it was in a really rough part of London and there was a lot of guys who'd come from gangs and were into drugs and they'd been shot in the head. there the guys that have had car accidents, So the personalities were very quite aggressive quite arrogant,

and it was a ward where everyone has their own rooms. But anyone could literally go into a room at any time. And that was probably more when I was worried when I met the guys, when at any point someone could come in my room. And yeah I was aware that I was in the situation there where I felt pretty much out of my depth, but I also knew I had to be there, I think it was just a risk you have to take just have to hope, I kept my phone with me at all times. And I made sure I was never my own and that kind of stuff.

Bill 27:43

it's survival, isn't it, I mean, another level of survival, you're trying to get over this thing that happened to you that you surviving, and now you got to worry about surviving you know potentially all the other this other stuff. And, you know,

Jenny 27:58

And also survivor in one of the oddest places which is ironic because you wouldn't think you'd be worried about other people who are also going through this.

Bill 28:07

And that's another thing, you know, interviewing all the people that I had so far you know we are up to Episode 46, every person has their own version of describing their concerns and their fears. And although I had a few the level and the depth and the breadth of them, it's just never ending it's so many different versions of what can go wrong for somebody who's vulnerable, you know, and then all the carers as well. They carers are also concerned no end about, you know, .

Jenny 28:38

yeah,

Bill 28:38

life and survival of the loved one. And then also, you know, how do we protect them when we can't be with them all the time. And we can't support them all the time. You know, so, so many challenges, so many things that we need to make people aware of. So that's why I truly appreciate you coming on to the podcast and sharing this stuff. It's just amazing. I think there is not enough of these types of conversations. So I really thank you for that.

What I also really enjoyed was seeing some of your work that you do with regards to products that you I think make available for people who need different types of

cutlery or plates all that kind of stuff.

Jenny 29:27

Yeah, so I don't actually make the products I just review products that are sent to me made by different organizations.

Bill 29:33

Awesome.

Jenny 29:34

Yeah.

Bill 29:35

So tell me about some of the products that you review that are even out there, because I never even knew, that these products are out there.

Jenny 29:43

So I started probably about 18 months or so. And just wanting to share my story, what I've been through, not only to help other people in the same situation, but also just to kind of educate, the medical professions and that kind of thing about what what is really like behind the scenes and to really go through this and then I just got in contact and a few different companies have contacted me and just about different products.

And one that I did recently and which is really fascinating is a company in the UK and they have developed tableware products so around cutlery, drinking kitchen aides that kind of stuff and, and it's for people with disabilities but the way they design it they make it look like it could do for just anyone and they have all these little hidden designs and features within them, that makes them accessible for people with a disability, but if you just looked at the product you wouldn't know it was specifically designed or made for someone with a disability. So that was really good. yeah that's been really interesting.

Bill 31:03

Okay, there's um, is there have you found a lot of products in Australia that are easily accessible to people in Australia that support people with disabilities, or are most of these products based overseas, wherever you found them,

Jenny 31:23

Most of them that I've done as been overseas, and in Australia, I don't have any links in Australia at the moment, and I am on a really big facebook page that i sort of sit on and it is all around assistive technology. So assistive technology. And the last couple of years has really brought itself to the, to the forefront for disabilities. And,

that Facebook page is just brilliant wealth of knowledge. And it's anyone all over the world can join it. And and it just teaches you about different assistive technology that can help with everyday life even things that aren't specifically for people with disabilities but can really help so, the smart light bulbs, smart doorbell, that kind of stuff. And that just enables the person's to be more independent and to live their life a lot easier, by having this technology in their life.

Bill 32:31

Okay, so what we'll do is we'll definitely post all the links to Facebook link and your blog link so that anyone listening or watching can easily get to it. And they could, you know, at their own leisure, they could go through it and see what what products are available. And hopefully, I know we get a lot of international listeners, not just Australian so hopefully they can buy it from online if they choose the right

Jenny 32:57

yeah,

Bill 32:58

Okay. So I want to touch a little bit about then your 20s you're come out of hospital by the time you come at a hospital, you're probably close to 23 or already 23, how does a young lad, a young lad, How does a young lady who spent from at 21st to 23rd birthday recovering from something quite dramatic, and then not being the same as she was before 21 and how do you go about entering back into life and then also, you know, going through and starting to work and university all the things that, take take me through that what happened after that?

Jenny 33:45

and I actually found the whole transition very difficult. I think part of me came home and just honestly believed it was going to be the same as it was before. I came home and everything that i new was different. Friends have moved on. They

had met partners they had settled down got married where having babies and places that I worked, you know the job I'd worked that had all changed and just everything that I knew before was now completely different and

I was still very much in this we have hospital outpatient bubble where all my time was around medical appointments and doing rehab at times it was really hard with severe fatigue and at this point you know I still couldn't eat and drink i was still tube fed I'm still hooked up to machines and it was just a really difficult time for e to try and to try and get my head around and also to try and fit back into this life I knew before but now I wasn't really a part of anymore and I felt I think I just felt very socially isolated especially at my age people have no idea what a stroke was

And when people will come and visit me and my friends and that they just look at me and say you don't look any differently you look like Jenny but I was sitting on the couch with tubes everywhere and you know a wheel chair next to me and couldn't really do anything but in terms of how I looked, I still looked like Jenny. I just really struggled and I think and some of it really came up actually the other day.

I was listening to your podcast and with Travis about post traumatic stress and really really resonated with me and I'm so grateful that you guys did that because I too like Travis all my focus was on the physical recovery and I was very much the kind of person, go hard or go home if I'm not putting in 120% I'm not doing enough and and very much like Travis I also completely let that whole mental and emotional side go by the wayside but didn't really deal with it cope with just pushed it away and I think that really was apparent when I got home that, kind of like shit got real and now I was in this life but I had no idea how to cope with and but that's really important because I think the focus is so much on that physical recovery that we forget that stroke affects all aspects of your life

The emotional and mental well being and recovery plays a huge part into the physical recovery you can't have one without the other. And it's really refreshing for you guy's to promote and talk about things that people often shy away from and don't talk about and but it's really out there and it's happening to a lot of people and myself like Travis I am 15 years post. And I still struggle with that mental side of stroke with that mental capacity to accept what's happened to look in the mirror and see that I'm physically different.

i think like for me and I suppose like anyone I'm so young fit and healthy had my whole life ahead of me and it was literally and instant where my life just changed and I felt like I had no time to catch up, you know?

Bill 38:05

Yeah, the thing of what I liked about Travis was well everything, but he contacted me to talk about that which to me, shows that he's come a heck of a long way. And that that courage to do that is a massive step in his healing. And what the, the lesson for us and everyone else listening and watching who's experienced stroke and going through this is that you can get there and be it's okay to focus on physical well being, whatever it is to get you going. Because physical well being does also help mental well being and vice versa. And together, they all help. And then what I really liked about Travis is that he had an awareness he had this like moment where he noticed, okay, I'm going to take care of this other side of me and

Jenny 39:03

yes,

Bill 39:03

he's starting to seek that out and he started to become brave and hopefully people listening can become brave at some point to face their demons and, and then take the first next step towards just sorting out what that is, whether it's and and I went through vigorous counselling and coaching and surrounding myself with really well, not positive, it's not positive people, but people that were supportive of me as a whole person, mentally, emotionally, you know, the whole lot. And what that did is, that gave me courage to do things like this, and to create communities and to do all the things that I do public speaking about stroke, you know, and, and the more I share, the better I feel.

Something is always under the lying in the layers, you know, that we all have, which is always never dealt with. And every time I deal with something, something else pops up. Now, what I want to say is, that's not uncommon to normal people want to say normal, you know, the big inverted commas which means that we're no different to anyone else. We're not experiencing anything different emotionally than anyone else experience. But sure, maybe some of it has been brought to the front to the forefront a little bit sooner than what we would have liked.

Jenny 40:34

Yeah.

Bill 40:35

And I feel like if we do the work, that emotional work, we're going to get a better a better result in all aspects of our life, just like anyone would. But for us specifically, who always comparing what it was like when I was okay, what it was like when my hand move properly. When my left side didn't feel strange. When my balance wasn't an issue. I try not to compare myself to then. And if I'm feeling well, emotionally, I almost forget about my deficits. the biggest challenge I have is I have nothing obvious my deficits are completely invisible. There's nothing there that people can see.

So when I'm having a bad day, it's really hard to communicate, I'm having a bad day. And I say this weird thing, like, you know, sometimes it's almost, and I know it's not it's such a silly thing to say. But sometimes it's almost easier when you have a deficit that's visible to say,

Jenny 41:38

yeah,

Bill 41:38

Look you know remember me, you know, like, I have this thing, right, ive me a break.

Jenny 41:43

Why i think people more aware because it's they can see it and they're aware of it. as well. And I don't know that I found, especially in the last probably the last 18 months but I've really started to make a conscious effort to to be kind to myself. And I think for a long time I felt and I don't know about other people. But I felt but this happened it was devastating what happened but it didn't just happen to me it have a ripple effect on the family friends. My partner at the time and I, I kind of for a long time was really hard on myself,

I always would say I've not done enough today i haven't worked hard today I haven't moved my hand enough today or haven't worked as best as I can today. And I always felt like I was letting everyone else down because one stroke happens as I said, it doesn't just affect you. It affects everyone else. So i was really conscious of my mom and dad and what they were going through and I just

wanted to recover as quick as possible.

And obviously, my journey has been a really long one and I haven't recovered you know, 100% as I wanted to I'm still recovering now. But for long time, I was so hard on myself, but I wasn't doing enough or wasn't good enough. But this is really detrimental to me. So in the last year probably 18 months to a year I really made a conscious effort of self compassion, being kind meditation, mindfulness, gratefulness, and gratitude is a really good thing to have in your life. And just remember that okay, things are hundred percent perfect. But when I'm looking at what I've got, compared to what I don't have i'm pretty lucky.

Bill 43:39

Yeah, gratitude to be one for me, self compassion. I remember I'm not sure who told me about the business thing like would you speak to somebody else the way you speak to yourself? And so I probably wouldn't say those things.

Jenny 43:56

you wouldn't talked to a friend like that so why would you talk to your self like that?

Bill 44:00

you'd motivate your friend you'd make them feel better as much as you could and you know you'd want the best for them you know so I think thats

Jenny 44:10

with stroke and I don't know about you but from me I just felt this immense amount of pressure probably put on myself partly that was my personality before I was always I said independent strong willed strong minded I felt this amount of pressure to just recover and just get back to normal

Bill 44:29

yeah of course I did to I mean I was 37 and for me it was about getting back to work making money all that kind of stuff. The stroke has probably cost me half a million dollars you know that's not a joke if there were and then when you think about and I'm not saying that and that's I was able to still bring an incoming and we're talking about over seven years we're not talking about over one or two years or seven years old are still able to bring an incoming but not at the level that I could before.

And I also couldn't grow my business the way I wanted to, which had just started happening and I was starting to you know all these things all these massive opportunities I missed out on immediately and then didn't never get never got them back again.

Jenny 45:12

Yeah,

Bill 45:13

and my wife who you know works and then became the main breadwinner that was an issue for me to deal with. Like, that wasn't good enough, that wasn't right, it was stupid. But that's how I thought it wasn't right for her to be the main breadwinner.

So, you know, all these things that I would, that we had to deal with. And I had to get back to normal and all that kind of stuff. And then I realized, you know, what, seven years out my new normal is to have less to do and make less money and don't give a crap. And what that means is, I've got a completely restructure my life, this is the one thing that I really want to help people do encourage people to do is find a new way to become able to make living without going back to the amount of hours and work that you did, which make you sick.

Jenny 46:06

Yeah,

Bill 46:08

And made you major dependent. And for me, it was investments in this and in that, and whatever, which meant, the more stuff I bought, invested in or, you know, the more I had to work, and the more I had to make money,

Jenny 46:20

it's like a never ending cycle.

Bill 46:21

Yeah, so now I've got to really sort of take stock of where I'm at. And just go back to basics and get rid of the extra things that I have to do to support non life enhancing pursuits. Because most of those pursuits were not life enhancing. They were just head brain enhancing things, you know, they were stuff that just made me able to, you know, tell my mates, I did this, and I bought that, and I drive here,

I went there, all that kind of stuff. So it does, it changes you. And now my recovery is, you know, it's kind of stagnated in that my physical recoveries is where it's going to be, because I've always been good at that.

But where it stagnated is in that mental space. And I feel like when I close off some of these projects, and wind everything down, and then just get back to basics, then I'll be able to feel, spend more time on my mental well being, and my emotional well being, and then supporting my family, caring for my wife, and not in that just, being there kind of way find a way and supporting my children who are coming into adulthood, and, you know, starting to, you know, go out on their own and do all those types of things. So, you know, it's enough, all this stuff for me is done. Now, it's stuff up for what makes my heart come alive. And

Jenny 47:49

yeah, and it's, as you said, it's just simplifying all that keeping it simple. And it's just about things that as you said, make your heart you know feel alive, rather than all the other stuff, which is just,

Bill 48:06

that's right. So tell me, what do you do for work these days, did you manage to go back to university?

Jenny 48:12

I didn't go back to studying for a while, I'm not working at the moment, I am actually doing I want to spend a bit more time really just on the blog and building that kind of profile side of it. And this year I have just started a Leadership course over in WA (Western Australia) it's run by Leadership WA, and it's the one I'm doing is called Leadability, which is all about all it's all the people either people with a disability or people in the disability sector and who want to go out there and make a difference, who want to generate change have a social impact and want to kind of be a leader in their community. And so i've just started that about a month ago, which was really cool.

So that a run for the next few months and and then hopefully I will graduate on to the next course. And, and it's really good not just in terms of networking and building the skill sets, but I've got this kind of lots of ideas and projects in my head, that I really want to work on and develop em around this kind of stroke recovery and working with health professionals. So it's a really good foundation

for me to build on and get my foot in the door in terms of talking to these people. And so I'm just doing that. And I'm also working on a couple of other projects, and over in WA with a couple of disability service providers, so helping them with their what they call about the clothes design team. Um looking the at customer experience. So when someone with a disability goes to these providers for service. What does that look like, from the initial diagnosis and assessment through to the end of whether it's therapy or whether it's equipment for a wheel chair and that kind of stuff, what is their services look like and sitting on clothes design team and helping them to sort of really streamline process and procedures and a really good customer experience from someone who's kind of been through it themselves. So that's kind of what I'm doing at the moment. And yeah, kind of where my passion, passion lies,

Bill 50:44

It seems like there's definitely a need for that. But it also seems like it's going to really support people who don't know what it's like to be disabled, we're trying to help people that are disabled, which is kind of weird, Like, I get the very able to, so they can do that. But they don't understand exactly what that's like. So anything that can help other people understand what it's like, and support is really valuable to, to those Disability Support Services, you know, So having an insider's view would be great.

I feel like there's a lot of work that needs to be done in the space of helping employers, you know, bring people back to work and supporting them in a way which is going to make it possible for them to come back. I know, for a short amount of time, I had to go and work in an office and because I couldn't do all my other stuff. And I was lucky enough to get a job through somebody that I knew who supported me to get back. But some of the other issues that I dealt with what I was there was the noise was ,the lighting lighting was a big issue for me the overhead lighting, just making my brain hurt ,was the computer work was a real big issue for me.

So yeah, the monitors so they were completely not set up to help somebody who has a neurological issue go back to work. And we never got there because I wasn't ,it was only a short tenure but I realized that you know, they'll be a lot of people going back to their office work, office job, who are then dealing with all of these additional things that people with neurological conditions need more

support around so I think there's a real opportunity for consulting in that space and helping people transition back into work without some of the additional challenges that we now have to face you know,

Jenny 52:49

yeah, completely

Bill 52:52

So tell me a little bit about your personal life now what what's that like you spoke about your work and all that type of thing

Jenny 53:00

Em I tried to sort of, like you I hate to use the term normal but I try to live as normal as possible so I still do a lot of rehab. For me and my stroke I suppose very different than yours but the physical was still a big issue and is still there is still a lot of room for improvement for me and I don't do a high —————

in that area. So I still do about we had around physiotherapy and occupational therapy a lot of upper limb stuff and lots of walking, bike riding and I might sit in the pool and I need some initiative so basically really busy and and I just like anyone else I enjoy going to the beach going for coffee, catching up with friends. I think now and again similar to what you said for me it's about the simple moments so I just really enjoy going to the beach and just having a coffee and people watching and just have that time to enjoy and be in the moment and really appreciate what I've got in that moment rather than constantly being on the go and constantly rushing. And yes, I suppose like everyone else just do all those things and tries to live life to the full.

Bill 54:27

Yeah, were you driving before you had the stroke?

Jenny 54:40

I was I'd only been driving probably for about two years maybe three years before. Yeah.

Bill 54:49

And now how long after that? Did you get back to driving are you driving now?

Jenny 54:53

So in the UK I had my assessment which I passed and then we moved to Australia and I didn't for what reason get back to it but this year I've just started to get back to driving lessons and get in the car, to get back on the road. So watch out everyone in WA

Bill 55:18

Yeah, yeah, fair enough.

Jenny 55:29

I wasn't that good a driver before I mean 18 years old, I was pretty terrible I am a bit worried about what I might be like right now? But

Bill 55:31

yeah, you know, what I'm curious about is there a lot of driving schools etc, that offer services, that are able to support people with disabilities? Can you find that easily,

Jenny 55:41

For me I live in Queensland, for the past 10 years, and only moved to WA coming up to two years now, and em I found WA to be really accessible em in terms of service providers so therapy,

there is a lot of access and driving instructors. They've got specialist driving instructors for people with disabilities and also I think because it's small, everyone knows everyone. So if you can't find a service you ask someone, and someone will know of someone who knows someone, and yeah, there seems to be a lot going on in the disability space em in WA, which for me is really exciting because that's what I'm passionate about and that's why I wanted to go with the blog and writing the book for me was really

and this is something that Travis might find helpful, I found it really cathartic. And to finally kind of talk and express all that I've gone through and to be completely open and honest and then we've also got to be vulnerable but it was really good to put pen to paper or tap on my laptop and to get all of this stuff out and to just finally share my story because for a really long time I didn't feel ready yeah I kept a lot of stuff to myself I was very private after the stroke a lot of friends probably didn't really know what happened and I didn't want to share and I think it came back to being you know, I was young female and all of a sudden I was dribbling like a baby I couldn't move I couldn't talk was really dependent, so I

kind of shied away from a lot of people for a long time.

So for me, the blog has been really nice to be expressive and to just share the good, the bad and the ugly. And just put it out on paper it's just, you know, finally let go I suppose of all that, what had been going on.

Bill 58:04

Yeah, I like the I like today's version of expressing yourself. Because in the past, we might have had a personal blog, sorry a personal diary that we would write in and nobody else would see it, you wouldn't your family wouldn't read it, they couldn't care. Um to find another human that was similar to you, you actually have to physically go out and find them and show them that was never going to happen. Whereas now what's beautiful now is we can express ourselves in that same way. I hate writing anyway.

So I hate reading. Although I love listening to audio books. So when these new versions of expressing yourself make it so much better, because I can get you on the other side of Australia on Skype. We can look at each other, we can share, we can express ourselves, we can learn about each other. And then we know we can put it out there. And everyone else can learn about themselves and us. So I love our version of doing it now, it's so much better. And um yeah, look, I encourage people who are listening to the podcast, get in touch, and let me know if they want to share something. If they want to get something off their chest feel like it does them good. It also does me good so I've been a bit bit selfish when I say that, by all means get in touch, you know.

So before I go completely dark, and nobody can see me anymore. I think what we'll do is we'll just end on that note. And look, I want to thank you so much for reaching out as well. And allowing me to interview you and for sharing your story. I think it's it's brave of you to do. And I think it's going to make a massive difference. And, you know, I hope that you continue to be brave as well and enable you to just go to those little places where you thought it's going to be too difficult or, you know, too hard to get to and and just go there and just be curious about what you might find. Even even though you might be a little bit hesitant or delving too deeply just be curious and see what's there and just deal with those things come up rather than over think it and worry worry too much about it. You know, just go there gently

Jenny 1:00:26

And thanks so much. But honestly, I know this is something you do because you're passionate about it but

you might not be aware of what an effect you are having on other people and not just other people who don't know about stroke but other stroke survivors for us to be able to listen to those podcasts and for me to here other stories and people who have gone through similar with locked in syndrome and to bring that experience to some someone who's also the had post traumatic stress, it's really comforting to have that

and to be able to access it on my phone easily. And to kind of now that they're not alone. There's always people out there that have also experienced and that it's just it's really nice to have that so thank you for doing what you're doing this it's really, hats off to you.

Bill 1:01:23

My pleasure. Thank you for saying so I'm going to continue doing it because I love doing it. And I love the feedback and I didn't realize it was going to be so necessary to people. I had no idea and it's such a blessing that it is and I don't know what made me do it. Like why I started it. I really don't know. I just know I did it. And I thought it would be a good idea. But wow like it's just been so much more rewarding, you know. So I'm going to follow your blog. I'm going to keep in touch and I'm going to be very keen just to see how you evolve and emerge from all the stuff that you're going through and and I really look forward to just learning more about you as the time goes

Intro 1:02:10

That's great thanks so much Bill

Bill 1:02:12

You're welcome. Thank you Jenny

Intro 1:02:13

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