

AVM Burst in the Brain: A Recovery Story of Patience, Aphasia, and Finding Your Way Back

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Jennifer Tomscha was 39, driving her three-and-a-half-year-old daughter home from preschool, when an AVM burst in her brain. She felt a wash of dizziness first. Then her vision started collapsing on the right side. She pulled onto a narrow verge on the highway between Greytown and Carterton in New Zealand, tried to reach her husband, got no answer, and dialled 111 instead. When the dispatcher asked what was wrong, she said something she still can't fully explain: "I think I'm having a stroke."

She didn't know yet that she had two arteriovenous malformations in her left frontal lobe — one discrete, one diffuse. She didn't know that within hours she'd be helicoptered to Wellington Hospital for an emergency craniotomy, or that the

following Monday a neurosurgeon named Dr. Woon would spend thirty hours trying to remove both malformations from her brain. She just knew something was wrong, and that her daughter was in the back seat, and that she couldn't keep driving.

That moment — pulling over, self-diagnosing, refusing the urge to simply lie down and rest — may be the reason she's alive.

What happens when an AVM bursts in the brain

An arteriovenous malformation is a tangle of abnormal blood vessels that connects arteries directly to veins, bypassing the capillary network that normally regulates blood flow. Most people with an AVM never know they have one. But when an AVM bursts in the brain, blood floods into surrounding tissue at high pressure, and the consequences are almost always severe: haemorrhagic stroke, seizures, sudden neurological deficits, and in many cases, death.

Jennifer's first surgery controlled the bleeding. The second, five days later, was supposed to remove both malformations. It didn't go as planned. The surgical team discovered that blood flow to the first AVM was feeding the second one, causing the brain around it to swell. Dr. Woon had to make an impossible decision in the middle of the operation: let her die, or remove a portion of healthy brain tissue along with the malformation.

He chose to keep her alive. The surgery took thirty hours. When it was finally over, he called her husband and said, "Well, you'll be lucky if she talks."

The six weeks she can't remember

Jennifer has no memories of the first six weeks after her AVM burst. She was in a medically induced coma for the surgery, then in intensive care, then transferred to rehabilitation. Everything she knows about that period has been told to her by other people.

When her memory started returning, she found herself in a rehabilitation ward in Masterton, using adult nappies, unable to sit up in bed. The front of her skull had

been removed and wouldn't be replaced for months. She wore a protective helmet whenever she walked. And yet — she insists — she felt fine.

[Quote block — mid-article]

"I kept saying, 'I'm okay, I'm fine. You guys should just take it easy around me.' But of course, I wasn't really fine." — Jennifer Tomscha

The honest recognition of what had happened to her didn't come for almost two years. It took that long for her brain to have enough capacity to think about her brain.

The myth of the one-year recovery window

Most stroke survivors are told, either directly or by implication, that the first year matters most. That after twelve months, improvements slow. That after two years, you've plateaued.

Jennifer's experience — and the experience of nearly every long-term survivor interviewed on this podcast — contradicts that narrative. Four years after her AVM burst, she is still discovering what recovery means. Her academic writing, once her profession as the Director of the Writing Program at NYU Shanghai, doesn't flow the way it used to. She can't recall songs from memory anymore, or sing the ones she used to sing. Her aphasia shows up most at night, when she's tired. She still takes an afternoon nap most days.

But she's also finishing a PhD. She can read as well as she ever could. She's speaking, articulately, in a podcast interview eighty minutes long. And the parts of recovery she thought had stopped improving are, quietly, still improving.

What Jennifer wants other survivors to know

Her advice, offered near the end of the conversation, is short and unsparing:

"You can rest, and that's okay. You can be as slow as you want to be, and that's also okay. But don't give up. Just keep going — at whatever pace feels right."

It's a rejection of both the productivity culture that tells survivors to push harder and the clinical culture that tells them to accept their limits. Recovery, for Jennifer, isn't a race against a deadline. It's a long, patient process of finding out what comes back and learning to live fully with whatever doesn't.

Bill's book and community

If Jennifer's story resonates with you, Bill Gasiamis's book — *The Unexpected Way That A Stroke Became The Best Thing That Happened To* — explores the same territory: the slow, unexpected, sometimes beautiful work of rebuilding a life after a brain event.

Get the book [here](#)

Readers who want to support the podcast and connect with the community of survivors it serves can do so at [Patreon](#).

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Jennifer Tomscha: An AVM Burst in Her Brain at 39, and the Four-Year Climb Back to Herself



She self-diagnosed her own stroke while driving with her daughter. Four years on, she's still discovering what recovery really means.

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Introduction and Background: AVM Burst in the Brain

Jennifer Tomscha (00:00)

Dr. Woon was my neurosurgeon. And he just said,

I'll never do another surgery like that ever again.

it was really long. And I think he definitely

had made me worse. Like they had taken out.

too much of my normal brain. when he called my husband after the surgery was over,

Dr. Woon said like, well, you'll be lucky if she talks.

he was just so discouraged from how the AVM surgery went.

when I finally talked to him on Zoom. was so you And I was like, yeah, yeah, yeah, of course I can. He was like, will you show me?

and I walked up and down the room and he was like laughing so hard at my being able to walk. He was like so enthusiastic about it.

Bill Gasiamis (00:44)

Welcome back everybody. I am Bill Gassiomas and my guest today is Jennifer Tomche. In March, 2022, Jennifer was 39 years old living in New Zealand,

finishing the first year of a PhD program when something happened to her brain that changed everything.

What followed was a medical emergency unlike anything I've heard described on this podcast and a recovery story that quietly dismantles one of the most damaging myths

in stroke survivor community. That after a certain point, the window for improvement closes. Jennifer is four years out from what happened to her. She still takes an afternoon nap every day. She still notices the edges of what her brain can and can't do. And she is also finishing a PhD, raising two children and speaking with a clarity and warmth that will stop you in your tracks.

This is a conversation about what it actually means to play the long game and why might be the most important thing any survivor can do.

Before we get into it, if this podcast has been part of your recovery journey, I'd love for you to check out my book, *The Unexpected Way That a Stroke Became the Best Thing That Happened*, at recoveryafterstroke.com/book.

And a genuine thank you to everyone supporting this work on Patreon. If you wanted to support the show, you can go to patreon.com/recoveryafterstroke.

really helps me keep the conversation going. Let's get into it.

Bill Gasiamis (02:12)

Jennifer Tomscha welcome to the podcast.

Jennifer Tomscha (02:14)

Thank you. I'm glad to be here.

Bill Gasiamis (02:17)

It's lovely to have a local with me. Usually all my guests are from the United States or Canada or the United Kingdom. You're just a hop, skip and a jump away in New Zealand.

Jennifer Tomscha (02:20)

Yeah.

Mm hmm. Yep. Yep. I'm American originally, but we moved here in 2020. So ~ we

I'm grew up in Iowa. And then and then I after but we were living in Shanghai for us for almost seven years, my husband and I were living in Shanghai and I was teaching at New York University, Shanghai and then when COVID happened in China.

Bill Gasiamis (02:35)

Where are we from in America?

Jennifer Tomscha (02:54)

they told us to leave the country because it was where it started. So, and we had two kids, so my husband didn't want to go back to the United States. And so my sister lives in New Zealand. So we moved here and then we just stayed here. mm-hmm. So, yeah.

Bill Gasiamis (03:11)

So

in China, was it just a request? Was it a directive? What was the situation?

Jennifer Tomscha (03:18)

From New York University, they said if you weren't a Chinese national citizen, they strongly urged us to leave because they just didn't know how they were gonna manage it. everyone, mean, in China, they had had SARS in the early 2000s, so they had already had it. And so right away, everyone had their masks on. They were ready to...

go and I was like, I want to get out of here. So we went to New Zealand and they also had a lockdown, but it was just for a month and then everyone could wander around because the virus was not here. we just stayed and I got into this PhD program. So that's why we're still in New Zealand.

Bill Gasiamis (04:00)

Wow.

That kind of brings us to the first question I ask most people these days is what was life like before stroke? So there was a little bit of stuff going on. was, work in China. There was a bit of, ~ travel from the United States to China. was children, but daily life. What, what was that like before the stroke?

Jennifer Tomscha (04:21)

When I saw my stroke happened in March of 2022 and at that time I had been in my PhD program for about a year. And I was just finishing up my research proposal. And so I was doing that during the day and my kids were both at, I have an older son who was in second grade year two. And then I have a daughter who was in preschool. And so my days were I dropped them off at their schools and then I would work for a little while. And then I would.

go and get them. So, and then they would come home and we would do all the other stuff in parenting. And my husband at that time was working at the library. So he had, he was at the libraries from nine to five every day. So he was at work. And that's what, that's what we were doing. Yeah. When I had my stroke. I was busy trying to finish up this research proposal. And then, yeah.

Bill Gasiamis (05:14)

39 years old at the time as well.

Jennifer Tomscha (05:16)

Yes, was 39.

Bill Gasiamis (05:18)

any signs, any kind of inkling that something was not right.

Jennifer Tomscha (05:23)

I didn't, weirdly, so I'm trying to think about, my whole life I've had this thing where if, especially at just certain points if I hit my, this is maybe nothing to do with anything, but if I hit my elbow or my wrist, then I would pass out. And sometimes I would have like a little seizure while I was passing out. So wasn't just like a regular fainting, it was like a seizure. And I had some of those in high school and I actually went to the,

hospital for those at one point and I think they didn't know what that was and they just did an EEG. I don't even think we had an MRI where I lived. So I didn't really know and then that sort of passed. But I was feeling when I have a daily journal that I was writing and when I go back and read that daily journal, the whole, for a couple months ahead of time, I was like, I just feel kind of weird.

I don't feel great. I feel like a little bit sick and I don't know what's wrong with me. And at that time they were allowing COVID to enter New Zealand. They were putting it in. So I was like, I think I might have COVID, but I took a bunch of tests.

They were all negative. And then my stroke happened on Tuesday, but the Friday before I was so sick. And then that weekend I was really sick too. And then I got, like, I kind of felt like I woke up, I felt really nauseous. And then I felt better on Monday and Tuesday.

And Tuesday was when my stroke happened. So I think that was all, it was all, think, my body reacting to, I was probably bleeding in my head at that time or something. mm-hmm.

Bill Gasiamis (06:57)

I got it. And we're to have to go back and talk about how it was that when you got hit on your, on your wrist and your elbow, how hard was the hit?

Jennifer Tomscha (07:05)

I don't know.

Not super hard, I just, I don't know what, I actually don't know, and maybe it's nothing to do with it. You know, maybe it's something else in my body that I am prone to fainting. But I don't know, I don't really know why that, and maybe it wasn't anything like that. But I had one day when I was 16 and I passed out three times and that did seem kind of funny. And I went to the doctor and I passed out while I was at the doctor's office.

So they were like, there's nothing wrong with you. So they put me to the hospital. They did the EG. stayed the night. And then they were like, there's nothing wrong with you. So that was it. But I think if nowadays they probably would have done an MRI, maybe, and they would have seen that I had my AVM and my whole life would have been different because I wouldn't have done all the stuff that I've done now. Like my mom was like, if we had known you had had an AVM, you would have gone to school.

in Sioux City, you know, or we would have done something to keep you nearby because we would be worried about you. Instead, I was just like, doing whatever I wanted to, which is good.

Bill Gasiamis (08:14)

Laze, but

that's kind of good. But also I get the preventative thing. One of the, my former

guests had a daughter who had an AVM and I think she was five when she passed away from a bleed in the brain because of an AVM. That's horrific. And one of the, it's actually worth listening to that episode and it's worth me interrupting this right now to jump on and find that episode so that I can share it with people.

And this particular lady has made it her life's mission to raise money, get an MRI machine and do preventative scans for people in case they have an AVM or some other undiagnosed neurological condition. I think it's Gina. Gina Keely. OK, it's. And her ~ foundation is now called the Paige

Keeley Foundation, it's the most heartbreaking story. It's episode 141 and I'll have the link in the show notes and I'll have it in the YouTube description. So for anyone listening, jump back and have a look at that. And also maybe even consider supporting the foundation because the story is heartbreaking and the efforts that this lady is going to ensure that this doesn't happen to other people is just amazing. So.

I wanted to, I raised that because I had a, in 2011, no, no, in 2010, about 18 months before my actual AVM bled, I had a really terrible negative episode, nauseous, room spinning, like all the signs of stroke, but completely missed the, completely missed

Jennifer Tomscha (09:47)
Mm.

Bill Gasiamis (09:55)
the AVM when I went and actually had an MRI. So yeah, I went to the hospital, gave them my, rundown of what was happening to me and they were so switched on and they got me in and they did all the tests, but they didn't find anything because they didn't know what they were looking for. And there was no obvious sign of bleeding. So they didn't dig deeper. And I have a friend of mine who is a radiographer who actually did my MRIs

Jennifer Tomscha (09:58)
~ really?

Mm.

Reflections on the Experience

Bill Gasiamis (10:22)

when I was in hospital being treated after my AVM burst in 2012. And he said to me, the preventative stuff is very difficult because if you don't specifically know what you're testing for, you don't know how to set up the machine and how many slices that it needs to take and at what resolution. So that when you deliver that to the radiologist and they're looking at it, can they see an AVM and then pass that on?

Jennifer Tomscha (10:37)

Mmm

Bill Gasiamis (10:49)

that information onto the neurologist. They might even miss it, even though they're doing MRI. But what Jena is doing, it sounds like they're specifically going after aneurysms, AVMs, other malformations, and therefore they have kind of this better opportunity to find it. So if somebody is considering getting a preventative scan of their brain, you have to be very specific.

Jennifer Tomscha (10:53)

Bye.

Bill Gasiamis (11:14)

with the team of doctors, radiographers, neurologists, as to what you want them to look for and make sure that they adjust the scan so that it's fit for purpose.

Jennifer Tomscha (11:25)

That's interesting. That's really interesting.

Bill Gasiamis (11:26)

Yeah.

So what was the day of the stroke like? Was it, you said you're feeling better on that Tuesday.

Jennifer Tomscha (11:34)

Mm-hmm. I had a good day. I have like lots of notes from my research proposal and I went to pick up. I don't know why I did it this way actually. I went, my

daughter's preschool is in our town, Greytown, and I went and picked up her first and then I went to get my son. His school is a Montessori school. It's in one town north. And so I went and got her and we were driving in the car and when I turned onto the highway that connects Greytown and Carterton,

I just felt like a wash of dizziness and I started losing sight, I think, in my right eye. And it's seven kilometers from Graytown to Carterton. And right before we got into Carterton, I pulled over onto the side of the highway. I tried, so by that time I think I had lost most of the sight in my one, my right eye. And so it wasn't very long actually. And so I tried to call my husband, he didn't answer. And then I just called

111 and I was like, I don't know why I was like, I think I'm having a stroke, but I don't know why I even thought that actually. Do know what I mean? I just, was like, something is wrong with me. And so my daughter was fussing in the back and, I don't really remember anything after that. I don't remember the paramedics coming. I don't remember talking to anyone. but so when they, I think the police came first and then

Then the paramedics came and they said I was nauseous, but talking a little bit. But then they moved me into the ambulance and, I started, choking and, or something, and they had to intubate me in the ambulance. And then they took me in. I was helicoptered off to Wellington hospital. So.

Bill Gasiamis (13:12)

How did you feel about it? I know you did the right things. You nailed it. But how did you feel? What were you thinking? I was completely oblivious to the risk I was at or in.

Jennifer Tomscha (13:14)

Yeah.

Mm-hmm.

Mm-hmm. I don't know. just, let's see, I think...

I think when I was losing my vision, that was hard. I mean, I'm really lucky. There was a little ~ path on the side of the road right before you enter Carterton. So I pulled over there so I could still control the car. You know what I mean? I wasn't

so bad. And I could dial 111 on my phone. I could still think about those things. But it wasn't very long after I dialed 111 and talked to those people that I'd

that my memory is gone. So I think, I mean, I have spent a lot of time trying to like go back and figure out like, what was it? What could I have done early? know, like I was really lucky I was in the car, because honestly, because if I was at home, I might've like laid down and taken a nap and not called anybody actually, or called Dan and half have not answered. So then I could just see myself.

Bill Gasiamis (14:14)

you

Jennifer Tomscha (14:22)

It was actually really lucky that I was in the car with my daughter because it made me, I mean, I couldn't keep driving very well. And so it made me pull over and it made me, I'd have to do something because I wasn't in town. So I had to like figure out how I was going to manage the situation. And so I was really lucky actually that I was in the car and that I was in a public space where I was easy to find and like I could, so I felt like really lucky that all that happened.

in that time period, but also that soul that my daughter was with me because it made me, I had this like parental responsibility that I had to, I couldn't keep driving with her in the car. Like I just, I knew I had to do something and quickly. I feel like, I feel really lucky that that was the situation that I was in because I could see a different day where I didn't go get the kids at that time. And I maybe would have tried to take a nap and it would have been totally different.

So you know what I mean.

Bill Gasiamis (15:19)

It's such a

common thing for people to go, oh, I'm not feeling well. I think I'll just go lay down and have a rest and see if I can just get over it, sleep through it or whatever. yeah. And then it just leads to even more and more trouble or problems. The fact that you said, I think I'm having a stroke, right? That is so cool and bizarre and amazing.

Jennifer Tomscha (15:29)

Mm-hmm. Mm-hmm.

The guy was like,

why? And I was like, well, I'm losing my sight. I was like, I mean, I don't know how it was. I was like, why do you think you're having a stroke? I was like, I don't know. But there was something wrong. You know what I mean.

Bill Gasiamis (15:52)

Yeah,

that's such a good question for me. Why do you think I'm going to strike? I don't know, but I just came up with it. What? That was enough though. Like that was such a response from you to say, I think I'm having a stroke. It's very, very rare that people get there, but the fact that you got there kind of gave, gave them also like an understanding of how to attend the site and what to do.

Jennifer Tomscha (16:01)

Mm.

Bill Gasiamis (16:18)

And that saves time as well. That saves a ton of time.

Jennifer Tomscha (16:21)

Right. Mm-hmm.

Mm-hmm.

Bill Gasiamis (16:23)

and gets them, even though you may have been wrong, right? Gets them looking in the direction because they're already got that in their mind. And then, well, let's look at that first and then let's suss it out. She might be completely wrong. But I walked into the hospital after my, while I was having the third blade and said, I'm having a brain hemorrhage or something like that. And I was in the hospital upright, standing, looking normal and

Jennifer Tomscha (16:27)

Yeah. Yeah, yeah, yeah, that's true. That's ~

Mm-hmm.

Bill Gasiamis (16:51)

They were looking at me like, okay, what are you on? This guy, this guy must be on something because it doesn't look like he's having a stroke. And then I had to try and convince them, but I wasn't giving them my contact details. So they weren't able to bring up my record. And all they were saying was just give us your name, give us your name. We'll put it in the system. We'll have a look. And eventually they got it out of me and, ~ and I was right. But yeah, such a good thing.

Jennifer Tomscha (16:54)

Oh, yeah, yeah, yeah, uh-huh.

no.

Hmm.

you

Bill Gasiamis (17:21)

I love those little bits and pieces that go well together because you often hear I often hear the bits and pieces that didn't go well and and it turned out differently and how old was your daughter at the time? Yeah, wow.

Jennifer Tomscha (17:30)

Mm-hmm. She was three and a half. And so she was still

in the backseat, know, backwards in her car seat. And then we stopped and she was like, why are we stopping or whatever in her three and a half year old voice? And I was like, I just had to make a couple of phone, you know, I don't know what I said to her. And then I think when the police came, she was asleep. Like she fell asleep back in the car. then, and then.

It's just, I, I'll, so then for the next six weeks I don't have any memories of anything. So all, all of the information has been given to me by other people. But, so, yeah.

Long-term Effects and Adaptations

Bill Gasiamis (18:04)

So was quite a large blade after all of that.

Jennifer Tomscha (18:06)

Yeah, it was

large. They took me, so I flew in the helicopter from Masterton to Wellington and I think they, by then my sister had gotten to the hospital and they, yeah, I think they said, yeah, they did an emergency, is it craniac? Or what's the?

Bill Gasiamis (18:25)

Craniotomy,

Jennifer Tomscha (18:26)

Yeah, they did an emergency cradionomy and they saw that I was bleeding. And then they saw that I had this large left frontal or frontal lobe AVM. So, and then they said that at that moment they couldn't tackle that AVM. So they, controlled the bleeding and then they, and they left my skull out and then, yeah. And then, then they, they talked to the neurosurgeon and

He, that was a Tuesday and he said, why don't you, I was in a coma, just keep her in a medical coma. And then Monday they would do the, the, the surgery to get rid of the AVM.

Bill Gasiamis (19:05)

And

then that surgery happened.

Jennifer Tomscha (19:07)

That happened

and it was, had my, actually had two AVMs. One was really discreet and they could see all the endings of it. And the other one was diffuse. I don't really understand it, but, the neurosurgeon said there was like parts of regular brain in and around the AVM. I don't really understand how that happens, but, ~ so they started in the morning and they did, they got rid of the one AVM. They were taking it out.

And then something about the blood vessels that had some of they had been putting blood into that AVM. They then started feeding into the other AVM. So then that AVM made my brain sort of swell where that AVM was. And so the neurosurgeons had to decide if, mean, basically it was like, let me die.

because they couldn't do anything about it, or they would get rid of that AVM and they would just take out the brain that was, the normal brain that was in the regular AVM. So they took, they decided not to let me die, thank goodness, and they decided to do that. so, but it was really long surgery, it was 30 hours, I think they just didn't, yeah, it was really long. And...

And I think Dr. Woon was my neurosurgeon. And he just said, when he went and sewed my head back together, he didn't think I was listening, but I was in the other room and I could hear him after I had my skull put back in. And he was like, I'll never do another surgery like that ever again. it was too, it was really long. And I think he definitely thought that he had made me worse. Like they had taken out.

too much of my normal brain. when he called my husband after the surgery was over, like they didn't call him. Dan, my husband was waiting for the whole 30 hours and they only called him one time at like 11 o'clock that night. And they were like, we're finishing up. But then they had all this other stuff happen. So they didn't actually call him again until noon the next day. And Dr. Woon said like, well, you'll be lucky if she talks. Because we had to take out.

he was just so discouraged from how the AVM surgery went. And so, yeah.

Bill Gasiamis (21:24)

Dr. Woon needs to give himself way more credit.

Jennifer Tomscha (21:27)

I know, I know, I also

think that. I also think that, I mean, it's, I mean, neurosurgeons, they're, it's amazing that you could, I've just, it'd be so weird if your job was to cut people up and go into their brains and try and fix something in that organ, which is so mysterious, do you know? Like, yeah, so.

Bill Gasiamis (21:48)

Wow. 30 hours.

So he also is thinking in his career, he's probably never going to come across another 30 hour surgery. Yeah. Well, only if it's necessary to make somebody better, but yeah, we definitely want to avoid that if we can for every human on the

planet and for Dr. Woon, but I just, I'm just completely in awe of these people. I bumped into my surgeon last year.

Jennifer Tomscha (21:57)

I hope not. mean, I hope, you know, yeah, I don't think, yeah.

Right.

Mm-hmm.

Bill Gasiamis (22:15)

because I had another MRI, because I had another bout of headaches and all that kind of stuff. still, you know, it hasn't ended. I still go through all these things. And I mean, I mean kind of, I get emotional when I'm around her and when I'm in the room with her. If she told me to jump off a cliff because there is something positive down there and I would do it. If she said, if she said punch a hole through that wall, I would do it. Like I would do whatever she said because

Jennifer Tomscha (22:20)

no.

Yes.

Yeah.

Bill Gasiamis (22:44)

I just cannot get over the, know, when, you know, when you make a decision, some people, my phone is weird. I've never done this before, but you have a piece of fabric and it's got some lines on it. And you know, if you cut it wrong, that you can't use that piece of fabric for that pair of trousers anymore. You've got to use it for something else. Like that's a pretty mild problem to happen. Like you cut wrong, you go in the wrong place. You pop that aside and.

You're useful. If you do that to a human, there's no going back. And you've got to make that decision every single time you walk into the operating theater. And imagine his family. Like, I feel like we need to reach out to his family and say, is there anything we need to make up for? I know we had your husband for 30 hours, but like, how can we support your family now that he's done that for my family?

Jennifer Tomscha (23:40)

Yeah, yeah, yeah.

Bill Gasiamis (23:40)

Do you know, like it's so

interesting that these people have been able to get to that level of capability.

Jennifer Tomscha (23:49)

Yes.

Bill Gasiamis (23:50)

with humans and helping people stay alive and be here with their family, be a mom, be a wife, be a daughter, be a member of the community.

Jennifer Tomscha (23:51)

Mm-hmm.

Yep. Yep, exactly. It's just, it's amazing. It's just so, and I'm so grateful to him and he had another neurosurgeon working with him and yeah, it did, I mean, yeah, it's amazing. I always think though, I'm trying to think about like, did, why, if he cut out those parts of my brain, why weren't they, why?

I mean, I have some things I can't do that I could do before. Like I can't, this is so weird. I can't recall songs very well and I can't sing songs from memory, like at all. Like that part of my brain is done, which is fine, but I used to sing a lot. but I think because if the AVM is there when you're in your, if it's there when you're in your mom's womb, like if you're, when you're developing.

It's probable that my brain was like, there's a little issue here in this brain. We'll move some of the stuff away from, don't you think that would be, yeah, because I just think like, I think where my AVMs were, my brain was like, we're gonna move, we're not gonna put stuff by those AVMs because yeah, because your brain is really adaptable. Like that's one of the things that I've been reading since I had my stroke.

Bill Gasiamis (24:59)

Wow. Yeah, I've never thought about that. Why not?

That makes sense, Jennifer. Because it's... Yeah.

Jennifer Tomscha (25:18)

My mom's like, your brain is so adaptable and flexible and it can do different things. You just have to try doing things, you know, and failing.

Bill Gasiamis (25:26)

And the blood flow

is not right. So you imagine with blood flow not being right, then the brain's not developing correctly in that spot anyway. And it's just developing where there is blood flow.

Jennifer Tomscha (25:37)

Yes, exactly. Exactly. I just I feel like that makes sense to me. And that's why if you're the neurosurgeon, I mean, you really don't know. Like Dr. Woon didn't know what was there. But I just feel like maybe my brain when it was developing was like, well, this isn't a good spot and this other spot isn't a good spot. So we'll just do everything in a different place. And the brain is really you can really do that. I think your brains are really plastic in the way that they can order themselves. And so I

So it's still all Dr. Woon. I'm just so grateful to him and everything that he did. Because honestly, I feel like I come from the States. I don't know that a neurosurgeon, I just don't know how long a neurosurgeon would have, they might be like, I'm done, I can't do this anymore. I just don't really know. It just all depends on the doctor and who sees you and everything. So I just felt so lucky to have been here.

Bill Gasiamis (26:30)

Imagine

doing a 30 hour shift on any day for anything.

Jennifer Tomscha (26:34)

No. And the thing about neurosurgery is like you're in, I mean you're doing like, you're in a microscope or whatever doing that little and you're tying off a little blood vein and I don't know, it's nuts, it's so nuts. mm-hmm.

Bill Gasiamis (26:39)

them.

Identity and Self-Perception Post-Stroke

Yeah.

And they talk about, you know, how dangerous it is to drive when you're off a take when you haven't slept, when all those things. And these guys are going for 30 hours and they're doing the most intricate, life altering surgery and it all goes perfectly well. So how wrapped was he when he realized how well it went.

Jennifer Tomscha (27:09)

I didn't talk to him until June, so that was at the end of March. And then I was in the ICU for a while. then they moved me to Masterton and I did rehab.

And then I went to this last clinic, this ABI, this brain clinic for people who had brain injuries. And that's when I finally talked to him on Zoom. And he was like, so can you walk? And I was like, yeah, yeah, yeah, of course I can. He was like, will you show me?

and I walked up and down the room and he was like laughing so hard at my being able to walk. He was like so enthusiastic about it.

I was, you know, I mean, we can talk about this too. was, everyone was like, when I finally have my memory back, I was in Masterton and I was using a diaper. I couldn't walk. I couldn't step in bed, but I remember being, actually,

~ I remember being like, I'm fine. I'm fine. Everyone is just fussing over me. But of course, they were right too. Do you know what I mean? But I was like, I'm okay. Everyone needs to just like, let me just relax around me. And everyone was like, everything I did, they would be like, you know, I couldn't feed myself. And then, you know, there's all this stuff. And I was like, I'm really okay. You guys should just.

take, like, I'm fine. I kept saying that, like, I'm okay, I'm fine. You guys are all. But of course, I wasn't really fine, but I felt like,

Bill Gasiamis (28:36)

It

sounds like you weren't physically there yet, but you were emotionally and mentally fine. Like it sounds like you were on the, you kind of knew that things

were going to turn out or.

Jennifer Tomscha (28:48)

I think so. I think, or maybe, I always think like maybe you can only manage so much. like at that time I had my front part of my skull was gone because it had been taken out when they did both my surgeries. And so I had to wear like a rugby helmet or whatever when I walked. But otherwise I would sit in my room and it looked terrible. It's just so terrible.

but I just didn't really recognize that. Like I didn't, wasn't, I couldn't do all the things at once. So I think I was just thinking about like, and finally at the middle of May, my mom and sister, I still had my like long hair in the back and short in the front. So my sister was gonna cut the long hair in the back. And I saw myself in a mirror and I was like, that doesn't look very good. You know, like I wasn't, I don't feel like I was totally aware. I wasn't, my brain wasn't.

totally back in it. It's a long time to recover and I feel like my brain only gave me, I don't know, I felt like I couldn't think about my own brain, maybe for like a year or something, really think about it in a second order way.

Bill Gasiamis (29:59)

allow yourself to kind of observe your state, your brain condition.

Jennifer Tomscha (30:02)

Yes.

Yes, I think I was like, it was like that my it was like maybe in October of the next year, October of 2023, where I was like, Oh, I can think about my brain and what it is in a way that I couldn't. Because I don't know, you have to go through, you just have to relearn a lot of stuff. But I didn't like

I'm lucky, like, it didn't affect my reading, so I could read right away. I'm not a very good writer, like, I don't have good handwriting anyway, and my handwriting still maybe isn't as good as it was before I had my stroke, but, yeah. I feel like, felt like, the actual healing was a longer process than I thought it was going to be, especially right when I first woke up, because I was like, I'm fine, but I wasn't really fine, actually. Do you know what I mean?

Bill Gasiamis (30:55)

100%, they can make doctors and neurosurgeons do a 30 hour surgery, find that part, fix it, ta-da-da-da-da, do all those things, but they can't make a helmet for God's sake look half decent after they've taken your skull out. Like as if it's bad enough, have skull missing and then they put this terrible looking thing over your head.

Jennifer Tomscha (31:11)

No.

It's true. It's true. It's true. Yeah. Yeah. So, yeah.

Bill Gasiamis (31:22)

And I know for women

like hair is a big deal and become.

Jennifer Tomscha (31:27)

It was really,

I have always liked my hair and it was, I had short hair for about a year and a half maybe, you know, and I started growing out more and that was a little bit hard. I felt like that's really vain, but I was like, man, I just did not like that short hair. Cause it's not very, I don't know. I just, wanted my old hair back. So I was lucky that it came back though. You know, everything, it's not cancer. It's a different thing. So you have a different, you know.

Bill Gasiamis (31:51)

I never would have told you that your hair didn't look good, but my favorite hair is brunette curly hair. Yeah. My wife is a brunette naturally and she has curls in her hair and she straightens it all the time. I haven't seen her brunette curly hair for 30 years.

Jennifer Tomscha (31:57)

Thank you.

~ yeah.

no.

Bill Gasiamis (32:13)

I'm like, woman, that's what I like. Like that's my thing. you stop straightening your hair, but I can't get it to stop. ~

Jennifer Tomscha (32:20)

Yeah, that's fine. Everyone has

to do what they want with their hair and everything. you know, that's something that one thing I think about my stroke is you just got to go live your life. Like you can't and you've done that beautifully. You know what I mean? Like this podcast is amazing. it's just like, you just got to go do what feels good for you at the time and what you want to do and just do it.

and stop saying no, or you know what I mean.

Bill Gasiamis (32:49)

I'm trying. am. know exactly what you mean. One of the biggest things is identity is a big, big thing. And I don't talk about me so much. I'll talk about what happened to me, my stroke journey, but I don't really give people a look behind the curtain. You know, sort of really understand what's going on. This is just all a facade. And one of the challenges that I have is this painting company that I started 20 years ago was the main source of income. And it stopped abruptly seven years in when I became.

Jennifer Tomscha (33:02)

Hmm.

Mm-hmm.

Great.

Bill Gasiamis (33:17)

and it sort of still kept bubbling along. And then I got back to it in 2019 because my clients were still calling me and I was well enough after seven years of going through stroke and all the stuff of surgery, learning to walk again and all that. I was good enough to sort of get back into it. And of course in 2019, I only had six months and then we were in lockdown.

And then in lockdown, we had two years of lockdown in Melbourne, and then I'm trying to keep that thing going again. And then there was this massive influx of work after lockdown because everyone's going, I've been looking at these walls

for two years. They look terrible. Let's get them painted. They had spare money because they hadn't spent anything for two years. And that was like, let's do this and let's do that. And there was this massive amount of work for about 18 months. And then that was done. It was gone.

And it's been a steady decline since as soon as Trump opened his mouth and did something in Iran and said what he said, and he plummeted like we've got no work. And I'm okay to have no work because I've been there before and we've managed our affairs so that we're okay. But I can't employ people right now at all. That's gone. And getting people back and starting that again is going to be extremely difficult because the curve

Jennifer Tomscha (34:27)

Yeah.

Mmm.

Hmm.

Bill Gasiamis (34:36)

is not it's not going to be a sharp dip and then it's going to be a big spike of work and demand and all that kind of stuff. this podcast has been my saving grace every time I've needed to occupy myself with a project and make it so that I'm not thinking about me. The podcast was there. I did. I did an interview. It got me over the line. But now the biggest void that's going to occur is not that I'm going to

Jennifer Tomscha (34:47)

Mm-hmm.

Bill Gasiamis (35:05)

potentially not have work in this field and after shut it down, which is gonna be fine if I do that, I'm okay with that. I'll kind of pass it on to my younger son who's looking to do some work in a similar space. I'll give him the phone number and he'll be able to take those types of inquiries and then he'll do it on his own, like very small, the way I started at the beginning. And is that I'm gonna have all the time in the world.

Jennifer Tomscha (35:23)

Mm.

Bill Gasiamis (35:29)

on my hands to do the thing that I've been avoiding doing because I had this business that relied on me and the thing was to do public speaking. Right. And to actually do it the way that I've wanted to do it for more than a decade, which was to talk about the topics that I want to talk about, which no one's talking about post-traumatic growth, overcoming trauma, how that's applicable in organizations.

Jennifer Tomscha (35:38)

yeah, yeah,

Mmm.

Bill Gasiamis (35:56)

how to

treat people better in an organization so they have less mental health issues, so they have less physical issues, so they're sick less, so they enjoy their work, so they're not hating their life. And now I'm going to have all the time in the world to do it. And I'm shitting myself.

That's the biggest issue, right? So that's a little bit of a look behind the curtain. I am loving this. This is an amazing thing. And I do remember when I first started it, I was concerned about what people would say about me. You're going to sound dumb, Bill. You you're not going to, you know, what authority do you have? All those kinds of things, they were coming up in my head. And then when I wrote the book, the same thing, I wrote my first book, *The Unexpected Way That a Strike Became the Best Thing That Happened to Me*. Everyone has said, don't write that book. Don't write that.

Jennifer Tomscha (36:27)

Mm.

Bill Gasiamis (36:39)

Don't let that be your title. It's bizarre, it's weird, like it's strange, it's too long and all these things. So I did it. And of course, the first time I spoke about it on YouTube, one of the first comments was a negative comment on my YouTube channel. It's like, ~ okay. My God, that's a kick in the guts.

Jennifer Tomscha (36:44)

really?

~ yeah.

Bill Gasiamis (37:03)

So those little kicks in the guts that I've had along the way have been few and far between, but they're the ones that seem to persist the most. And they stay in that part of your head, which says, you know, that public speaking gig, you're probably going to do the first one and they're going to say you were terrible. And then you're to feel all sad at 52 about, you know, yourself and all these things.

Jennifer Tomscha (37:15)

Yeah.

you

Bill Gasiamis (37:29)

how you're going to overcome that emotionally and mentally and all this kind of stuff. It's like, Bill, relax. You're gonna have time to build your new career at 52. You're gonna have time to do it. So that's like, all right. I find myself getting pushed into a corner and only then responding with, all right, all right, I better step up again. I better do this again.

Jennifer Tomscha (37:33)

Mm-hmm.

Yeah.

Mm-hmm.

Mm-hmm. Mm-hmm. Yeah.

Bill Gasiamis (37:58)

Very

strange, re-imagining yourself and recreating yourself after stroke is a huge thing because you're also doing it with a stroke brain. Whereas before I had no excuses, I was doing it still. Like the pattern is the same. The stroke brain part of it is an obstacle that I wish I didn't have, but somehow this stroke brain part has made

me do things I've never done before.

Jennifer Tomscha (38:14)

You

The Long Game of Recovery

Bill Gasiamis (38:27)

a podcast, a book.

You know, I was a tradie. I was like, I didn't study. didn't read. In my, by the time I got to the age of 37, honestly, Jennifer, I reckon I'd read maybe seven books. And they were about this criminal underworld figure in Melbourne who had this, who had this career and of being like really terrible and somehow.

He was the thing that I was interested in reading about. Like that's the only thing that captured my imagination. Everything else, everything else I picked up from listening to podcasts or watching shows on TV and that kind of stuff. So I wanna just, I wanna make people understand that the battles that you're fighting, I'm fighting, it's real. Like you're not doing it alone. Everyone's fighting this. How do I reimagine myself?

Jennifer Tomscha (38:56)

Bye!

Bill Gasiamis (39:20)

after stroke, you know, I don't tell people I'm an author. Still, this book has been out for three years. I've had amazing reviews. I've had a couple of, you know, negative reviews and that's okay. I'm not, I'm not an intellectual. I haven't, I've never studied how to write literature, any of that stuff. And it's sold about seven or 800 copies just through the podcast.

Jennifer Tomscha (39:21)

Mm-hmm.

Mm-hmm.

Mm-hmm.

That's pretty good.

That's actually quite a bit, I feel like. It's quite a bit, actually. Mm-hmm.

Bill Gasiamis (39:47)

I feel like to like I don't promote it. I don't tell anyone about it just in the podcast.

And it's like, I still don't say I've authored a book. Nobody knows.

Jennifer Tomscha (39:56)

You

should say it. mean, I do think the what are you going to do after you have a stroke? How are you going to do it? It's all very strange and scary, I think. And like, yeah, I, I totally get your feeling about it. And it's just really tricky to know what is the

You know, for me, I feel like I was in middle of my PhD, so I took 22 months or 20 months off of doing the PhD just to rest. And then I went back in and it was, it is still, it was really hard. I like, wasn't very good at figuring out how to write in the academic way.

Which was my position. I was director of the writing program at NYU Shanghai. So I was like, that was my thing. And it was very hard to figure out how to return to do the critical work of my thesis. was just, it's just, I don't know, my brain just couldn't figure out how to do it right. It was really interesting. was like, the sentences I was writing weren't as good. They probably still aren't as good.

You know, like when I look at what I was writing before I had my stroke, which is part of my thesis, and then the stuff I wrote after my stroke, I feel like I can tell a little bit of a difference in the fluency of my writing, for sure. So, yeah. And I just, so... Yeah, I don't know. It's tricky. It's tricky to figure out. But I was really lucky, actually. I think the PhD was helpful because...

I could just go at it on my own time and I could just take however much time I needed. And I, I had a deadline. but it was good to just, it was actually like a really good place to start to work my brain again, to be like, okay, I have to, I'm going to write on this author and what she thinks about character. And I'm just going to, and I have these other texts that I'm interested in and I have to figure out how I'm going to.

Represent them in my own work. And so it was really good to do all that. It was a

good stepping stone for me I think actually to get back into it and to see What I could and couldn't do very well, like I feel like I'm a really good reader. I'm a really good Critic and I'm not so good at ~ writing down what I think anymore as well So I'm just I really have to work on and I don't know how you get it back like

Bill Gasiamis (42:26)

articulating

Jennifer Tomscha (42:28)

Yeah, articulating what I mean and yeah, I feel like I can't, I can't say things as artfully or as proficiently as I used to. So I don't know, this woman who is getting her PhD at Vic too, she's like, she studies how people learn to read. And she was like, if you're having problems with academic writing,

you should get a, and I still haven't done this, you should get an academic book and you should listen to it because a lot of learning to read is listening to how sentences sound. She was like, so you should listen to an academic book and that will help you think about how those sentences work and how they're maybe different from like, I write fiction. So fiction is one thing and then this is a different way of writing. So she said that was one thing that she thought I should do to help.

develop my proficiency in academic writing, which was really interesting. So.

Bill Gasiamis (43:25)

Yeah,

it's a different approach. You know, it's coming from the auditory, you know, system and therefore the auditory digital system. Therefore you go in and you you, you pick up nuances that you wouldn't have known were there if you've never heard an academic speak or if you've never read an academic document in that way. So you might read it.

Jennifer Tomscha (43:28)

Mm-hmm.

Yeah.

Bill Gasiamis (43:51)

to get something out of it. Like, okay, what is this academic saying about this

topic? But that's not paying attention to the structure of how it's written. That's a different filter.

Jennifer Tomscha (43:55)

Mm-hmm.

No, exactly.

Mm-hmm. Mm-hmm. Exactly. So I thought that was an interesting way to think about, like, how I could get better at that thing. That was, like, a really important thing for me. That, for some reason, it did just get a little bit, I don't know, stunted? Or I don't know what happened, you know? Or I just haven't been in academia as much. So you know what I mean? So, yeah.

Bill Gasiamis (44:17)

Yeah.

Yeah,

100%. The skill is not as refined or, or practiced as your other skills. So it's not the thing that you're the best at. and you're getting better at it. The thing about it is also, may I add you're only four years out from all the drama that you had with your brain. So there's a lot of healing to happen that is going to improve. That's going to get better and better. And in four or five years from now, you will have

Jennifer Tomscha (44:29)

Mm-hmm.

Bill Gasiamis (44:49)

turn the corner again, you'll see that there's more and more improvement. It's really important for people to hear this, who are three, two, one, five, six years in, there's still heaps of healing and recovery to come. So it'll happen.

Jennifer Tomscha (45:07)

Yeah, that was something that my husband and I, in my first year after my stroke, he would be like, go to the gym. And he did. He, I went to the gym and I, had me lift weights and he wanted me to like exercise. And he was like, what are you doing to improve your mind and your body over this first year? And I was like, I'm, I'm again, I was like, I'm fine. I'm really fine. And, and, ~ he thought I wasn't doing enough.

Like he wanted me to just go at it with this intensity. I don't know. was an, cause I was like, I am going at it with my own sort of intensity, but he wanted me to be more aggressive than I wanted to or something. You know what I mean? He wanted me to be like, he wanted to see me really working at it and like sweating or doing, you know what I mean? And I was like, I don't wanna, I don't know.

Bill Gasiamis (45:59)

He wanted it to be more

masculine.

Jennifer Tomscha (46:01)

Yeah, I guess. And he's not very masculine guy. I mean, he's a masculine guy, but he's like, he was just he just wanted to see me sweating it out or doing the really see my focus. And I just yeah. And that has been an issue because he's like, yeah, he's just like, are you going to work again? I was like, yes, I'll work. I just don't know what I'll do. And I don't know if I could do a full eight hour day right now. I still take a nap every day in the afternoon. So

But yeah, it's just, don't, yeah, so.

Bill Gasiamis (46:34)

It's

easy for a caregiver to say that because they haven't had a stroke. Thank God. Thank God. ~

Jennifer Tomscha (46:40)

No, I know. Thank goodness. Yeah, yeah, yeah. Actually,

I mean, I feel really bad for Dan and my mom and my sister. Like, it's actually worse to be the caregiver in some ways because you just, you don't go through it. So you, you don't really know what it's like.

Bill Gasiamis (46:55)

I and you, and if you've got an imagination, a wild imagination, you could turn it into something completely way worse than what it is. And if you're ignorant, which most family members and caregivers are, let's face it. And that's okay. Then you do the other thing. You play it down and you assume she should be going harder than that or

Jennifer Tomscha (47:11)

Yeah.

Mm-hmm.

Bill Gasiamis (47:19)

If I was, if it was me, I'd be doing that. But your brain has actually been injured and in that space, perhaps where motivation is for some people. And there is no way that you can make that person more motivated by willing them on or telling them to go to the gym or whatever. That could actually be missing the motivation part. So there's a whole bunch of things that caregivers and family members miss. And it's for me, it's when I'm surrounded, when, when the people that are around me are

Jennifer Tomscha (47:33)

Mm-hmm.

Bill Gasiamis (47:46)

~

people who don't want to engage deeply in those types of troubles, life and all that kind of stuff. they're great people. They're just like, emotionally they don't go deep, right? They love it that there's ambiguity around like what's wrong with me. Cause they look at me, I look right. And then they just go, everything's fine. He looks amazing. I feel better now. And when I'm around him, I can just talk about dumb stuff.

Jennifer Tomscha (48:07)

Mmm, yeah, yeah.

Bill Gasiamis (48:14)

And we can talk about things that are not important and everything's fine. And it's kind of like head in the sand. It's a, you know, one step, one emotional step removed from the actual goings on. And it kind of also helps me strangely enough, because then I don't have to deal with their inability to handle actual life and the real things that are going on.

Jennifer Tomscha (48:39)

Mm. Yeah.

Bill Gasiamis (48:43)

that can just be living in La La Land and I don't have to deal with that level of complexity. So it's kind of, they're both situations are helping me in a way. Whereas at the beginning I was taking that negatively. The thing I do, the thing I would like to do is challenge caregivers to listen to the podcast, especially of the spouse who I've interviewed.

Jennifer Tomscha (48:50)

Yeah.

Yeah, that's true.

Bill Gasiamis (49:09)

You know, and then

a couple more after that to get an insight so that they're not guessing or second guessing or think they know better, et cetera. No doubt about it. they, know, they know some things about us that they can see that we're not doing a pattern in behavior that we're avoiding. Perhaps they know that part and all that type of thing. But we'll say, we're also dealing with a messed up brain. So have a bit of a kind of a Q

Jennifer Tomscha (49:13)

Hmm.

Right, right.

Bill Gasiamis (49:36)

be curious about where that person's coming from, not how you're feeling about where they're coming from. And that's what family members and caregivers do. They make it about them. And I had to say a few times to people in my circles, like, it's not about you.

Jennifer Tomscha (49:43)

Right.

Ha Tomscha Tomscha! Yeah, yeah, yeah, yeah, yeah.

Bill Gasiamis (49:56)

It's actually really about me. cannot walk and I can't use my left hand. It's not

about you. Like I know you woke up with a numb leg one day because you slept on it wrong, but it's not the same.

Jennifer Tomscha (50:05)

Yeah, yeah, yeah.

Yeah, yeah, yeah. That's funny. Yeah.

Bill Gasiamis (50:14)

My

wife was dragging my foot in the wheelchair. It had fallen off the, you know, the rest where your leg, your feet sit. It had fallen off and I hadn't noticed. This is like day three or day four after brain surgery. And it was dragging underneath the footrest. And she noticed that the wheelchair wasn't moving and she was shoving it until we realized.

Jennifer Tomscha (50:22)

higher.

Bill Gasiamis (50:40)

My foot was stuck underneath the rest and we had a laugh. that kind of like, that's one of those, if those people were there and they saw that, they would realize like, it's not about your numb leg when you slept on it weird one night. take your stuff and just, you know, park it for now. So it's interesting. That's kind of why I think I do this podcast. I think it's for those

Jennifer Tomscha (50:44)

Yeah, yeah,

Mm-hmm.

Mm-hmm.

The Journey of Recovery

Bill Gasiamis (51:08)

people if they, I've never told them that they should jump on, but if they, for example, get curious one day and they want to know what it's like to be in Bill's head, pick one of the 400 episodes. Just have a listen.

Jennifer Tomscha (51:09)

Mmm.

I have a question for you. you, this is something that, so you think you could just, you can keep improving from your stroke. There's not like a deadline. There's not like a couple of years or any.

Bill Gasiamis (51:36)

One of the things I learned from my wife and my brother, my brother is my biggest nemesis. You he's older and he's the most loving guy. He's the most supportive guy, but he has a weird way of doing it. Just, you know, we're different characters, right? So he just is a bit different in the way. one, one of the things my brother said was that I picked up, I reckon it was five, six years ago is he's in it for the long game.

Jennifer Tomscha (52:03)

Hmm.

Bill Gasiamis (52:04)

When I was young, I had 20 jobs in 10 years. He said two jobs in 40 years or 30 in 30 years. So he just chips away, works away, works away, works away. This is an analogy, right? But also a true story. My wife started her, her, her master's in psychology. She only started that a few years ago, but the whole.

Jennifer Tomscha (52:08)

Hmm.

Hmm.

Bill Gasiamis (52:28)

journey to get to the Masters of Psych started in I think late 2011 or early 2011, about a year before I ended up in hospital. She is just now finishing the last part of her Masters degree and she found a job literally a week ago in her field two days a week.

Jennifer Tomscha (52:35)

Mm.

Mmm.

~
Bill Gasiamis (52:56)

to work as a provisional psychologist so that she can get the 1500 hours of work in the field before she actually gets her actual full psychology license. And I'm like, dude, I get it. So what you're telling me is that if you just start and never stop, you're gonna see some kind of progress. And I apply that to...

Jennifer Tomscha (53:08)

Right.

That's amazing.

Mmm. Mm-hmm.

Bill Gasiamis (53:27)

stroke recovery. I know that people are dealing with far more deficits that perhaps you and I show visibly and that their hand may not specifically work the way that it always that they wanted it to work or that the way that it worked before. But that doesn't mean the brain's not continuously continuously healing that part of the brain might be gone. But as far as healing the parts around the brain that are still there, that's continuing.

Jennifer Tomscha (53:28)

Uh-huh.

Mm-hmm. Mm-hmm.

Bill Gasiamis (53:58)

And if, and, and one of the questions that I have for people is like, is what I'm doing supporting my recovery or is it hindering my recovery? Because I've met stroke survivors who have gone back to the smokes, who have gone back to alcohol. And if you're doing things that are getting in the way of recovery, then you're not allowing the brain to continuously do what it does best, which is overcome challenges, rewire.

Jennifer Tomscha (54:05)

Mmm.

Bill Gasiamis (54:25)

find new ways around, know, develop new neural pathways and adapt. And that's kind of where I think it's at adaption, right? And the great thing about understanding these days about neurodiversity and understanding what somebody with ADHD goes through is the one skill they're really, really good at is adaption.

Jennifer Tomscha (54:31)

Mm-hmm.

Mm, that's interesting. Yeah, yeah. Mm-hmm.

Bill Gasiamis (54:49)

because and people with dyslexia. my God, like some of the biggest, most wealthy billionaires on the planet had dyslexia. Richard Branson is a classic example of that. Yeah. And they adapt. They find a way to somehow overcome the normal world and be weird in the way that they see letters and what letters do and how they move on a page and all that kind of stuff because their brain adapts and they can just continuously improve their adaption strategy.

Jennifer Tomscha (54:57)

really? didn't know that.

Mm-hmm.

Bill Gasiamis (55:17)

to get to a point where no one knows that they have this condition. So that's what I'm really passionate about. That's why the podcast exists. I've interviewed in my 400 episodes, I've certainly interviewed stroke survivors who I've had improvement 10, 11, 12, 13 years post stroke, got a finger movement back. Yeah, got sensation back, something rewired. So yeah.

Jennifer Tomscha (55:19)

Right.

Mm-hmm.

really?

That's amazing. Yeah, because I feel like when when you read about stroke recovery, they're like, the first year is really important. Next couple years are

important. And then after that, it's slow going and maybe nothing, you know, they're like, you got to get going right away. And that's interesting. Yeah. I mean, that's I still feel like. Like,

my brain's still coming back to me. I maybe can't describe the way like I feel that a little bit. Like, yeah, I can definitely feel like I'm getting better at a little better at talking about the stroke and not wanting to push it away. Or, you know, like, I was at a party a couple months ago, and there was a 16 year old girl there and she was, she had had a she had been homeschooled for something and I was like, what happened and she had had a traumatic brain injury.

And I was like, okay, so should I talk about it? And I finally, I was like, I had a stroke and I had this brain injury and it allowed us to, and I had never really told that to somebody before. And so I was like, it's good, it's good to share. You know what I mean? So.

Bill Gasiamis (56:46)

Absolutely. I had an

interview last week.

with Maggie Widom. It's 11 years since her stroke. I had the first time I interviewed Maggie was in 2019. And experiencing Maggie in 2019 was a completely different Maggie than the one I was chatting to this time. And I say that in that by 2019, she had only been three or four years into her stroke recovery journey. But she was dealing with so many deficits because she had a brainstem stroke.

Jennifer Tomscha (57:02)

Really.

Bill Gasiamis (57:16)

So it took off so much of her. impacted her, the way she feels on one side of her body, how she feels on the other side of her body, her eyes, her balance, a whole bunch of things. And she was doing it hard. Like recovery was really hard. And she had been an actress amongst other things. And she was 33. Again, she had an AVM.

Jennifer Tomscha (57:29)

Wow.

yeah,

Bill Gasiamis (57:46)

burst or some other malformation and the and the challenge back then for me, I was early on in the podcast journey as well. And in the stroke recovery as well was me kind of understanding what happens after like, long does it take? What happens that are and Maggie is the classic. I started a project. It was called the great now what?

Jennifer Tomscha (58:04)

Mmm.

Bill Gasiamis (58:14)

in 20, I think she started in 2017, 2018. This is only a short number of years after her very serious stroke where you would have forgiven her if she didn't. You would have thought, yeah, makes sense. You were dealing with all these deficits. And the project was to tell the story of stroke from a stroke survivor's perspective, because there wasn't a real story where somebody was giving that.

Jennifer Tomscha (58:29)

Right.

Mm.

Bill Gasiamis (58:44)

that version of it and she wanted to make sure that it was an accurate retelling of what stroke is like for somebody to go through what she went through. That project hasn't completed yet.

because of funding, because of her health, because of COVID, all those things got in the way and yet the perseverance, the persistence, the fact that she started it and it hasn't finished yet. The last episode that we did was to bring awareness to the project so that if anyone wanted to go, who listened to the podcast, wanted to go and support the crowdfunding part of the, I think the editing or the audio or the last part of putting that

Jennifer Tomscha (58:59)

Hmm

Hmm.

Bill Gasiamis (59:27)

documentary together and that's the thing. And Maggie talks differently than before, like more, better than before. Her sentences come out differently, her voice sounds differently, her eyes focus better. ~ Her head doesn't move as much because it used to involuntary move. And she spoke about some of the other deficits that have resolved, that have.

Jennifer Tomscha (59:42)

Wow.

Bill Gasiamis (59:51)

kind of got less worse than what they were. And also she spoke about how she's adapted and overcome and changed. That's 11 years since stroke. Like it never ever stops. I've been doing this. I've been going through my journey since February, 2012. I'm still talking about it.

Jennifer Tomscha (1:00:06)

~ Okay.

Yeah, yeah, yeah.

Bill Gasiamis (1:00:10)

And it's so bizarre. Like I've never done a project that's lasted this long other than the painting company. And then I did that out of necessity, work, money, you know, all that kind of stuff. This is a completely different experience. So I want to encourage people to play the long game like my brother does.

Jennifer Tomscha (1:00:18)

Right, right.

Mm.

Bill Gasiamis (1:00:29)

and my wife and Maggie. And if you play that game, you'll get through the dips, the troughs in this journey. You'll get through them a lot more calmly and easier. And when you do that, you recover and you rest better and your brain heals better. And it's just a different way to go about it.

Jennifer Tomscha (1:00:47)

Mm-hmm.

Mm-hmm. That's great. I think that's just so powerful and important for people to hear about. Because I know sometimes, especially at the beginning, I was just stressed out and frustrated. And I had a lot of aphasia, so I had a lot of words that I

I just did say weird words that weren't even English words, but you know what mean? I didn't, couldn't think of the word for the moment and it would be so frustrating and it's just good to.

to have the long game in mind, I think would have been really helpful for me in those times to be like, I'll get through this, it'll be okay. And even if it's not okay, even if I have aphasia for forever, which I still do, especially at night when I'm tired, that's okay too. You know what I mean? Like it's okay. It just is what it is and you can manage it. And yeah, I think that's a really helpful way to frame it for people.

And their caregivers both, yeah.

Bill Gasiamis (1:01:45)

Yeah.

What's really cool. Someone asked me on YouTube. I think that they have accessibility issues to, therapists for aphasia, that kind of stuff. Accessibility being they may not have either the funding or there might be not, might be near somebody or whatever. It just a couple of days ago and they were like, what do I do? Like, how do I start this aphasia recovery journey? Jump on YouTube.

Jennifer Tomscha (1:01:55)

~

Mmm.

Bill Gasiamis (1:02:08)

type in aphasia for your condition, there's somebody doing therapy, 100%.

Jennifer Tomscha (1:02:13)

Interesting.

Yeah, yeah, yeah, yeah. Uh-huh. And yeah, that's interesting. Yeah, I hadn't thought about that. You're totally right. Yeah. Mm-hmm. Mm-hmm.

Bill Gasiamis (1:02:21)

So

there are resources that now most people can access that don't cost any extra that you can jump on and that you can do rehabilitation at home even if it's just 20 minutes a day or one hour a week or whatever it is. if you feel like it's gonna be okay even if it's not okay, then that's gonna be okay like it will.

Jennifer Tomscha (1:02:35)

Mm-hmm.

Yeah, I think I I understood what you meant. Yeah.

Bill Gasiamis (1:02:47)

Yeah, convoluted,

but it makes sense in my mind. And and you know, my book, the first one from idea to publication, took four years.

Jennifer Tomscha (1:02:51)

huh.

that's interesting. Mm-hmm. Mm-hmm. Mm-hmm.

Bill Gasiamis (1:03:02)

I had no idea what I was doing. I didn't even

know how to start a book. I got somebody to help me. had to pay them to help me to write this book. They guided me to a certain point and then we got it published. And it says it at the beginning of the book. This is not a scientific book. It's not an academic book. This is not being written by somebody who's studied writing or knows how to write a book. I made sure that people understand it's just a stroke survivor.

Jennifer Tomscha (1:03:18)

Right.

You

The Evolution of the Podcast

Bill Gasiamis (1:03:29)

who came across this weird story that other people were saying that they thought that stroke was the best thing that happened to them. And I thought we've got to tell this story. There's a 10 people I've got to tell that story because why the hell are they saying that? And they had these 10 things in common. And if I could bring those 10 things to you and you did that, then maybe, not the experience of stroke because I totally don't think that was the best thing that happened to me, but the lessons that come.

Jennifer Tomscha (1:03:54)

You

Bill Gasiamis (1:03:56)

and the growth that's possible and the new opportunities that could open.

Jennifer Tomscha (1:04:01)

Mm-hmm. Mm-hmm.

Bill Gasiamis (1:04:02)

That's been the best thing that happened to me. Cause the trading life, the painting life has proven to be the same the next 13 years as it was the first seven years. Somebody either wanted a house painted or a wall painted, or they didn't want one painted. They either wanted me to pay that much money for it, to pay me that much money for it, or they didn't want me to pay that, be paid that much money.

Jennifer Tomscha (1:04:13)

Right, right, right, right.

Mm-hmm.

Right.

Right.

Bill Gasiamis (1:04:28)

Nothing's changed there. Everything has changed and all the opportunities came outside of that. And there's this thing in business, the opportunity cost. If you're

focused on a particular task and you'll think you're kicking goals and you're loving that, and you're doing that for something that's substandard to you, the return is substandard to you, then not only are you doing something that you don't love, that you don't enjoy,

Jennifer Tomscha (1:04:29)

Mm-hmm.

Mm-hmm.

Bill Gasiamis (1:04:55)

that you're not making enough money for all that kind of stuff. But you're also taking your resources away from the other thing that you could be doing that could be bringing you more money, more joy, more meaning, more purpose, more whatever. The opportunity is lost as well as I'm not getting satisfaction over here. And kind of that's like another way to think about how you're doing your current life and what recovery

Jennifer Tomscha (1:05:03)

Mm-hmm.

Bill Gasiamis (1:05:23)

or when you get to the fork in the road, like why you might take the other path.

Jennifer Tomscha (1:05:29)

Mm-hmm. Mm-hmm. Yeah, that makes sense. Yeah, definitely. Yeah, I have my ~ oral exam for my PhD is next Thursday. So I'm like, I was just thinking about like, hopefully I pass it and then I'll have my PhD or I'll have to probably do some revisions on my thesis, but then I'll have my PhD. And then I don't know what we'll do. You know, it's just like, don't, I don't know what I'll do.

I don't think I can, you know, it's just so, and I've been just looking at all different kinds of jobs, trying to figure out like what type of work I can do and full-time or part-time and all that stuff. yeah, it's, I like that idea about the opportunity cost and like,

what am I doing now that maybe I should do something different or, you know, yeah, like what is it preventing me from doing something? So that's really good.

~

Bill Gasiamis (1:06:17)

Yeah. For me,

just, what ended up happening, why I kind of stumbled in this, I just took on the challenge when somebody said to me, um, the guy who wrote my forward is an amazing mate of mine. I met him in 20, in 2013, and he knew how unwell I was and he would just keep in touch and he just turned up at really bizarre times and would just keep in touch and

Jennifer Tomscha (1:06:39)

~

Bill Gasiamis (1:06:46)

He would just keep in touch and then it came to my rehab hospital after surgery. And I was just amazed by this guy. Just, we really didn't have much of a connection. Anyhow, I call him Mike the marketing guy, cause he's in marketing. And he said to me, so, know, with all this stuff that you're telling me about how you're going to go about your recovery and how you're going to heal your brain and all that kind of stuff.

Jennifer Tomscha (1:06:53)

Mm.

Bill Gasiamis (1:07:11)

Because what do you want to do with that information? So I'd love to tell other people about it, you And he goes to me, how, do you want to share that? I said, I could go to my local community here where I live and I could talk to people, you know, at the, at the town hall and I can meet people locally. He said to me, have you ever heard about this thing called the internet?

And I said, I don't know. Like, why do you mean he goes, you know, YouTube and there's podcasts and people are sharing all the information that they know, but it's going to a global audience. And that was it. He just put the seed in my head.

And then the podcast happened. That is all he did. And I've just taken those kind of little bits of beautiful advice and thought, I'm not going to do it. I didn't think I was going to do it for 10 years. I just thought, I'm going to give it a go. Let's see what's cool about it and what hard things I have to overcome and learn about myself to do this.

Jennifer Tomscha (1:07:57)

Yeah, yeah, yeah, yeah.

What did you, did you have like, did you have five people lined up to interview or how did you, no, okay.

Bill Gasiamis (1:08:13)

The first 10, maybe more, certainly the first kind of 15 people were not stroke survivors. And I was just building stories of people had overcome difficulties in life. And they may have been, cancer, the death of a loved one, all kinds of different things, but it wasn't really resonating with me. And it wasn't resonating with people who I was telling about this podcast.

Jennifer Tomscha (1:08:20)

~ okay.

Right.

Bill Gasiamis (1:08:40)

It was so early that I didn't really think I wasn't doing well. And I was really unwell also. My head was still messed up and I was still recovering.

Jennifer Tomscha (1:08:50)

Yeah, I know.

How long after your, because you had three different stroke. How long after did you start the podcast?

Bill Gasiamis (1:08:55)

Yeah.

The podcast started in 2015 and by 2019 there wasn't a lot of episodes, but in 2019.

Jennifer Tomscha (1:09:02)

Okay.

Okay.

Bill Gasiamis (1:09:07)

When was it that I decided to start doing an episode a week? I think around 2018,

2019, I started, I decided I'm going to do episode a week. But, but what changed was at around episode 20, I had the aha moment that my podcast is not about all those other people. It's about stroke survivors. Yeah. And then when that happened, I started to get really good momentum and then people started to listen and actually continue at least.

Jennifer Tomscha (1:09:12)

Okay.

Mm. Mm, that's interesting. Yeah. Mm-hmm.

Bill Gasiamis (1:09:35)

listen and reach out and tell me that they loved it and all that kind of stuff. Like that's when it turned and then it

Jennifer Tomscha (1:09:41)

Because my husband and were just talking about this. He's also figuring out what he wants to do for work. And he was like, he's just trying all these different things. So he's doing some Instagram reels. And he was like, I'm just going to do 10 of them or 15. And then we'll see. He was like, but I'm going to let myself do a certain number.

And then after I have that number, then I can be like, is this good or what do need to change about it? And that's what it seems like you did with this podcast. You're like, I'm just going to try it. And then after I have like 15 or 20, then I can look at it see how can I reshape it or that's really interesting actually. Yeah.

Bill Gasiamis (1:10:15)

Yeah, you kind of

got to do it wrong or not make it feel a bit weird or whatever, but just persevere through it. And then you kind of have the, actually I know what the angle should be now. You don't get to learn what the angle is until you've done the other ones that you weren't really pleased about or happy about.

Jennifer Tomscha (1:10:28)

Mm-hmm. Mm-hmm.

Yeah, that's really interesting. Yeah, that's I mean, that's amazing. I just remember because Dan was the one who told me about your podcast, my

husband, and he was like, there's a guy he just interviewed stroke survivors. And I was like, that's interesting. It was after I had my stroke, obviously. But and I was like, wow, that's a it's like a there are tons of people who have strokes. That's not but but I had never heard of anybody doing that. And it was it's I mean, it's been amazing. I listened to your podcast.

Bill Gasiamis (1:10:40)

Thank

Yeah.

Jennifer Tomscha (1:11:02)

Not every week, but once a month, I'll just see who's on. I really love it. And it's so wonderful that you're doing this for people. ~

Bill Gasiamis (1:11:11)

Yeah. I,

I, I, it's a selfish pursuit. It's for me. Everyone else gets the benefit because I, I do it, but, um, yeah, it's honestly, I don't know why I'm still doing it. Like I, I don't know why. Like it just, cannot not do it. Like it's so weird. I don't have an intellectual answer. I just have it. I wake up in the morning. There's a booking. I sit at the chair, people come on. I press record. We talk. I upload it.

Jennifer Tomscha (1:11:15)

you

Hmm.

Mm-hmm.

Bill Gasiamis (1:11:38)

I don't

understand it. I don't get it. think cause it's so automated now and people reach out to me, it's a lot less effort. Initially I was doing Instagram outreach, just following hashtag stroke, stroke recovery, stroke awareness, that kind of thing. And then I was just reaching out to those people going any chance you want to come on the podcast. And my gosh, people wanted to come on the podcast and I just couldn't believe that they did. But my suspicion was that there was more of

us out there.

Jennifer Tomscha (1:11:48)

~

Bill Gasiamis (1:12:07)

that were willing to talk about it. And we didn't have, when I started this whole journey in 2012, my gosh, there was nothing out there for stroke survivors, nothing. It's not sexy. It's not sexy like all these cancer awareness things and multiple sclerosis and MND.

Jennifer Tomscha (1:12:09)

I

Yeah. Mm-hmm. Mm-hmm.

you

I know, no. Because stroke is kind of, it's not random, but it feels random or it's like, what I think is interesting about like the hospital care that I had here in New Zealand was amazing. But it's actually funny that we have a system in place where people will go help me because it was my brain fighting against itself. And the people were like,

we can help you. I'm just amazed that we have that system in place where I could call 111 and they would come and they would fly me to Wellington. I mean, that's incredible. It's just amazing. And I feel like, but I think the stroke itself is not, nah, it's not sexy. No.

Bill Gasiamis (1:13:03)

No, not at all.

And ~ I'm not, I'm not the guy to make it sexy, but if somebody out there knows how to make it sexy, please come forward. Let's do something because we need to bring way more awareness. Cause we can feel in Melbourne, we're sports mad. This is the sports capital of the Southern hemisphere. Almost now I'm overdoing it. At least of Australia, we can fill a stadium with a hundred thousand people.

Jennifer Tomscha (1:13:19)

Mm.

Bill Gasiamis (1:13:33)

who all will donate money to you name the cause that the particular footballer is promoting. And as if there haven't been footballers and people of that kind of level of influence who have had a stroke, like as if they haven't been those people. But there is this lack of ability to kind of bring those people into that awareness space where they're doing a great job.

Jennifer Tomscha (1:13:37)

Mm.

~ yeah, yeah,

Right, right.

Bill Gasiamis (1:14:00)

of raising awareness. There's a lack of people who are able to do that, but we can somehow do it for all these other conditions, which I love. I'm, which is amazing. I just feel like something has to change. So anyway, that's why I kind of do this in a way. It's like to just fill that gap

Jennifer Tomscha (1:14:00)

Mm. Mm-hmm.

Yeah.

That's one thing. I mean, you're a great interviewer, but I always feel like I don't ever leave when I listen to your podcast. I never feel discouraged, like ever. And that's amazing because that it just because you could definitely have talks with people who had strokes where you're complaining the whole time and you can't get but you don't you don't you don't elicit that from the people who are coming to your show, which is great.

Bill Gasiamis (1:14:42)

No, what's the

I want to thank you for reaching out to be on the podcast. really appreciate that. hopefully our conversation has been helpful, but I'll, I do ask most of the people who listen is like one piece of advice, one thing that you can impart on stroke survivors that might be earlier on in the journey than you or I, like, what would you say to somebody who's just come across this podcast and you know, they're

Jennifer Tomscha (1:14:45)

yeah.

Hmm.

Bill Gasiamis (1:15:06)

They're doing it tough right now.

Jennifer Tomscha (1:15:07)

Yeah, I think I would say you can rest you can take a nap, you know, that's really helpful. Like you can be as slow as you want it to be and that's also okay, but don't give up. just keep going I think is the main thing, but go as slower, as fast as you want to and it's okay.

Like I felt like my recovery was a little bit slower than other people's. Like it took me a little bit longer to do some of the,

be able to talk and think about my own brain just took me a little bit longer than they say it does. But that's not, it doesn't really matter because I got there anyway.

Yeah, thank you. was great. Thank you so much. was wonderful to talk to you.

Bill Gasiamis (1:15:43)

On that note, thank you so much for joining me on the podcast.

Bill Gasiamis (1:15:51)

That was Jennifer Tomche speaking with me from New Zealand four years after an AVM burst in her brain and changed the course of her life. I wanna thank Jennifer for her generosity, for her patience and for her honesty in this conversation. There are very few people who can articulate what it feels like to lose access to their own brain it. And Jennifer is one of them.

essential message that recovery takes as long as it takes, that rest is legitimate and that you don't have to give up even if the progress is one that every stroke survivor and caregiver needs to hear. If you'd like to go deeper into some of the themes in today's episode,

I want to point out to you two earlier conversations. The first is episode 262 with Gina Keely, whose work with the Paige Keely Foundation focuses on preventative

brain scans to catch AVMs before they burst. Her story is devastating and important, and it directly connects to the questions

Jennifer and I raised today about what might have been.

The second is episode 399 with long-term recovery from a brain stem stroke reflects exactly what Jennifer spoke about, that recovery continues well beyond the first year, the people who say otherwise are simply

If Jennifer's story moved you, please share this episode with someone who needs to hear it, a survivor in year two, year four, year 10, who's been told they're done improving.

They're not done improving.

If you haven't yet picked up my book, you can find the unexpected way that a stroke became the best thing that happened at recoveryafterstroke.com/book. And to everyone who supports this podcast, thank you.

This podcast exists because you believe it should. I'm Bill Gosialmus. This has been the Recovery After Stroke Podcast. Take care of yourselves. Look after the people you love And I'll see you next week.