Cryptogenic Stroke – Andy Dobinson

Andy Dobinson is an ultra-marathon runner and an endurance bicycle rider who experienced a cryptogenic stroke

Socials:
www.instagram.com/andyd2574/
www.instagram.com/andy_stroke_of_luck/

Highlights:

00:55 Introduction
03:17 The stroke symptoms
09:38 Andy Dobinson was fit but not healthy
17:29 The first few weeks after stroke
21:39 Underlying cause of depression
31:02 Fear of demonstrating failure
40:09 What a stroke can give
44::08 The brain, the heart, and the gut.
53:28 The mountain analogy
1:01:48 You're not alone

Transcription:

Andy 0:00
Yes, I did. And I was kind of wracked with guilt. Although the stroke wasn't quite well, I thought, have I caused the stroke? It was a cryptogenic stroke. So we have no idea why it happened. It was a massive clot at the back of my head and affected both sides of my body.

Andy 0:14
So the conversations we had were will I ever be the same? And how can I work again? Can we work as a team? And you know, I remember thinking to myself, I'm not the guy she married will she want to split, which she was mortified that like oh my God no!

Intro 0:42
This is the recovery after stroke podcast, with Bill Gasiamis, helping you navigate recovery after stroke.

Introduction



Bill 0:55
Bill from recoveryafterstroke.com. This is Episode 130. And my guest today is Andy Dobinson, and he is an ultra-marathon runner and an endurance cyclist who experienced a cryptogenic stroke in 2017.

Bill 1:10
Now before we get started, you may notice that the audio of this episode is not that amazing, and this is due to technical difficulties we had with the zoom connection between Australia and the United Kingdom.

Bill 1:22
I've done my best to remove the background noise and tried hard to level out the volume. But the sound quality is far from perfect. I ask you though to persevere as this interview will give you an insight into how important mindset is during stroke recovery.

Bill 1:39
Also, if you ever wondered what else I can do to help you with your stroke recovery, you should know that you can now get recovery after stroke coaching right from the comfort of your own home.

Bill 1:49
I too am a three times stroke survivor and I've built for you what I was missing when I was sent home from hospital in the hope that you don't have to do stroke recovery as tough as I did.

Bill 2:00
Support packages give you access to a variety of tools 24 hours a day, seven days a week so that you can also work on other areas of show recovery, like adjusting to your new normal, even managing the grief that you may be feeling for your former self.

Bill 2:15
With tailored support available from $8.50 per week, all recovery after stroke support packages, bring stroke recovery to you in the comfort of your own home. To try out recovery after stroke support and see if it is right for you, you will get the first seven days free as well as a 30-day money-back guarantee no questions asked.

Bill 2:35
As a bonus, you will also get to face to face zoom support calls with myself to take your recovery to the next level. Go to recoveryafterstroke.com/momentum to sign up. You won't cost you anything for the first seven days. And you will get a full refund. If you're not happy after 30 days. You have nothing to lose and everything to gain. Now it's on with the show.

Bill 3:10
Andy Dobinson, welcome to the podcast.

Andy 3:13
Thank you very much Bill. Good to meet you.

The Cryptogenic Stroke symptoms



Bill 3:17
Yeah my pleasure. Good to meet you too. Tell me a little bit about what happened to you?

Bill 3:23
Oh my goodness. It was quarter to five in the afternoon. I remember it well on the 9th of February 2017. I was sitting right here because I work from home. And I was on a conference call. And literally out of the blue with no warning nor precursor, no symptoms, nothing at all.

Andy 3:51
That was if somebody had them lit a blowtorch at the back of my head and pressed every single pin into the back of my head and instantly the beads of sweat appeared and started dripping onto the desk. And then you see what happened to me at that time I didn't have a clue, I didn't know.

Andy 4:14
So I was on a conference call. So I put myself on mute because I thought it would be very tricky to dial off the conference call. Then I started feeling a bit oh my goodness, I don't feel very good.

Andy 4:26
So you know you do the usual, you start with Google dizziness and leaning to the left. And then it came up with this thing called peripheral vertigo. So I thought right, that's it. I have peripheral vertigo.

Andy 4:42

I’m wearing an earpiece I must have an ear infection of some sort. What to do? What to do? Now I’ve started feeling quite confused and cloudy and just this pain is intense pain paracetamol, nurofen, so I stood up, and I just thought I was holding on to my desk swaying about thinking, what is going on?

Andy 5:08
And someone is still on the call, went downstairs and by the time I’ve taken the paracetamol and dropped to the bottom of the stairs, I couldn’t walk. So I kind of climed up the stairs. And by this time I started thinking, a bit concerned here.

Andy 5:26
So luckily the call have finished and I’ve plucked my earpiece and throw them in the office then I was leaning against the wall. I thought I’m going to go in lie down, because I was starting to feel a bit scared. I was by myself at the time.

Andy 5:39
Then I was leaning against the wall because I was on my own two feet, but I was really unsteady and I laid down not knowing that apparently lying down flat can help recovery, I didn’t know that at the time.

Andy 5:52
And then I rang my wife and I said, Nikki, I don’t feel too good. She said what’s wrong? I think I’ve got a migraine, she went you never get migraines. You’ve been working too hard, I just lie there. I’m going off my fitness class, I’ll see you at six o’clock.

Andy 6:09
And I’ve drifted off to sleep luckily but feeling a bit funky is the best way I can describe it. Confused, scared, clouded. Next thing I know, I hear this voice Andy it’s me where are you? I said lying on the bed.

Andy 6:26
And as my wife opened the doors, her words were, oh my god, when she said I look gray. And we still don’t know what the hell was going on. And she flipped the lights on and I didn’t react to it.

Andy 6:42
So she thought that’s not a migraine he’s not reactive to the light. So she says, right. And she’d actually seen the FAST acronym on Facebook. So she went look, I

don’t know if this is a stroke but let’s just double check so I swung my legs off the desk.

Andy 7:02
And she said say chicken soup. And I had a sticky mouth and I couldn’t talk properly. And I was internally thinking, What’s happening here? She said raise your arms, and I was a bit lopsided and she said I think we need to get an ambulance.

Andy 7:18
And I was like, No, no, no, it’s fine, I’ll be fine. And I don’t wanna be a burden on anybody. So I wouldn’t allow a 999, so that was a number in the UK 111, which is advice. And based on what my wife said, he said I think we need to get you an ambulance.

Andy 7:38
So these two big paramedics arrived and came in and hooked me up to all sorts and the words were “not the best but it’s not the worst”, but I think we need to get to the hospital. So maybe I may have tried to get up, but I couldn’t walk that was it, I couldn’t walk. So I was like this across two guys and dragging my feet along the ground and in the ambulance.

Bill 8:03
And that was it was getting late to the hospital screaming. And next thing you see these faces looking down on you. And that was the start of them trying to work out what happened and it took them over a day two establish it was a stroke they thought it was chronic fatigue.

Andy 8:23
And you know, they go through morphine, which was just crazy, and horrendous sickness and they just didn’t know what was going on. And so they put me to the critical illness unit, and I was writhing about, and being sick, just beyond scared.

Andy 8:46
Then they give you a lumbar puncture, which is the most unpleasant thing in the world. And then they said okay you got a lumbar puncture, just lay there and get comfy and I felt like, I can’t walk where the hell am I gonna go?

Andy 9:02

And then an MRI. And that was still we don't know what's happened. And it wasn't until five o'clock the next day to give me a CT scan. And I remember being in a wheelchair, just being stick. There's a junior doctor walking up to me and like Mr. Dobinson. I was like yeah? Okay, so you had a stroke. I'm like, what? And it was just like my world ended.

Andy Dobinson was fit but not healthy



Bill 9:38
What kind of lifestyle were you leading before this episode in your life? What type of bloke were you? How did you live your life?

Bill 9:51
I was fit. But I don't think I was healthy, which I've now learned because I was a fanatical cyclist where I would do, my speciality was 24-hour bike races. And I would do 250 to 400 mile.

Bill 10:12
Hang on a sec 24-hours straight?

Bill 10:17
Yeah, yeah. So, example, I did a mountain bike race from 10 o'clock on Saturday morning, you finish at 10 o'clock on Sunday morning, and you just go round and round. So I did quite a lot of the 24 hour races, and I used to do big endurance race, like 2, 3, 400 miles.

Andy 10:42

And I did a lot of team trailers. So I love cycling and I just started trail running which has kind of become a passion. But yeah, I was hugely active, hugely active, but was I healthy? I don't know.

Bill 11:00
How did you get to the point where you, I've got a bike, and I've always had a bike. And one day, I wake up in the morning, and I go for a ride, it takes about an hour, and then I come home and I'll put the bike back. How do you go from riding the bike like that to eventually getting to the point where you're riding it for 24 hours?

Bill 11:20
Like did that just happen in your head? One day, I'm gonna do this 24 hour thing? Or is it a slow burn? And then eventually, you look back one day and you go, Oh, my God, I just ride my bike for 24 hours.

Bill 11:33
I think it's kind of in you. I've always loved the challenge, love the challenge. And I've always, if somebody said to me, that can't be done, I've always thought okay, I'll give it a try.

Andy 11:48
But I've always been kind of, I like the really challenging stuff. And you know, a 50, 60 mile bike ride was the norm on a Sunday 24 hours. And I think I just thought you know what, I'm going to give this a try. And I went and tried one is because it's a team, and I thought I think I might try this myself.

Andy 12:09
And it's actually a hugely lonely thing to do. You're on a bike by yourself for 24 hours. But then once you've done one, you immediately say to yourself, I am never doing that again in my life. And then the next day you think, when is the next one becomes quite addictive.

Bill 12:28
Tell me about that day. Tell me about that entire day. Now, for stroke survivors. The reason why I want to go into this is because it's gonna give us an insight into your mindset.

Bill 12:40

And I'm really intrigued about that. But tell me about that day you wake up in the morning, you jump on the bike at 10 o'clock? And how many times do you stop? How do you go to the loo? How do you eat, what happens?

Bill 12:55
Usually, it's a lap event. So I'll give you an example of a one that I've won a couple of times, it was actually a race circuit. So you can just ride around the race circuit, it makes it even more boring, and mind numbing actually, you come through every single lap.

Andy 13:15
So I would say I'm going to lay for two hours, then I'm going to come in for 20 minute, 10 minutes, stop, hit stop change of clothes, toilet, food, out which becomes a challenge in itself, because you've got a pit crew the stall, food, comfort chair, and you could be in the depths of the night in Scotland, that's where I live.

Andy 13:39
And wonder where I could get enough water It was freezing. You're coming in at three, four o'clock in the morning, we've got the sleeping bag, comfy bed, tent with all the pit crew sleeping and the challenges coming in and then getting yourself back in the saddle.

Andy 13:59
And I always have this goal of I want to achieve so many miles I want to achieve so much elevation and by sitting in a chair in the pit crew, you're not going to do that. So it's more mental than physical. And I think anybody's got it in them physically, mentally. And definitely mentally.

Bill 14:23
I imagined myself on a bike. And I've never had the idea to ride for 24-hours but I imagined myself on a bike and at some point your legs start to hurt. And for you, how long does it take before your legs start to hurt and for how many hours are you riding with your legs hurting?

Bill 14:48
About 18 hours that you're hurting. But I think this is why I enjoy Ultra Trail Marathon running which I've become since my store. So now I run 50 mile trail marathon and that's since my stroke so I can be running for 13 hours.

Andy 15:09
So I'm lucky that I'm able to do this kind of stuff post stroke. But it's still in me something I'm wired a certain way, I think that I loved. I don't love the pain, because that sounds really odd, but I love challenging my mind and my body to say at the end of it I did it. It's even more special now that I had a stroke.

Bill 15:43
Is it egotistical?

Bill 15:45
Absolutely. Totally. Because at the end of it, you put a post on facebook I did a 24 hour race, and you're on this place, and you go, Oh, I'm fantastic. Which is what I've searched for pre-stroke but post-stroke is completely different. Totally different.

Bill 16:05
Tell me.

Bill 16:05
There's not one bit of ego, it is so personal to me now. So give you an example. Pre-stroke, I would choose times, speeds, power numbers, elevation, mileage, were in September, I struggled to start laying 50 mile ultra trail marathon a couldn't walk in February 2017.

Andy 16:32
And I don't care how many people beat me, I don't care. I stopped for photographs and stop when I got tired. I stopped to rest, stop for feed stations. And it was the adventure and the journey. I believe that so much I've got a memorial tattoo on my ribs about the journey and adventure with a stroke survivor symbol I'm passionate about that now.

Andy 16:58
But you know, you think I'll do it in 12 hours, or 12 hours comes into make it 13 they might do it in 14, I don't care. What I care about is getting to the end. And that is so much different to try and cheers, please and cheese there. I don't care about that anymore. I've got nothing to prove.

The first few weeks for Andy Dobinson after stroke



Bill 17:30
The way you look to me is that most people wouldn't know that you've had a stroke, but what was it like in those first few weeks of stroke? How bad did it get?

Bill 17:45
I've never, ever experienced, and I hope I never experienced again. And I hope nobody experiences the darkness of a stroke, it was horrendous, horrendous. And I called my stroke phase one, phase two. So you know from being a 24 hour cyclist to sitting on a hospital bed and getting knife, a fork, and a hairbrush put infront of me and say, show me that you can feed yourself.

Intro 18:17
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?

Intro 18:34
Doctors will explain things that obviously you've never had a strike before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself in that situation? Stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you.

Intro 18:57
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.

Bill 19:26
Oh my God it’s horrendous. So a week after I got back from hospital, I was told my dad had acute myeloid leukemia and he was gonna die. So I just had a stroke, I’m recovering, I’m learning to walke, and learning to be independent.

Andy 19:46
And I thought my dad’s gonna die and all I could think about is when I’m gonna carry his coffin. I don’t know what happened but by May. I could walk I was lucky enough to carry his coffin but the day after his funeral, it was like my body and mindset, like enough is enough. And I went, I couldn’t walk again.

Andy 20:02
And I was back in hospital back in hydrotherapy back in physiotherapy, and I started 18 months of counseling, depression tablets, which I labeled as anxiety tablets, because I wouldn’t take depression tablets, I haven’t got depressed it was horrible. And that was the hardest two years of my life, the darkness you experience when I ride and in marathon is nothing compared to darkness in stroke. And nobody sees that because physically I look okay.

Bill 20:45
For sure stroke makes it possible for you to relate to people who, quote unquote, have mental health issues. The question though is, you were depressed? I know, the stroke had a role to play there.

The underlying cause of depression of Andy Dobinson

Bill 21:01
But what’s the underlying cause of the depression at the time? Have you been able to reflect on that? I know it happened, sort of during the process of stroke and all that kind of stuff. But it’s not the stroke that did it. There’s an underlying,

cause it's something else that's making you depressed. What was it? Do you feel that was creating emotions that you described as depression?

Andy 21:29
Yeah, I think there's an element of dealing with my dad's death, because I had a very complicated relationship with him really complicated, which I think fed the pre-stroke craving for (inaudible). But that's a whole different conversation.

Andy 21:45
But what probably fed it, was that in my mind, and I was weak, I wasn't good enough, I was disabled, I was brain damaged, I wasn't the guy, my wife had married. And I struggled with, confidence, and cognitive thought.

Andy 22:10
And I just thought that I'm a poorer version of what I was and it really locked me. And I didn't like, I didn't like who I was right now who I was, who I am. And now I can see the stroke the best thing that ever happened to me, but it's taken a long time to say that.

Bill 22:31
Interesting. Okay, so I say that, and I've interviewed many, many people that say that, and they're all in different various levels of recovery. They have different physical symptoms that have deficits, but they can say that.

Bill 22:54
How do you get to the point where you know that you didn't like who you were, or you didn't like parts of yourself? What happens where one day you go, I don't like that anymore about me, or who I was or how I behaved, what's the aha moment? How does that happen?

Bill 23:11
I don't think there's been like an epiphany or an aha moment, I think my counselor, Luise took the lid off the box and help me verbalize everything that I kept inside, everything needs to be in boxes for me mostly in boxes. Still has to be but I'm learning to leave those boxes open.

Andy 23:42
And if something falls out the box, I throw away but but she made me question what I used to do and what my wife's been through without my wife (inaudible)

but she questions, the whys, how, would you think, what about, and I'm still going through that process.

Andy 24:07
So you know, I'm not saying that look how I am and I'm fine. You never recover from the stroke, you adapt and you live with it. And you have reminders every day some tablets morning and night, I still got physical things I live with, I've got mental challenges, my thought process gets really mumbled at times but, what made me realize is that maybe the way that I've rewired myself and I've always had this visual picture that I need to feel right to get the wiring right in my head.

Andy 24:44
And I try to live by this place "Be kind to yourself". If I'm kind to me, I want to be kind to other people and I've developed a more thoughtful process where I could be really selfish before, quite short.

Andy 25:02
And it's really hard to explain because there hasn't been an aha moment, it's kind of a developing this more rounded pebble that used to be quite a jagged rock. And I'm just a bit more yeah I'll just kind of move on. But I'm still hugely anxious.

Bill 25:25
Let me explain how I feel about what you just said, because I relate to that. Being somebody that's growing up in Australia, and our culture is very similar to the culture in Glasgow. We blokes don't talk about problems, feelings, that type of thing. We take the weight of the world on our shoulders, and then we blame the world for it, like we're the ones being impacted by everybody else.

Bill 25:55
But it's not really everybody else. It's our own thoughts and processes. And then I realized after the stroke that what I wanted to do was, if I did die, I wanted to just make it so that my kids didn't think I was a complete idiot afterwards, and that, you know, dad was a good guy.

Bill 26:15
And he taught us a lot, and we respect him and all that kind of stuff. Because before the stroke, I didn't feel that, but I never contemplated that, because I never needed to, it never entered my mind that I might die at 37. But then afterwards, I contemplated that and the goal of having my kids look at their dad

in a positive light, in remembrance of their dad, not just because he was dead, but because he really was a good guy is what set in motion, all the other changes that needed to happen that I didn't know they needed to happen.

Bill 26:59
And it's like that bike ride that you do, or that run that you start, you know, where the goal is, you don't know, on the track, what are the obstacles are going to be? Yeah, if you have to think about all those obstacles, you're never going to solve those problems, because the obstacles are potentially endless.

Bill 27:18
But what you actually do get is you get problems that pop up that you were unaware of, and with the help of somebody like a counselor, psychologist, coach, whatever, they give you the permission to open the box. And when they open the box, and something comes out, you address it when it comes out.

Bill 27:42
And once it's addressed, you close the box, and then it's kind of done. It's been addressed. It might not be solved totally. But the fact that it was addressed, kind of enables for that hurdle to just be moved beyond and then working towards the next hurdle, which you're completely not expecting the next hurdle again.

Bill 28:06
But then it just pops up. Does that resonate with you? That's how I got to stroke's, the best thing that ever happened to me, it just happened one day. But when I look at all the things that I addressed, there was 10 specific key things that I addressed that other stroke survivors who say that also addressed, but they didn't set out to address them, they set out to be a better version of themselves in the future.

Bill 28:37
Yes. I can relate to that, because I think I am a beter version. It's a really difficult one, because I think I was a nice guy before my stroke. Otherwise, why would my wife had married me? But I just think I'm a much better version of myself, for example I've learned to open up and allow people in.

Andy 29:05
So pre-stroke it would be a case of No I'm find I'll deal with that, I don't need your help, where now, I've got no qualms about you know what I need some help.

And hat's how my counseling started, I broke broke down, and my wife said, we need to get your help.

Andy 29:22
And I rang the counselor up and I said, help me, I need help. I've never done that before in my life, ever. But now, I don't have a problem showing my emotions letting people know you have a fail, ask them for help, letting people in. And I think I'm a lot more considerate in my approach.

Andy 29:43
And yes, I have opinions where instead of giving them and saying this as the correct way I kind of offer just this is what I think. You know, do with it what you want, but this is what I think, and I've found now that people oftenly, not ask for my advice, but I've probably got quite a conservative approach because my attitude now is, if I can deal with the stroke, and survive a stroke and come out a positive human being.

Andy 30:23
I can deal with anything so if somebody comes to me with a problem always in the back of my mind going it isn't a stroke. So it's not as bad as a stroke. So I've got a kind of coping mechanism for lots and lots of stuff. So you have a system to go through. And, you know, my box and my visualization, and muddy, murky, water and all these systems in my mind. It's just made me a more and not sensible but level headed.

Fear of demonstrating failure

Bill 31:02
What were you afraid of in the past, when somebody offered you help? Or when people were trying to get in to your psyche? Or to your emotional side? What were you afraid of? Why was this such a barrier around letting people in?

Bill 31:20
Demonstrating failure, I didn't want anybody to know that I ever fail or I needed, it was quite a northeastern mindset. My dad asume where you're only a man, if you're strong and dependable, and you don't cry, you don't show your feelings, and you're not a failure. You know what? I do all that stuff now. And I'm fine with that. But I think the overriding thing was that I was petrified of anybody thinking

I was a failure.

Bill 31:57
And where did you get the definition of failure? You got it from your dad, who was afraid of anyone thinking that he was a failure. In fact, the opposite is true when you cry, when you express your emotions, when you apologize for acting like an idiot. When you can just experience raw emotions, for just a short amount of time.

Bill 32:21
You're actually the opposite of a failure, you're a winner. Because that's what life is supposed to be these ridiculous ideas of what winning, and losing, failing, and succeeding are, come from a stupid place.

Bill 32:43
Some people, well not some people with me, I would put myself under so much pressure to perform, whether that be at work, my bike, or anything, where in the grand scheme of things. There's far, far more important things and you know, what's important to me now is time with my wife, time doing things that I like and I love love for the right reasons.

Andy 33:12
And like I said before, I don't have to prove anything to anybody. Some people say that you've won ultramarathons now, will you still do it? No I don't. I do this stuff for the absolute passion and love that I have for it. I like putting stuff to me but I still can't get rid of the fact that I had a stroke prove that I can still challenge myself. But if I don't do it one day, and I'm gonna say, you know what, I'm not gonna finish this race this ride this run. It doesn't matter at all.

Bill 33:48
Yeah, I got to that point of being able to get to a stage where I know, my body's saying rest, relax, don't do this anymore. And that was something that I hadn't been able to do. In the past, I had to push through and I had to find a way. And I used to also do it begrudgingly, you know, those difficult things that I knew that I didn't want to do, but I was still doing, I still do begrudgingly.

Bill 34:21
And I used to find myself getting cranky at the world around me for you know, supposedly making me do these things that I didn't want to do. And what what I realized was that I was focusing on the problem all the time.

Bill 34:36
I was focusing on the problem, the amount of problems, how many problems there were the impossibility of solving the problems. I focused all my time on all that stuff. And then at some point, I had to focus on solutions because I had you know, day, the day before stroke, I had a million problems, the day after stroke, I had 20 million problems.

Bill 34:58
There was no hope in being able to put all my effort into focusing on solutions. And that is kind of what moved me through that whole pushing through barriers that I didn't want to push through. Because there was no enjoyment out of it. Forget about pushing through a barrier of an ultra marathon.

Bill 35:21
I know at the end for you, there's some kind of a pleasurable experience from it. But for me, I wasn't doing things that I loved. I was doing things that I hated for other people. And it was terrible. So where are you at with other parts of your life? Because at some point, I imagine you had to go back to work, you had to do all those things. How did that go? But before you answer that, let me just go and get a tissue for a sec.

Bill 36:31
Yes, so straight after my stroke, I was obviously off work. And my time was spent walking 30 seconds on a treadmill every day and Bosu balls and all that kind of stuff. But I went back to work far too quickly. Because I still had a bit of a pre-stroke mindset where I need to demonstrate I'm okay.

Andy 36:57
When I went back and graduated, then I worked in Vodafone at the time, who were hugely supportive they were really, really good. And I kind of changed roles. And I went back and I graduated the term, but I've never experienced higher (inaudble) the mental drain was huge.

Andy 37:16
But then in the May when my dad passed away, and I feel I just crumble beyond belief, it was off work for a month. And, that's when it hit me where I thought, I probably rushed the first part of my recovery. This time, I'm going to really get it right. But even now, I've got to be very, very conscious for tiredness. And I

manage my tiredness very, very cleverly, because I recognize it now.

Andy 37:45
And like you said, If I'm tired, I stop, I don't push through anything, I stop.

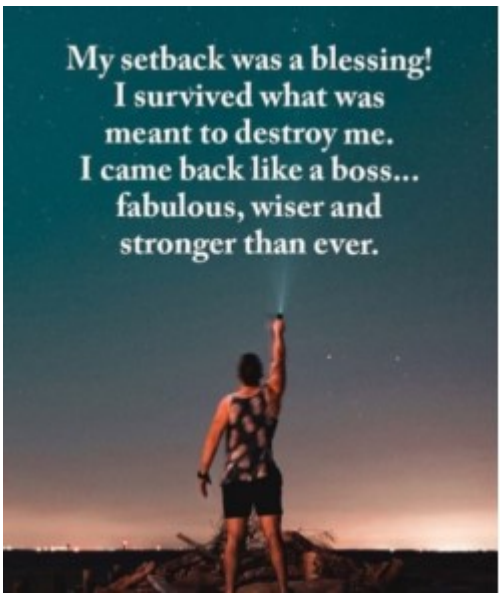
Andy 37:51
I still work in Telecom. So it's hugely demanding on laptops and projects and costings and all that kind of stuff. But I've learned now that I have to work in a different way. And if I don't finish something, that's fine. And if I do, great, that's a win. If I needed to take a rest my goodness, I will take a rest.

Andy 38:19
But the rest of my life is, as I want it now. You know, I don't do anything for the sake of doing it. I don't do anything because I feel I should. If I want to do it, I'll do it, if I don't I don't. And my life is hugely different now, because it's not this I must ride my bike, I must do this, I must prove x, y and z. And me and my wife are so much happier for it as well, but I've learned how to read the signs because a stroke survivor has signs all the time. And if you ignore them. If I ignore the signs I'm game over for a few days I'm done.

Bill 39:14
Yeah, I'm the same. You can create more suffering during stroke recovery by being as stupid as you were before the stroke. And the stroke causes enough pain and suffering and problems just on its own. You exacerbating that is not helpful in any way, shape or form.

Bill 39:42
And it's really important that you take responsibility for the part of the suffering that you're creating. And stop being a martyr and stop being somebody who needs to have the upper hand on stroke. You're not going to get it. It's not possible, stoke is going to win every single one of those battles. And I think you can work with stroke.

What a stroke can give



Bill 40:09
And I think that's one of the gifts that stroke gives is that it gives a lot of information about when it's time to stop. And when it's time to rest. Where before mind over matter, we push through the body's pains. We push through the biting signals and information that it's telling us and we just get to the point of feeling really crap for a certain amount of days.

Bill 40:35
And we haven't become aware of how we got to that point. But if we paid attention, there was plenty of information available, that concept that we're talking about is still bizarre that I'm speaking to you about it, because you still do push through pain barriers, and you still do things that most people don't do, even though if you decide to stop an ultra marathon race at mile 30 you've still run 30 bloody miles to get there.

Bill 41:08
Yeah, I know it's quite, it's quite an odd concept. And some people see they do what? I'll follow you around? But again, it kinda goes back to the mindset I've now got, I've got no agenda, no agenda whatsoever.

Bill 41:29
It's like Forrest Gump. Just start running.

Bill 41:32
Yeah, exactly. Do you know why it's really quite liberating. It's fantastic. Because you could put your stuff on an oil, and I just kind of roll with it. It's fun. It's great I've got from last, 1st, 7th, a million, doesn't really matter. But that's kind of how

I approach everything now.

Andy 41:55
Strokes, kind of give me this helicopter view. Because I'm still quite anxious. I'm hugely anxious, right. And I've got loads of these mental processes. And I can be quite obsessive, and useless in making decisions but I'm aware of all this. So, you know, if I obsess about something, it's like, I can remove myself and go I know I'm doing that.

Andy 42:20
But I'll be fine in a couple of days. So I allow myself to be obsessive about something. And that will just kind of fall away. I'm like oh, my God, I'm obsessing over something. I kind of go I'm watching myself being obsessive. But yeah it'll pass in a few days.

Bill 42:35
Nice. That's so good. Instead of obsessing, that you're obsessing. And making it more complicated, the obsession, one part of you says, I'm going to allow that obsession to occur. And when it goes away, it'll be gone. And that is how I describe to people who I'm helping with stroke recovery, in coaching to do about emotions, like, allow, you observe yourself to be an idiot, let yourself, be an idiot, and then apologize for being an idiot when the time comes.

Bill 43:06
And then that way, you're giving the other person permission in your life to also be an idiot. Because they are normal, and we're not special, just because we've had a stroke, they're normal, they're gonna have a bad day. And if you can do the same helicopter view for them, you're going okay, they're being an idiot, they're gonna get over it. And eventually, things will get back to normal. That's a really good approach.

Bill 43:27
I've always had a good guy and a bad guy, and pre-stroke, the bad guy ruled everything. So the bad guy comes knocking quite often. But now the good guy has a real voice, most of the time the good guy, I;ve got a real go with this guy. But I allow the good guy to communicate with the bad guy.

Andy 43:50
And this might sound like I've gotten mental. This is just a really good, I don't let

the bad guy rule me anymore. The good guy negotiate for the bad guy. And I listen to the good guy now but they're always there they're never going to go away.

The brain, the heart, and the gut.

Bill 44:08
Let me ask you, if you can identify in your body, which organ does the bad guy reside in?

Andy 44:19
Here. (Brain)

Bill 44:20
And which organ does the good guy reside in?

Andy 44:25
Heart.

Bill 44:26
So that is not a coincidence that I said that and that you pointed there the head is a neural network. It has billions of neurons. And it does thinking it does making meaning it does creativity, It does all that sort of stuff.

Bill 44:46
The heart is also a neural network. People don't realize that it has between 30,000 120,000 neurons. It has memory. That's why you hear that song and you remember a loved one from 10 years ago, or 20 or 30 years ago. And not only is the heart and neural network, that's where your emotions are.

Bill 45:09
That's where you touch when you say I love you to somebody that's on the other side of the planet, and you're doing a zoom call. But your gut is also a neural network, it has the same amount of neurons in it that the cat's brain has. So it's a full level of intelligence.

Bill 45:29
And when you ask people, if I ask you, where do you take action from? Where do you take action from?

Andy 45:39
Depends on who's talking to me.

Bill 45:42
But what makes you move forward? What makes you give you the push to go forward? Most people will point to the action center is that gut, I took gutsy action. And that's a neural network and dopamine. And a lot of the neurotransmitters that the brain uses actually are created in the gut, the immune system is supported in the gut.

Bill 46:09
And if we've got a healthy gut, we've got a healthy brain, because there's more ability for the brain to take those neurotransmitters from the gut and use them when they need them.

Bill 46:19
Dopamine, serotonin, all that sort of stuff, right? So it's very interesting that you have identified these good guy and bad guy kind of concept. And that's how you describe it, but they reside somewhere in your body. And it's really easy for you to point to them. So when you listen to your heart, your life expands.

Bill 46:40
When you listen to your head, you become anxious when you overthink. But your head, really Its job is to analyze things like my heart desires a bike ride your head's responsibility is how am I going to make that happen? And give me the creative solutions to the problems that my gut is telling me it's not difficult for me to overcome for me to do this, because the gut is telling you, I'm feeling like there's knots in my stomach.

Bill 47:15
I'm feeling uneasy in my stomach about making this decision, right? And the head's going, No, don't worry about that we've got solutions, we'll ride there'll be a guy at the 30 kilometer mark, or mile mark, who's gonna give us food he's going to do this he's going to do that.

Bill 47:30
If something bad goes wrong, you know, we'll be able to repair that fix that puncture, fix that chain. Whatever the problems that the gut comes up with to stop movement from happening, the head does the solution. So you make

business decisions at the head, and at the gut, but the head does the calculations.

Bill 47:52
If the numbers work. Then we move forward, if the guts happy, and we solve the guts problems, we move forward. But you don't make business decisions with the heart, you don't buy a company because I would love to buy that without looking at the numbers.

Andy 48:07
Yeah.

Bill 48:09
So this is resonating with you, right? And we're doing this every day. But sometimes they get the mix, they get the method incorrect. So they use their head to make heart based decisions. And they use the gut to make head based decisions. And they don't work.

Bill 48:26
And when you're using the head to make decisions of the heart and of the gut, you're over analyzing, and you're causing anxiety, and you're causing inability to move forward. So all of that, that I just said, is to ask you, what do you get anxious about? What does your head make you anxious about? And how do you do anxiety?

Bill 48:53
When I get anxious about decision making, that possibly affects other people. And I actually get anxious about general decision making, which stems back to confidence still growing It's not what it was, which is a different type of confidence I've got I'm hugely more confident in some areas than others.

Andy 49:23
I get quite obsessively anxious about things could go wrong. And I get OCD kind of anxious about things that just aren't right and not in the right place I'm anxious about that. It's quite trivial things that I get anxious about. And then that anxiety turns sort of obsessive OCD kind of, action.

Bill 49:55
It kind of does so. Do you give yourself the same Helicopter opportunity when you're anxious to view yourself being anxious and allow yourself to be anxious,

knowing that it'll pass. Do you do that?

Bill 50:10
I try to because I know that if I don't it will escalate, then it will stick. And it will break the processes I have in my mind. And I need to go through those processes to put things in place for me.

Andy 50:35
And it might not be a place for you or my wife or anyone else. But if it fits in that place in my mind, then, you know what that's okay, it might be the wrong place. But it can live there for a while. And I've learned to allow it to live there for a while. But yes, I do take that view, because if I don't, I don't know quite where I'll end up.

Bill 50:59
So I asked you specifically so that people listening can go, Ah, maybe I'm not taking the third person view, and I am stuck in the problem, rather than observing the problem. And if you're stuck in the problem, you're the problem, you're causing the problem, you're making the problem worse.

Bill 51:18
If you're observing yourself being stuck in the problem, you've separated yourself at one level, and you're giving yourself the opportunity to a observe yourself and be being the problem. And as you're observing yourself, you're able to pay attention to how stupid it is this problem that you're potentially creating unnecessarily, but from a good cause, perhaps, but realistically unnecessarily.

Bill 51:47
And then, as a curious person observing yourself being stuck in the problem, you can go, how is that serving me? And why am I even doing it? And can I find a way to alleviate the need to do it? Because all you've done is create neural patterns and pathways to support that. What are the opposite neural patterns and pathways that you can create, to replace that?

Andy 52:12
There's another thing that goes along side that Bill, for me it's so pre-stroke, I would focus on the end result. So whatever I'm doing whatever decision is the end result. And that's all I focus on.

Andy 52:27
I'm not able to deal with the gravity of that now, whatever it may be, could be a small journey, big journey, big desicion, whatever. There is an end result. But what I'll do now is to compliment the potential anxiety and the view I'm taking towards the first little step? Then okay win I've done that one, that leads to the second one, it will eventually get me to that big end result that is there but I'm not focusing on that.

Andy 52:57
Because you know what? I might not get there this time and if I don't, I've done A, B, C, D, E, and I might just manage F to do. Where before, if I don't get to Zed the world's gonna crumble. But if you tie in that step by step by step by step with okay, I'm aware of that. And I'm going to allow that to happen, oh my God that is so liberating it just kinda smoothes things out.

The mountain analogy

Bill 53:28
It's the mountain analogy that I like to use, it's like Everest is there. If we try to get to Everest and think about every possible thing that can go wrong to get to Everest, you might as well not even start, but if you set out on a walk, and when you get to Basecamp you've achieved all these things that you never knew you could achieve.

Bill 53:52
And now you're at Basecamp. And you reflect on all those new experiences, new solutions that you found new barriers that you push through all these things. If you focus on everything that is better and different about you for just getting to Basecamp then there's no point, getting to Everest is not necessary.

Bill 54:12
Because there's so many, so much gold and so much beauty in what you've already achieved. And now, if you think that Basecamp was really easily doable, take the lessons that you learn that helped you get to Basecamp and just use them on the next journey.

Bill 54:30
And allow you to get a little further beyond base camp and a little further up the

mountain. Always without the mountain, the peak being the must do. It's just wouldn't it be great if I could get there and reflect on all the lessons and the journey and all the amazing things in the path.

Bill 54:53
But you know what, as well, I've learned and it's taken me years to get where I am it's a huge journey is I've learned not to fight what it does for me, because you know what? You can't change a damn thing. I had a stroke, the facts are part of my brain has died and it's never coming back.

Andy 55:18
I can't change that. So did I accept that at the start? No, do I accept it now? Yes, and things are different. And the minute any one who suffered a stroke can start to may not fully accept that will accept all of that and said, You know what, there's no point of fighting it because I've wasted energy.

Andy 55:42
And this goes back to you just got to kind of roll with it because I can't do anything about it. That I can't, it's happened. So what's the best path to follow instead of this fight, fight, fight, I've had a stroke. That's just a waste of energy. It's a long time to get there.

Bill 56:03
It can, it can take a long time. And it can take a short amount of time, it just depends on who you are, and how willing you are to be flexible now. I'm building a course it's called 10 steps to brain health for stroke survivors. It's not really about brain health. But one of the modules that I've just done recently is mindset.

Bill 56:21
I've been planning this course, for four years, I cannot build 10 steps to a course, in 12 months or 18 months or six months, I just don't have the capacity to do it is going to take as long as it takes. And when it's ready. Even if it's in 10 years, it's going to be valuable because lessons two stroke recovery don't change. They're always the same lessons.

Bill 56:46
One of the modules is mindset. And with mindset, I really talk about, I try and talk about whose mindset are you? What do you have? Whose mindset are you running? Is it your parents? Is it your teachers? Is it your doctors? Is it your

brothers? Is it somebody else's mindset that has been combined over these years, and you've taken on as your own mindset?

Bill 57:13
And it's not serving you and you haven't become aware of that? Because you just haven't asked, no one's asked you the right question about like, whose life? Are you really leading? Are you running? Yeah. And for me, that was one of the big revelations in my life was I realized that I was running fears, anxieties, and all that kind of bullshit from other people. And they came from various parts of my life.

Bill 57:38
And now I recognize when I'm running those patterns from other people that they've instilled in me. And I stopped a lot sooner than I used to. And I have that awkward conversation with Well, that's just my dad's pattern. I don't need to run that anymore. He ran it because it was useful in the time that he grew up in to get him through a problem that he had.

Bill 58:01
And he didn't realize that he could stop doing that. He just continued doing that. I'm not going to continue doing that till I'm 80. There's no point there's no chance. And that's how I feel like people who are ultra marathon runners, and all this kind of stuff, even you, you're running somebody else's mindset to keep a part of it to keep you running to 60 miles, you're running somebody else's mindset.

Bill 58:28
And that could be the guy that did it before you. And that's okay, because that's part of a run that is part of a marathon that is part of an ultra marathon. But that is not part of stroke recovery. That mindset is the correct one for running an ultra marathon. It's got nothing to do with stroke recovery.

Bill 58:46
Because if you keep pushing, and you keep trying to get the 60 mile mark of a stroke, recovery, it's going to fail, it's not gonna succeed. The mindset needs to be flexible, and applied to each individual situation of your life. appropriately.

Andy 59:02
Yeah. I agree.

Bill 59:06
Tell me about when it happened. What was some of those conversations real serious ones that you had with your wife? Did you have them?

Bill 59:18
Yes, I did. And I was kind of wracked with guilt. Although the stroke wasn't my , well I thought, had I caused the stroke? It was a cryptogenic stroke. So we have no idea why happened. It was a massive clot at the back of my head and affected both sides of my body so the conversations we had were, will I ever be the same?

Andy 59:40
And can I walk again? Can we work as a team and you know, I remember thinking to myself, I'm not the guy she married will she went to split? Which she was mortified at, like, Oh, my God, no, whoever, whatever you are your still Andy, I love you, and I'm never going anywhere.

Andy 1:00:03
And that was like Oh my God thank God for that, I'm not going to be stuck in a home somewhere getting fed. But yeah, there were some pretty harsh conversations. And when you're in the depths of anxiety and depression, you can be a really nasty person to be around unconsciously.

Andy 1:00:30
Because, you know, going on that depression tablets are great, nobody tells you coming off them is the worst thing you'll ever do in your life. Apart from having a stroke. I was a horrendous person, because it took me about five, six weeks to come off them from that period of time.

Andy 1:00:47
At the time, I was horrible, just horrible. And nobody tells you that part. And that was some really brutal conversations about that period of time the person I've become. And when it happened, yeah, there's some quite a life changing conversations you have because you know, there's an element of you feeling sorry for yourself.

Andy 1:01:18
How am I the husband that she had. (inaudible) I'm here struggling to verbalize it. Because it's just so horrible. I sometimes struggle to get the words out that was just horrible.

You’re not alone

Bill 1:01:47
I really appreciate the way that we’ve had this conversation because you verbalize some things that I can’t verbalize. And the reason why I have podcasts is to give people the opportunity to say all those things about stroke that I want to, but I don’t know how to.

Bill 1:02:08
And I find that every person that I interviewed, there’s gold comes out of their mouth, every single episode, this is going to be Episode 130. So if you ever thought you were alone in stroke recovery, if you ever thought that you’re the only one experienced something, just pick up one of those episodes, and listen to it, you’re not going to feel alone anymore, you know, you’re not going to feel weird, strange, different.

Bill 1:02:34
And hopefully what that does is that creates an opportunity for people to question everything they’ve ever done or ever been, and in ever thought so that they can start from scratch, and redefine their life and redefine who they are and how they can go about their life, even after they are completely their identities completely tested, change the whatever you want to call it.

Bill 1:03:05
And they can’t recognize themselves again, like it’s an opportunity for rebirth. And I say, I say that, from my perspective, and you as a stroke survivor might not be there yet. But one day, I hope that stroke survivors get there, I know that you’re well on your way of redefining who you are, and and completing the rebirth. And that makes me really excited. That makes me really happy to have this conversation with you. Because I think it offers hope for other people.

Bill 1:03:40
And you know what Bill, that puts a huge smile on my face. Because you know, I feel hugely privileged to have been able to chat to you and, tell a story. And you know, if one person was gonna listen to this podcast, and it helped one person, that’s a huge tick in the box for me.

Andy 1:04:01

Because nobody can write down on paper, the challenge of a stroke, you can't define that place. And if it helps one person even find a glimmer of hope or get on a slightly different path, you know what? That would make me so happy. And any help that's offered to anyone that's going through this is absolute gorgeous.

Bill 1:04:31
That's a beautiful way to end the podcast. Andy, thank you so much for being on the podcast. I really enjoyed our chat.

Andy 1:04:38
Thank you very much Bill.

Intro 1:04:43
Discover how to heal your brain after stroke, go to recoveryafterstroke.com

Intro 1:04:53
Importantly, we present many podcasts designed to give you an insight and understanding into the experiences of other animals. visuals, opinions and treatment 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.

Intro 1:05:10
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.

Intro 1:05:23
The content is intended to complement your medical treatment and support healing. It is not intended to be a substitute for professional medical advice and should not be relied on as health advice. The information is general and may not be suitable for your personal injuries, circumstances or health objectives.

Intro 1:05:38
Do not use our content as a standalone resource to diagnose treat, cure or prevent any disease for therapeutic purposes or as a substitute for the advice of a health professional. Never delay seeking advice or disregard the advice of a medical professional, your doctor or your rehabilitation program based on our content.

Intro 1:05:55
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 think you might be? Call 000 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 1:06:14
While we aim to provide current quality information and our content we did not provide any guarantees and assume no legal liability or responsibility for the accuracy, currency or completeness of the content. If you choose to rely on any information within our content, you do so solely at your own risk. We are careful with links we provide however third party links from our website I follow that your own risk and we are not responsible for any information you find there.