

Living with Invisible Stroke Deficits: The Challenges No One Sees

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Living with Invisible Stroke Deficits: For many stroke survivors, the hardest battles aren't the ones that people can see. They're the invisible struggles—fatigue that knocks you down before the day even starts, sensations that are impossible to explain, and the mental weight of feeling misunderstood.

Recently, I shared a video where I opened up about these challenges in a way I hadn't before. I simply walked, talked, and shared my unfiltered experience of life after stroke. To be honest, I wasn't sure how it would be received. But the overwhelming response—messages from fellow survivors saying, “*Yes, that's exactly how I feel!*”—has been both humbling and deeply moving.

Why Invisible Deficits Matter

When people see me walking “normally” or hear me speak without hesitation, they assume I'm fully recovered. And while I *have* come a long way in my recovery since my first stroke in 2012, the truth is that I live with persistent neurological deficits every single day.

Some of the things I deal with include:

- **Fatigue that isn't just tiredness**—It's an all-encompassing exhaustion that makes even simple tasks feel impossible.
- **Strange, unexplainable sensations**—I can feel each step I take in the back of my head. My left side always feels different from my right, like I've already run a marathon on one side while the other is fresh.
- **Spasticity and muscle tightness**—It's constant, and it affects everything from walking to simply holding onto objects.

□ **Light sensitivity**—Cloudy days are worse than sunny ones, and sunglasses aren't just a fashion choice; they're a necessity.

□ **Misunderstanding from others**—Most people think I've made a "full recovery" because my deficits aren't obvious. But inside, I know I'm still adapting every day.

The Emotional Side of Recovery

One of the biggest struggles with living with invisible stroke deficits is the feeling of not being understood. How do you explain to someone that you're exhausted but haven't "done" anything? Or that you need to stop walking because your brain is tired, not your legs?

It's something I've learned to navigate over the years. Sometimes, I give the easy answer: "*I'm doing well.*" Other times, if the person is willing to listen, I share more. And when I really need to be heard, I turn to counseling or the stroke survivor community—because we *get* each other in a way that no one else can.

Shifting My Perspective on Recovery

Early on, I thought recovery meant going back to the way things were before my stroke. I believed that if I worked hard enough, I could erase all traces of what happened.

Now, I see recovery differently.

I'm **fully healed, but with scars**. My brain has adapted, my body has adjusted, and I've found ways to keep moving forward. But I will always carry the impact of my stroke with me. And that's okay.

What's Next?

After seeing the response to my video, I realize how important it is to continue these conversations. Many survivors feel isolated in their struggles, believing they are alone in their experiences. I want to change that.

I'll be creating more content that sheds light on these invisible aspects of stroke recovery—so that no one feels like they have to navigate this journey alone.

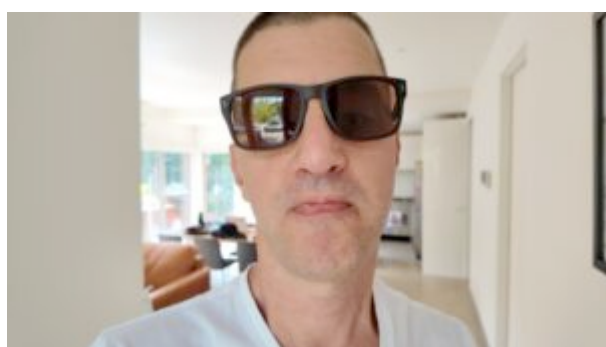
If you're a stroke survivor (or know someone who is), I'd love to hear from you.

What are some of the **invisible challenges** you've faced in your recovery? Let's start a conversation.

Want more insights?

Listen to the Recovery After Stroke Podcast - New episodes every Monday.

Check out my book, *The Unexpected Way That a Stroke Became the Best Thing That Happened*, for a deeper dive into stroke recovery and post-traumatic growth.



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Transcript:

Bill Gasiamis 0:00

I realize that I do a lot of talking about stroke recovery on the podcast with people, and I share a little bit of my story there. It's where people hear what I've got to say, but it's always broken up in a way where they don't get the full picture. And that's not a bad thing in the podcast, because the podcast is about the other person. But I wanted to share a little bit about my journey with stroke recovery.

Bill Gasiamis 0:30

Let me just put the alarm on as I head out, because the people that I come across often assume that my stroke condition is not that bad, and sometimes it's an issue that they think that perhaps they should be at My stage of their stroke recovery, and they should be there really quickly.

Bill Gasiamis 1:04

But I've been on this journey since 2012 and when I'm recording this, it's just

past the 13-year mark in 2025 so today has been an interesting day, and I'm at home, and I'm doing the kind of work that somebody might do in an office. So I've taken a step back from my property maintenance business.

Bill Gasiamis 1:38

Instead of being on the tools I've I've taken an administrative role where I try to ensure that the guys that work with me have an ample amount of work to keep them busy full time. One of them is my son. The other one is my business partner.

Bill Gasiamis 1:58

We're a proper small business you know, we don't turn over multiple millions of dollars a year. We turn over enough money to keep everyone employed and earning a decent living. So my job is to be at home and be productive. And today, I'm feeling really guilty because I haven't been productive at all, haven't managed to get any work done, because I woke up feeling fatigued, like I can't concentrate.

Bill Gasiamis 2:29

And no matter how much time I spend in front of the computer trying to get the work done, what's happening is I'm falling asleep in front of the computer, and my brain is hurting me. You know that hurt that stroke survivors describe, which is not real pain, but it's kind of like a strange pain, and it hurts because I can't describe it any other way. I don't know how to describe it.

Bill Gasiamis 3:00

It's a feeling of overwhelm. It's a feeling that sort of starts in the back of the eyes and takes over the entire head. And I don't know, I don't know what the point of it is, other than to tell me that I shouldn't be doing that work, but that's what I'm employed to do. That's what I'm supposed to do, not rest, and after 13 years I'm not earning a decent income, I want to be in a position where I can catch up a little bit on the income that I haven't received while I've been unwell, recovering from three brain injuries and brain surgery and then learning how to walk again.

Bill Gasiamis 3:44

So it's an interesting thing to experience, and I haven't really been able to get my head around it, and I haven't been able to work out what to do so that I don't feel bad when I'm finding fatigue, I know what I should do, like I tell people that on the podcast, I encourage people all the time to not be hard on themselves, etc. But look, it also happens to me, and I can't always be positive.

Bill Gasiamis 4:13

I maybe can be on the podcast to an extent, because we're trying to motivate people and encourage people, but it's not possible for me to always be in a positive mindset. It's quite sunny out here today, so I hope you don't mind me wearing my sunglasses. The Sun is Also something that overwhelms my brain and can create neurological problems, so sunglasses are very important. I found that sunglasses are really important even on cloudy days.

Bill Gasiamis 4:49

In fact, they're more important on cloudy days because somehow the way the light reflects through the clouds really fits. Eggs my brain. So instead of sitting in front of the computer and getting nothing done, I thought I'd be productive and go for a walk and take you guys with me and just share a few things that I've been experiencing.

Bill Gasiamis 5:18

One of the challenges I face is that people assume that I'm fully recovered because I don't look like someone who had a stroke, and typically I walk, quote, unquote, like a normal person. And while that's definitely a good thing, and I'm grateful for that, it's really hard to describe to people what I'm going through.

Bill Gasiamis 5:40

It's really hard to tell them what it feels like to be me, and not that I need people to know, to feel sorry for me or anything like that, but I definitely need to tell them when I'm not up to doing something, or I'm not in a position to participate in an activity or a sport, in something as enthusiastically as they would want to participate in it.

Bill Gasiamis 6:15

Now I'm walking now, and every step, every step I take, I can feel my left leg on the ground, barely through the shoes, but it refers all the way like it's so tight on that left side because of spasticity and because of the way that the muscles these days, it's so tight that I can feel the walking in the back of my head like just in this space here in the back of my head.

Bill Gasiamis 6:53

And it's really bizarre because I don't know what to do about that, other than to just experience it. And then how do you explain that to somebody when you're

walking? When you're walking? I can feel each step in the back of my head when I'm walking, that creates more fatigue, requires more energy, and that makes walking harder.

Bill Gasiamis 7:15

Because I never noticed that on my other side. I never noticed that before the stroke. I notice it now, and it's a really weird thing to notice. And then my left side feels like it's already done 20 laps of this block that I'm going to walk, but my right side doesn't feel like it's even started. And there's always that imbalance that I experience the imbalance between how my left side feels and how my right side feels, and am always trying to get my head around it, and sometimes I have to tell my left side I don't believe you.

Bill Gasiamis 7:53

You are not tired. You are just you just think you tired. You're fake tired because the right side is not tired because we haven't done enough to be tired. So you are not tired, so you have to keep going. Even if it hurts, you have to keep going. And that tends to work for me.

Bill Gasiamis 8:17

The recovery afterward isn't too bad, but it doesn't make things like walking that enjoyable, and I look for excuses to stop doing it, especially on warm days, where the weather makes it a little bit harder under normal conditions, for "normal" people to walk. So it's really interesting.

Bill Gasiamis 8:46

One of the other challenges that I have is that when people don't get you, they don't understand how you feel after a stroke. The only way they'll ever understand how you feel is if they go through something similar, and let's face it, that's not what we want people to do. We don't want them to feel what we feel.

Bill Gasiamis 9:12

I mean, you wouldn't wish a stroke on your worst enemy. Why would you want people to feel how you feel so that just they can understand you if you've it's a problem when you've felt you've been misunderstood in the past, when you thought that people don't understand you like it's one of those things that we all go through from time to time, I feel misunderstood, or people don't understand me, or I can't explain to people what's going on in my mind.

Bill Gasiamis 9:39

And then, if you felt like that under normal conditions, it's pretty common for you to feel that way after a stroke. Not only were you misunderstood before, but now, you have even less, way, even less chance of explaining to people how you feel, and it's a bit of a problem for you.

Bill Gasiamis 10:02

So I find myself dealing with it in a couple of different ways. Sometimes I won't engage in a conversation with somebody who asks me about how I feel, or who assumes that I'm great because I look okay. I just don't go into the conversation too deeply. And I answer questions generally, I'll say things like, if they ask me how I am, I'll say things like, I'm okay, and if they ask me how you're going after the stroke, I always say, I'm okay and I'm doing really well, and I've recovered really well.

Bill Gasiamis 10:34

But I don't go into too much detail, because that's really what they want to hear. They don't really want to hear anything else. They just want to hear that I'm okay and that I'm doing well, and that kind of allays the concerns that they have about me, and I don't want people to be concerned about me.

Bill Gasiamis 10:53

Everyone goes through something difficult in their life, so I'm no different, I don't think you can get through life without going through difficult things you would nobody comes out of life unscathed. So I think it's okay for me to just tell people that I'm okay and leave it at that. Now other times, if it's the right person, I go into a bit of detail.

Bill Gasiamis 11:16

We might have a little bit of a heart-to-heart or a deep and meaningful and that's good because that's also necessary having a heart-to-heart and a deep and meaningful from time to time. And I love doing that with the right people. And when you do that, it's a good release. But I've got to pick the people that I do that with because some are not equipped to have deep and meaningful and Heart to Heart conversations.

Bill Gasiamis 11:45

So I try not to burden people, the wrong people, with too much information, and

that seems to be fair to them and fair to me because it takes a lot of energy for me to explain what I go through, and if it's landing on deaf ears, well, there's no point in that.

Bill Gasiamis 12:04

There's no point taking people through that type of a conversation when they're not really interested, or when they're afraid to be interested, or it makes them question their own mortality, or their own health, or ill health, or all sorts of things. So sometimes that's the approach I take, and other times I just seek out counseling.

Bill Gasiamis 12:28

I go to people who are paid to sit there with me for an hour to listen to what I got to say, without judgment, without advice, without opinions, and just to let me vent and get it off my chest. So I find that to be really helpful also, but that's not something I do all the time. I used to go to counseling once a month, and I found myself doing that less and less these days.

Bill Gasiamis 13:03

And that's not a good thing or a bad thing. It's just the need has decreased, so I go less often. If the need increases, I'll go more and I'll do more counseling, and that's okay. I had a massive wake-up call, a couple of well, almost nine months ago now, because of my deficits on my left side and the numbness and the tingling and the way that the left side feels and the way that it fatigues, I was at work and I climbed on the ladder because we installed the scaffold at this particular job we were doing to make sure that the job was safe so nobody had any falls off the ladder.

Bill Gasiamis 13:47

I was climbing the ladder to the first level of the scaffold to do a little job at the end of the day. And I was really tired and fatigued. And I was holding a paintbrush and a paint bucket with one hand, which is something I always do, and I was climbing up with the other hand, and it wasn't far to go. It was only three or four rungs, and I was going to place the paintbrush and the bucket on the landing and continue climbing up the rest of the way.

Bill Gasiamis 14:16

And then what happened was, as I was doing that I was getting a little bit higher

to just sneak above the landing and place my brush down my left hand and let go of the ladder without me realizing, and I'm kind of smiling and laughing about it now. Was no laughing matter, let me tell you.

Bill Gasiamis 14:37

What happened was I ended up falling backward onto a metal bar of the scaffold, and I hurt my back. I really hit my back hard, and then from the middle bar that I hit, I had about another three feet or a meter to go further down to the ground and land flat on my back on the deck. And. So I hit my back about a meter off the ground, and then I hit it again on the ground, and let me tell you, it wasn't pleasant, and I was bruised and battered, and I didn't know how I got down there, and I was a bit winded, and it took more than three weeks to recover.

Bill Gasiamis 15:19

Thankfully, I didn't break anything, but it was a big wake-up call, because my left hand decided to let go, and I had no say in the matter. And that's one side of my deficits that people don't see. I also dropped a lot of things on my left side because of the same reason. So it was very interesting to experience that and get away with it. Wow, it was really good to get away with it. I mean, a lot of people don't get away with that.

Bill Gasiamis 15:53

I know people who have injured themselves far worse falling from smaller heights off of ladders than I did. So I am very grateful, you know? This brings me to the point of my definition of my recovery, you know what? When I say I've recovered to people now, what does that mean? I've changed my definition initially. I thought the recovery should be something that happens fully.

Bill Gasiamis 16:23

I go back to who I was before the stroke. Now, not the ill-informed version of me before the stroke, not the guy who smoked and drank and did all of that, but you know, before my deficits existed and before the blood vessel burst where I was oblivious of what it was like to need to know how to walk, to pay attention to every step, to feel the step that I'm taking in the back of my head, you know, to feel the wind on a cold day hurting my skin, and to feel annoyed when my wife touches my left hand because she's being nice, and all I can feel is burning and irritation.

Bill Gasiamis 17:09

I thought that that's what I was going to do. I thought I was going to go back to normal, and then you hear about this new normal that you have to accept, and that's kind of where I am at. I've accepted this new normal where I am fully healthy because the blood vessels in my brain don't exist anymore, the one that bled will not bleed again, and the risk of me having another stroke has dropped dramatically.

Bill Gasiamis 17:38

So that's a good thing, which means I'm healthy, I'm fully out of the woods with that part of the situation, but I am still living with these deficits. And these deficits are just part of everyday life, and they don't go away. And when I wake up in the morning, they're always there, even though I might forget that they're always there.

Bill Gasiamis 18:05

They are always there. Let me just show you this on my walk. Look at this amazing orange door. Well, that's beautiful. This is my neighborhood, so I think that's one new definition of recovered. Fully recovered is My body feels like this. It's always going to feel like this. It's never going to change. Some days it feels worse, other days it feels better. And when it's feeling worse, I need to attend to it, I need to rest, I need to get more sleep, I need to do fewer activities.

Bill Gasiamis 18:45

And perhaps I need to go and get a massage and make sure that the muscles are released and that I do some self-care. So, yeah, I'm fully healed, but with scars, that's it. That's the best way to describe it, fully healed with scars. And it's no different to somebody being fully capable of living a regular life with a knee injury or an elbow injury or missing a limb, or whatever their injury is that they've had to live with their entire life.

Bill Gasiamis 19:30

So, yeah, I'm fully healed. People always ask me for advice. I get a lot of requests for advice. What do I do now, any tips for this and any tips for that? And it's like my stroke is so different to yours, and I'm such a different person than you that making those types of comments are probably not helpful, although I understand why people asks.

Bill Gasiamis 20:00

They want some guidance, and they want to decrease the amount of time that it takes for them to go through their recovery. So I do have some tips to offer people, and that's be curious about what you need to do next to improve your recovery. Always learn, never stop learning. Spend as much time as you possibly can learning about what you need, specifically for your body and your stroke and your brain and your injury to recover and get better, because you're the person who has to be responsible for that recovery.

Bill Gasiamis 20:46

You're the person who has to be in charge of it, even though it's hard, and even though you're dealing with an injured brain, and even though you don't have all the resources you need to find ways to deal with your own version of your injury and your own version of your recovery.

Bill Gasiamis 21:14

Be kind to yourself, and I suppose that's a reminder for me as well, is to be kind to myself, and when computer productivity is not possible, come out and be productive in another way, because it's a real, big desire of mine to be productive, and this is helping me overcome that issue that I've had about, what about my productivity or lack thereof on certain days when the fatigue is against me and when stroke is doing what it does, rather than me doing what I do, rather than me taking charge of my particular day or my life when stroke takes charge.

Bill Gasiamis 22:07

Find a way to do a work around. Find a way to achieve your goals in a slightly different way. Anyway, I hope you found this little walking vlog insightful and thanks for listening. If you like this type of content, subscribe, leave a comment below, and if you are interested in episodes from stroke survivors sharing their journey on the recovery after stroke podcast.

Bill Gasiamis 22:43

New episode comes out every Monday, and there are interviews with people who have had a stroke and want to share their story in the hopes that they will help somebody. But they also find the interviews that we do cathartic, just like I do, they really help.