

Cavernoma Recovery - Deb Brandon

Bed Brandon believes that life is much fuller after multiple bleeds in the brain caused by a hereditary condition known as Cavernous Hemangioma.

Socials:

Instagram: https://www.instagram.com/deb_brandon1/

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Transcription:

Bill Gasiamis 0:00

You mentioned depression. Is it something that came on the scene after the brain bleeds? Or was it something that you were dealing with previously?

Deb Brandon 0:11

I wasn't dealing with it previously, my therapists thought that I might have had low grade depression before. And at first I thought it was situational, you know, and I'd say to people, well, you know, I've been through a lot, it's not surprising, and as I recover, it will get better.

Deb Brandon 0:31

But it didn't, and I became suicidal a couple times. One of the times was really bad. I didn't want to tell anyone about it because I didn't want them to stop me if I actually did it, or wanted to do it or whatever. And that's when I realized that I needed to go, therapist wasn't enough that I needed medication.

Intro 0:56

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

Introduction



Bill Gasiamis 1:09

Hello, and welcome to another episode of the recovery after stroke podcast. This is episode 177. And my guest today is Deb Brandon. Deb was a mathematics professor when she experienced multiple brain bleeds at the age of 46, which turned her life upside down.

Bill Gasiamis 1:26

Although she's at risk of more bleeds, these days, Deb says her life has been much fuller and richer because of her stroke experience. I hope you enjoyed the episode. Deb Brandon, welcome to the podcast.

Deb Brandon 1:42

Thank you very much for inviting me.

Bill Gasiamis 1:44

My pleasure. Thank you for being here. Tell me a little bit about what happened

to you.

Deb Brandon 1:51

Let's see, I have clusters of malformed blood vessels in my brain that are referred to as cavernous angiomas or CCMs, cavernomas. And that thin walls and they can bleed two of mine did bleed. And the first time they did I didn't really know what was going on.

Deb Brandon 2:13

But the I mentioned it to my family doctor, and she sent me for a brain MRI and they found them. I only had fleeting symptoms, but a year later, I had acute bleeds from the same angiomas I have quite a few of them. I don't know how many exactly.

Deb Brandon 2:38

And that turned my life upside down. And I ended up having the only way to prevent future bleeds from these things is to remove them surgically. So I ended up having three brain surgeries. And life was interesting after that.

Bill Gasiamis 3:00

I love your spin on that. So how long were they in your head for before they started to play up or act up? How old were you when you first started to have problems with them?

Deb Brandon 3:14

The first time I was 46. And all hell broke loose when I was 47. But I've had them apparently since birth. They're hereditary. Yes they're not as vicious cousins to the AVMs. Yes.

Bill Gasiamis 3:36

Is that right?

Deb Brandon 3:38

They bleed the blood flow through them is fairly slow. I mean, they can bleed. They can cause pretty devastating symptoms. But on the other hand, they can't cause much much of anything.

Deb Brandon 3:57

My father has them and he's been asymptomatic all his life. My sister on the other

hand, she has them and she ended up she is 12 years younger than I am 11 years after I had my bleeds she had hers and ended up having brain surgery as well. So you just never know.

Bill Gasiamis 4:25

So it runs in the family. Totally.

Deb Brandon 4:28

Yes, my nephew has them, he's been asymptomatic. Everyone was tested my kids as well and they don't seem to have them.

Bill Gasiamis 4:43

How has it turned your life upside down? I have a feeling that I can relate but tell me your version.

Deb Brandon Post-stroke Deficits

Deb Brandon 4:54

Well, there are certainly symptoms that are common to most brain injury survivors. like short-term memory loss, attention span that's shortened. I didn't have any issues with the paralysis, maybe slight weakness on one side, I ended up with having seizures, tremors, vertigo, loss of balance, I still can't walk heel to toe without losing my balance.

Deb Brandon 5:33

What else, well, lots of cognitive deficits, my sequential thinking was damaged, which made it interesting for a mathematician of course. What else I don't know a lot of things, but I couldn't because of the seizures. I couldn't drive anymore. I had two teenagers at the time. Of course, fatigue, neuro fatigue, which is crippling. I don't know a lot of stuff.

Bill Gasiamis 6:07

That's plenty. But that's more than enough. I can relate to all of those things. Except I have more milder days these days. So I'm 10 years, since my stroke, I had that at 37. Mine was due to an AVM, it bled three times. And then we had brain surgery to remove the AVM.

Bill Gasiamis 6:32

And it was the brain surgery that made matters worse, the bleeds kept causing

problems initially, but it was settling down once the bleed was under control. All the all the deficits were coming back.

Bill Gasiamis 6:32

And that was the tricky part because it was making us think that it was less, it was more benign than what it was. So it was kind of creating this sense of oh, things are getting better. It's okay.

Bill Gasiamis 7:04

And then after surgery, I woke up with my left side feeling numb and I couldn't walk anymore and use my left arm and but the benefit of the surgery is that the AVM is not there any and will never bleed again. So that's the solution.

Deb Brandon 7:25

So they don't grow back AVMs?

Bill Gasiamis 7:28

No, just once again, you're born with them, they are created in utero, they're there, and they can remain benign and do nothing. But for very many of us they bleed, they're not often in the head, often they're in other parts of the body as well. So the ones in the head tend to be the ones that cause obviously a lot more problems for people.

Deb Brandon 7:55

Yeah, CCMs are mostly in the brain and the spinal cord. And they can regrow. So you remove them, they can grow back. And so there's always that fear, and also you can bring new ones.

Deb Brandon 8:19

So there's always that fear that will happen again. So whenever I have a new symptom, which happens, I mean, for instance, recently, I've had a lot of problems with vertigo. And immediately my thoughts are is it another bleed? You know, that kind of thing.

Bill Gasiamis 8:33

Right? So they are duplicating? Replicating? Or just growing in new places?

Deb Brandon 8:42

Both, well the thing is, because it's due to a messed up gene, it's a mutation. For

instance, x rays can generate new ones. Now as far as bleeds are concerned, there are all sorts of theories what can cause that and things like high elevation, stress, things like that. But yeah, life is interesting.

Bill Gasiamis 9:24

Yeah. If life's interesting. I like that application of the word interesting does that make it better than life's shit, or life's crappy or life's hard. Is that why you use that word?

The Bloody Brain - Deb Brandon



Deb Brandon 9:42

No, not really. That's just me. I tell you the truth. Now, I mean, it's been a while now. I can't think how long but more than 10 years. That's a lot. And I so I am a lot better. except, you know, when I'm dealing with fatigue, the symptoms get worse, but still, it's a lot better than it was.

Deb Brandon 10:11

And ultimately, yes, life is harder. But for me, it's better, much fuller. I was a math professor, I just retired a couple years ago, a year and a half ago. And I used to teach and enjoy it after the bloody brain, which is what I refer to it. After the bloody brain I had losing track, which as you know, is standard.

Deb Brandon 10:50

After the bloody brain, I had to relearn things. I mean, I didn't remember the multiplication tables. So I had to relearn that I wanted to go back into the classroom. So I re-learned college algebra, and calculus.

Deb Brandon 11:05

And after a year, went back into the classroom, my first semester back was pretty horrible, in my mind, apparently it wasn't as bad as I thought. But you know, and then. But in time, I'd say, by the end of that, well, by the beginning of the following year, which was, ends up being two years after the surgeries.

Deb Brandon 11:33

I because I'm having to relearn the material. And also I became more of an extrovert I used to be very much an introvert, think mathematics, think, socially inept mathematician. That's me. And I had to take a crash course in learning to ask for help. And in doing that, I realized that, hey, talking to people isn't that bad.

Deb Brandon 12:09

So I became much more sociable. And I enjoyed socializing, which I didn't really before. And through that, I connected better with my students. I also because my sequential thinking was damaged, my brain had to rewire around that. And I ended up learning to think in several different styles.

Deb Brandon 12:33

So it's also helped me teach, it helped me address a variety of thinking styles. So overall, I became a much much better teacher and I became really passionate about teaching. So as far as I was concerned, this was a huge game.

Deb Brandon 12:53

Also, after I got back from the hospital, I started writing, I had no idea what was going on. I felt like, I was lost in her without a compass and some sort of alien landscape. And I found that I started looking everywhere for books on the internet, I wasn't looking for medical data. I mean, I had that. I wasn't looking from the caregiver point of view.

Deb Brandon 13:27

I wanted to hear from brain injury survivors who are going through a similar journey, hearing anecdotal stories, there was nothing, there really was nothing. There was one book I found by Claudia Osborne. But so I went, Okay, I'll write my own book. And I figured that maybe other brain injury survivors would, maybe it would help them through my story.

Deb Brandon 13:54

So I discovered writing I never wrote before well as a teenager in school. But then I found that I, you know, when you start hanging out with people, and you see the lack of awareness, I wanted to reach a broader audience.

Deb Brandon 14:13

So then I started, I wanted to improve my writing. So I spoke to a friend of mine about it. And she suggested that I go to these workshops and I couldn't do it because of the bloody brain. So then I ended up working with a writing coach, and it was from there on I became a writer and later on also I came to really love writing that's another passion of mine a day without writing. Unless it's a headache day. Yeah, bad brain day.

Deb Brandon 14:52

A day without writing feels empty. So in many ways, the bloody brain gave me some there are gains from it first of all fact that I became an extrovert and as the writing the teaching, and I connect better with people. I feel like the gains far outweigh the losses. And yes, life is harder, but I'm happier. And I like who I am that I'm much more comfortable in my own skin.

Bill Gasiamis 15:29

So you tell me that as a introvert, do you not like yourself at the time? Do you know that you don't like yourself? Or do you know that now? Because you have this other version of yourself.

Deb Brandon 15:46

I know that now. I wasn't aware of, in many ways, I my self awareness really grew up to the surgeries. So I was often you know, when I think back to things that went on, I was often lala land half the time as I said, think, mathematician socially inept, you know, out of it, you're busy doing your thing.

Deb Brandon 16:12

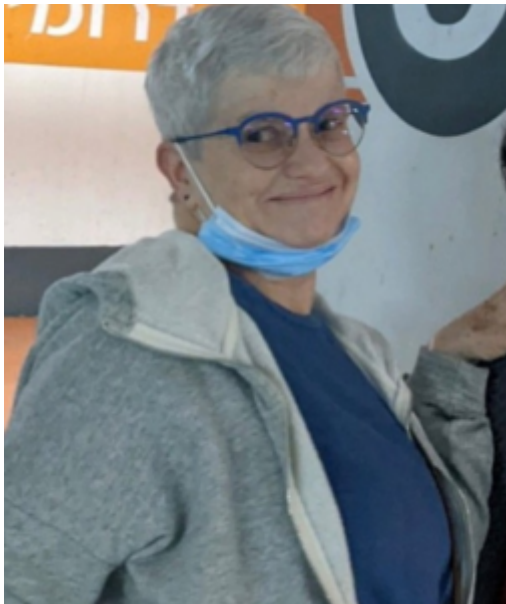
The most social don't mean, mathematicians socialize, but yeah, they talk about maths, sickly. Through my kids, I socialized but I found it was sort of, yeah, chit chat. never did anything for me.

Deb Brandon 16:34

It was all right. But in parties, I always kept to a corner somewhere or I went into the kitchen and pretended to be busy. I just wasn't comfortable with sociable situations. But I wasn't. I knew I didn't like crowds. But beyond that, there was a

lack of awareness on my side.

Deb Brandon From Introvert to Extrovert



Bill Gasiamis 17:03

So what made it so that you can become an extrovert? What was the shift was? How did you regain that awareness? How did you become an extrovert? That's like a really weird and interesting thing. And I'm sure people would love to hear that insight if you have it.

Deb Brandon 17:24

Well, okay, so think about it like this. I used to be fiercely independent, and here I am needing help. And there was no question I could not manage on my own. And the only way to get help is to ask for it. I mean, sometimes not. But in most cases, yes. And when you ask for help, you're exposing your weaknesses. And when you expose your weaknesses, at some level, you are showing that you trust the person.

Deb Brandon 17:33

And they reciprocate, you open up to people, they'll open up to you, they feel more comfortable. You know, I used to be very open with my students about you know, if I'm teaching and I lose some words, and then I have to hit the reset button that used to go, you know, I get tangled up in words, and then can't able to get back to it.

Deb Brandon 18:19

At first, I was really hesitant to tell my students, because you know, you're a math professor. You shouldn't have brain problems. But then I just went, I had to it was part of who I was, I was connecting with the students, why would I hide this from them. And I found that the students, and one of the things I talked to them, I talked to them about my issues as a brain injury survivor.

Deb Brandon 18:51

And it sort of evolved into talking about a lot of other issues, I was more aware of students having, I became more empathetic, I was more aware of problems that students were having, like mental health problems. And to help them feel more comfortable about it.

Deb Brandon 19:10

I talked about mine, because one of the yeah, I forgot to mention, it's one of the things that happened from all this, you know, you have someone rummaging around in your brain, it's bound to mess up the chemistry, and I have severe depression.

Deb Brandon 19:25

I've actually been suicidal a few times. And so I was open to my students about that. And they'd come and confide in me. And I realized that's when I started making the connection that people who never you know, exposed any kind of weaknesses to me where and I sort of make that connection.

Deb Brandon 19:54

So it was really needing help. As I said, you're fiercely independent and suddenly you have to ask for help. That's rough. And you put that effort into it. And you're more aware of how things develop, I think.

Bill Gasiamis 20:11

And as a mathematics professor, you're also teaching likely, most of the people in the class are going to be similarly introverted to you because mathematics tends to bring people of that nature together, or is that a big assumption that I've just made?

Deb Brandon 20:34

No, you're right in general. But I was really lucky. I was afraid to go back to teach, I was afraid that I wouldn't be up to it. So I asked to teach the lowest level classes. Now Carnegie Mellon is a very technical level, university. I mean, it also

has a drama department. But the I was in the Mellon College of Science.

Deb Brandon 21:01

So there are a lot of scientists, they're socially inept, and all that stuff. The lowest level course that we teach is calculus of humanity students. So my students, were usually those who usually struggled with math. So they actually made eye contact, they actually could hold conversations.

Deb Brandon 21:29

And I came to really love working with them. Now, the interesting thing is most mathematician in my department, most of them didn't want to, for them, it was like teaching calculus and slow motion. And I was working on. I was working on the process as an unfolding the analytical thinking skills, and relating to them, and it worked.

Deb Brandon 21:55

But so at one point, I was asked to teach a more advanced course. And I was scared out of my mind. But I did it. And I came away thinking I did a lousy job. I'm told that's not the case, that there were no complaints. But I still feel that I couldn't. I felt like I couldn't respond in real time that my brain was working more slowly.

Deb Brandon 22:26

And I know that it does. My neuropsychologist told me that my thought and it was getting better. I mean, I even though I think more slowly than I did, I used to think really, really fast. And I think a friend of mine just yesterday said to me, Well, you caught down with us, which is nonsense, but I found that speed of my thinking wasn't much of an issue after a couple years or so.

Deb Brandon 23:04

But yeah, so working with the humanities kids, it wasn't, they're very much extroverts. And I learned a lot from them. I love teaching them, they came up with different ways of thinking about things. And I had to find new ways of addressing certain questions that I never thought of, because it came so easily to me. So it was a lot of fun.

Bill Gasiamis 23:33

So we were an introvert as a child, and is math something that introverts do. And then as a result of the whole path towards mathematics and introversion, then do

you stay that way? Simply because it's a it's a mindset thing. Do you then adopt a mindset of I am, you label yourself I am an introvert I am a mathematician.

Bill Gasiamis 24:00

I don't talk to people I don't do is it just the stories that you're telling yourself that ends you up 40 years later in a situation where you're uncomfortable with yourself and the way that you're interacting with people and you're not aware of it because you've never given yourself the opportunity to try new things. Does that resonate?

Deb Brandon 24:26

That's an interesting question. I was painfully shy as a kid. Well, okay, so there's an interesting side to it, the angiomas that bled on the right hand side. So one theory is that the left brain left side was compensating for whatever and over, over develop. I don't know if that's true. My biologist cousin says that the brain is squishy probably doesn't make that much of a difference.

Deb Brandon 25:09

But you do wonder, as I said, I was painfully shy. I did not like being with more than two three people at a time. I did when I was a young adult, I did try and force myself but it was tough. I'm not sure what the reason is, but it is a bit of a mindset.

Deb Brandon 25:45

I mean, I have to teach calculus, computer science kids. And there was the mathematicians, I mean, that in the sense that socially, that just, they can't look you in the eye and that kind of thing. That's another kind of mindset, it's, it is a mindset, but you know, I was surrounded by this mindset.

Bill Gasiamis 26:19

Normal, it appeared normal is how people behave or interact, or this is what people normally do.

Deb Brandon 26:27

And my father was in academia. So I grew up amongst academics. There, you know, that's what I knew academics, first through my father, and then through my own work. So I think it is a mindset, what changed with the bloody brain was, I think it happened organically. I don't think it was. There was no decision involved. I don't know.

Bill Gasiamis 27:04

It emerged.

Deb Brandon 27:06

Yeah. Yeah.

Emotional Intelligence

Bill Gasiamis 27:08

Interesting. I describe a lot of the things that happened to me that my brain completely had to switch off. And my heart came online. And because my head switched off my heart had space to, just be itself. And then I started to like, what I was seeing and how I was interacting.

Bill Gasiamis 27:29

And what people saw. And then I was like, Hmm, that's interesting. I love how that person responded to me. Okay, what do I have to do to get that response at home at home, I was being an angry dad, you know, 37 years old, all the pressures of the world. Mortgage, you know, intrapreneurial kind of style running my life, no real focus on health, being happy and doing things that please me just work, work, work, work, work.

Bill Gasiamis 28:06

And it was like, No, I can't work. I've got time on my hands. Now I can't have any excuses for all the things that are going on. Basically, it was all me. And now this new me can't do those things. Because it was physically impossible to do my life the way I was doing it before. But my brain was also not working.

Bill Gasiamis 28:31

So at one point, I couldn't finish sentences. I didn't remember who had come to visit me, I couldn't type an email. I couldn't drive. I didn't, I had fatigue, serious fatigue, I couldn't go from the bedroom, to the bathroom and and then be able to be active, I was gone for the rest of the afternoon.

Bill Gasiamis 28:56

So the only thing that remained was my ability to experience other people. And I had some regrets. I thought that if I did die, what would my children think of me, and that I wasn't a terrible person, but I behaved inappropriately, too often. And I wanted to address that.

Bill Gasiamis 29:19

And I wanted to make sure that they knew that that wasn't really me. That was my behavior. But it wasn't an excuse that I was making. But I sought. I put time into remedying the things that I knew were inappropriate at the time, but I did them anyway and made excuses as to why I was doing. So with my head offline. I never had to overthink anything, because I couldn't overthink anymore.

Intro 29:49

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be. You're likely to have a lot of questions going through your mind like this. How long will it take to recover? Will I actually recover? What things should I avoid? In case I make matters worse, and doctors will explain things that obviously, you've never had a stroke before, you probably don't know what questions to ask.

Intro 30:14

If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called seven questions to ask your doctor about your stroke.

Intro 30:33

These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery. Head to the website now, recoveryafterstroke.com and download the guide. It's free.

Bill Gasiamis 30:52

So I had this increase in emotional intelligence or would you say that you experienced emotional intelligence upgrade?

Deb Brandon 31:00

Oh, very much so no question about that. And I don't know, you know, okay, so my explanation was now there's room in my brain once they took out the bleeders. But I don't I you know, it's a good way of thinking about it in terms of heart versus mind. Yeah, definitely my emotional intelligence grew.

Deb Brandon 31:27

I think part of it is also the writing because I was trying to understand what was

going on, so that I became more self aware. And I reflected a lot on what was going on. I think, before the brain bleeds, I thought I was happy. You know, I did stuff with my kids. I enjoyed them, I enjoyed life, but it's such a different level now, well, it's not just at a different level, it's on a different plane. It's in a very different way. I tend to throw myself into things more, but there's much more passion in what I do.

Bill Gasiamis 32:11

The people who you hang around with who are your friends before all of the bleeding, did they remain your friends, and how did they find you this different version of Deb? What was their experience like?

Deb Brandon 32:29

Well, the interesting thing about that is that I was thinking about that not long ago the friends from most of the people who are now my friends weren't really friends of mine before. I mean, I knew them maybe or not. The people who are friends, well, first of all, people I considered as friends when I think back to how we interacted I think of them as acquaintances now.

Deb Brandon 33:09

So the only ones where I have a connection with from the past, my elementary school friends. One of the things when I wanted to understand what was going on, I started looking back to who I used to be. And I reconnected with people through social media. And I ended up talking to friends from way back when and now it started up a thing where we get together every so often.

Deb Brandon 33:48

I mean, it's not through zoom and well in person a few times through zoom a few times. And they're friends, I consider them friends. I think they consider me as friends. But that's an elementary school. That's pre-everything, pre-bratty teenager, all that kind of stuff. The ones that were more recent, I lost touch with them by as I said they were more acquaintances I didn't, I didn't really have a connection with them.

Deb Brandon 34:25

And the connection that I did have, which was tenuous at best, didn't really hold out for instance, one of my colleagues really nice guy. We connected actually, to Englishness he was from England and all that. As I said we were acquaintances,

his wife I sort of knew after the brain surgeries I connected with her more I found that the people around me in the sciences didn't quite know how to well certainly didn't understand.

Deb Brandon 35:13

And they didn't have the tools to understand is my feeling I don't think they had that empathy. And we're back to is socially inept, you know, you don't have that ability. So I ended up connecting more with, I'm a weaver. So I connected more to the weaving community, I was a dragon boaters, I connected more with the dragon boating community, not science.

Bill Gasiamis 35:47

I love what you said just then about, they didn't have the tools to understand and appreciate and that is such a lovely way to spin that issue that we face, which I faced, which was that certain friends had no idea what to do. And at times, I may have got upset with them and annoyed with them.

Bill Gasiamis 36:12

But it was short lived, I didn't take it to heart, they didn't know how to respond or react or behave after I'd had three bleeds and brain surgery and couldn't walk anymore. But your version of it is beautiful, because then not having the tools is not about them, it's just that they actually don't have the tools to respond in a way that is going to make me feel better about my interaction with them.

Bill Gasiamis 36:42

And, it's almost also that, nor should they, I mean, they've never been through something as serious as we have. And we don't want them to go through something like that. And they haven't had to use those skills before. Because perhaps they haven't known anybody that's been so unwell before.

Bill Gasiamis 36:59

So you can kind of give them a little bit of slack. And it doesn't matter whether they whether they stop being so prolific in your circles or stop being around so often doesn't matter. It just matters that we don't take it personally when people don't know how to respond around us.

Bill Gasiamis 37:21

Because I certainly found that and then I found other friends who I thought were completely emotionless, I found them are the ones that stepped up and came

forward and did things I never expected. Because they were just playing a emotionless game, they were pretending to be emotionless.

Bill Gasiamis 37:42

And then when it came down to the crunch, they really were able to step up. So it was kind of more of a bravado thing that we were doing, you know, male bravado and interacting, like, you know, like, we never had feelings or anything like that. But these people stepped forward and actually surprised the heck out of me.

Bill Gasiamis 38:05

And they find it difficult to admit that they've done an amazing thing for me, they really find that difficult when I say to them, Look, you stepped up and you've changed my life in one way, in a certain way.

Bill Gasiamis 38:23

That really helped when it was necessary, but it really made a huge difference to my life, they find it really difficult to have that conversation so I'm not sure what that's about but that that's my experiences people dropped off and then the people that were on the periphery came on. And it was just stunning.

Deb Brandon 38:46

Yeah, the interesting thing was family they all care they all worry but most of them didn't really understand. And a lot of them I got the impression felt that after three months you should be fine right? And with me it's more unlike you with not being able to walk with me it's more invisible.

Family Issues



Deb Brandon 39:12

My disabilities are much more, me my balance. Unless I try to walk heel to toe or

if I'm really really tired you wouldn't know that I have balanced problems and also we're very good at hiding things you know me nonchalantly against the wall, you know that kind of thing.

Deb Brandon 39:35

But after the worst of it after the early days, that's when you start seeing the reaction of well you should be over it by now. And I introduced my mother to the term sensory overload because I have huge issues with it. And, there was one time where I went to visit them.

Deb Brandon 40:06

And my mother was going on and on and on at me about something and I just couldn't deal with it. I just left, because I didn't want to snap at her. And then I came back and apologized and explained. She said, Well, I have sensory overload, too. So I said, Oh, does it bring you to the point where you're having a meltdown?

Deb Brandon 40:26

She says well I feel like crying. Okay, we don't quite get it do we. Or I tell her I'm really tired. And she'd go, you were always a napper. So my mother was there for me during the surgeries and all that. But after the fact I don't know what it was. She likes being the center of attention.

Deb Brandon 40:59

So maybe that's what it was, there was a level there of some tension that wasn't really there before. On the other hand, my sister who went through something similar, we're very, very close now. I mean, we were always close. But the connection became much, much stronger.

Bill Gasiamis 41:18

Yeah. Well, you guys completely understand each other you guys. Oh, yeah. I totally know what sensory overload means. You both totally know what fatigue means. And you guys can relate to each other like never before you completely understand each other.

Bill Gasiamis 41:35

And the people who you described and say lovely, like when somebody is used to being the center of attention. And previously, Deb is definitely not the center of attention. She's the introvert who tries to not have any attention, then that person who has been the center of attention can just experience all the attention that

their heart desires.

Bill Gasiamis 42:03

And now there's somebody else competing for that attention that makes sense that they would feel uncomfortable about that. And of course, we both know that that says more about them than it says about you. And we can kind of from that we can conclude that it's a time for growth and adjustment for that person as well. Hopefully they know it.

Deb Brandon 42:28

Yeah, actually, with the growth thing, with the growth issue, one thing that, well, you've talked about, not that I experienced enormous personal growth. And that's another thing that I can't say that I regret what happened, I don't want to repeat it. But I'm not unhappy that it happened. Because it brought me so much, and it made me who I am now. And I like myself a lot better than who I was before.

Bill Gasiamis 43:07

Yeah, I was gonna say I have the same experience, I feel that I like myself better, I am more aware of doing things that are not appropriate that I don't like, I stopped them sooner, I apologized quicker. And that's just one aspect of my life. You know, that's just one thing that's enhanced.

Bill Gasiamis 43:31

Like you. I've set to write a book about this experience. It's in my book is a book about post traumatic growth. That's what it's about. Everyone talks about post traumatic stress, but I'd like I'm gonna try to highlight the post traumatic growth aspect of it half, you know, glass half full kind of guy.

Bill Gasiamis 43:52

And, that's been the hardest thing for me to do. Because I was never somebody who read books. I was never somebody who wrote books, I never could identify as that kind of person. I could never relate to writers, and book readers.

Bill Gasiamis 44:12

And I just thought it was something that, you know, that the nerds did, which is something that I picked up when I was in school when I was probably 13 or 14 years old. And now, I'm like you, I want to write and I can't write quick enough. I can't write often enough.

Bill Gasiamis 44:31

There's never enough time for me to write now. And it's always on my mind when I'm not writing. I'm always thinking I would love to be writing now. Wow, wouldn't it be good to put that chapter together now and finish that and I just, it's the project that's going to take the longest that I've ever done. And I've never done long projects because you don't do that. I don't do long projects. It's too boring.

Deb Brandon 44:57

Okay, a couple things about that. One is is an interesting thing about what you're writing. I'm currently working on a sequel to my memoir about recovering brain injury, and it's more or less about living with brain injury. And it's basically about how it changed my perspective of the world.

Deb Brandon 45:17

So it's, like you said, post-traumatic growth. And I find it really interesting. That's a nice way of putting it. I find myself writing about things I never thought of before, unlike a lot of brain injury survivors, or any kind of ordeal, survivors, I didn't get religion. But my relationship towards religion changed.

Deb Brandon 45:50

And so I wrote about that I wrote about who I am now versus who I was before that. You know, I don't know if you've read the book head cases by Michael Cole Mason. He's a he's a case manager. He writes his short story, he wrote the short story, he was a journalist to about various cases that he worked on one of the things he said, he said that the question of identity, How has my identity changed, is very common amongst brain injury survivors.

Deb Brandon 46:29

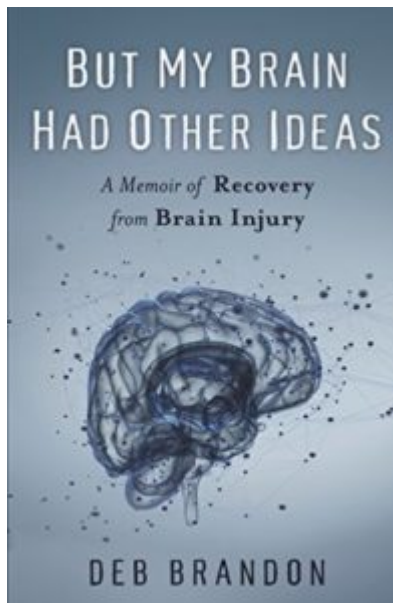
And that's something so I wanted to try and understand what had changed in me What's mind, what's brain, what's me what soul whatever, all that kind of stuff. So I wrote about that I wrote about appreciating nature more about, because one thing was sensory overload, it brings everything every, every piece of data comes in with the same value, which means that you can't differentiate between a whisper and allow whatever yell something, everything comes in.

Deb Brandon 47:09

But on the other hand, the other side, the flip side of that is that you are aware of

details that you didn't even notice before. So hence, you know, doing you notice, you see beauty and things that you didn't even see before. So there's a lot of a lot of stuff that has changed dramatically for me, and I've been writing about that. I think I'm getting close to the final draft now the final full draft now.

Cavernoma Recovery Reading And Writing Issues



Deb Brandon 47:47

So hopefully anyway, because I'm ready for it to come to fruition. As the other thing I wanted to tell you about is writing not having time for writing, I can't do okay, the only way I can do big projects is in chunks. Because attention span, fatigue, all that. So I do it in chunks. And sometimes the chunks are five minutes, 15 minutes, I can't work more than an hour and a half at a time.

Deb Brandon 48:22

After an hour and a half I'm chances are I'll get really bad headaches the next day or something I'm working full time was rough was really tough. And when I retired, I took early retirement because I just couldn't do it anymore. When I retired, I started being able to write more, but still I was limited.

Deb Brandon 49:01

The last two years before I retired, I reached a point at work where even writing was tough for me just doing anything extra. So to get back into it, what I did was I started writing 15 minutes a day. Give me a writing prompt, I'll write about it for 15 minutes, whether it's a photo that you see or poem that you read, or you just see something.

Deb Brandon 49:34

And that got me back into it got me back into the passion of writing. Now I've always been a voracious reader. Unfortunately, because of my short term memory issues and my short attention span I couldn't read I mean, I could read the words but I couldn't string them together into a sentence.

Deb Brandon 49:56

That got better but then again, because of being overwhelmed by too much I couldn't read dense books, I could read children's books where the type was large, and the words were sparse. But I couldn't read books I wanted to read. And then I discovered the ereader, Kindle or whatever, where you can control that, and I became a voracious reader again.

Bill Gasiamis 50:27

Okay. I like the sound of that. And see, I've never thought of that, because I was given a book to read while I was in hospital, it was the worst thing that I could have been given. But of course, I didn't say that at the time was a lovely gesture, but there was no chance I was gonna read.

Bill Gasiamis 50:45

And I gave that book back unread, many years later, seven years later. So I get what you're saying. And still, I struggle to to read if I've had a big day, because I still have my property maintenance business that has been operating since 2005. So if I have a busy day doing that stuff, then I can't, I don't have enough capacity to come home later and look at a monitor.

Bill Gasiamis 51:17

So I'd like to wake up early. And when I wake up early, and if everything before the stars have aligned and all the planets are aligned, I just come into my space here, and I sit down and I start writing. And I might get an hour or two into it. And then I'm done. And I might be done. Like you said, for a couple of days or whatever.

Bill Gasiamis 51:45

And then that challenges me and frustrates me. And that's kind of where the learning is coming from. Because I'm so passionate about getting the project finished, but I have way more obstacles in front of me than I ever had. And when I never had any obstacles in front of me, I never thought I never gave it a second

thought that I was going to write anything I never considered at all.

Bill Gasiamis 52:09

So now yesterday, I had a massive migraine. And it didn't start off in the morning, it started off about, you know, 11:30 I started to notice it. But I did sit down from between 7am at about 9:30am. And I did put together a few additional pages of words. And then I was kind of feeling what's the word like, it's not enough that I have a migraine, and that I have to deal with.

Bill Gasiamis 52:44

That didn't end up being so dramatic, but it was a pretty reasonably decent one kind of leveled off quite quickly for some reason. It's not only that I was dealing with that I was also dealing with myself going, man, you should be writing you should be writing. Why aren't you writing? I can't write I've got a migraine.

Bill Gasiamis 53:06

But I really want to be like this little dialog of just go and lie down and don't worry about it and move on. And we'll get there at some stage. But I've never had that fear of missing out so much. I feel like I'm missing out when I'm not writing it. Or if you don't complete this bill, I tell you, you're gonna hate yourself. And it's like, no, no, I will complete it. I will complete it.

Deb Brandon 53:34

Okay, okay, we've got, we've got to do something about this. Okay, not one thing. There's something called conditions of enoughness that you set yourself, what you're going to do today, and it's got to be doable. I mean, and not in the sense of, you're going to finish a chapter.

Deb Brandon 53:54

But you'll write a page, or someone who has major depression issues, get up and brush your teeth, this kind of thing. And at the end of the day, did you do it? Are you happy with what you did sort of thing. So it shouldn't be, you've got to be more realistic with this and you have to and this is something when I retired, I thought oh, I'll be able to write four hours a day and this that, it was tough.

Deb Brandon 54:25

I was in really bad shape emotionally for a good year and a half, until I realized that I've got to change my mindset with that, that it's okay with what I do. And if there are days when I don't, right, it's okay. So, yeah, that's a tough one, but I

don't. And one thing that I do is that every evening, I actually set the alarm for this, what did I do today?

Deb Brandon 54:57

And if I didn't do anything, I don't think of it in terms of I didn't do anything I rested, I needed to rest. And that's really helped me. And for instance, yesterday, I had a meeting with someone. And then I wrote for 15 minutes. I said, Wow, I even wrote, so I was really happy. But you know, so it's really helped me with handling that just asking yourself at the end of the day, what did you do? And what did it do for you?

Bill Gasiamis 55:31

I often deal plenty. And it all does something positive for me. It's very rare I don't do anything because I'm being lazy. It's not because I'm being lazy it is because you're resting and I need to rest my brain and I definitely need to. If I don't rest my brain, then my buddy suffers and then the loop starts and then it goes too long. I've started to learn where my limits are so that I can be at exhaustion for the smallest amount of time.

Bill Gasiamis 56:08

Okay, I'm in exhaustion now I get it. Okay. Rest. And, I don't do those loops that I was doing about the book and not writing. I didn't do it about anything else I just doing about this writing project it's so important to me, is fantastic. People have stepped up to help out, etc. I owe that to everybody who has decided to be a part of it in some way. And I owe it to myself, and it's going to happen, but I'm just I'm impatient. That's what it is. I'm impatient for it to to see it, you know, done.

Deb Brandon 56:47

It's tough. I mean, I've had to learn patience. And believe me, it doesn't always work. Yeah, no, I mean, I actually something that I was whining to a friend of mine about if you know before the brain injury, I could have written for four hours. I said before the brain injury you weren't writing? Oh, yeah.

Bill Gasiamis 57:08

I did. I had that regret, too. I remember getting up in front of a room many years ago, it was probably a year into the second bleed, not even a year into the first kind of stage of my life altering sort of brain bleeds. And I got up and I said, Look, you know, I used to take my brain for granted and I never really paid attention to

what I could and can't do. And therefore I haven't done a lot of things that I should have done.

Bill Gasiamis 57:38

And I don't know if I'll ever get it back again. I don't know if I'll ever be able to get it back again. And I haven't caught up back the same way it was before. Because before I never experienced neurological fatigue and sensory overload and all the challenges we've spoken about that are common to stroke survivors and brain injury survivors.

Bill Gasiamis 58:01

And I wasn't writing but I felt like if I can't write because of this, or I can't do certain things because of this. I'm going to be such an idiot. Because I had the opportunity I had a perfectly good brain back then. I'm going to be such an idiot for not making the most of it back then. But I got over that after a while but it was definitely something that played on my mind.

Deb Brandon 58:28

No, I didn't. I learned very quickly not to well maybe not very quickly, I learned that the old Deb was the old Dab and the new Deb is the new Deb that comes every so often. Yes, I could have worked for four hours at a time. But I mean, I used to have focus used to be I used to have no trouble at all focusing on something.

Task Initiation Issues

Deb Brandon 58:56

Now I do. I used to whenever I started something, I always finished it it was almost like I was you know OCD about it. If I started washing dishes, I always finished it now I can't. So I start not a big deal. You know, anything like that, and I had to learn that it's okay not to finish things. And sometimes you never get to finish them. Do you have issues with task initiation?

Deb Brandon 59:28

Getting started?

Deb Brandon 59:31

Yeah. You want to do something and yeah, I mean, that's something that I originally thought was procrastination, but my neuro psychologist told me that it's

very different and it feels completely different. I mean, you just can't do it. I mean things I really wanted to do and I can't do it.

Bill Gasiamis 59:53

I have at the end of the day and also sometimes. So the whole thing that I'm doing online The recovery after stroke project, that's an ongoing project that started in 2015. And it's nowhere near where I want it to be. But and there's a lot of reasons first, because I'm learning about how to behave online, what to do online what to offer.

Bill Gasiamis 1:00:18

So I'm doing what I can and when I can, and when I'm feeling up to it, I'm a stroke survivor, after all, so I have to deal with all the challenges as well. And I have this other job, that is the job that keeps the family going and brings in an income and pays the bills and all that kind of thing.

Bill Gasiamis 1:00:35

So it's a passion project. But according to the social media experts, you have to be posting a certain amount of time and you have to be doing all these things on a regular basis. And it's true, because the algorithm likes it when I'm providing certain bits of information on a regular basis that's predictable that people can consume, and therefore, it suits the social media algorithm to show my posts more often.

Bill Gasiamis 1:01:14

But if I come home, and I've had a big day, and then I'm either experiencing fatigue or sensory overload, or whatever, that task that must be done today, will not get done today, under any circumstances. And I just it's not that I haven't got the desire, I don't know the benefit of doing it, it's that it just physically cannot get done. My brain cannot compute what it made to do to start the task, and then finish it.

Bill Gasiamis 1:01:51

So I find myself having these fleeting moments yesterday, I was driving home from a chiropractic appointment. And the next post on my for my Instagram page came up in my head. And I knew what it was. And I knew that I had the energy to do it. So I stopped the car apart.

Bill Gasiamis 1:02:13

I wrote the post, and I posted it. It wasn't when I was meant to do it. It wasn't a normal way for me to do those things. But I just did it. And if I had forgotten about it and said I'll do it later. Later might have been two days later.

Deb Brandon 1:02:35

Sometimes the later is a year later, even more. I wanted to get back in touch with my cousin. And it took me 10 years. And it was too late by then he was his feelings were hurt, blah, blah, blah. And I apologized. But you know, there was nothing I could do about it. I just couldn't do it.

Deb Brandon 1:02:59

And it's funny, it's as though there's a disconnect there as though it's almost a tangible, something blocking you from starting it. And very often I have trouble starting something. But when I do get started, then it's as though I never had a problem. It's really odd another other times, I have trouble starting something and out of the blue.

Deb Brandon 1:03:26

I get started on it. It's really strange. And I talked to my neuropsychologist about it and he said, Yeah, that's the way it is. And that's something that people automatically assumes procrastination. I've had students with that problem had brain injuries and had problem. They said, Oh, yeah, I procrastinate a lot more than I used to, and I correct them. And it helps knowing what it is. It really does.

Bill Gasiamis 1:03:54

I have exactly what you said the same experience with my godparents. So for me, when we grew up, my parents and my godparents were really close. And I really, really loved my godparents, I had a great connection with them. And then, about 20 years ago, they had a separation where they stopped interacting with each other so much.

Bill Gasiamis 1:04:20

And that meant that I was in my 20s then and that meant that naturally because they stopped interacting, my interaction levels went down because as a 22 year old, I wasn't really interested in hanging around with any oldies at all. So it wasn't personal, it was just timing.

Bill Gasiamis 1:04:38

And, however, I would make an effort to go and see my godparents probably once

every 18 months or two years or something, just drop in, say hello, have a cup of tea. And that lasted for the majority of the time until I got sick and then at 37 after say, let's say another 10 years, from my mid 20s, say about 12 years of me just popping in and seeing them.

Bill Gasiamis 1:05:07

Of course, when you're dealing with a brain injury, it took me six or seven years to feel like I'm back to my, I'm going to use the term old self. But it wasn't my hours of my new version of me. And I hadn't been to visit them for six or seven years. And they took a person, they thought that it was me that was stopping to come and say, because they did something, and they upset me.

Bill Gasiamis 1:05:34

And I was like, no you didn't do anything to upset me, I was recovering. And I always wanted to come and see you, but I just couldn't. And it's not because I didn't want to, it's I just couldn't. And that's what you just described, right now. That's exactly what it was. I had them on my mind. And I would say to myself, I'm going to go visit them next month, next week, next year.

Bill Gasiamis 1:05:56

And it will just go by and I wouldn't get there. And then it happened when I when I had it on my mind had it on my mind. And then I found out that my godfather was unwell, and he had a tumor in his brain. And it was close to the last days of his life. And that's when I made it back there.

Bill Gasiamis 1:06:20

But when I got there, he was not able to recognize me. He didn't know who I was and what was happening. And my godmother apologize, because she thought that he had upset me five or whatever years earlier.

Bill Gasiamis 1:06:38

And I say well, no, like, I wasn't upset. I just was sick. I was unwell. And I had other reasons why I couldn't get in that wasn't it. So that's the exact same thing that you just said. And I never thought about it as this. How you describe it this inability to start or how did you describe it?

Deb Brandon 1:07:01

Task Initiation and that's what my neuropsychologist referred to it. Yeah, it's a bonafide symptom it is. And it can happen with anything can be with a book that

you really want to read, it could be it hits out of the blue, once a my neuropsychologist suggested he said, you do a daily task list. And it's not a to do list, it has no more than two tasks on it, task that you've had problems get starting.

Deb Brandon 1:07:33

And you block off time on your calendar, you're going to spend, you know, here's an hour during which you'll do this task. And here's an hour and a half during which you will do that task. And if you do more than that great if you complete them. So it's like the conditions of enoughness type thing.

Deb Brandon 1:07:53

The only problem is, there was one time I did the first task. And I couldn't do the second I was too tired. So I'm lying in bed. I'm going I didn't do the second task. I've got to do it. Because it's I had to do it. It's on the list. Just too tired, you know. And then I go on and on and on and on. And finally I go oh, I can put this is on my list tomorrow.

Deb Brandon 1:08:22

So when I mentioned it to my neuropsychologist Oh, yeah, I forgot to tell you that. But also, the other problem with it is it's self-defeating. Because you have to write down the task list. What if you can't start writing down the task list? And it can't be more than two. He told me don't put more than two items on it. And he told me why he said more than two you won't do anything.

Deb Brandon 1:08:53

And I thought Yeah, yeah, right. But three on couldn't do any of them too much. Yeah, it could be as I said it could be. And the other problem with it is identifying what it is that you can't do. Because when you know you have to do something, you know, you have to do it, you know, you will do it. I mean, you know it.

Deb Brandon 1:09:15

It's not like procrastination, where you'll eventually get to it. It's you are going to do it just not right now. So you don't it takes a long time. Now now that I've identified that I have trouble identifying. It doesn't take me as long but it sometimes it took me a long time to really figure out that this was something that I needed to put on my task list. So it doesn't always work. But it can.

Post-stroke Depression



Bill Gasiamis 1:09:47

Yeah, I hear it's a good strategy. It's worth having in the toolbox. Yeah. You mentioned depression. Is it something that came on the scene after The brain bleeds for Was it something that you were dealing with previously?

Deb Brandon 1:10:05

I wasn't dealing with it previously, my therapists thought that I might have had low-grade depression before. And at first I thought it was situational, you know, and I'd say to people, well, you know, I've been through a lot, it's not surprising. And as I recover, it will get better.

Deb Brandon 1:10:26

But it didn't and I became suicidal a couple times. One of the times was really bad. I didn't want to tell anyone about it, because I didn't want them to stop me if I actually did it, or wanted to do it, or whatever. And that's when I realized that I needed to go, the therapist wasn't enough that I needed medication.

Deb Brandon 1:10:54

And even then, something that a lot of people with depression do is they feel better. And they say, Oh, I don't need their medication anymore, or I can cut back. So I've done that a couple of times. Don't do that anymore. And the suicide ideation came back. So yeah, this is definitely from someone rummaging around in my brain.

Bill Gasiamis 1:11:22

And yet, life is fuller.

Deb Brandon 1:11:25

Oh, yeah. And I'm more content. Isn't that odd?

Bill Gasiamis 1:11:30

That's amazingly odd. You yeah, fabulously odd. I like it. I mean, that's kind of to me. So she's telling me her life is fuller. And she has depression, people who normally have depression don't have a fuller life, they appears to be a different version of how they experienced depression.

Bill Gasiamis 1:11:50

You've seen it as something that can be managed and handled. And therefore medication helps you live the full version of your life. And that's a great thing. Well, that's amazing. That's completely different to what I've ever heard of other people saying, but yeah, that's just really interesting. I really like that version of it. And I don't like it that you have depression, but I like that version. You know what I mean?

Bill Gasiamis 1:12:24

Really interesting.

Deb Brandon 1:12:27

I can't explain it's just the way it is. I mean, I'm one of these people. I don't take myself very seriously, which helps a lot. I laugh at myself quite a bit. So references with the short-term memory issues and some of them are long-term issues. I I find them hilarious most of the time, you know, well, the funniest funniest one was I it was two days after I got back from my third surgery.

Deb Brandon 1:13:03

I went over next door to talk to my next door neighbor, with my friends. And she had a guest over and three of us were sitting around the dining room table. And the neighbors, you know, starts talking about a movie she just seen. She said, Oh, it's really good. You should go see it. It's, oh, it's the one you know, it just came out.

Deb Brandon 1:13:30

And the other woman goes, Yeah, I know. which one you mean. It's the one with the with the you know, now I have no clue. I'd been out of commission for a good while. But I'd seen a video last night that was really good. And I said, I don't know which movie you think you're talking about.

Deb Brandon 1:13:45

But I saw this great video. It's, oh, it's new. It's the one with the actor, the one with the hair. And it's Okay, so I'm the brain injury survivor who just came home from brain surgery. The next door neighbor was chemo brain and the other one was going through menopause.

Deb Brandon 1:14:07

And we just started roaring so I find it amusing more than anything else. I mean, there are times you know, I missed a couple of important meetings and one was not a good outcome, but I just went not much I can do about it.

Deb Brandon 1:14:27

Another one I just I explained it laughing and they went Oh, jeez. I'm sorry to hear that but it's okay. We can reschedule. Most of the time I find these things hilarious means like as I said leaning nonchalantly against the wall when you look like a drunk.

Bill Gasiamis 1:14:48

I was out yesterday. We mentioned it earlier a little bit. I was out yesterday and it's really hot in Melbourne at the moment so I don't drink but beer goes down well when it's really hot and I had a beer and the people I was with said to me, you look like really tired and really wrecked, I said I am, I am really tired and really wrecked.

Bill Gasiamis 1:15:10

And I can't hide it anymore where before you could hide it, I look at myself in the mirror some days and I think, dude you look extremely tired, but what can I do, that's just the way it is. And I have to go about my day like that.

Bill Gasiamis 1:15:28

And I have these really kind of droopy puppy dog eyes, you know, so they look like I'm half asleep normally, and then added a little bit of fatigue, a little bit of heat, and some alcohol, which I very rarely do with the alcohol, but add that and then the droopy it almost looks like I'm sleeping on the table, you know, but I'm not.

Bill Gasiamis 1:15:54

And if I if I miss out on that opportunity to be out with my friends, you know, because of COVID and all the stuff we've been through, I really weren't like that. And so I made an effort to make sure that I went out, knowing that I'm not feeling

the best. But I knew that that wasn't going to impact me in the next day or the day after I knew that I had done just enough so that I don't miss out.

Bill Gasiamis 1:16:19

But also not too much so that I pay the price tomorrow. So that's really interesting. And and yeah, I don't know enough people around me who are near me that can relate to me. That's the reason for the podcast I get to interact with people from all around the world, get me and know me.

Bill Gasiamis 1:16:46

So I'm still navigating a lot of the expectations that people have about my own recovery from the point of view, and it's like that it's we don't talk about me anymore. But I do explain why I can't do what we used to do. I'm not going down there or I'm not attending that event or whatever I explained to him.

How Am I Doing?

Bill Gasiamis 1:17:11

It's because of the fatigue, or it's because of the sensory overload or it's because of something related to what happened to me 10 years ago. But we kind of have stopped talking about how are you doing? How's your health? You know, that has stopped? Because you still have those conversations with people about you know, when they make it about you? Are you okay, do they do that still?

Deb Brandon 1:17:41

People who know, will ask me how I'm doing. I mean, for instance, I'm still in touch with some of my students, and they'll ask, well, how are you doing? How are things going? Is this still affecting you? That kind of thing. One of the things yes, it's really only people who know, if I also in terms of explaining it, I've learned to gauge how much they really want to know, because you know how they get that glazed look in their eyes.

Deb Brandon 1:18:15

So, you know, so you say, how are you doing? Oh, I'm fine, I'm fine. Because I know that their eyes are gonna glaze over. And otherwise I'll say, doing okay, you know, you never quite recovered from bla bla bla bla bla. So, you learn to who really is interested in who isn't.

Deb Brandon 1:18:41

With new people. You know, if I have trouble with something like for instance, if I have to cancel something at the last minute, I explain. And either they understand or they don't. There's not much I can do about it. I used to really worry about people understanding or not understanding and now I just don't anymore.

Deb Brandon 1:19:08

One project I'm working on is I'm working with a friend of mine. Who's a caregiver to a brain injury survivor. And we're working on we're co writing a book based on conversations between us on the parallel journeys of caregivers and survivors, and I'm learning a lot from her.

Deb Brandon 1:19:31

Because things that I didn't even realize and the thing that's amazing is with even with survivors, there's a lot we don't know a lot we're not aware of a bonafide symptom or a lot things like we don't know how to cope with something and you learn a lot from each other. We learn a lot from each other and I find that I lost my train of thought there.

Bill Gasiamis 1:20:07

Caregiver's perspective. You were talking about.

Deb Brandon 1:20:10

Oh yeah. So I learned a lot from her about how it looks on the outside. And a lot of stuff that I really wasn't aware of. Someone took a photo of me when I was, oh, during a seizure was one where I lost muscle tone and whatnot. And I suddenly realized from seeing the the photo, I thought, my God, no wonder people really worry.

Deb Brandon 1:20:43

But so there's a lot you don't realize what you're projecting. Yes. I mean, you talk, talk about the fatigue. You know, somebody, a friend of mine said to me, Oh, sounds like you're really tired. And I said, no, no, I'm fine. And then I happened to catch a reflection of myself, and boy, did I look tired I had no idea, like you said, the eyes drooping and all that kind of stuff.

Bill Gasiamis 1:21:20

That's all right. That was me yesterday, that tiredness that look of tiredness. That I'm projecting was terrifying. But not uncommon for me now. So they kind of see it and they know where I met. And they'll even say, is a time to go? And I might,

I'll have the final call on that. I'm having too much fun. Let's stay or, yeah, I'm completely wrecked. And let's go. So yeah, I do project, tiredness. And then people see that, and then they have to somehow know how to how to respond or react to that.

Deb Brandon 1:22:01

Do you sometimes reach a point where there's a point of no return with a sensory overload where you can't escape? Because you're having fun, but it's too much. But you want to stay but you know, you need to go and you reach a point where you can't physically go?

Bill Gasiamis 1:22:24

Oh I'm not I'm usually not alone. So if I'm at an event that I'm going to experience, I'm with my wife. And I'll say, I think it's time to go.

Deb Brandon 1:22:35

Yes, but other times when? Okay, so I've been in situations where somebody where I know, but my dysfunctions reached a point where I can't communicate, I can't move. And sometimes I have meltdowns. And I am usually with people who know I usually warn people in advance that something like this might happen. This is what to watch out for.

Deb Brandon 1:23:06

But people aren't always in tune. And I've been stuck in situations and eventually I can get out of it myself. But it can take a long, long time. When I've when I go shopping supermarket, I often get sensory overload. And I end up freezing because I couldn't get out of there and I just stand there.

Deb Brandon 1:23:33

But I've learned that I can only manage two aisles at a time. I can't do more than that. That there's one problem is the milk aisle is always in the back. So buy milk. Now go into milk Milk Milk, Nicole got to get milk Milk, milk milk, and sometimes it's enough sometimes it isn't. So getting milk is still an issue. I have a friend who usually gets me milk because I have problems getting milk.

Bill Gasiamis 1:24:02

Yeah. Wow. Now I've never had that experience of sensory overload to that extent. I am usually so fatigued and exhausted it's just like we have to go right now there's so maybe that next level the window of opportunity to go is right now

let's go that's it and so my wife's like yeah, sorry, I'm stuffed I gotta go now.

Bill Gasiamis 1:24:28

So that's kind of as far as a golfer me but I do have days where I haven't done much and I'm just around the house and I'm feeling like all I can do is just go and lie down on the bed. Close the doors, close the windows, close the shutters and make it as dark and as quiet as possible.

Bill Gasiamis 1:24:50

Even sometimes I even put headphones on those noise cancelling ones that are not on there just on my head switched off. Just so that things stop interfering. And that really helps and you know, that goes back to educating me and giving me an insight into what people on the autistic spectrum experience and suffer.

Bill Gasiamis 1:25:17

Because I could never understand what they were going through what was happening for them. But now I do. And I appreciate so much the quiet. I just love the quiet, you know, to put this on and things go quiet. It's such a beautiful experience to go through and that recharges me that might give me an hour or two. And then recharges.

Deb Brandon 1:25:46

Yeah, that feels good. It really is.

Bill Gasiamis 1:25:51

It is I, like you, I feel like this has enhanced my life. It's tough everyday to be me. My left side is always reminding me that I've been through this neuro-fatigue, lack of concentration, all these issues that we've spoken about are there every day, they weren't there before.

Bill Gasiamis 1:26:14

And because they're there, I've learned where to go, I have found these deeper places where I can go to deal with my emotional response to those situations. So I have a broader level of ways to respond to things. And it's not just the freak out and act like an idiot anymore.

Bill Gasiamis 1:26:38

Now I can indicate what's going on to me I can apologize for when I'm being an idiot and then also have these new understanding of okay. I don't need to push

through, I can stop, I can take a breather. So everything that we've spoken about has come to me dramatically. After the first bleed, it's come to me.

Bill Gasiamis 1:27:06

And it's helped me have this what we call like an additional, like perspective, I'm not sure if that's the word. I think it's perspective. And therefore I realized how shallow I was as a person before that. And it wasn't my fault. But that's kind what I was shallow, and now I have depth and layers and different directions. And that's far better.

Deb Brandon Learning Empathy

Deb Brandon 1:27:43

Oh, yeah. There's another one. Oh, God, I lost it again. Actually putting it in terms of shallow that that that really resonates? I think that's very true of me. Oh, yeah. In terms of empathy towards other people. One thing that I learned that I find fascinating is if you look at any kind of neurological disorder, we experience similar symptoms.

Deb Brandon 1:28:23

For instance, if you look at people with autism, sensory overload, I mean, I found myself one day doing this and I'm going, Oh, my God, I'm autistic. And then I realized what it was, it's that you're, you're the repetitive stuff. It calms you down. It really does. with bipolar disorder, people who have bipolar disorder, they also have short term memory issues.

Deb Brandon 1:28:54

Depression, in terms of you know, I talked about the task initiation stuff, people with depression, that's a big thing. And I actually, a couple of my students, I told them about the task list thing. There's so much overlap. It's amazing. I mean, things that you never thought of before.

Deb Brandon 1:29:22

One of my nephew's he's, you know, there's no label on what he has, but a lot of his issues. I get it because I experienced them to a friend and he has issues with sensory overload. And he was six years old, and he'd have these huge meltdowns.

Deb Brandon 1:29:42

And we had some sort of family reunion and I was observing him and I said, I

think this is what's going on. And suddenly, there was this huge aha thing and they could they knew what to do. So really, it makes you much more empathetic towards such a broad range of issues that people have.

Bill Gasiamis 1:30:11

And I also had that other understanding of when I was in a wheelchair, I couldn't walk, I had the understanding of, oh my god, what people in wheelchairs are just sitting down. And therefore, everything's okay. In their world. Like, there's so much going on. That means that they have to be in a wheelchair.

Bill Gasiamis 1:30:34

And it's like, You're such an idiot, you only ever thought that they were just didn't have use of their legs. And that was the only issue. Oh my God it's such a narrow minded view of the world. And, again, I wasn't being hard on myself, I was just, I had a massive awareness. It's like, oh, so I can't walk. But it's only one side of me that can't walk the other side chain.

Bill Gasiamis 1:31:04

Alright, I'm emotionally annoyed and distressed about that. Oh, okay. That's another thing that's happening to me, I can't get to the toilet. Ah, that's another thing that's happening to me that I got to deal with, oh like, I can't feel my left side, but I can feel my right side.

Bill Gasiamis 1:31:19

I Oh, okay. That's another thing that's, that's like, every person is in a bloody wheelchair, is therefore, a completely different or similar reason or whatever. And it's not the fact that they can't use their legs. That's the only issue grow a brain, like, appreciate these things for more than what they just appear to be. And that's a good part because I can say somebody in a wheelchair now and interact with them where before I didn't know how.

Deb Brandon 1:31:51

You see the person. You see the person the way we didn't before. We were attached to the labels, and you didn't see the person behind the labels. Oh, there's a handicapped person in a wheelchair. But he's person?

Bill Gasiamis 1:32:07

Yeah, that's it.

Deb Brandon 1:32:08

There's stuff going on in his life. Yeah, yeah. No, it's huge. And you sort of my daughter is a recovering drug addict. And, you know, she went through 12 STEP program and things like that. And I was talking to her friends and, we were saying, she sent me a copy of Narcotics Anonymous, because she thought I'd be interested.

Deb Brandon 1:32:39

And I was, I was interested in the 12 step, some of all that, and we were talking about how a lot of people would benefit from it. So I will always tell my students, I bought a baseball bat in my office, if you want me to hit you over the head, feel free to ask me because there are benefits to it.

Deb Brandon 1:33:00

Yeah. I mean, this is another interesting thing. So talk to recovering addicts. And you find that you've got stuff in common with them, too. It's, it's really amazing. It's a big world out there, a lot of really good stuff, a lot of bad stuff. There's a lot it's really fascinating.

Bill Gasiamis 1:33:34

And if you look at what makes a similar or were, were the same or or what brings us together, there's way more of that stuff. It's our differences are so little which political party you vote for. And there's so there's so minor, I mean, the things that actually bring us together, there's so much more of those. That's what I found.

Bill Gasiamis 1:33:56

And it's not about the political party that you vote for. And it's not about what you think about vaccination. And it's not about any of that stuff. It's just, that's that's kind of the very irrelevant stuff. It's that I think that's the stuff to dish that distract people from the actual seeing the person.

Telling The Story

Deb Brandon 1:34:20

Another book that I wrote was about textile techniques from around the world. And at first I wrote it because I'm fascinated by as a weaver's, of making myself I was interested in the techniques, but as I grew as a writer, I realized the

importance of stories and telling the stories. You see the person, I mean, you can label you can say, okay, there's a Guatemalan Weaver there who makes beautiful textiles.

Deb Brandon 1:34:47

Well, what does that tell you? Well, you know, I don't know her from you know, so I'm writing the stories and bringing these people to you look that people like you. So there's the the labels they're good as a starting point, to help you recognize something, you know, like she's got gray hair and glasses.

Deb Brandon 1:35:17

But when you go beyond the labels, you have to go beyond the labels to see the person. And the strength that the Power Stories is, you know, as human beings, that's exactly what helps us prevent us from losing our humanities, the stories behind them. And if you look at that, with with textile traditions, it's interesting, because on the one hand, they celebrate our differences.

Deb Brandon 1:35:52

But on the other hand, through the stories, you get the universal, you see the commonalities. So they really address a lot of the aspects of humanity. So I mean, this is another thing that I became passionate about this whole thing about telling stories and preventing us from losing our humanity.

Deb Brandon 1:36:17

And with Desmond Tutu dying, social media was flooded with quotes. And one thing that he said, was something along the lines of You can't become a person, when you recognize the person and other people. So humanity is not just yours, you have to show humanity must come from both sides, all sides. Before it can be. I forget the actual quote, but it's something along those lines.

Bill Gasiamis 1:36:53

That's a profound statement because that that's the podcast exactly what's happened in the podcast, I've interviewed 170 or 180 people now. And I've never spoken about politics and Donald Trump and, and Joe Biden, and the Australian version of all of that junk, I've never done any of that stuff, right?

Bill Gasiamis 1:37:14

All we've ever spoken to, is what life was like, before stroke, what life is like, with stroke, and what it's like, after stroke, or you know, when certain number of years

have elapsed, and still, like me living with what it's done, but also have moved beyond that somewhat. And everyone is exactly the same everyone wants to be well, they want to have a roof over their head, they want to be fed, they want to be loved, they want to be nurtured.

Bill Gasiamis 1:37:47

They want to express themselves, they want to have people together, around them community, they want to have all these things that are exactly the same. And all the other junk goes away, the politics goes away, all the other rubbish, the religion goes away, everything goes away.

Bill Gasiamis 1:38:10

Get rid of all of that junk, and then everyone is the same underneath. That's what and the people I've interviewed are from a lot of backgrounds, diverse backgrounds, in every way, shape, or form people that I would never interact with yet. I would never, for example, interact with, in Australia with people from Mexico, or people from on my way, it doesn't matter where you know, because I'm too far away from them. Because I live in Australia, they live over there.

Bill Gasiamis 1:38:36

Now I'm interacting with them. And I'm getting this really rich tapestry of life, experience, and beliefs and understandings and all that type of thing. But then once they all go away, the story underneath is all the same story. Everybody desires for the same things, they just get caught up in.

Bill Gasiamis 1:39:11

Well, what other people want us to get caught up in life, whether you're Democrat or Republican, whether you're a Vaxxer or Anti-Vaxxer all that junk, right. And, that's what the podcast has done exactly what you just described, it's created this opportunity for me to see the people and therefore when I see somebody homeless, in our city down the road.

Bill Gasiamis 1:39:41

It doesn't mean anything to me. And I'll go up and I'll talk to that person say, Hey, hang on, how's things what's happening? And we did that with my wife a couple of weeks ago, which just before Christmas, it just sort of started with a sort of guy lying down. And he wasn't sitting like a regular homeless person. He didn't have a container or a board asking for money or anything like that he was just lying

down in this awkward way.

Bill Gasiamis 1:40:07

And I walked past him initially thinking that he was sleeping and I didn't want to disturb him sometimes. They'll do that during the day. And then I said to my wife, hang on a sec, he might be having a stroke, let me go back and just check up on him and make sure he's not having a stroke.

Bill Gasiamis 1:40:26

And then I went there, and I said, Man, are you okay? And he said, Ah, sorry, sorry, man, I'm just, you know, I just needed to lie down, whatever, don't apologize, I thought maybe you were unwell. And then we had this conversation. And that led to he's been out of prison a short amount of time, and he hasn't got enough money for a phone call.

Bill Gasiamis 1:40:47

And he needed some money for a phone call. And then I said to him, when was the last time you ate? And he said, I ate three days ago. And I said, Well, let's go and get something to eat.

Bill Gasiamis 1:40:55

And it just created this conversation as if he was a friend of mine, and I was treating him for lunch. That was something that I do all the time. And that's how the conversation went. And that was not me before the stroke. And I'm not saying that to brag about how I help homeless people.

Deb Brandon 1:41:13

Yeah, no, I know exactly what you mean.

Bill Gasiamis 1:41:16

I don't really. But I just realized that the guy lying down with his hands on his head, could be unwell. And I should be curious about that. And find out if he needs help. And the help that he needed was a warm meal. And he actually needed a haircut. He didn't look too scruffy.

Bill Gasiamis 1:41:33

But he goes, Man, I need a haircut. I said to him sweet, let's go and get you a \$20 Haircut from the lady that's just down the road. And, he agreed, and he came along and we got to know each other. And he told me a story. And the story was

the same story that the stroke survivors tell me.

Deb Brandon 1:41:51

Interesting thing, you know that 80% of the prison population, brain injury survivors? Yeah. mind boggling. Mind boggling and very disturbing.

Bill Gasiamis 1:42:04

Very disturbing, because it makes sense that, you know, people don't know sometimes aren't able to interact in a way that's going to be useful or non confronting, and they don't know how to not do that because their brain doesn't work properly. I totally get that. Because that's, that can be me from time to time.

Deb Brandon 1:42:30

There's also the rage issues, the disinhibition, the lack of control.

Bill Gasiamis 1:42:43

Deb. I really have enjoyed this conversation. Thank you so much for reaching out. I really appreciate it, thank you for sharing your story. And I look forward to interacting with you on Instagram and get to know you more. And just thinking from the bottom of my heart has been a really profound conversation.

Deb Brandon 1:43:05

No, thank you. No, I enjoyed it very much, too. I as you said, you make interesting connections. I've made connections all over the world through this. It's fantastic.

Bill Gasiamis 1:43:15

I've never met a math professor. And now I can say that I have.

Deb Brandon 1:43:22

Not anymore.

Bill Gasiamis 1:43:24

If I have a math conundrum, I definitely am going to let you know.

Deb Brandon 1:43:29

Yeah, math emergencies. That's me.

Bill Gasiamis 1:43:33

Well, thanks so much for listening. I hope you enjoyed that episode. And I would like to ask you if it's possible to live the show a five star review on either iTunes

or the podcast app that you use to listen to podcasts. And also, if you're watching on YouTube, also give the show a thumbs up and leave a comment below.

Bill Gasiamis 1:43:54

And let me know what you thought of the particular episode. Doing this is going to make a big difference to how search engines rank the podcast. And if they rank it. Now, well, that might make it easier for other stroke survivors who are going through something similar to what we have been through to find the podcast and that might make it better for them in their path to recovery. So thanks so much for doing that. Thanks so much for listening, and I'll see you on the next episode.

Intro 1:44:25

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Intro 1:44:43

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Intro 1:45:05

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Intro 1:45:20

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Intro 1:45:44

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