

From Locked-In to Lit Up: Harshada's Story of Reclaiming Her Voice, Body, and Future

Locked-in Syndrome and Recovery: Reclaiming Voice, Identity, and Life After Stroke

What happens when your mind is fully awake, but your body no longer responds? For stroke survivors living with or recovering from *locked-in syndrome*, that question is not hypothetical. It's their daily reality, one that challenges not just the body, but the spirit.

But recovery, though complex and deeply personal, is possible. And today, we're sharing a glimpse into one such journey, that of Harshada Rajani, to illuminate what's *really* possible when the odds are high and hope seems out of reach.

What Is Locked-in Syndrome?

Locked-in syndrome is a rare neurological condition most often caused by a stroke in the **brainstem**, typically the **pons**. It results in **complete paralysis of all voluntary muscles** except for those that control eye movement. A person with locked-in syndrome is **fully conscious and aware** but unable to speak or move.

Communication is limited, often to eye blinks or coded systems, and the initial prognosis can seem grim. But this diagnosis does *not* mean the end of growth, joy, or even functional recovery.

Harshada's Story: A Glimpse Into Locked-in Syndrome and What Comes After

At just 23 years old, Harshada was a second-year medical student, sharp, driven, and deeply passionate about pediatric oncology. When an unexpected stroke left

her trapped in her own body, her life changed instantly. She couldn't speak, move, or even blink.

But she was still very much there.

And so began her journey through **locked-in syndrome and recovery**, one built on persistence, support, and an unshakable will to be seen as more than a diagnosis.

A Slow Awakening and the Power of Small Wins

Recovery didn't come all at once. Harshada's journey started with *passive limb movement, electrical stimulation*, and what felt like endless waiting. But then, months later, a twitch. Then a flicker. Then the movement.

Over time, speech returned. Slowly. Word by word. Syllable by syllable. Even today, her voice is a product of hard-won effort, a symbol of how far she's come.

(Note: In our podcast episode, we slightly sped up Harshada's voice to better match the pacing of the conversation. This gentle adjustment allows for a smoother listening experience without compromising the clarity or emotion of her story.)

Writing Her Way Back to the World

With speech still difficult, **writing became Harshada's lifeline**, not just as a communication tool, but as a means of reclaiming identity. Through personal essays, memoir work, and disability advocacy, she began speaking louder than ever.

One of her viral pieces, "*I'm Entering My Hot Girl Era*", captured attention not just for its bold title but for its deeper message: that disabled individuals deserve to be seen as full, expressive human beings with style, sexuality, and agency.

What Stroke Survivors Can Learn from Harshada's Recovery

Whether you're newly diagnosed or years into recovery, Harshada's journey offers powerful lessons:

1. Progress Can Be Invisible Before It's Transformative

In the early stages, recovery might feel like *nothing is happening*. But internally, your nervous system is adapting. Small movements today may be the foundation for major milestones later.

2. Support Matters, But So Does Self-Expression

Harshada's family and caregivers were essential to her progress. But her growth accelerated when she began expressing herself, first through writing, then through advocacy. Don't underestimate the power of your story.

3. Hope is a Strategy, Not a Cliché

Even when doctors offered no clear path forward, Harshada chose to believe that *something* could get better. That hope, backed by consistent effort, created space for change.

4. Identity Isn't Lost, It Evolves

Recovery doesn't mean returning to who you *were*. It means discovering who you *can become*. Harshada didn't get her old life back, but she found something new, powerful, and deeply authentic.

What You Can Do If You're Facing Locked-in Syndrome or Severe Stroke Deficits

Start with presence. You're still here. That matters.

Focus on what's next, not what's missing. Even the smallest action, like attempting to move a finger or blink with intention, is a beginning.

Use every tool available. Physical therapy, speech therapy, writing, adaptive devices, meditation, explore what resonates.

Find your community. Stroke can be isolating, but you are *not* alone. Podcasts, support groups, and survivor stories can connect you to people who truly get it.

You Are More Than Your Deficits

Locked-in syndrome is devastating, but not defining.

As Harshada proves, recovery isn't linear. It's layered. Emotional. Messy. But it's

also filled with potential, beauty, and rebirth.

If you're walking this path, or wheeling, or blinking your way through it, know this:

Your mind still works.

Your breath still flows.

Your story is still unfolding.

And as long as you're here, recovery is still possible.

Locked-In But Not Lost: A Stroke Survivor's Journey Back to Herself

Trapped inside her body but fully awake, Harshada rebuilt her life word by word. This is her journey of hope, healing, and powerful transformation.

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Transcript:

Hashada's Background and Stroke Incident



Bill Gasiamis 0:00

Harshada Rajani was a high-achieving med student on a clear path until everything changed. What followed challenged her identity, her voice and her sense of control, and what she's done since is nothing short of extraordinary. Now, before we dive in, you might notice something a little different about this episode. Harshada's voice has been gently sped up by about 30% she speaks clearly and beautifully, but due to her experience with stroke and the journey her voice has taken to recover, her natural speaking pace is a little slower than mine.

Bill Gasiamis 0:40

I made this adjustment to create a more balanced and easier listening experience, one where our conversation flows at a similar rhythm, without losing any of her tone, insight or presence. If you're a stroke survivor feeling stuck, dismissed or unsure how to move forward, this episode is for you. I'm Bill Gasiamis. I've lived through stroke, I've faced the silence, the fear and the unknown, and I created this podcast to offer the support that I hoped I had back then.

Bill Gasiamis 1:10

Harshada's story is a powerful reminder that recovery isn't about going back, it's about becoming and if today's conversation resonates, I'd love for you to check out my book, *The Unexpected Way That A Stroke Became The Best Thing That Happened*. You'll find it at recoveryafterstroke.com/book. Harshada Rajani, welcome to the podcast.

Harshada Rajani 1:34

Thank you.

Bill Gasiamis 1:37

Did I say that well, or did I butcher it?

Harshada Rajani 1:40

No, it was pretty good.

Bill Gasiamis 1:42

Hey, tell me a little bit about what life was like before the stroke.

Harshada Rajani 1:48

So before my stroke, I was a typical young South Asian American Girl, really close family, lots of friends, lots of fun, but obviously, as with most immigrant families, academics was our number one priority. So I was in med school and took before my stroke, and I wanted to be a pediatric oncologist, and I was dating another South Asian Doctor that was kind of picture perfect way.

Bill Gasiamis 2:48

And what happened with regards to the stroke? What did you notice leading up to the day of the stroke? Anything that gave you any signs that something was wrong.

Harshada Rajani 3:04

So nothing really. I had just gotten new glasses, and whenever I wore them, I would get a headache, and sometimes I would feel sensitive to light, and I went to my student doctor on campus, Student Health about them, and they said they were hemiplegic migraines.

Bill Gasiamis 3:41

Were you at campus on the day of the stroke?

Stroke Symptoms and Diagnosis

Harshada Rajani 3:45

So luckily, it was Thanksgiving weekend, so I'd come home, but I wake up and I was actually getting a second opinion on my migraines. And then suddenly, as the world started shifting and moving in front of me, I had vertigo for the first time, and then my parents took me to urgent care to get the shot, while the nausea that the verdict was calling and I passed out.

Bill Gasiamis 4:40

So the stroke was caused by a vertebral artery dissection. Yes, do you have any idea, any recollection when or how that occurred? Was there any obvious signs?

Harshada Rajani 4:59

It doesn't it was spontaneous, which is good and bad, because there's nothing I can point to and blame. Keep so it's kind of freeing.

Bill Gasiamis 5:28

So the randomness of it is a bit of a blessing.

Harshada Rajani 5:32

I think so.

Bill Gasiamis 5:34

That's interesting, because the blade that happened in my head, the artery, well, not the artery, the blood vessel that burst and started to leak. I kind of saw there as a random event as well. I didn't know that it was there. I didn't know it was happening. I lived with it for 37 years, and then it just happened. And I kind of felt like the randomness was okay, like again, it was something that perhaps my lifestyle wasn't the best.

Bill Gasiamis 6:07

It may not have made my situation better, but I didn't actually have something that I ignored. I didn't have something that I should have done something about. Nobody knew. So it just happened, and it was one of those events.

Harshada Rajani 6:24

Exactly, the burden is taken off your shoulders a little, yeah, and I've thought about this a lot, because in our culture, where good things happen to good people, bad things happen to bad people. So disability is always seen as some kind of moral punishment for something done in this way, or the past life, so trying to unlearn that and taking control of the fact that it was just random.

Bill Gasiamis 7:16

Yeah, I like that idea of unlearning that specific cultural piece of stuff that people cling to or make, make, make part of the conversation, which then turns stroke into something that is taboo.

Harshada Rajani 7:38

Yeah, definitely.

Cultural and Philosophical Perspectives

Bill Gasiamis 7:42

How old were you?

Harshada Rajani 7:45

I was 23 so I was in my second year of medical school.

Bill Gasiamis 7:52

What nationality back? What background is it? What nationality?

Harshada Rajani 7:59

I'm Indian and Hindu.

Bill Gasiamis 8:03

Indian and Hindu. Okay, so that karma conversation comes into it?

Harshada Rajani 8:10

All the time. I guess people always are trying to find answers and explanations for why bad things happen, and I guess it's whatever gives you hope, whatever makes sense to you. Have you read any of the philosopher?

Bill Gasiamis 8:41

No, heaven.

Harshada Rajani 8:43

Well, it talks about oppression, just it talks about how there's no meaning to us a brain, no meaning that whatever happened in our lives. But as humans, we crave rationality and we crave an explanation, and that distance between wanting an answer and there not being an answer, he calls that the upside.

Bill Gasiamis 9:25

It's so true. I mean the meaning is the only. The only meaning is the one that we apply to it. My meaning can be totally different from the next person and the next person, and they are both. They are all constructs. We've constructed the meaning of that event, and somehow, I'm not sure how it serves us, hopefully or it doesn't serve us.

Bill Gasiamis 9:47

And we were and we become aware of that, I think if we become aware of meaning that we apply to something that doesn't serve us, I think that that's probably where you want to get to.

Harshada Rajani 10:00

Yeah, but everyone has their own time to reach that point.

Bill Gasiamis 10:07

Yeah, the correct that's the journey, isn't it? Everyone needs to go on the journey to understand and discover. Hey, it's Bill here. I just wanted to pause for a moment, if you're thinking, if you've been listening and thinking, this is the kind of support I wish I had more of, you're not alone. Recovery can feel isolated. Recovery can feel isolating. Many of us know what it's like to leave the hospital and suddenly feel like we're on our own, no roadmap, no guidance, just trying to figure it out day by day. That's exactly why I created the Recovery After Stroke Podcast.

Bill Gasiamis 10:50

When you support the show on Patreon, you're helping ensure that no one has to go through this alone, not now and not in the future. Your support helps keep these stories alive for every stroke survivor currently in recovery, and for all of those who and for all of those who will come after us. I'm on a mission to reach 1000 episodes and beyond, because every conversation brings light, clarity and connection to someone who needs it. Visit patreon.com/recoveryafterstroke and consider supporting the show today.

Bill Gasiamis 11:30

What a journey from being completely locked in to becoming a powerful voice for disability advocacy. Harshada shows us what's possible, not just physically, but emotionally, spiritually and creatively. Her story is a reminder that your worth is never measured by your deficits, and that healing is not always about getting back to who you were, but about discovering who you can become. If you're listening to this today and you're still in the thick of it, early days, facing setbacks or just plain exhausted, let this be your proof that growth is still on the table.

Bill Gasiamis 12:11

Here's what I'd love you to here's what I'd love for you to do. Reflect on Harshada's courage. Try something new, even if it's small, reach out to a friend, to this community, or to yourself. Thank you for listening, your reviews, your comments, your support. It keeps this show going, and to those who bought the book or join me on Patreon. Thank you so much. You're part of something bigger than just a podcast. You're helping stroke survivors everywhere. Find their way forward, stay connected, stay curious, and remember you're still here and you're still growing.

Bill Gasiamis 12:49

And that the story and the story is not over. I'll catch you in the next episode, if you've been listening and thinking, this is the kind of support I wished I had more of, you're not alone. Recovery can feel isolating many of us know what it's like to leave the hospital and suddenly feel like we're on our own, no roadmap, no guidance, just trying to figure it out day by day, that's exactly why I created the Recovery After Stroke Podcast. When you support the show on Patreon, you're helping ensure that no one has to go through this alone, not now and not in the future.

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Bill Gasiamis 14:14

And my understanding of it was that karmic actions were as a result of ignorance, not as a result of events like something that happened to you in your brain. And for example, in my ignorance, I never, I was never aware that people in a wheelchair were potentially going through a difficult time or had some challenges that they had to overcome. I had this very ignorant idea that people in a wheelchair were just sitting down. I didn't see beyond, you know, their physical situation. I just assumed, well, they're going about life. They must just be sitting down.

Bill Gasiamis 15:00

Everything should be fine, but of course, after having spent some time in a wheelchair, I discovered that people in wheelchairs are not just sitting down. There's a lot more going on that we are not aware of. And because I was never curious enough to ask or find out, I was ignorant, and my ignorance put me in a situation where it was difficult for me to wrap my head around finding myself in that situation later on in my life, when I was in my 40s.

Harshada Rajani 15:30

That's so interesting, like it didn't have the empathy. So the wild was like, Well, now you have to experience.

Bill Gasiamis 15:42

I here's a little bit of what's the word, here's a little bit of life experience for you. And now that you know that, what are you going to do to remedy that? And for me, it wasn't, I didn't feel bad about it, but that lesson, that learning, that philosophical kind of teaching, allowed me to then gain that the I the understanding that things are far more complex and they're not surface level is the tip of the iceberg, and that you need to, you need to go deeper as a result of that.

Bill Gasiamis 16:19

The Recovery After Stroke Podcast happened, and you know, we're more than nearly 360 episodes in at this stage, and here we go. You know, it's okay. I'm listening and I'm taking the lesson, and I am attempting to cease to be ignorant, even though I still am.

Harshada Rajani 16:42

No, I think this is great. I wish I had found this podcast when I had my but the Papa wasn't around that.

Bill Gasiamis 16:54

It wasn't because your stroke was in 2008 I had the first bleed in my head was in 2012 and like you, there was no nowhere for me to go and learn and discover and hear stories.

Locked-in Syndrome Recovery and Rehabilitation



Harshada Rajani 17:09

Yeah, online at that time was really, really negative, not helpful at all.

Bill Gasiamis 17:24

So when you experience the stroke, you ended up in hospital. How long were you in hospital for? When did you wake up? How long were you in the in the acute phase?

Harshada Rajani 17:39

I'm not sure that took. Me to wake up? I was on some Friday, every Saturday, so I was in and out, but then I was alone in the ice for three weeks, and we have a hospital for five months.

Bill Gasiamis 18:06

Did you wake up? Were you locked in?

Harshada Rajani 18:09

Yeah, totally locked in. I couldn't even move my eyes in the beginning, some people didn't even realize I was there?

Bill Gasiamis 18:22

Yeah, and would have been surreal situation to find yourself in, and then for the people that turning up to see you.

Harshada Rajani 18:33

Over here, that nurses talking like I wasn't there, no one realized that I was.

Bill Gasiamis 18:46

Fully cognitive aware.

Harshada Rajani 18:53

My mom finally noticed my eyes looking.

Bill Gasiamis 19:00

Wow. Your story is familiar to me, because I've interviewed a number of people that have been locked in and Dylan, whose episode is not out yet, but it will be out by the time this episode goes live, and a number of other people who are locked in Duncan. Campling is another person who I interviewed who was locked in and he was in a similar situation, and he had global deficits, not only, you know, cognitive, but also physical, because the pontine is such in such a location, where if a stroke happens there, it affects both sides of the brain.

Harshada Rajani 19:48

Yeah, I was paralyzed bilaterally, from head to toe, including my vocal muscles. So just completely, I saw a prison, a corpse with living eyes.

Bill Gasiamis 20:13

A corpse with living eyes. How? How long after did rehabilitation start? The kind

the rehabilitation where they took you away from hospital, and they were fully focusing on your physical recovery.

Harshada Rajani 20:34

So when we got to physical therapy, right away, but the man, I was like, What's the point? It felt like such a permanent situation, like I didn't realize anything was ever going to change, but we started physical therapy right away. First, it was just passively moving my limbs and lots of electrical stimulation and slowly, about two or three months, three months, I saw my left arm like whoever, and that was the first Big Thing. And for the rest of the year, slowly, slowly, there would be a muscle contraction, a volitional muscle contraction all through my limbs.

Harshada Rajani 21:55

And we just continued physical therapy. I don't know how it is in other countries, but insurance will not cover many sessions on ongoing injury. So after I was discharged after about a year from the hospital, I started going to a place called Race to walk a narrow recovery gym, and I went twice a week for two hours. And I still do that to this day, but just over the years, the muscle contractions would get a little bit stronger, little bit stronger, and turning that into function has been hard, but I realized I'm definitely made progress, and I'm still making progress.

Bill Gasiamis 23:14

Yeah, fantastic. So the voice as well, when I meet people who have had a stroke like yours and have been locked in, have a similar speaking voice, their big breath and a big effort to get the words out. Is it effortful?

Harshada Rajani 23:36

Definitely, in the beginning, I can only get one sound out for breath and slowly expand to what it keeps getting better and better. We've worked a lot on my diaphragm to help with that, and I found a few tricks that have helped. But I think that's why I've also gotten so into writing, because it's easier and less applicable to get my words onto the page, then it is the speed my feelings.

Bill Gasiamis 24:29

Okay, so you prefer writing if you can.

Academic and Personal Growth After **Locked-in Syndrome**

Harshada Rajani 24:37

But then that's why that muscle has developed in me.

Bill Gasiamis 24:48

So writing is more efficient. Perhaps there's more effort to talk, and writing is a good way to communicate, but talking is also a. A real good training to help you improve.

Harshada Rajani 25:02

Yeah, definitely. And there's direct human connection with talking. And I think I missed a lot when I couldn't speak for so long. So I always appreciate that.

Bill Gasiamis 25:24

You've been writing for a while. Yeah, and your website, you have a little website where you show some of those writings. Yeah, have you ever considered combining them and turning them into a book or anything?

Harshada Rajani 25:47

I'm actually currently doing an MFA at Randolph College and a Master of Fine Art in creative writing, and I'm working on a memoir.

Bill Gasiamis 26:03

Excellent.

Harshada Rajani 26:11

That everyone can find online.

Bill Gasiamis 26:19

Okay, so the works, not the work that you're doing there, is not necessarily publishable in a book format. You're going to have to come up with a new idea. Yeah, as a master of, what was the master of?

Harshada Rajani 26:38

Fine Arts.

Bill Gasiamis 26:40

Yeah, you should be able to come up with something, yeah, okay, well, that would be a good project to get it out there. And the good thing about a project like that is publishing. These days, you don't need to have a publisher. You can self publish.

Bill Gasiamis 27:00

When did you start your your university again?

Harshada Rajani 27:12

Last year, last summer.

Bill Gasiamis 27:16

Are you attending university at Campus?

Harshada Rajani 27:22

It's a low residency program. So just the first 10 days of every semester I have to be on campus, then the rest of the semester is online.

Bill Gasiamis 27:40

Do you get somebody coming out to campus with you, to support you, to help you through all that?

Harshada Rajani 27:48

So, my caregiver stays with me.

Bill Gasiamis 27:53

Okay. How long are those days at Campus?

Harshada Rajani 27:59

9am to 10pm Yeah, because I'm trying to stuff an entire semester's worth of stuff into 10 days. But I love it academics. I love all of that stuff.

Bill Gasiamis 28:24

Fair enough. It's a big day for most people. I imagine at the end of the 10 days, you're wiped out.

Harshada Rajani 28:34

Yeah, I just sleep.

Bill Gasiamis 28:37

You just sleep, yeah, how long before it's complete? Before the course is complete? One more year.

Harshada Rajani 28:47

So four semesters total.

Bill Gasiamis 28:50

And what's your living arrangement like?

Harshada Rajani 28:54

Right now? So right when I got back from the hospital, I moved back in with my parents, and that's where I'm still living, my parents and my grandmother.

Bill Gasiamis 29:13

Okay, so you have plenty of support at home as well.

Harshada Rajani 29:16

Yeah, I have the same social support is so important through all this? Probably the one factor, I think, the right people will still make progress and still find the way forward. And people kind of like come through the darkness.

Bill Gasiamis 29:51

Yeah. How do you avoid that? Because even people who haven't been through the stroke the way that you have will talk about the. Darkness, the difficult times and the challenges. How do you overcome that?

Harshada Rajani 30:28

Human connection? Feeling like people I feeling like people see you and hear you and value you, that makes you feel alive, but also you do need some hope, that thing might get better, tomorrow can be better. I wasn't getting any further down. Feedback from my name my daughter, when I was in the hospital, no hope at all. But my family is really religious, so they always have been but they always have so much positive I can't know I pushed me to have hope.

Bill Gasiamis 31:52

So hope is a really important like hope that things will improve. And I think you're proving that things do improve, even though things are very challenging, you most likely in 2009 and 2010 weren't talking the way you're talking you. You definitely weren't attending university.

Bill Gasiamis 32:21

That's the whole point of this podcast, because people listening are very different ends of their stroke journey, and offering hope is really difficult to somebody who's deep in the initial stages of recovery, you know, where things may be dramatic for them, and it's kind of like, how do I sort of paint a picture for everybody on every interview that I do that things were terrible at some stage, and then slowly that improves and improves and improves.

Locked-in Syndrome, Recovery Challenges, and Empowerment



Harshada Rajani 32:56

And continues to improve. The only positive ever got from my doctor was one of them gotten close to me. I was just up, and she came up to me and said, It's all up. I from here, and it was just like, so I opened it for me, and so empowering, I was able to helpful.

Bill Gasiamis 33:46

So that was kind of making you aware of the rock bottom moment, that that was rock bottom you had actually got there.

Harshada Rajani 33:55

Definitely, maybe a few levels deeper than rock bottom.

Bill Gasiamis 34:02

Fair enough, is there even a word for the level that you were at?

Harshada Rajani 34:11

I don't really know.

Bill Gasiamis 34:13

Fair enough. I appreciate that. I mean, that's an expression, again, of my ignorance right rock bottom, that's as far as I know I've been there. Deeper than that, I haven't been. Take my hat off to anyone who else who has been and come back from that. I really appreciate watching people overcome challenges and deficits and problems that stroke causes, it is so valuable for me to receive those stories from my stroke survivor community who has been on my podcast. I mean, that's why I do it.

Fashion and Self-Expression

Bill Gasiamis 34:53

I do it so I can see what they've done so I can feel hope and inspired to continue doing what I need to do for my self. So I love, I love that you said that, that you found that rock bottom is probably just, it sounds like rock bottom is just like a like a basic level of rock bottom. And then there's this other, more advanced levels, yeah, I hear you. Fair enough. So how old are you now?

Harshada Rajani 35:32

I'm 40.

Bill Gasiamis 35:34

So you're you've lived with this condition, this situation, for quite a long time. I imagine you've understood a lot and learned a lot about yourself and other people and the challenges that other people face when they deal with you. What? What's it like to to have had the the not the, what's the word I'm trying to come up with, not the not the mental.

Bill Gasiamis 36:06

But the knowledge that you have about the situation that you found yourself in, and how people react to you and and how you People like in your situation, move in the community and in the world, that's a big is that's a big journey. You would have a deeper understanding of people, I imagine, than somebody else.

Harshada Rajani 36:36

That's actually been one of the hardest parts, especially because I was so

respected by my mind before my stroke, so then afterwards, feeling so dismissed and I slide up on people. Experiment so when people see me, they say my wheelchair. They say my first dead end, and they assume, since my body has broken, my mind must be broken too.

Harshada Rajani 37:27

Some people say the most ridiculous thing to me, dental hygienist was like, "Do we have a football just like favorite infantilizing, favorite demonizer and adjustment really harmful." And I don't think something I can ever really get past because people are interacting with them right there in front of you, and in the moment, find the courage to be like, hey, no, I'm actually a smart person treatment normally.

Bill Gasiamis 38:34

The mind it's still there always has been, yeah, yeah. I and people like I might I may have early on in those days when I was ignorant, may make massive assumptions when they see somebody with the physical deficits that you have. Yeah, and then you know that you probably would have done something similar, and you may have even done that as well just be ignorant, which is, you know, it's, it's not an attack to say that, to use that word to describe myself for you, because it's just the reality, and it's if you haven't been in a situation, how can you possibly know?

Bill Gasiamis 39:29

Have you had the opportunity to bring people around from their ignorance and to go hang on a sec. Come here. Let me just explain something to you, or you need to know this about me?

Harshada Rajani 39:42

So I guess that's why I found so much empowerment with my writing, because you can read one sentence and know that I'm completely cognitive, right? Intact, and so I noticed some family friends who did once treat me like a child have now, after reading some of my writing, well, I directly address the problem with the way people speak to me. I've seen some of those people definitely become more attentive and understanding and not dismiss about me.

Bill Gasiamis 40:41

You made some pretty big you made some pretty big you ended up on the Today

Show, I think. Did you end up in on the Today Show, in person or?

Harshada Rajani 41:00

Just website, yeah.

Bill Gasiamis 41:06

And it says, I'm sick of being the cute girl in the wheelchair. I'm entering my hot girl era. Why I'm done hiding my body, yeah. So what was behind that article?

Harshada Rajani 41:20

Yeah. So it was just kind of me trying to take back control of the narrative that people had placed on me, that I was this sad girl in a wheelchair and that bitch eaten with kiddie gloves, I thought down to like I was trying to wear the sweats black holes. Just tried to hide myself from the public, hoping that no one would say me. And then one day, I looked in the mirror with something I had stopped doing after my stroke, and that was like, I don't look that bad. Like and I just started getting into cute clothes and crop fun dresses.

Harshada Rajani 42:35

I loved fashion before my Spro, so now it was a song as to embrace that part of my life again and read a book that didn't mention the term weaponized grammar. And so it was kind of what you wear is making a statement to the world about the person you are. It's kind of supporting their expectations of you. So I just found so much power in that.

Bill Gasiamis 43:18

Yeah, weaponizing glamor, you see people who are 30 years old and dressed like a 60 year old, whatever that, whatever that even means, right? But they just dress older, I suppose. And it's like, Yeah, it's interesting choice to notice somebody dressing that way. But what you're saying is you're you're in a wheelchair. Perhaps your body doesn't work or move in the way that it used to.

Bill Gasiamis 43:50

But that doesn't mean I need to wear clothes that conform to potentially some kind of what wheelchair people in wheelchairs are supposed to wear, or how you're supposed to dress, that's not, there's not a real how you're supposed to do that thing. And what you're saying is to better fix like it's a form of expression you can express yourself in that way.

Harshada Rajani 44:17

Yeah, definitely, form of expression. I think that's a really good way of funding.

Bill Gasiamis 44:29

Yeah, because you see rock stars and pop stars, you know they'll have different hairstyles, they'll have different hair colors, they'll wear different clothes, they might have tattoos, they might have all these things. And it's actually just a way of telling people, this is this is who I am, this is how I turn up. This is what I do, this is how you know I want you to know me, not only by the song that I sing or by, you know, the life that I've had or the upbringing or the challenges that I've faced.

Harshada Rajani 45:01

Also as a woman, it was kind of also where to take back my femininity. You can feel so infantilized and desexualized by the rest of the world, I'm still a woman.

Bill Gasiamis 45:31

Yeah, and nor should you. I love that. I love that idea that you're taking back your femininity and that you're going to express yourself in many ways, including and as a woman, definitely, yeah, a lot of people, I feel like, in my situation, even though I've been through my own challenges, I don't think they would realize how, What's the word, like, how, how disability like yours can take away all those things that make you your unique self because of the way that you are spoken about or treated or or looked at, and always through kind of like a medical eye.

Bill Gasiamis 46:19

Even if the person is not a medical person, they always look at you, okay, what's wrong with her? What happened to her? It's never, what shoes do you love or which lipstick do you use? Is that right? Would that be more conversations about your physical situation rather than your personality traits or your quirks, the things that you love.

Harshada Rajani 46:43

Definitely, it's always like people passing me and a problem that needs fixing, and that's kind of what frames the whole dynamic. So I think when they had to work for a while, well that's not people who got reaction to disability and as people, just like anyone else.

Impact of Social Media and Community



Bill Gasiamis 47:18

Yeah, how? So if you had a stroke in 2008 no social media, basically no online world at that stage. How has that changed? That change of social media becoming a thing made a difference for you.

Harshada Rajani 47:41

I feel so much and so much less alone in what I went through at that time. My daughter was the only one. It felt so rare and so different and so huge, but now so many Facebook groups, people talking about therapies and what's happening, supporting each other, and then really then disability actress and empowering the pleasure and right now.

Bill Gasiamis 48:37

I'm so glad for social media as well. I mean, I know there's those parts of social media that people talk about I'm not so good, but I know that it's been a massive thing for me as well, because it's helped me find people my community. It's helped me share other people's messages. It's so important, and it's helped me feel even though I've not met many people that live near me who have had a stroke, where I can connect with or go to or hang out with or catch up with, even that doesn't happen for me. So I needed the podcast to find my people, my community.

Bill Gasiamis 49:21

And it was, it was such a man, it was such a blessing, where, at your best, I'm based in Melbourne, in Australia. It's a big, bad city. It's got everything that you could possibly imagine a city and a suburb and all that kind of stuff has that. But you know, trying to get together with people and find people and bring them together at the same time and have them all overcome all their challenges to get to one location is really rare, and it sometimes happens through the Stroke Foundation, which is the foundation in.

Bill Gasiamis 49:59

Here in Australia that advocates for stroke survivors, but you know, they can only run events once a year or every so often, so you don't get to catch up with that type of community very often unless somebody else is arranging it. So it's good

that social media exists. You and I met because of social media, and that was shared to you by Dylan, whose interview is going to go out a few weeks before this. So, I mean, that's the most amazing thing to me. I can't believe that this has even occurred, that we've been able to create this community and have 300 and nearly, nearly 360 interviews.

Overcoming **Locked-in Syndrome Recovery** Challenges and Achieving Goals



Bill Gasiamis 50:46

Does these long conversations fatigue you and the effort to talk? Does it fatigue you these days? Or have you become better at being engaged for such a long amount of time?

Harshada Rajani 51:00

Better, definitely, doesn't really I wrote an article for a South Asian magazine, and because of it, I met a lot of other South Asian women in wheelchair, and that, I think, was so huge for my journey. They've all had their injuries longer than me. So they were I had much more insight and reflection about all that, so I was able to learn so much about like how to unlearn the things culture also say that they deal with The same issues I'm dealing with in my community, and just as human connectedness was also helpful, so that you can still have a good Life and a will too.

Bill Gasiamis 52:21

Absolutely I agree with that. Sometimes I tell the story of Stephen Hawking, the

most amazing, you know, philosophy, physicist in his field, you know, extremely popular, very like the top of his, his, you know, topic of conversation, and the most amazing person, and then completely and utterly, totally disabled as well, and not being able to move any part of his body because of MND, I think it was or something like That, motor neuros, yeah. And I say that story just to remind people what people with serious disability have been able to achieve.

Bill Gasiamis 53:07

And say, I know it's hard. I know it's difficult. I know there's a ton of challenges. I don't know what they are, what it's like, because I'm not there, but we need to look up to people like Stephen Hawking beyond his physicist accomplishments and and we need to say to people like you, need to head in a direction where you try stuff that you are afraid to try, that you're worried about trying that you think is not possible, you know, and you need to get out of your own way and allow yourself to achieve the things that you don't know, you can.

Harshada Rajani 53:54

Disability advocate, Judith Heumann.

Bill Gasiamis 53:59

Judith Heumann, I don't know who.

Harshada Rajani 54:02

So I saw her on Trevor Noah's late night TV show. Last time I've ever seen a power wheel to use a prime time TV and first I noticed a wheelchair, but as soon as she opened her mouth, the wheelchair was the least interesting thing about her. She has like, worked in the government and been on the front lines of disability advocacy in America, and it was just so important, so important for me to say that seeing a power chair, but saying laugh, how unimportant that was.

Bill Gasiamis 55:06

Yeah, I love that. I have a friend of mine here from Australia who is a stroke survivor. And Brooke is someone who had a stroke, I think, when she was 13 or 14, something like that, and she's in an electric chair wheelchair, and she is now, I think, around 40 years old as well. And she's a massive advocate. She's involved in every study trial you can possibly imagine. She speaks at the conferences here in Australia. And a little while ago, she saw there was an opening to have a discussion on disability, some topic on disability, at the United Nations, and she

applied, and she got accepted.

Bill Gasiamis 55:49

And in a couple of months time, she's going to fly from Melbourne, Australia all the way to the United Nations to address the United Nations on her topic of stroke or disability or whatever. Yeah, isn't it amazing, and when I said to her, like, what were you thinking about when you decided to apply, not from a not not from the perspective of, I don't think you should have done it, but just curious about the way that Brooke thinks she goes, Well, I didn't really think about it. I mean, there was an opportunity. I applied, I got it, and I'm going, so that was about it.

Bill Gasiamis 56:26

There wasn't really much more thought about it. Of course, it's her passion, it's a topic. It's something that she's deeply knowledgeable about and has lived experience as well. So she thought it was a no brainer. I have to do this. I have to apply, and if I get in, I'm gonna go.

Harshada Rajani 56:44

And then we do overthink things too much, and that limits us from reaching for so many opportunities. I was like, that was going back to school too. Because I was like, How will I ever How will I ever be at school? How will I afford it? Like, this is so ridiculous. And then I just fell in love with this pro program and applied, and everything fell into place.

Bill Gasiamis 57:20

Yeah, and that's a thing, right? You're not going to solve the problems that you you don't know are going to be there until you're there. You can't anticipate them all. You can't possibly know the challenges that you're going to face. You just have to go for and deal with them one at a time, if and when they arrive. Yeah, I really appreciate you reaching out and asking to join me on the podcast. It is an absolute pleasure to interview people who have the wisdom that you have, and who are willing to share it and are doing exactly what you're saying, you're practicing what you preach.

Bill Gasiamis 58:03

And that's I love that. I just love the fact that you've contributed articles to places, that you're writing, that you're going to uni and getting more qualified. That's

exactly what we're talking about. You know, you have to not just give up and think that things are not possible. You've got to find a way forward. I look forward to seeing what else that you achieve and what else you write, and especially if a book comes out of.

Harshada Rajani 58:40

It's taken many, many years to get to this point, and then the first couple years, I was just so focused on getting my old life back, and only recently.

Bill Gasiamis 59:02

It's a new life. Yeah, getting your old life back is probably unachievable for 99% of stroke survivors, and it takes some time for some people to discover that as well and to have acceptance of the situation they find themselves in.

Harshada Rajani 59:26

Everyone has their own that realization when I'm also realizing with what you're saying, it's not just 99% of struggle with them. It's 99% of everyone. Life just changes on you.

Final Thoughts and Encouragement

Bill Gasiamis 59:58

Man, it showed that. Hey, thank you so much for joining me on the podcast. I really appreciate it. Well, what a journey from being completely locked in to becoming a powerful voice for Disability Advocacy, Harshada shows us what's possible, not just physically but emotionally, spiritually and creatively, her story is a reminder that your worth is never measured by your deficits, and that healing is not always about getting back to who you were, but about discovering who you can become.

Bill Gasiamis 1:00:38

If you're listening to this today and you're still in the thick of it, early days, facing setbacks or just plain exhausted. Let this be your proof that growth is still on the table. Here's what I'd love for you to do, reflect on Harshada's Courage. Try something new, even if it's small, reach out to a friend, to this community, or to yourself. Thank you for listening, your reviews, your comments, your support.

Bill Gasiamis 1:01:04

It keeps this show going, and to those who bought the book or join me on Patreon.

Thank you so much. You're part of something bigger than just a podcast. You're helping stroke survivors everywhere find their way forward. Stay connected, stay curious, and remember, you're still here and you're still growing, and the story is not over. I'll catch you in the next episode.

Intro 1:01:28

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Intro 1:01:58

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Intro 1:02:23

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Intro 1:02:49

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