# Cerebellum Stroke Recovery -Andy Dovey

Andy Dovey was formally employed as a musician before a cerebellum stroke changed things. 9 years on he is still noticing some minor improvements.

Facebook Twitter Website Highlights: 01:35 Introduction 03:16 Initial Stroke Symptoms 09:21 Cerebellar Stroke 15:41 Hydrocephalus Caused By Cerebellum Stroke 23:43 Physical Therapy 33:47 Meditation 40:14 Time Management 47:59 The Invisible Injury 55:36 Sensory Neuron Issue 1:03:03 The Brain Attack Music Project 1:12:26 Living With The Deficits

Transcription:

Andy Dovey 0:00

So the first thing they did was the transfusion and then brain surgery. So I ended up with a hole which I still got here, there's only skin over it, where they put in a drain tube to drain off the fluid.

Andy Dovey 0:10

And they took about a fist-sized lump of skull out of the back of my head at the base of my skull. So that's still missing, to give my brain room to swell into in the hope that when the swelling went down, the fluid would drain out naturally, and I'd be okay.

Andy Dovey 0:29

Which luckily it was, they did say that if we can't get the fluid drain out normally we put a stent in which is effectively a bit of buffering that goes from your head down and just drains the fluid away.

# Intro 0:45

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

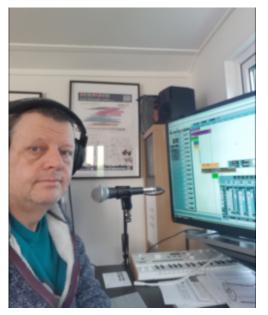
# Bill Gasiamis 0:58

Hello, and welcome to episode 206 of the recovery after stroke podcast. My name is Bill Gasiamis. If you are a stroke survivor with a story to share about your experience with stroke, and you have been thinking about reaching out to be a guest on the show, but we're waiting for the right time to reach out.

# Bill Gasiamis 1:14

Well. This is it. If you go to recoveryafterstroke.com/contact, you'll find a form that you can fill out apply to be a guest on the show. And as soon as I receive it, I will respond with more details on how you can choose a time that works for you. And for me to meet over zoom and record an episode.

# **Introduction - Andy Dovey**



Bill Gasiamis 1:35

My guest today is Andy Dovey, a musician who experienced an ischemic cerebellar stroke in 2013, who is still living with some of the deficits today that

the stroke caused and left him with. And at the moment he has not been able to return to work. Andy Dovey welcome to the podcast.

Andy Dovey 1:56 Thanks, Bill.

Bill Gasiamis 1:57 Thank you. Tell me a little bit about what happened to you mate?

# Andy Dovey 2:01

Yeah, I suppose like many of us, I had no idea what a stroke was I'd heard the word stroke. I thought it was something to do with your heart. Some kind of mild heart issue, I had no idea that it was a brain injury. So at the time it happened which was May the end of May 2013.

# Andy Dovey 2:32

I was earning my crust as a professional musician, a drummer. And I was teaching in schools teaching in my home studio and also playing, gigging with bands and so on. And it was the midterm break in the UK spring break. So I had a week of no teaching, but I had a load of music to learn for the various bands that I was playing in and stuff.

# Andy Dovey 2:57

So I had a very leisurely week planned. And it was I suppose about 5:30 one morning, and I heard a really loud bang, that woke me up and there was a kind of vibration with it. And I thought maybe it was our side gate had banged in the wind or something had happened outside or whatever, I don't know.

# **Andy Dovey Initial Stroke Symptoms**

# Andy Dovey 3:16

But I sat bolt upright in bed. And then just crashed back down on the pillow again, when I realized that actually, you know, there was nothing happening outside. And I started to feel unwell a bit kind of nauseous, like I wanted to throw up.

# Andy Dovey 3:33

So I thought I better head for the bathroom. So I went to get out of bed and just collapsed into a heap on the floor. And the room was just spinning, the world was

spinning around and spinning around. Like, I don't know if you've ever made yourself dizzy as an adult Bill.

Bill Gasiamis 3:51 How about drank myself to oblivion? How about that?

Andy Dovey 3:55 Well, the analogy I use is it's that game that you play when you've had a few beers and you're having a barbecue outside and somebody puts a broom down, right and you run around the broom.

Bill Gasiamis 4:09 I know the one.

# Andy Dovey 4:10

And then you stand up and then you just disappear to one side normally end up in a rhododendron bush or something, you know. But it was just like that only that feeling that you get when you do that wears off after 15-20 seconds and the world gradually comes back to normal.

# Andy Dovey 4:26

And you put yourself out the rhododendron bushes and life carries on. But it was like that all the time it the was most bizarre feeling and I had this horrendous, I nicknamed it later the force as in Star Wars, but this force pulling me to the left. It was like gravity and a huge magnet was pulling me to the left.

# Andy Dovey 4:48

I couldn't get off the ground. So I'm literally on my hands and knees, trying to crawl to the bathroom. And all this thrashing around and banging into furniture and stuff has woken my wife up. She says to me, are you okay? I said yeah, just not feeling too good Hun I need to get to the bathroom.

#### Andy Dovey 5:07

And I tried to crawl in a straight line and I couldn't I kept going to the left this force was pulling me to the left and I couldn't bring my head up, and the head was hanging down. I guess if you're a test pilot, and you put in 10G or something, it's like that.

Andy Dovey 5:23

Anyway, most bizarre, so I've actually made it to the bathroom. And I hold myself up. Luckily, because of the drumming, and I played a lot of sport as a kid. I've got quite good upper body strength, so I literally hold myself up onto the toilet. And I'm kneeling on the floor with my head over the toilet bowl retching.

# Andy Dovey 5:44

And when I was 16, my dad was 54. And he had a heart attack. And the last image I had of him before we dive was kneeling over a toilet bowl retching. So I'm there, and I'm thinking, I'm gonna go the same way as my dad. I'm having a heart attack.

# Andy Dovey 6:07

I didn't have any pain. I had no shooting pains or anything. I just felt really awful and just thought this is what it is. How ironic. He was 54, I then was 55, and I'm now 64. I thought, talking about karma. I'm gonna go the same way as my dad, retching kneeling over a toilet bowl.

#### Bill Gasiamis 6:31

That's pretty dramatic. But I'm gonna take you back for a second because I picked up something and you're gonna elaborate on this for me. So you fell out of bed, you were crawling to the toilet, your wife asked you are you okay? Is everything okay? You responded yes even though you were crawling to the bloody toilet?

# Andy Dovey 6:56

Yeah. She subsequently nicknamed me the Black Knight, Monty Python and the Holy Grail. "Only a flesh wound" "Only a scratch". There he is, with no legs, no arms he's like, come back here, I'll bite your knees off. She's nicknamed me the Black Knight.

# Bill Gasiamis 7:16

Unbelievable. Were you in denial? Or were you just not cognitively aware of how serious the situation was? Like what was the frame of mind? Did you have a frame of mind?

#### Andy Dovey 7:32

Very good question, Bill. There was an element of denial. And I think something we might come on to I had probably about 16 months of neuropsychology visits, which were fantastic. And I think looking back now, what happened to me was seeing my dad die at age 16. And that was never spoken about within the family after with my brother, my sister, or my mother never spoken about.

# Andy Dovey 8:05

And I went back to college and life carried on as normal. And I think that became my default position was wired into me at the age of 16. You don't talk about stuff you get on with it. Now my dad was a professional cricketer, I played a lot of cricket as a young person. And you know, you get hit by a cricket ball, it hurts.

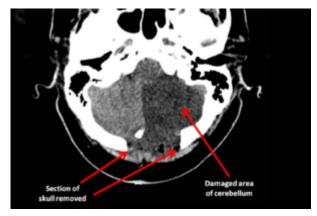
# Andy Dovey 8:30

But you're taught just get on with it. Now, when I was playing age 14-15 in men's cricket, helmet they weren't invented. So you get hit in the head a few times with a cricket ball. Thigh pad, didn't start wearing the Thigh Pads until I was about 16, so you're getting hit quite regularly on the top of the thigh between the pad and all you had was a box protector to protect your privates.

# Andy Dovey 8:58

And that was it. No arm, like you'll see all the guys these days stuff up their arms and none of that. So you got hit a lot. You just get on with it. And that became my default position. I think and there's this element to isn't there that we're men, we're blokes, we're all tough and all and you know we can handle it and all that kind of stuff.

# **Andy Dovey Had A Cerebellar Stroke**



Andy Dovey 9:21

So I think that was the background. In terms of cognition. I just didn't know what the hell was going on. It was just the world was spinning around my head was really heavy. I felt lousy I because of this bathroom issue. I just assumed it was a heart attack. Even though I've got no chest pains. I've got no pains up my arm or anything like that I just assumed that's what it was.

# Andy Dovey 9:47

So ultimately, my wife had called 999 Emergency Services, the paramedics came out none of the F.A.S.T you know, face arms. None of that applied. To me, I didn't know I was having a cerebellar stroke, hence the dizziness and the balance and the rest of it.

# Andy Dovey 10:05

So I could talk, I was quite confident talking, I didn't have any issues, my face wasn't drooping. speech was fine. Just felt weird, awful. And so I said to them, I think I'm having a heart attack. They did an ECG there and then said no, your heart's fine. We think it's labyrinthitis, which is an infection of the inner ear.

# Andy Dovey 10:34

And that's what's giving me the balance problems. So they gave me an anti nausea injection, and they disappeared. So at this stage, it's probably 7:30 In the morning, something like that. I managed to get back to bed. The paramedics have said to my wife, if he's no better call the doctors and you know, what have you.

#### Andy Dovey 10:56

So at nine o'clock she called the doctors they prescribed some more anti nausea meds she went, picked up prescription, cashed in the prescription, came back, I took some more pills, sitting up in bed, just everything. The doctors said like if he's no better by lunchtime, we'll do a house visit.

# Andy Dovey 11:16

So my GP came out at one o'clock, and said, touch the end of your nose with your right forefinger. So fine. Yeah, there we go. Do it with the left forefinger. So I did. And my hand just went and I nearly punched myself in the face. I hit the pillow behind me.

# Andy Dovey 11:34

And he said, I think you've had a stroke. So he phoned 999 again paramedic different team came out and I was taken in a wheelchair to hospital. And I vaguely remember getting to A&E, accident and emergency. The emergency department, I vaguely remember getting there.

#### Andy Dovey 11:59

And the next thing I know that I'm conscious of is that my stepdaughter is there. And I was like what are you doing here? You should be at work. But I've come to see you to make sure you're okay. She was with my wife. I thought she's got here quick. She lives in London.

# Andy Dovey 12:23

It's about an hour away. But I've just got to A&E and she's here. And then there's lots of beeping and machines beeping I just wish these machines would shut up. I need to get some sleep. The next thing is, there's a three dimensional screensaver all around me.

# Andy Dovey 12:44

And you've probably seen on the TV, lava, volcanoes, lava pools, and they bubble and these slow moving bubbles come up yellows, oranges, reds, beautiful colors. That's all around me with these bubbles coming up. One of these bubbles comes up and there's a little black dot in the middle. It develops into an eye. And it's the eye of a dog.

# Andy Dovey 13:12

And I see this dog's head slowly come out of this lava pool. Beautiful, lovely little spaniel. And then it just disappears. And there's another bubble with another black dot in and that becomes another eye and that's another dog and that just disappears off and then there's another bubble comes up and there's another black dot in and that covers this monster leaps off at me what the hell, my eyes open and I'm gonna sit in up in a hospital bed.

# Andy Dovey 13:38

It's like, what is going on? And there's just nurses going about their businesses, other guys sitting in bed around them. It's like, oh, I just feel really awful. And my eyes closed. And now I realize what's happening. It's a hallucination, with the lava and the dogs and the monster. And that starts all over again until I get shocked and my eyes open. And I'm trying to keep my eyes open. But I can't. I don't realize it. But this is now five days later.

Andy Dovey 14:11

And I'm in the neurosurgery ward of the hospital. And I had six hours of emergency brain surgery

Bill Gasiamis 14:16 Already. Andy Dovey 14:17

Already. Yeah. And I guess the hallucinations are partly the meds that they have given me for the brain surgery. Partly I didn't realize it, I developed hydrocephalus, you familiar with hydrocephalus?

Bill Gasiamis 14:32 Yeah, fluid on the brain,

Andy Dovey 14:33 Basically, yeah. So what had happened, apparently, was that I'd spent two days in the stroke ward, which I have no memory of whatsoever. Where my wife would come to see me and I'd be slumped in bed, the doctors would come around. And I've switched into what my wife calls performance mode. Like I'm on stage at a gig or something right?

Bill Gasiamis 14:58 Pretending everything's okay.

Andy Dovey 14:59

Well, you know, as you can probably appreciate, if you're feeling a bit ill, right. You can't just say I can't do it tonight. I can't do the gig tonight. Because you're not just letting down the rest of the band, you're letting down the whole audience.

Bill Gasiamis 15:16 A. you're a bloke, B. You don't talk about your problems. C. you cop the pain at cricket, you just move on with it. And D, the show must go on.

Andy Dovey 15:29 Absolutely. Absolutely.

Bill Gasiamis 15:31 And it might be everything working against you.

Andy Dovey 15:33

Yeah, absolutely. And, you know, if it's a gig for a fun band, you're playing with some mates or something, that's fine. But you might be playing at a wedding, and you're getting paid two grand to do somebody's wedding. So you can't just say, Oh, I can't do it. Sorry. You carry on.

Andy Dovey 15:38

So whether your backs bad or whether you're throwing up in a bucket, every two songs at the side of the stage, or whatever you carry on so the doctors would come and see me and I'd be Hi, I'm Andy, pleased to meet you.

# **Hydrocephalus Caused By Cerebellum Stroke**

# Andy Dovey 15:41

Your name is Oh, pleased to know you. Okay. How you feeling? Oh, yeah, fine. My is wife sitting there thinking what? The doctor will disappear. And I go... So two days of this, my wife would say to them look, something's not right.

# Andy Dovey 16:04

Tere that there's something going on I don't know what it is, but he's fine when you're here, but the minute you go, he's weird, he's saying to me, he wants some paracetamol. And I say to him, you've just had some No, I haven't. Yes, you have.

# Andy Dovey 16:37

So she persuaded a lady consultant. that something wasn't right. And the lady consultant said that, okay, we've been told that we must listen to family members because they know the patient better than we do. And she the lady consultant, wheeled me down for an MRI.

# Andy Dovey 16:54

They did an MRI, and it was like, Oh, he's got hydrocephalus. Wow, we need to do emergency brain surgery. So what had happened was the stroke, which was in my cerebellum, had caused my brain to swell. And my brain had swollen against the back of my skull, and was preventing most of the cerebrospinal fluid from draining out of my brain.

# Andy Dovey 17:24

I'm still producing CSF. And my brain is slowly being crushed by the pressure of the fluid that I'm producing, which is hydrocephalus. So first of all, I had to have a transfusion, because they've been filling me with aspirin and you know, stuff. Not ideal if you can have six hours of surgery, and your blood's like water. So you go from having a clot to maybe bleeding out.

# Intro 17:57

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 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. If this is you, you may be missing out on doing things that could help speed up your recovery.

# Intro 18:27

If you're finding yourself in that situation. Stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery, head to the website. Now, recoveryafterstroke.com and download the guide. It's free.

# Andy Dovey 18:59

So the first thing they did was the transfusion and then brain surgery. So I ended up with a hole which I still got here. It's only skin over it where they put in a drain tube to drain off the fluid. And they took about a fist sized lump of skull out of the back of my head at the base of my skull.

# Andy Dovey 19:16

So that that's still missing. To give my brain room to swell into in the hope that when the swelling went down, the fluid would drain out naturally and I'd be okay. which luckily it was they did say look, if we can't get the fluid drain out normally we'll put a stent in which is effectively a bit of guttering that goes from your head down and just drains the fluid away.

Bill Gasiamis 19:42 I love the analogy. A little bit of gutter.

Andy Dovey 19:48 I like to keep things simple mate.

Bill Gasiamis 19:50 Yeah. I totally understand guttering in your head. I totally get it.

Andy Dovey 19:54 Yeah. When it rains, so that was it. So I found myself sitting up in the neurosurgery ward once these hallucinations had worn off, trying to absorb all of this stuff that had happened to me, right. And that, I think for all of us a huge challenge.

# Andy Dovey 20:19

I've seen a bit about your story. So you were already on the same page of I'll just carry on. I know I've got a meeting to go to, right. But then you reach a point where you've got to absorb what's happened. Now, the longest I'd ever been ill was off work, you know, a couple of weeks with a bad back or something. So I'm sitting up in hospital bed, I've got a tube, a drain tube coming out of my head here. I've got another one coming out my back here. I've got an IV in this arm.

# Andy Dovey 20:50

I've got an I.V, I've got a catheter fitted, and a monitor and I'm thinking "Where are we? Early June?" Yeah, well, I know probably, six, seven weeks I'll be back at work. No comprehension, no understanding of what happened, the magnitude of it, the seriousness of it, I can't get out of bed on my own. I can't walk. I've got a catheter fitted, so that's fine. If I need to go number two, I've got to call a nurse. I've got to have two nurses to get me out of bed, put me on a commode, wheel me to the toilet. And I'm going to be back at work in six weeks. Drumming.

# Bill Gasiamis 21:35

Alright, let's fast forward really quickly to how long did it take to get back to work? I want to make a point here.

Andy Dovey 21:41 I haven't.

Bill Gasiamis 21:44 Right. Okay.

# Andy Dovey 21:46

9 years later, I haven't. I could walk short distances with a stick. Now I can sit and I can communicate and I look okay. I'll spend the next two days recovering from this call. I spent two days preparing for it. Because I suffer from very bad fatigue, neuro fatigue. So I haven't made it back to work.

Bill Gasiamis 22:07 Well, okay. So the point I wanted to try to make is, there'll be people listening, that are just very early on in their recovery journey. And what they've done is already given themselves a deadline. And we're going to be back in two weeks, in three weeks, whatever it is. And that was me, and one of the biggest disappointments. In my recovery. The things that set me back a lot was the deadlines that I gave myself that were unrealistic, because again, I didn't understand the gravity of the situation.

# Bill Gasiamis 22:37

And then I kept feeling bad "Oh, my God, I still am not there. I'm still not there". And when I coach people on their own stroke recovery journey, one of the things I say to them is improvement every day. No deadlines, just improvement every day, and try and reach little milestones. And the milestones are smaller, shorter windows.

# Bill Gasiamis 23:05

Well, they're milestones, they're not deadlines, there's not a hard and fast, I must get there. They're just milestones, they're in the future. And one day we'll get there. And that is kind of what I wanted to make a point of it now. Tell me about this whole last nine years. You've come out of hospital and are you straight at home? What happens there? Do you go into rehabilitation first?

# Andy Dovey 23:30

No, I kind of put pressure on them to discharge me and send me home.

# Physical Therapy And Cerebellum Stroke Recovery

# Andy Dovey 23:44

There was talk about me going to a rehab facility. I didn't want to go to a rehab facility because I think it took me several years to get it. So I was in hospital for three weeks. And after I moved out of the neurosurgery ward back to the stroke ward where I had been, but had no memory of it, all started going "Oh hello Mr. Dovey. How are you? What? Well, don't you remember when you first came in?" No, never met you who are you, but they started some basic physiotherapy with me.

Andy Dovey 24:23 Which I couldn't do anything of, because they work into standard sheets. So as an example, stand up for 30 seconds and look up at the ceiling. Now I couldn't stand up full stop without people beside me because I'm still at this stage, got no balance whatsoever. And then put your foot on a step in front of me, just one step at a time, like this. Well I could do that providing somebody was holding me on my left. I couldn't get my left foot off the ground. It was like super glued to the floor.

#### Andy Dovey 24:58

So if there's anything I could do was parallel bars, shuffle along, parallel bars, turn round and shuffle back again. And the reason I could do that, because I've got good upper body strength. And they're saying to me, you've got to get 50 points before you can go home. So a score 20 or something, you know. So, the gym became in my head, the room of abject despair. Because every time I went in there, got to get 50 points, got to get 50 points, and I was getting 20. And it's like, how the hell am I going to get it and trust me, I couldn't do it now, because I couldn't get 50 points now.

# Andy Dovey 25:40

So technically I should still be there, nine years later. Now, eventually, what happened was, I had physiotherapy and I had OT, so the OT would come to me and say, well, let's go and make a cup of tea. And in my head, I'm thinking occupation. That's drumming, that's work. Brilliant. Is it gonna be stuff to help me get back to work? Make a cup of tea? Yeah, fine, right, wherever. Make some toast yet. Okay, fine.

#### Andy Dovey 26:05

Then she came to me one day and said she had some marbles and some paper clips. Now, one of the results of my surgery in stroke was that I had really bad double vision. So I had horizontal double vision and vertical double vision and the stigmas, which is your eyes flicker around, right? And she's trying to get me to daisy chain paper clips.

#### Andy Dovey 26:33

Now, I can't really grip anything in my left hand. So straightaway, I'm thinking "How the hell am I gonna hold the drumstick? I can't get back to work, how am I gonna earn money, I can't get back to work." So I'm having to force a paper clip into my left hand to grip it, and then try and daisy chain another paper clip into it. And I've got double vision. So I've got four paper clips here, I know! I'll close one

eye. Brilliant! So I've got one paper clip, one paper clip with no depth perception. So I can't do any of this stuff. And I'm getting really, really frustrated.

# Andy Dovey 27:07

So the OT came to me one day and said, Let's make the cake, shall we? I lost it. I just lost it. I just completely lost it. And I just turned over in fetal position and said no. Not doing it. I'm on strike. I'm convinced I'm the only man in history ever to have gone on strike in a stroke ward. And I just said that I don't see the point in doing any of this. If I'm down at the gym, I can't do any of the work out of this stuff that you're doing. I can't, I've had a cerebellar stroke. I've got no balance. I can't see the point in what we're trying to do.

# Andy Dovey 27:49

I just want to go home. So anyway, they had a meeting and it was like, yeah, we only see about 2% of stroke, cerebellar strokes, we don't really see them. We don't really understand them. All our staff is geared up for your bog standard. If there is such a thing. Though yeah, you can go home, when you go home today. So I basically put pressure on them by being a bolshie bastard. And they let me go home with a bag of meds and a wheelchair.

Bill Gasiamis 28:24 Mistake now looking back?

# Andy Dovey 28:30

Possibly, possibly not. I think the thing is that I don't know whether it's better sometimes to learn through trial and error. I mean, my basic personality Bill, my wife will tell you I'm stubborn. I will say I'm determined. So, put it this way if you're going to learn to play drums, and you're going to learn all the various stickings right, left, right, right, left, right, left, right, left, right, left, right, left, you know, any musical notes or whatever it is, you're going to have to be a certain mindset, which is I'm going to do this.

#### Andy Dovey 29:04

I don't care if I got blisters on my hands, don't care if I got bruises. I'm going to do this. So I think through sheer determination, I kind of worked out what to do. I did have physio and OT visit me at home. I did go to a wonderful place called the Oxford Centre For Enablement. I was living near Oxford in the south of England at the time.

# Andy Dovey 29:27

And this was outpatient and you could be an inpatient there but I was an outpatient. And the first time I went there, I felt like a fraud because I'm walking and doddering on my stick and there's guys in wheelchairs. And a lot of exservicemen are having been fitted for prosthetic legs. They've had their legs blown off in Afghanistan and stuff and I'm thinking what am I doing here?

#### Bill Gasiamis 29:39

Still beating yourself up about it? Still you haven't been scarred or damaged or battered enough to be there feeling like a fraud like an imposter.

#### Andy Dovey 30:05

Yeah. Absolutely, and it wasn't until it was about six months after my stroke, I had to go and have another MRI. And I had a panic attack. Because I've discovered now one of the outcomes of the stroke is I have chronic claustrophobia never had it before.

#### Andy Dovey 30:29

Quite happy potholing caving, all kinds of stuff. Now even the thought of being in a small room freaks me out, my wife accidentally locked me in the car once I completely lost it, completely lost it. Anyway, so I had this MRI.

Bill Gasiamis 30:48 So you couldn't open the door?

#### Andy Dovey 30:50

No we parked and she was going to our local pharmacist picked up some meds. And she didn't think as she crossed the road to pharmacy she just went beep and locked me in a car. Just habit, you know? So I'm trying to get out, it's a hot day, I can't breathe and I'm just banging on the window. There's a guy walking past I said, "my wife is in the pharmacy and she's locked me in, not deliberately" anyway. So I had a meltdown and an MRI scanner. And when I got outside, I just burst into tears. And I've got a problem.

#### Bill Gasiamis 31:37

I did that. I'll tell you what happened to me. Before the stroke in 2012, I had a shoulder injury from going to the gym. And it was a tear in my rotator cuff muscle in my back. And in order to work out where the tear was, they asked me to go and get an MRI.

#### Bill Gasiamis 31:59

And on the way there, I'd seen somebody who had been hit by a car covered with a sheet on the freeway. Just by coincidence, just drove past, the person was a cyclist got hit by a car was covered, because he had passed away. So I'm heading to this appointment, you know, a bit stunned and whatever.

#### Bill Gasiamis 32:22

And then I've gone to go into the MRI machine. First time ever, I didn't know what what it was about. And then they told me when you go in there, this lady was quite terrible at communicating what was necessary. She goes, you gotta go in there, it's 30 minutes and you can't move.

#### Bill Gasiamis 32:39

I said, Well, who can go into a machine and not move for 30 minutes. What she didn't tell me was that the scans take about two or three minutes each, then there's a pause, then you go back in and then so on. And I went in and they kind of got started on the first scan I said no, get me out here I'm not doing this for 54 for 30 minutes solid, who you the hell can do that?

#### Bill Gasiamis 33:03

And if I move, I'm not doing it again. There's no chance to get me out of there. Anyway, so literally, three or four months later, I'm in hospital now dealing with brain hemorrhages. And there's an MRI every three seconds. In order to go through the MRI, I had them sedate me.

# Bill Gasiamis 33:25

So now I'm going through this whole process over the three years that I had my brain hemorrhages and brain surgery I had countless MRIs I don't remember how many I had. And then I was having them after surgery for three years to check my progress to see how the brain settling down all the usual stuff.

# **Meditation In Cerebellum Stroke Recovery**

#### Bill Gasiamis 33:47

And then by the last couple, I said no. Fuck this. I am not going to be sedated any more for my MRIs, I'm gonna go in there, and I'm gonna breathe through them. So what I did is I practiced I put some meditation music on it, you know, when they asked you to put music on for you.

# Bill Gasiamis 34:06

Asked them to put some meditation music on close my eyes and I had practiced before going into the machines, I'd practiced a lot. And then I would go into the machines, close my eyes, and then I would breathe for six seconds in and six seconds out and I would count six seconds in six seconds out.

#### Bill Gasiamis 34:23

And that was how I freed myself from the claustrophobia. And the issue that I had with the MRIs and also the other issue of being sedated every time. It can't be good for you to be sedated. Often and I thought Nah, I'm not doing this anymore.

#### Bill Gasiamis 34:43

And I don't want my wife to take a day off work to come and pick me up again because I can't drive home. So I was going to go there independently, drive my car, have the MRI without sedation and then jump in the car and go home. So I know how you feel because, man, those first, well, those lots of MRIs were difficult to overcome the fear and the thought that was, you know, coming in my mind days before or the day before or the night before or whatever. And then it's like, nah stuff at, I'm not doing that anymore. And that's kind of how I got through it.

# Andy Dovey 35:28

Good for you. Good for you. I need to take a lesson from that. Yeah, just coming back at you just made me think of something that you said earlier about what you do with your coaching that you don't have fixed timescales, you don't have deadlines.

# Andy Dovey 35:49

My first session with the occupational therapist out of hospital when I was an outpatient at the Oxford Centre for enablement was about planning out my week was planning out my week, what are you going to do, how you're going to do it, etc, etc. And I turned up at my next session with a spreadsheet. Five columns Monday, Tuesday, Wednesday, Thursday, Friday, because I thought, I have Saturday and Sunday off.

#### Andy Dovey 36:24

Nine to five. Every half an hour. What I'm going to do five days a week, nine starting at nine finishing at 599 3010 Center after lunch. She was really blown

away by this she said this is this is really impressive. Okay. When I went back to see her the following week, I was almost in tears because I hadn't done any of it wasn't cake wasn't capable of doing any of it.

# Andy Dovey 36:51

Started the Monday felt really awful, did try to do one or two things, couldn't do any of them carried them over to the Tuesday this this this then kind of carried on. So I had all this wonderful looks on paper, it looked absolutely fantastic. The reality was it was way beyond my capabilities way beyond.

# Andy Dovey 37:12

So I got demoralized, depressed, demotivated because I'm giving myself these deadlines, which, at the time, I didn't realize it were completely unrealistic, completely unachievable. And all I'm doing is I'm now beating myself up with a large sledgehammer because I'm failing to achieve what I thought I could achieve. And that was a huge, that was a huge lesson.

# Andy Dovey 37:43

For me, because I it again, it was all part of this thinking, I'll be back at work in a week or two. I'll be back at work in a week. And when I started working with a neuropsychologist, he was brilliant, because he was saying to me, maybe you need to think about looking at that going back to work part time. Thinking Think of it in those terms. Trying to soften the blow.

# Andy Dovey 38:05

Maybe try a drum lesson with somebody just for half an hour. See how you get on once good idea. The lad lives down the road, I've been given him drum lessons. So I phoned him up said all you know, we can we can start off again, do the first one for free because I don't know how I'm going to be just make it half an hour, not an hour. So he came along.

# Andy Dovey 38:25

And after 10 minutes, my brain had melted. He was asking me questions about oh, how did you do that? And it's like, I don't know. I can do it. I can't play any slot. I can't break it, I don't know what it is. What's it called? It's a sticking range? Was it? I don't know. And he was saying how can you not know but you can do it. I said, I don't know. I used to know. I can do it. But I don't know what it is. So it was like, okay, a 10 minute lesson and my brains melted. And I don't know what I'm doing. And then he left. And I spent the next two days in bed recovering.

## Bill Gasiamis 39:13

I remember those recoveries, I remember him because I used to go and exert myself on a Saturday to the gym. And, or I might go for a half an hour bike ride. And when I say exert myself, I was doing a light stuff, nothing major. And then the rest of the day would be wiped out will be gone.

#### Bill Gasiamis 39:30

And if I was going out to dinner, or to a party or something like that, late on one particular evening might be a Friday or Saturday night. I knew that I had to have nothing planned for the next day. And I would often tell my wife, do not make any plans for Sunday. I'm not interested. I'm not doing anything. I'm going to be recovering. And she's like, Oh, that's a bit.

# Bill Gasiamis 39:51

What do you mean? And I'm like, I'm going to be wiped out. I can't do it. But then, every once in a while, what I found was my expectation wasn't met, and then the Sunday I was fine. And I would say to her, hey, you know how that wipe-out thing was gonna happen. That's not happening today, let's get on to doing whatever you had planned and it will do well.

# Time Management



Bill Gasiamis 40:14 So we take the opportunity to make the most of that energy or like great feeling or whatever it was. And we'd go for it. But I really did plan so that if I'm going out Friday for my mates party, which there's no way I'm missing, on Thursday, I'm making sure that I'm not doing anything ridiculous. I go there on Friday, and then I'll make sure I've got nothing to do on Saturday. So that then there's this big window, so I can achieve the thing I want to achieve and get to the party and not miss out.

# Andy Dovey 40:46

Yeah, and I think that's a very important message again, for people who might be looking at this. And they're, you know, a few days a few weeks a few months into their stroke survivor experience is that I reckon, probably for about two years, I was in denial about what had happened and the magnitude of it and it took me two years to kind of adjust and get to the stage where I kind of understood what had gone on.

# Andy Dovey 41:20

And in that two year period, I've got some energy so I'll do stuff. Boof, crash and burn, week in bed, got a bit of energy, do stuff, crash and burn? There was no it was just up and down, up, down, up, down, up, down. And my wife didn't she says we look.

# Andy Dovey 41:46

Use the kitchen timer, we got a magnetic chemical timer that you wind up stick on the side of the fridge, stick it for 15 Take it with you stick it on 15 minutes when it goes off. Stop what you're doing. And of course, me being me, it will go off. And I'll be feeling fine. It's just like, give it another 15 minutes, it goes off.  $\$ 

# Andy Dovey 42:17

That's now half an hour. I'll still feel okay, give it another 15 minutes. Goes off foot here. I feel a bit rough now. And that was then now two days in bed. It's like right. Okay. So eventually, I got the message that even if I was okay, the timer went off at 15 minutes. Stop. Because when you stop when you feel bad, you've gone too far. You've gone beyond.

# Andy Dovey 42:46

But you're absolutely right. My oldest son got married last year. We're in Scotland. Now they're down in the south of England. So it's a seven-hour drive to get down there. And we had our other kids to see the rest of it. So that was a week away. And it was planned like a military operation like right, day one is travel. Day two is rest. Day three, I can do something meet some of the kids for lunch, day four is rest day five, that's the wedding.

#### Andy Dovey 43:16

Day six is rest. Day seven. That's the trip back diaries clear for the next week different recover from you know, and that that's unfortunately for me, I have to do it. I have to have to plan out. But like I said you earlier, you know, two days of doing nothing to get ready for this call. I've got two days of doing nothing afterwards because I know I'll need that to recover from it.

#### Andy Dovey 43:38

Even though I kind of seem okay now. It's that how you use your time and allocate your time is as much about how you allocate your time for not doing anything. As you do allocate your time to doing stuff. I think any us pain in the ass it really is.

Andy Dovey 44:01 But it's the only way of doing it. You see all this stuff behind me?

Bill Gasiamis 44:06 Your music equipment? Yeah.

# Andy Dovey 44:08

Yeah, it's all wired into the computer. And there's an electronic drum kit over here. To actually set it all up and unpack it all, pre-stroke I reckon would probably be about two weeks of work, took me about three or four months.

#### Bill Gasiamis 44:34

Is it like inability to kind of begin the task as well? So sometimes I struggle with beginning a task like just trying to put in a row the things that need to happen one after the other for the task to be initiated and And it usually happens when I've got a lot of, well, some neurological fatigue, or something like that. So that takes a while for me to get to the point where that's gone.

#### Bill Gasiamis 45:13

And then when it's gone, then bang, the task can be initiated, and I can do it. But task initiation is like a real challenge sometimes. And I might have something that takes three months to start and do and finish in one day. But the thought that just the thought process of it just drains me, and I can't do it, no matter how much it

needs to be done, no matter what extent of the like, no matter how little it is, or how big the task is, there's just no bringing my brain around to the point of it feeling like it's capable of doing it. It's such a weird thing.

# Andy Dovey 45:59

Yeah. And I totally get that Bill. And if you think about it, the task of planning something is a task in itself. So to get to point one, which is to start doing the thing, still requires thought processes planning, brain activity, all the rest of it. And if we're not in the right place, for whatever reason, brain processing-wise, it's not going to happen.

# Andy Dovey 46:32

And the analogy I use is, it's a bit like, if you've got an old computer, and you load up some new software, and you haven't quite gotten, you've got enough RAM to kind of get it going, but not really enough RAM, you know, or you have too many windows open and it starts going a bit slow and spooling, and all the rest of it. My feeling is it's very much like that, it's kind of like, go on, you can't oh.

# Andy Dovey 47:01

And even looking at something can be daunting. And, you know, I've been working on my music project, which is about my stroke story, hopefully will raise when it's finished. We'll raise some money for charity and all the rest of it. But it's also partly therapy for me as well to to have a hand in doing something.

# Andy Dovey 47:25

I've been doing this for about eight years now. And I will very often come in here with the intention of doing something. And I'll turn all my gear on. And I look at the screen and think no, I can't, I just which button was it? Which is it? What? Where's the manual? I can't read the manual. Oh, no. And just turn it all off again and go back in the house.

# The Invisible Injury

# Bill Gasiamis 47:59

How bad is it when you come across people? Because you look "normal". And people who don't get that part of the disability the invisible part of it like, is it still frustrating? You still coming across people like that? Does the family still misunderstand?

#### Andy Dovey 48:22

Now luckily, my family, my wife is incredible. She's done an awful lot of research herself into the brain, stroke, brain injury, and she really understands it. I've got two boys, my wife's got a boy and a girl. I say boys and girls, the youngest is 32 the oldest is 37. But they get it they understand.

#### Andy Dovey 48:58

But outside of a close family, you know, neighbors, I was chatting to one of our neighbors the other day. And he said to me, Oh, you've got a stick. And we've lived here six years, right? I've bumped into him in the town. We're not been dawdling around with a stick and he says you've got to stick I said, Yeah, you said it before, George.

# Andy Dovey 49:21

Whoa, are you not that good at the moment? I said, No, I always walk with a stick. It's just that I've got it here now because we're in the car on our way out. Normally if I'm sort of mooching around the garage and all the rest of it, you know, because it's level. I don't have my stick and there's a fence that I can hold on to and all the rest of it.

#### Andy Dovey 49:43

So, you know, and I get that it's frustrating, but I get that I understand that because I was the same before it happened to me. I probably wouldn't have been very observant about other people whether they had a walking stick, whether they were wobbly, and all the rest of it. But the cost, the standard line is, you know, you meet people and they'll see the stick or they see you wobble and they say, are you all right?

# Andy Dovey 50:09

I used to say, yeah, I had a stroke. And the standard line would be you look really good, you're speaking okay, because most people, and I didn't, because I didn't know what a stroke was. Most people don't understand what a stroke is. I generally now say, yeah, I have a brain injury.

Bill Gasiamis 50:31 Yeah, that's a smarter way.

Andy Dovey 50:32 Yeah that gets more of a reaction now of a storm people stop and think, as opposed to a stroke. But you know, but it is frustrating. But I tend now to say I have a brain injury. And if it's, if it's somebody who doesn't sort of register when I say I have a brain injury, I'll then say, so I have brain damage.

Bill Gasiamis 51:06 Yes. I like that, that is a great way to connect the dots really quickly in a conversation for people.

Andy Dovey 51:16 Well, it's interesting Bill, becauesl it took me a long time to accept that myself. Right? So for a long time, I would say, I have a stroke. Mags, my wife, had to say that try saying you have a brain injury. Actually, I think that have more effect. And she's right. And she's absolutely right. It does. Because if somebody had said to me, before I had a stroke and knew all the stroke was I've had a stroke, I'd be like, Oh, right. Okay. Because the word is wrong.

Bill Gasiamis 51:55 The word doesn't mean anything doesn't it?

Andy Dovey 51:59

Stroke, stroke soft, strokes nice, stroke is what we do to cats and dogs, and we stroke our loved ones, and there you go. It's not, stroke doesn't generate that. And that's what it is a professor of neurorehabilitation said to me once, what you've got to realize, Andy, is that you've had your head kicked in from the inside.

Bill Gasiamis 52:35

So you know, those parts of your skull that are missing? Are they never going back in? Is that part of your head safe? Is it okay? What the situation with that?

Andy Dovey 52:46

Yeah, it's, I don't know whether you can see around my back. So from about here, down to about there is the scar. So it's kind of that sort of semi-circular bit of scar is missing. So that here is all soft, there's a scar there. So that's never going back in because, what if you have a cranioplasty where they take a bit out here or a bit out here.

# Andy Dovey 53:19

Generally that goes back in or they give you a little helmet, depending on how big the areas but the feeling was because it's round the back. You tend not to bang your head around the back if you're going to bang your head it's on the front. And because the skin round there is quite thick as well that that's enough.

# **Sensory Neuron Issue**

# Andy Dovey 53:36

So that's been out. It does make you very sensitive to climatic conditions I found. So when it's a high-pressure area, you know, when it's a high-pressure area moving in, this gives me really bad headaches, really bad headaches, because my skull is no longer a closed system.

# Andy Dovey 53:57

So air pressure that can get in this little hole here or around the back there. Really bizarre. I had to do research and I found other people with similar things. It's like we all have the same thing. We all much prefer a low pressure, we don't get headaches when it's low pressure, which is part of the reason for us moving up to Scotland from the south of England, because it's generally a cooler climate, there's less high pressure so it makes it a bit easier on the head.

# Bill Gasiamis 54:25

Yeah, that is interesting and bizarre because the weather affects me always has I prefer high-pressure kind of systems and days cold low-pressure ones don't really do me any favors and that's not because of my might my head or anything it's just always been that way. And now with the left side numbness, cold, low-pressure days hurt my left side for some reason more than when it's hot and warmer. And I feel like I always come up.

# Andy Dovey 54:57

Did you? Did you have any mid Line shift. Did you have a midline shift in your brain? Do you know? It's basically were the two halves of the brain get twisted? Okay, no, I read this. I read this the other day somebody was saying if you had midline shift and my hospital discharge notes said that I did with all the swelling it kind of stuff my brain that can affect that that can affect the hypothalamus. And it can it can make you sensitive to cold or heat. It can just muck up your hypothalamus if you have a midline shift, apparently.

# Bill Gasiamis 55:36

I never heard of it. I don't think so. Mine's more of a sensory neuron issue. So it's

very common, so what happens is that the sensation on my left hand, it feels like it's numb all the time. And the sensory neurons are hyperactive so they feel everything even like a breeze like a slow breeze, I can feel it on my...

#### Andy Dovey 56:08

Is it almost like when you've had a bit of light sunburn?

# Bill Gasiamis 56:12

Something like that. And what it does when you feel just slight wind, the wind on the skin, and also on the hair follicles hurts. So we're just talking about a light breeze and in winter, that side is always colder than my right side. So in winter, it gets colder, and the cold, makes it hurt.

# Bill Gasiamis 56:37

And then that slight breeze makes it hurt. So the best way for me to avoid it is to have a lot of pressure on it. So at night, I sleep on my left side so that it's completely being impacted directly by the mattress so that the sheets are not making my skin hurt, as they kind of just swish over the top. Very rarely do I slip on my right side.

# Bill Gasiamis 57:05

Although I'd like to. It's gonna keep me awake, I don't do it. So it's a very common thing with people who have stroke. My stroke was near the cerebellum as well, it was not in the cerebellum was kind of like just outside the cerebellum. And when the second blood clot was in there after the second bleed, I had nausea, vomiting and balance issues and the room was spinning and all that kind of stuff.

# Bill Gasiamis 57:37

And now my biggest issue is because of the sensory part of the situation where the numbness is impacting the message from my leg to my brain telling my brain that it's on the ground, the right side, overcompensates, it gets really stiff.

# Bill Gasiamis 57:57

And as a result of that, I feel like I'm kind of losing balance to my right side. And my left side is always not stable and doesn't, you know, I can't ground as much as I can ground my right side. So I'm often doing the whole leaning on walls, you know, and all that kind of stuff around the house. And sometimes when I go through walkways, on my left side, if it's a tired day, and it's a fatigue day, I kind of bump into the doorframe.

#### Andy Dovey 58:21

Yeah. Same for me. I was forever getting bruises on this left side, because I would go over the left side. And I think I was upright. And I think I was going through the gap. And then as I go through, crash! So I totally understand that Bill, it's weird, because your perception is that you are upright but when you go through a door and you've crashed into it, it's like I'm not.

#### Bill Gasiamis 59:04

And spatial awareness are issue is like, I feel like I'm in the middle of the doorway. But I think I'm in the middle of a doorway, it appears as I'm in the middle of the doorway, but when I get to the doorway, I run into the doorway. So the whole thing is completely out of whack.

#### Bill Gasiamis 59:23

But most days, it's not that bad. But some days it's worse. And it's usually towards the end of the day for me in the morning, I'm best. And I reckon I'm probably good till about 2pm. And then after that, I needed to lay off and do a lot less than I was doing in the middle of the day.

#### Bill Gasiamis 59:43

So if I get up early, and I can be productive, say between 8am and 2pm. That's usually a full day for me and then the rest of the day is just doing minor non highly productive things. So, one of the other things that's been really difficult for maze, that task initiation was, I'm writing a book at the moment and to get to my set, get myself motivated to write the book was one issue.

#### Bill Gasiamis 1:00:08

And then to be able to sit down, say, for two or three hours to write consistently and not be distracted, and not I have to get up and move to actually make progress on this thing was really difficult as well. So they're the little bits and pieces that kind of interfere I suppose in my day.

#### Bill Gasiamis 1:00:27

But and that means that deadlines, you know, especially like we spoke about earlier, but deadlines on say, completing a book, just completely ridiculous, there is just no way that I can say I'm going to take a month off and finish the book in the next month, because that next month might be a bad month, and then and then nothing gets done. So it's a little bit about what happens then.

# Andy Dovey 1:00:53

I totally understand that I have found that making commitments, incredibly difficult, incredibly difficult, because I cannot say, with any accuracy, that if somebody wants me to be somewhere at three o'clock on Tuesday, next week, that I can actually be there and do it, I stand more chance with something sedentary like this, where I can have two days before not doing anything, do it two days afterwards, and recover.

#### Andy Dovey 1:01:32

But in terms of a meeting for something, I mean, I started having some neuropsychology appointments up here when we moved up here to Scotland. And I ended up being kicked out. Because I cancelled three appointments, three strikes and out only found this out afterwards, I'd always phone up and say I can't make it. Or I'd email and say I can't make it. But it was basically there are people queuing up for this service.

#### Andy Dovey 1:02:04

And you still owe the you're unreliable, unfortunately. And it's kind of like well, hold on. Surely it's the unreliable people that will need it more than everybody. So I totally get that, that. So I don't really have much of a social life because I can't, commit to be the number of gigs, I've bought tickets for my wife and I to go to see that I haven't I don't bother now.

#### Andy Dovey 1:02:33

Because there is no point in saying oh it's the band, I'd love to go and see in Edinburgh, in September, I'll buy some tickets. Because I have no idea how I'm going to be when it comes to that time. And I've not gone to more gigs than anything else in the last nine years. So I just don't blow them out. I'll wait for the DVD to come out or watch it on YouTube or something. But that's how it is, that's the reality.

# The Brain Attack Music Project By Andy Dovey



Bill Gasiamis 1:03:03

So what do you love to do? Now? How do you occupy your time and keep it creative? How do you get some pleasure and enjoyment out of your day?

# Andy Dovey 1:03:14

Yeah, it's a lot of it depends on how I feel. So I started this brain attack music project. Probably about six to nine months after my stroke. My wife has said to me, you've always been really good at writing. Why don't you write a book or something? So I started writing things down, and they would kind of be like song lyrics.

# Andy Dovey 1:03:41

So it was like I could do something for charity, maybe my stroke story for charity. So I started mucking around with some musical ideas. And I thought, Well, I'm gonna need a website, aren't I? So how'd you go about setting up a website, so researched that and set up a website.

# Andy Dovey 1:04:01

And then it was like, boy, I could maybe do some blogs that might help other strokes survivors, I could write some blogs or put some blogs on the website and then that evolved into vlogs. So I set up a YouTube channel so I then do videos on the YouTube channel about my stroke experience.

# Andy Dovey 1:04:20

And that's now podcasts. So I've got podcast set up and as well as the music so I've got these and then my blogs that I've been writing I could use those, that could go into the books. Basically, I've got the music projects on the go book projects on the go, YouTube channel on the go podcasts on the go. And on the website. There are blogs on the go.

# Andy Dovey 1:04:48

So most of my time is about my stroke story and trying to do stuff to help other stroke survivors and that's very much up and down. So I can do I can have a splurge where in maybe a few months, I can do mainly music. And I forget about the other stuff. And then I get an idea about something to do with a blog. And I'll get obsessed about that. And I'll spend time on the book and all the rest of it.

#### Andy Dovey 1:05:20

So before I've got to set myself deadlines, as I write, you've got to have this done by this, you've got to have this done by now. But I'm a bit of a butterfly now sort of fluttering around, doing different things. But that's really what I do to occupy my time and a bit of reading, but a movie watching. Listening to music is difficult. I can only cope for about half an hour. With listening to music, I find a boredom threshold is dreadful now.

#### Andy Dovey 1:05:55

So to sit down and watch a soccer match, I'll get bored after 10 or 15 minutes. Or you know, when I was a kid, I'd sit down and watch a cricket match all day on the test matches on the TV Dennis Lilly, Jeff Thompson, those guys fantastic. Watch that. Now, flittering and I'll watch something it's like, if it doesn't grab me within a few minutes, it's no I can't be doing that. So I tend to flitter around and do different stuff.

#### Bill Gasiamis 1:06:32

That reminds me of me, I'm better these days. But early on, I reckon. I started the podcast in 2015. And I did nothing for a couple of months, then there'd be maybe a couple of episodes, and then nothing for a little while and I couldn't get a consistent, sort of run on it, because I just didn't have the ability to. And it only started to really get serious with it, maybe three or four years ago, where I decided I'm going to try and release an episode a week. And I've achieved that most weeks for the last two or three years nearly.

Andy Dovey 1:07:12 That's quite a tall order, isn't it?

# Bill Gasiamis 1:07:15

Oh it's huge. Well, this is interview number four today. So I've got to then edit these. And then I've got to get them off to my guy to transcribe them. And then

I've got to get them on YouTube and Spotify and other places. And each episode takes between eight and 10 hours to complete my time, the other guy's time.

# Bill Gasiamis 1:07:38

So it's a huge undertaking, I couldn't do it on my own. And, you can imagine, like focusing and concentrating on something for eight hours. It's just not possible, it's completely not possible, it was hardly possible for me to sit down and, be still for eight hours before the stroke, let alone after the stroke. So we're getting there now. And I'm getting better.

# Bill Gasiamis 1:08:05

And I suppose I've trained myself as well. So I hit my capacities, and then I push a little bit further, and then I don't and then I do and then I don't. And if I can't do anything, then nothing get's done. And sometimes nothing gets done. And I'll get a burst of energy on Sunday night at 9pm. And then I'll smash one out and it's like, Oh, my God, like, but that's the only time I can do it. Because that's when it comes so.

# Andy Dovey 1:08:41

It's tough to get to that point, though, isn't it? To where you can kind of be happy. Accept, adjust, whatever you want to call it to that, frame of working. It takes a long time to get to that point.

# Bill Gasiamis 1:08:56

And it goes against everything you've ever been taught and told and trained to do. So you have to really be different, and you have to exist differently in a "normal world" you have to be different, and you don't have a choice not to be you have to be and sometimes it doesn't work well and it interferes with lots of things and other people and the rest of it.

# Bill Gasiamis 1:09:20

So look, it's getting there, but I'm like you you know, I've got the book project and I sit and do that when I get some spurts of focus and then I do the podcast and then you know, all that stuff. So I think it's still rewarding. I still enjoy it. I love doing I love meeting people from all around the world. You know, especially love it when I put out a request, you know, come on my podcast and 30 people respond. It's like, Oh, that's too many, what am I going to do?

Bill Gasiamis 1:09:49

All right, well, I guess I'm gonna have to interview them now. And that's why I'm doing four today. It's just mental but two years ago, I would not have been able to do four no chance not in a million years, I would have canceled a couple of them for sure. I may have booked them, but then I want to let people down. And that's the part that I hate the most.

# Andy Dovey 1:10:12

I think that's quite a key point, probably because we're getting near the end now, I think that's a key point for people who are on the early days of their stroke journey, is that, you know, for me, it's nine and a bit years further down, I can't remember how long it is for you, Bill.

# Andy Dovey 1:10:34

But things still change, things still improve. Now, they might be tiny, little improvements. They might be tiny, little improvements over a reasonable period of time. But they're still happening, as opposed to after two or three years thinking this is it.

# Andy Dovey 1:10:56

I remember sitting up in hospital, in the neurosurgery ward tubes coming out of everywhere, and a physio visiting me saying what you got to do Andy is look at your recovery in six-week chunks. And I remember sitting there thinking, sixweek chunks, plural, not a six-week chunk of recovering six weeks, chunks, plural. And in my head, I'm thinking, may I'll be out of here in six weeks. I'll be back at work in six weeks. What are you talking about six weeks chunks?

# Andy Dovey 1:11:37

Yeah, I mean, I laughed. I think he undersold it. I think it should be six-month chunks. Quite frankly, you know, because it is incredibly long term. But the fact that you're 10 years, I'm nine years, but we were still in a way of adjusting, still discovering new things, still making little tiny improvements in little funny ways here and there is testament to the fact that yeah, it's a long journey, and you need to look at your recovery over a long period of time.

# Andy Dovey 1:12:11

And it's probably open-ended because I don't think either of us will get back to how we were pre-stroke. Nevertheless, the journey still continues, you can still make improvements, you put the work in.

# **Living With The Deficits**

#### Bill Gasiamis 1:12:26

Agreed, I've been living with these deficits the rest of my life, they're getting better, they're not going away. And I've come to accept that. And it's kind of alright to experience this different version of my body where literally halfway down my body, like from top to bottom, every part of my body, right through the middle is different on one side different on the other side.

#### Bill Gasiamis 1:12:53

It suits my star sign I'm a Gemini, so you know now, the left side is one guy and right side is another guy. So you know, whatever, I've come to accept that. It's not ideal, and I don't enjoy it every day. And sometimes I actually dislike it. Especially if it's a painful day.

Andy Dovey 1:13:13 Would you go back to how you were, if you could?

#### Bill Gasiamis 1:13:20

No. And the reason is, is because I have done so much personal development and so much personal growth. I'm a different version of myself than what I was all in the last 10 years. And I'm the guy that is writing the book with the working title that strokes the best thing that ever happened to me, so I wouldn't go back. And I'm not saying that it's all been roses, and it's all been enjoyable.

#### Bill Gasiamis 1:13:50

It hasn't, it's been shit and terrible and difficult and scary and tough on everybody, including my family and my kids and my parents. We've been traumatized. So I would love to avoid the trauma, but I can't see me learning the lessons that I've learned any other bloody way, that thick-headed, you know? And therefore, I can only take from it the whole.. Why would I change the growth that I've had? My story is a post-traumatic growth story. Not a post-traumatic stress one.

#### Bill Gasiamis 1:14:30

There was a bit of that there. But that's all gone and now it's something else. So I can't take that life lesson away. And not only that, I never did podcasts before. I never met people from around the world I never had in common.

#### Bill Gasiamis 1:14:49

These things that I have in common with so many people from around the planet. It's just completely opened my world to things that I never knew that even on the horizon that alone possible, like I just didn't know about podcasts I didn't know that existed. And that I could be a guy behind the recovery after stroke podcast and have in excess of 200 episodes and get all the comments and the feedback that I get like how do you change that and go back to the old idiot that I was before that, it's not possible.

#### Andy Dovey 1:15:26

I agree with you totally. I remember, pre stroke, sitting in traffic jams. And they would stress me out so much. There's a preset amount of days that I would rather turn around and go in the opposite direction, and be moving, thank God, I'm moving. But I'm again, going away from where I want to go to try and find the back waves round. That's how bad my stress levels were, I'd rather go in the opposite bloody direction than sitting in a traffic jam.

#### Andy Dovey 1:16:04

I remember another occasion where I was driving back from a gig. And the sun was just going down. And it was just the most glorious sunset and I was just like, Oh, God, look at that. Just beautiful. Just coming up the motorway to the turn off that I need to take to go home. And then I realized it was close to four in the morning. And it was sunrise. It wasn't fun. Sounds like "oh shit, it's quarter four in the morning"

#### Andy Dovey 1:16:35

And I've got my first lesson tomorrow at nine, would I want those days back again? No. Not really. You know, like you I've done things now post stroke that I would never have done before. Yes, of course, there's been horrible stuff been going on, as you might say a lot of crap that goes along with it. But you look, you learn.

#### Andy Dovey 1:17:08

And you develop and you change and you grow. And I'm often asked, Oh, you must miss your old life. It's like, No, I don't actually, I did. And I spent probably about I would suspect four or five years, being really jealous when I'd see people that I knew playing in bands I'd like to have played with although they've got a new CD out and it's not fast today, I would really get quite jealous about it.

# Andy Dovey 1:17:45

And I'd have daft romantic moments where I'd be starting to look through the internet and see if there were bands looking for drummers. And so I could see an ad for a band looking for a drummer and all that. I could do that. And there have been like, okay mate, you could load up all your gear in the car, you can drive two hours to the gig, you could unload all your gear, you can go up four or five flights of stairs to the stay, you can unpack all your gear, you could set it all up.

#### Andy Dovey 1:18:14

You could soundcheck, you could then play for two and a half hours and you could then pack it all away, drive home and go to work. No. He couldn't, of course he couldn't. So it was the one side which was the idealized romantic side. And then the other side, that's the practical, you know, bring you back down to earth.

#### Andy Dovey 1:18:34

So it's kind of like, No, I wouldn't want to go back. I've spent more time with my wife in the last nine years than I have ever since we've been together. And that's been fantastic. And I wouldn't want to lose that at all.

#### Bill Gasiamis 1:18:41

Yeah. Mate, I really appreciate you reaching out. Thank you so much for joining me on the podcast. If some of the people listening wanted to find out a little bit more about you and brain attack music and your projects, where would they go?

#### Andy Dovey 1:19:14

Very easy brainattackmusic.com. Excellent. There are links there to YouTube, Twitter, Facebook, podcasts, as well as demos of some of the music and stuff about me. So brainattackmusic.com is the place to go.

#### Bill Gasiamis 1:19:31

And I'll have all of that stuff in the show notes. Anyway, thank you for joining me. I really appreciate it. wishing you well. And good luck on the rest of the journey.

# Andy Dovey 1:19:44

Thank you Bill and same to you. It's been a pleasure to meet you, my absolute pleasure.

Bill Gasiamis 1:19:48 Well, thanks for joining us on today's episode. I hope you enjoyed my conversation with Andy to learn more about my guests, including the links and how to find out more about them and to download the full transcript of the entire interview, please go to recoveryafterstroke.com/episodes.

# Bill Gasiamis 1:20:06

If you would like to support this podcast, the best way to do it is to leave a five star review, and a few words about what the show means to you on iTunes, and Spotify. If you're watching on YouTube, comment on the video below. If you liked this episode, give it a thumbs up. And to get notifications of future episodes, subscribe to the show, and hit the notification bell.

# Bill Gasiamis 1:20:32

Sharing the show with family and friends on social media will make a massive difference. And it'll make it possible for people who may need this type of content to find it easier. And that may make a massive difference to somebody that is on the road to recovery after their own experience with stroke. One in six people will have a stroke in their lifetime. So chances are somebody you know has already had a stroke.

# Bill Gasiamis 1:20:56

And if they haven't, you know somebody that will have a stroke. So it's really important for people to know where they can get this kind of information. That's why I'm asking you to share. So thanks so much for doing that. Now, thanks for being here and listening again. I really appreciate you. I'll see you on the next episode.

# Intro 1:21:15

Importantly, we present many podcast designed to give you an insight and understanding into the experiences of other individual's opinions and treatments. Protocols discussed during any podcast are the individual's own experience and we do not necessarily share the same opinion nor do we recommend any treatment protocol discussed all content on this website at any linked blog, podcast or video material controlled this website or content is created and produced for informational purposes only and is largely based on the personal experience of Bill Gasiamis the content is intended to complement your medical treatment and support healing.

Intro 1:21:48

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#### Intro 1:22:09

Never delay seeking advice or disregard the advice of a medical professional, your doctor or your rehabilitation program based on our content if you have any questions or concerns about your health or medical condition, please seek guidance from a doctor or other medical professional if you are experiencing a health emergency or things you might be called triple zero if in Australia or your local emergency number immediately for emergency assistance or go to the nearest hospital emergency department medical information changes constantly.

# Intro 1:22:36

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