

# Living With Fatigue After Stroke - Carolina Aguilera

**Living with fatigue after a stroke is how Carolina Aguilera describes life at the moment. A previously undiagnosed AVM was behind the brain hemorrhage that bled when she was just 26 years old.**

Instagram

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Transcription:

Carolina Aguilera 0:00

I hate the fatigue. It's the one that is leading my life. So there is no other option here. So sleep is the only thing that is gonna recharge. So now I do need nine hours of sleep. And it's not necessarily a priority, but it's the body, it's the one that is asking for it. So there's no other choice here.

Intro 0:30

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

Bill Gasiamis 0:43

Hello, and welcome to episode 209 of the recovery after stroke podcast. If you are a stroke survivor have a story to share about your experience with stroke. And you have been thinking about reaching out to be a guest on the show But were waiting for the right time to reach out? This is it.

Bill Gasiamis 1:00

If you go to [recoveryafterstroke.com/contact](https://recoveryafterstroke.com/contact), you will find a form that you can fill out to apply to be a guest on the show. As soon as I receive it. I will respond with more details on how you can choose a time that works for you, for us to meet over zoom.

## **Introduction**

Bill Gasiamis 1:17

Now my guest today is Carol Aguilera, who in September 2020, was only 26 years old when she experienced the bleed in the brain. It was a previously undiagnosed arteriovenous malformation that was behind the cause of the brain hemorrhage. Carol Aguilera welcome to the podcast.

Carolina Aguilera 1:40

Thank you so much. Nice to meet you. Thank you for having me.

Bill Gasiamis 1:44

My pleasure. Lovely to meet you, too, thank you for reaching out. Tell me a little bit about what happened to you, Carol?

## **Arteriovenous Malformation (AVM)**

Carolina Aguilera 1:51

Okay, so maybe two months after my 26th birthday, I had the rupture of an aneurysm. So, yeah, that happened. And well, it was in the middle of the pandemic. So that was also great for everything that happened. And well, it turns out that I had a malformation that I didn't know about.

Carolina Aguilera 2:18

So with everything that was going on in my life, the pandemic work life, my body couldn't handle it anymore. So I suffered a rupture. And at that time, I was just feeling the headaches, nauseous. And I passed out, and then 20 days in the hospital, amazing surgery, great time.

Bill Gasiamis 2:49

So you had bad headaches? How long? Did you have the bad headaches before you actually knew there was something wrong?

Carolina Aguilera 2:59

Well, my friends told me and my family that I complained like two weeks before about headaches, which I thought it was maybe just a regular migraine. I'm just taking ibuprofen, something to kind of pass it through. And while that was happening, I never thought it was something else. So we didn't even go to the doctor. Just the quick fix, take something for it and move on I guess.

Bill Gasiamis 3:27

Yeah. And how bad were you before you went to the hospital? To what extent had the condition deteriorated before you went and got help?

Carolina Aguilera 3:37

Well, no one knew. It was just in one day that I had a migraine. I thought it was because I haven't eaten lunch at that time. So it seems like maybe it's just because I haven't ate anything. So I went for lunch. And well I didn't even get to my bedroom. I just passed out in the hallway.

Carolina Aguilera 3:59

And then they needed to call the paramedics because I was out. And then on the same day, we have the intervention, the blockage of the rupture, and the brain surgery all in one day. So I didn't have time to go back and forth. Look for a possible diagnosis. It was just spontaneous. Yeah. Immediate.

Bill Gasiamis 4:24

Which part of the world do you live in?

Carolina Aguilera 4:27

I'm actually based in Panama. So you know that little land that connects North America and South America. There I am.

Bill Gasiamis 4:35

And is that a place where the medical system supports you? And you can get good medical care?

Carolina Aguilera 4:49

Not really, the public system is not that great. And again, it was in the middle of the pandemic so if we weren't going to choose for a public solution, it was just out of possible hands. So I was really fortunate that, first of all, I was at home. So we were able to do something.

Carolina Aguilera 5:12

At the beginning, of course, we didn't know anything about my possible conditions. And I was also lucky because my neighbor was at home. So he was able to help with a diagnosis. He's a doctor. So he was taking out options like a diabetic shock or something else. So they were able to diagnose us really fast what was happening to me.

Carolina Aguilera 5:39

And other thing, because in my country, we choose for a private ambulance, a private hospital, and not all hospitals are stroke centers. So my neighbor also helped select the hospital. That was really a game changer.

## **Life Before AVM Rupture**

Bill Gasiamis 5:59

Yeah, that seems like it was really helpful. So your rupture happened in September 2020? What was going on for you in life? What were you up to? How busy were you? What kind of things were you doing? It sounds like you think that the way that you were living your life did impact this situation? And perhaps make it occur or support it occurring? Is that accurate?

Carolina Aguilera 6:37

Of course, well, first, the pandemic was really awful all around the world. For us, I took more responsibilities within my home, so that I didn't do before. Well, we were in almost completely locked down here. So the stress of maybe needing to go out to do something was not that great. I actually worked in a freight forwarder.

Carolina Aguilera 7:04

And I worked in the department that was handling the movement of vaccines all around the world. So I was the supervisor of a 24/7 team, working in the pandemic, doing the part of the work that it was needed. So I was doing maybe 18 hours, chipped. More or less, I didn't have to stop. Also, you know, people take some hobbies in the pandemic, and here, it was becoming a bartender.

Carolina Aguilera 7:41

So I was testing all those options, my dad was into the hobby, becoming the back bartender and doing drinks. So I think that I drank too much at the time. And the

stress levels of course were up high in the sky. Instead of maybe sleeping or resting, I was going until maybe 200% of my energy.

Bill Gasiamis 8:12

And was that just to keep yourself occupied? Were you having difficult mental health issues at the time, because of all of those things that were going on? It's very familiar story that I hear about people drinking more during the pandemic and increasing the amount of stress that they had and decreasing the amount of time they took to look after themselves.

Bill Gasiamis 8:35

And they often say that it was because of the mental health situation that they weren't aware of at the time, and they needed something to cope. Is that what happened to you?

Carolina Aguilera 8:46

Well, I guess so. Definitely, before I didn't pay that much attention to mental health. At some point, I think that it was not just to keep me busy. But because you have the pressure that you need to do things at the time that were consider important for my work. And of course, for my family.

Carolina Aguilera 9:13

Well, you didn't want to lose your job in a pandemic, you still need to try to make time to do the other things that you didn't do before. So it was something. I think that maybe I did find some other ways to reduce my stress. But at that day, the couple of things that I remembered was a tough one.

Bill Gasiamis 9:39

Yeah. I found myself struggling during that time with a lockdown in Melbourne, where I'm from, in Australia. We had the biggest lockdown of any city around the world. We were locked down for more time than anyone in the world. So in the first two years, we were more than a year in lockdown. And it was just intense, and people were stressed out. And they were really struggling with all the things that they weren't able to do.

Bill Gasiamis 10:19

Because we weren't also allowed to travel out of the house, we weren't allowed to go more than five kilometers from our home. We weren't allowed to be out after dark. It was pretty serious stuff, you know. So I find out this conversation brings

back those memories that were definitely all unpleasant.

Bill Gasiamis 10:43

And even though I had been through difficult times before, like stroke, and recovery from that, and all the things that stroke takes away from you. To me, it felt a little bit different because, even though the stroke took a lot away from me at the beginning, I still had the freedom to move around if I was feeling well enough to move around and go places and see people.

Bill Gasiamis 11:10

And this restriction was far more difficult, especially in the second year of the pandemic, when we had been going through it for one year already. They weren't allowing us to work. They were paying everybody to be at home. So did the government support anybody in Panama? If they weren't working? Was there any way that they supported people, workers or organizations that had employees to stay at home?

Carolina Aguilera 11:45

Yeah. But again, it was not our case here at home. So we were lucky enough to have two different incomes. And at some point, the pandemic and the lockdown, it may sound really tough, maybe some people really had hard time. But for us, it was actually a blessing. I could even say use that word. For us. As a family, I live with my parents, my two brother and my sister.

Carolina Aguilera 12:18

We didn't spend that much time together before. So it was a really a great environment that we had here at home. And well, even though I'm from Latin America, I'm not that person that needs to go out that much. It was not that much of an impact to being at home.

Carolina Aguilera 12:39

And if I bring that to what, Eric, what, oh, everything that happened with the stroke, the surgery and my recovery, I think it also had a positive side in me. Definitely being in lockdown, and with everything that happened. And working in my recovery, had the positive thing that I didn't have that many people around me, which at some point, yes, you need that for your, your skills to not lose that.

Carolina Aguilera 13:09

But for me, it was creating a safe environment, I was able to focus on me not

having that much of noise. And not many things in my surrounding. I don't know how it happens. But at least here, as we are really close in terms of family, and not only my core. But here you have a big family, almost everyone. So imagine being in a recovery with everyone here, calling you every day, it's a blessing.

Carolina Aguilera 13:41

Don't get me wrong, but for me, the noises was too much. So it was a positive thing. I had the opportunity to also have private therapist, my parents went to the next level with that. So everything was at home, really safe. And going out was a lot of stress. Going to the doctor and to those appointments was I don't know, it was really crazy.

Bill Gasiamis 14:11

Was that difficult. Neurologically, you're saying was overwhelming for your brain and for your energy levels to go through the process of seeing the doctors on the appointments?

Carolina Aguilera 14:24

Yes, of course it took a lot more time. So you need to select the right doctors. Not only that, but to the right center. That day, we didn't want to go to COVID hospitals. Where they were working with COVID patients or where the main centers of those.

Carolina Aguilera 14:41

So we choose other type of clinical centers here in Panama. And also, we took the opportunity of hiring private therapists, the ones that are the psychological part of it. We were using Zoom as a tool for physical therapy, he was coming here.

Bill Gasiamis 15:06

Okay, so you had a little bit of a mix, some physical therapy at home, some zoom, and then some appointments, that sounds like it was really good. And overall, you enjoyed the fact that well, locked down came at the right time for you so that it could decrease the number of people that were coming to see you, I understand what you mean from a Greek background.

Bill Gasiamis 15:26

So the family is also very over-concerned, and they expressed their love by coming and seeing you and hanging around and wondering what they can do for you, and all that kind of stuff. And like you said, it's useful, but it's also very

draining.

Bill Gasiamis 15:48

When they don't understand what it is that you're going through, they can see that you're unwell, but they don't actually understand what's happening inside because of the invisible part of the challenges that are associated to a stroke.

Bill Gasiamis 16:02

So yeah, it is a little bit of a blessing that you were in lockdown, and you didn't have to experience all of the family coming to see as much as you love them. What was your mindset like, during recovery? Did you end up reflecting on the serious nature of this event?

## **Thinking About Mortality After an AVM**

Bill Gasiamis 16:23

Did you feel like, wow, this nearly took my life or that it ended? Or that it could have ended? Did you have any shift in your thinking about mortality and those types of things?

Carolina Aguilera 16:39

Of course, well, first, the fact that I was a ticking bomb, if you think about the malformation, so at any point in my life, that rupture could happen. That's the first thing and of course, it's a life changing accident experience, that of course it makes you think a lot.

Carolina Aguilera 17:04

For me, I did change a lot after my stroke. And it happened that, I don't know if it was your experience. But after you are in a recovery, you really get to be with the people who are really going to stick with you, in anything that could happen. So it was having that realization, that these are my real people, the path or the goals, objectives that I had in life, change confidently.

Carolina Aguilera 17:40

So really briefly, let's say I was this millennial who had this plan for her life, I need to finish college, I'm going to take a master, maybe a doctorate, I'm going to be dispersed in the logistic world, which I worked on, but everything lost that value or that sense of importance in me. So I was able to say I don't want to do any of that. I need to change my priorities. I want to do something else. And well,



it has been almost two years. I haven't found it yet. But hey, that's the joy right? Trying to find what I'm doing.

Bill Gasiamis 18:25

Yeah, so your work, working logistics is just one of the things that you do. It sounds like in Panama, a lot of people would be involved in logistics because of the Panama Canal. I expect that as a big employer in that area. So did you end up there by chance? Or was it a career path that you wanted to follow before the stroke?

Carolina Aguilera 18:53

Thanks, gents. My experience, I always thought I was going to be an engineer. I was going to continue with my parents company. But that didn't happen. So I ended up there by chance. I ended up loving it. And well, I think my career path was mostly into administration and more on business management than anything else.

Carolina Aguilera 19:18

So I did those two things together. So I was kind of working in the logistics transportation industry. You can get more focus on being a manager trying to really help others. But yes, well, I think one of the most shocking things was that question that the therapists asked me a lot like how you want them to remember you, those characteristics that will define myself.

Carolina Aguilera 19:55

And there were almost everything about work, about my studies. I mean, they have some good things but I think that you don't want people to remember you because you were great at school or you were someone smart. I wanted more.

Bill Gasiamis 20:17

She was very good in logistics, she was the best logistics person in the industry.

Intro 20:23

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

Intro 20:47

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](http://recoveryafterstroke.com) where you can download a guide that will help you it's called seven questions to ask your doctor about your stroke.

Intro 21:06

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. And they'll help you take a more active role in your recovery, head to the website. Now, [recoveryafterstroke.com](http://recoveryafterstroke.com) and download the guide, it's free.

Bill Gasiamis 21:25

It is a good thing for people to say about you when you're employed there. If your employer believes that and the people that you work with believe that, that's a great thing, because that helps you get promoted more money, or it makes your job easier, or it makes other people's jobs easier. That is a good title. She's the best at logistics.

Bill Gasiamis 21:45

But it doesn't go towards a fulfilling life, does it? There's more to life than just logistics or just work. And what people think of you at work, it's really important to get to know what you love, and to practice that and to do some of that.

Bill Gasiamis 22:03

So that you can experience joy at a different level, not just one that's about performance of work or performance as an athlete or performance as anything. So what are some of the things that make your heart sing that makes your heart smile and come alive?

Carolina Aguilera 22:26

It's actually helping others. I found that as the most gratifying thing ever. And well, by working one of my lists, it was a flop. But I took care too much about my teammates, and working to make sure that everyone was doing okay. So it was that kind of style of management that I used to have. That was kind of my label on it.

Carolina Aguilera 22:58

Now after the stroke, one of the things was that my emotions were heightened.

The part of my brain that was mostly affected was the frontal lobe. So it was all emotions, or not able to control a lot of my reactions. So unfortunately, I was not able to continue on that role as supervisor as manager. So they took up that responsibility of having people under my wing.

Carolina Aguilera 23:27

So after the stroke, and coming back to a little bit of normal, I needed to find something else to do. So I'm going through the path of maybe working with foundations, I now do a lot of work or try to connect with more in the church, more instance of the community of healthy.

Carolina Aguilera 23:49

But definitely, through that, I found out that I'm the one creating the limitations. I'm the one who thinks that I'm not able to help that much, or that I'm the burden. So that's still ongoing project. And to find that place where I feel better about it.

Bill Gasiamis 24:08

I think you're gonna find that, it doesn't come straight away. It's part of finding your purpose. And people think that with purpose, you need to work it out before you start going towards your purpose, but you don't. I think it starts from helping people just like you described that. Now your mindset has shifted from being somebody that helps people work better in an organization to people being better in themselves.

Bill Gasiamis 24:34

And emotional intelligence is part of that because you need to be able to connect to your heart to be able to reach other people at that level, so that they can feel like a similar connection. That's not about productivity. That's not about shipping or work or any of that stuff. It's just about connection, for the sake of connection sometimes, and that's going to start changing your identity.

Bill Gasiamis 25:01

And as you do more and more work in that space, you're going to find that people will come to you. And they'll start sharing how helpful your support was, or how helpful the things that you did were. And I'm speaking from my own experience, because that's what happened to me with the podcast, people would reach out to me and tell me that they thought it was amazing what a fantastic job, I'm doing all that type of stuff.

Bill Gasiamis 25:01

And I never expected that when I started the podcast. And that started to fulfill me, because nobody ever told me that the work that I was doing before the stroke was amazing. And it was fantastic. And it was what the world needed. And it's going to change lives, it was just work, no one really taught me about that. So it didn't have that feeling where other people valued what I was doing.

Bill Gasiamis 25:56

In that part of their life, that's going to make a difference in the life, it was just a task that I was doing, that they needed to be done that I was getting paid for. So very, very different. And as your identity shifts from being the person that you were before the stroke to somebody who helps other people, you're going to find that that's fulfilling.

Bill Gasiamis 26:25

And once you understand the level of fulfillment that you get from it, it's going to be very difficult to stop going down that path, I certainly can't see myself stopping the podcast anytime soon. There's about 200 episodes, and there's going to be a lot more because it is what I needed when I was unwell, which wasn't available. And I still need it.

Bill Gasiamis 26:53

Now that's why I reached out to connect with people from all around the world that's been through something like I've been through because you're helping me. Hopefully, I'm helping you. And we're both helping other people. And that's when I realized that I was starting to fulfill my role on the planet, the reason for why I'm around not just to go to work and make money for somebody else.

Carolina Aguilera 27:22

I think it's really beautiful when you try to redefine everything that happened to us. Well, I don't know if I'm ready there. But I think you are and you're talking by experience. So definitely, they ask those questions at the beginning that it's something positive, with your grief trying to see the positive side of it. And that's difficult on the first month. Definitely.

Carolina Aguilera 27:51

But that comes like, out of nowhere. And mainly by telling my story, it has come to that point. And well, people will say that they don't know that I had a stroke. So

they're always shocked about that part. But every single time I tell my story, have a better outcome on what's going on. And you never know when you're helping.

Bill Gasiamis 28:21

I think you're helping a lot. So you didn't have good sleep routine, because you're working way too many hours. So if you're working up to 18 hours a day, was that seven days a week? How many days a week you're doing that?

Carolina Aguilera 28:41

Well, I did try to sleep from Monday to Friday. But my schedule was really crazy. I didn't have an official schedule. So at least those 18 hours were not that common. There was maybe something that required my attention, then I will do that. And I will do that mainly because at that time if I fall asleep, and then try to work, that didn't happen for me. So I prefer to stay up in that period of time. But yeah, mainly it was not that much.

## **Managing Fatigue After Stroke**

Bill Gasiamis 29:22

Yeah. And have you made sleep a priority now? Do you spend more time asleep or making sure you get to sleep on time? What do you do now?

Carolina Aguilera 29:32

I hate the fatigue. It's the one that is leading my life. So there is no other option here. So sleep is the only thing that is gonna recharge. So now I do need nine hours of sleep. And it's not necessarily a priority, but it's the body, it's the one that is asking for it. So there's no other choice here.

Bill Gasiamis 30:00

There's no getting away from fatigue, once the fatigue kicks in, then it's time to rest. So, is that getting better? Or are you still getting fatigued a lot during the day? How often do you feel very drained and very fatigued?

Carolina Aguilera 30:15

Well, it's getting a lot better. Now I'm working eight hours at the beginning, maybe eight months ago, I did need to take resting time, maybe three hours of sleep, and then the rest of the day. Now I can go through my day completely without needing naps, or those power rest.

Carolina Aguilera 30:42

And I'm often asleep by 10pm maximum. Well it also varies according to my day. Because if you want me to go and do a whole lot of walking, I'm going to be tired. So I will need a nap. So again, it will vary it according to my day, it did get better. Whenever I increase my activity, I need to keep that up. Because then the fatigue is going to take you away one day of rest, you're gone, you can keep up the next week.

Bill Gasiamis 31:20

Yeah, I recall all of those difficult days, after pushing myself beyond my limits. And then struggling the next few days, you really quickly learn your lesson to stop before your limit or near your limit or just after your limit not to exceed it for too long. Because then you pay a big price the next couple of days, I used to be like that as well.

Bill Gasiamis 31:48

And I think that's improving for me. So it doesn't happen now. But I've been on this journey for 10 years now. So things are changing all the time and improving for the better. So immediately after the bleed, I imagine that you stopped drinking alcohol, you weren't in a position to drink alcohol. Where are you with your nutrition now? How has that changed?

Carolina Aguilera 32:17

Well, the nutrition is the topic. And mainly because as I mentioned, my emotions are going crazy and anxiety was up to the sky. So believe it or not with me on a diet, I was angry all the time, I was not able to do much in my physical part in physical therapy of my arm, which is the one that is the most affected of my left arm.

Carolina Aguilera 32:46

So I was so angry that I was not able to improve on my arm. So we needed to take decisions there. So it's all about that changing my lifestyle, not necessarily being on a diet, it's about the choices that I made. The goal is to make sure I'm stable as in my mood, because my hand is 100% emotion, even thought that I was having spasms or any type of really low epilepsy in my arm. But it was just my emotions. So it has been quite a few months, trying to figure out why I was not improving. Not as fast but as I should have been doing with my arm.

Bill Gasiamis 33:37

As you should have been doing according to you, or did somebody tell you that you are going to be recovering better?

Carolina Aguilera 33:44

My therapist. So again, your recoveries never aligned, right? I've learned that the hard way. But it was so frustrating that my hand will not open. So he knew that I could do some level of movements. But it was not making sense that I was completely stuck at some point during the session.

Bill Gasiamis 34:09

So it was a little bit difficult to understand?

Carolina Aguilera 34:14

Yes that's why they recommend that to deep dive and see what's going on. Is it the muscles, the brain, or any electric part that we need to maybe help you a little bit with medicine. So yeah, the tests show that I'm just a big emotions bin and that my hand is reflecting everything. If I'm angry if I'm upset.

Bill Gasiamis 34:43

Right. Okay. I know that when I am angry, my deficits are worse. If I'm less angry, my deficits are better. So I noticed that as well. The performance of my body changes Depending on how I'm feeling and how I'm behaving and what emotional state I'm in, so I can relate to that.

Bill Gasiamis 35:06

I know there'll be a lot of people listening who can also relate to that. I also noticed some foods make my deficits worse, like foods that are high in sugar, like breads, or sweets, or pasta or something like that will make my deficit worse and the numbness worse.

Carolina Aguilera 35:26

On the contrary it does make me happy. So at some point, they even bad joke, they call me the Hulk. So they try to bring me down, at least with food, like, go on, relax, come back.

Bill Gasiamis 35:41

Yeah everyone's different, I wouldn't be able to tell you what's going on with you. But yeah, I know that food does impact people differently. So maybe for you it

helps, but for me. Some foods help, but some foods don't. And I avoid them that's all. So you mentioned that also, now that are you're more physical with exercise than you used to be before stroke? What's that like? How has that shifted your amount of exercise level?

Carolina Aguilera 36:12

No, actually, before, I think I'd had this crazy scheduled before even pandemic. So besides working, I went all mornings to the gym, then college, or university, whatever you any call it. So before I had so many more activities. Now of course, with the fatigue, we needed to find something that helped me. So I found Pilates I think it's pronounced that way.

Carolina Aguilera 36:47

The main activitie is Pilates, three times a week. But I do some cardio. Of course, our for some people, they recommend you to do daily walks, maybe 30 minutes, try to relax yourself with yoga, things like that. But guess what, for me, it was the country I couldn't stand the walks, I couldn't stand the yoga, I will get mad.

Carolina Aguilera 37:11

So yeah, The crazy part was that I didn't know how to deal with that, with all the motions happening. So that was a topic for me. I don't know how to say it, definitely I came from a person that before the stroke was considered to be controlled, really focused. After that, I'm just a teenager again. So that was fun for my parents, I guess.

Bill Gasiamis 38:00

All emotional things all over the place. So yoga didn't help you at all? You didn't enjoy yoga.

Carolina Aguilera 38:06

No, I was so mad. Like, I need to breathe. I was mad, all sessions. Like, no, it's okay, maybe you should not do that.

Bill Gasiamis 38:19

How is Pilates different?

Carolina Aguilera 38:23

You do the breathing exercise, but for me, they do something personalized, where they try to push me a little bit more. And that's something that happens through



all the different type of therapist that I have. For me does not work the relaxing part or trying to sugarcoat me through the sessions.

Carolina Aguilera 38:46

More like, I need that challenge, I need to make sure that we are doing important things are not important, but I can see that I'm working for it. That's what I need, that they don't treat me softly in Pilates. I don't believe that Pilates is easy or yoga is easy, but I needed that a little bit more of speed.

Bill Gasiamis 39:25

Yeah, I understand they are different Pilates sounds to me like it's more of a rehabilitation therapy in a way. And yoga is more of a spiritual quiet thing you know, where as well as stretching and moving your body and connecting to your body. You're also going internal. Does that sound like it? Does that sound similar to what your experience was?

Carolina Aguilera 39:56

Yeah so maybe that's that's part of the focus that I was not that into the mindfulness or the spiritual part of the yoga that maybe that's why it didn't work for me. And of course, they recommended maybe to be connected with nature, but didn't work at all for me. And hear in Panama I do live in a city, but like, go to the park and see the forest, the trees, that doesn't work. It's great but not for me.

Bill Gasiamis 40:39

Not for you. Yeah, it's great. Whatever, everyone's different. That's the beauty of this, it doesn't have to be the way that somebody else did it. And that's what's good about you making the recovery the way that you prefer, you know, because if it's, if I'm trying, if you're trying to recover the way I prefer, that's not going to be useful, that's not going to be supportive.

Bill Gasiamis 41:02

And isn't it interesting that you hear a lot of talk about mindfulness about going in about meditation, and how important that is for a lot of people. And it is important because it is helpful, but for you, you can't go there? Is your mind is racing? Or it's too quiet? Too still? What is it that's unsettling for you about that?

Carolina Aguilera 41:28

So I'm my worst nightmare. So the noise, I'm creating the noise. So that was not helping at all. So usually, those two options that I mentioned, make you create the

silence, but I never was able to reach there. So let's say for my therapy, and in terms of my mindset, my psychological and mental health.

Carolina Aguilera 41:56

Instead of trying to make it quiet, we always try to accept it, that it's okay that I had the noise that I am always, maybe using that negative part. But accepting that it's there using it more as a fuel, instead of making it stop me. So I mean, it's been two years. So it's a lot of work, instead of trying to, maybe that's something that I never felt related with, that you need to see the positive side of things and trying to maybe accomplish or focus more on that.

Carolina Aguilera 42:35

For me, the path was I do have the noise, I do feel angry, I do feel sad. It's never going to go or at least not right now. But I'm going with it. And that's my partner at some point. And it's to find a way to live with it. And this is the funny part because not only the disability, everything physical, that is the challenge that you mostly focus on. But understanding that also how you work how my mind change from before and after.

Carolina Aguilera 43:13

And the challenges of talking with someone making the difference that how your energy is always drowning, with some, activities. And besides that, of course, exposing yourself, it's really difficult, whenever you have that noise in your head that maybe they are seeing how I'm doing or, or you know, all the things that go through your mind, especially during the recovery. So that was a tough one.

Carolina Aguilera 43:51

Accepting that part, there's always a payment on everything that I was doing. I mean, the process of accepting that I had the noise, that it had all these challenges that I needed still to continue, but not only with my physical things, but my thoughts that was not helping. As I mentioned, my hand how I was always angry.

Carolina Aguilera 44:23

So at some point, it's making the decision that you're still going to be doing your work on the recovery. And now you have this amazing partner of yourself telling you bad things. So yep, now it's your decision what are you going to be doing? Are you going to stop yourself or are you going to still do it? Are you gonna still

go out? I don't know that's always the challenge.

## **Managing Your Emotions**

Bill Gasiamis 44:55

Yeah, I like what you said about what you're doing is you're recognizing that you have these emotions, happiness, sadness, anger, frustration, and they are all just part of your life every single day, they're part of everybody's life normally.

Bill Gasiamis 45:12

And what you're doing is instead of letting them define you, or letting them control you, what you're doing is you're using those emotions to channel them in a direction that is going to be supportive and useful for you. And it sounds like, for example, in Pilates, it's, you need the challenge, you need somebody to tell you, we're going to do this, and you have to challenge yourself, and you have to push yourself and you have to go further.

Bill Gasiamis 45:40

So it sounds like you're channeling that energy from those emotions into this thing, which is getting you a good outcome at the end. And at the same time, you're not making yourself feel bad about having emotions that are not always supportive, like anger, or frustration, you're just going well, I'm a person, and I'm experiencing these emotions. And I'm not going to worry about them or stress about them, I'm going to accept them. And I'm just going to use them in a positive way, even though they appear to be a negative emotion.

Carolina Aguilera 46:15

I think it's a lot about the perception that they were usually bad emotions, nothing is bad, but you should not be feeling or focusing that much. If you're trying to recover. I don't know if you have experienced that, that you need to be positive during your recovery, you need to think positive, you need to think that you're gonna overcome it. And definitely the words that people often tell you, it's not that they do it with a bad intention.

Carolina Aguilera 46:52

But it's just the norm, I guess, that they prefer to tell you that everything's gonna be okay, that you need to be patient that you need to see the positive. But for me, it was making me feel angrier all the time. And I guess for anyone who is feeling

that way, it's not bad, not good. But it's what works for you. Right?

Bill Gasiamis 47:15

Yeah, I certainly didn't appreciate when some people told me to be patient. Because I'm not sure what that means. How do I be patient, I can't walk, I can't use the left side of my body, I can't remember who came to visit me. You know, it's a bit difficult to be patient for all of that stuff to come back.

Bill Gasiamis 47:35

It makes sense now that I look back on it, patience would have been supportive. But at the time, I didn't know how to be patient. At the time, I was new to not knowing why my left side of my body doesn't work? You know, I'm brand new at it. I didn't have 37 years of experience of not knowing how to use my left side of my body that just happened overnight.

Bill Gasiamis 48:01

After brain surgery, I couldn't use my body. So I'm learning about it. At that time, I'm trying to learn what does this all mean for me? How am I supposed to exist in the world with half of my body not working that for 37 years did? What do I do now? How do I be me? And how do I go about business?

Bill Gasiamis 48:26

But not only that is I'm learning about how to ask for help, what kind of help I need to ask for. And when I want to go to the toilet, and I can't go there on my own patience isn't going to be helpful. It's something else that's going to be helpful. It's determination, maybe it's anger, put in the right direction, or maybe it's something else but I was in the toilet calling the nurses.

Bill Gasiamis 48:55

I was in my hospital bed calling the nurses to come and help me but because they were busy, they weren't able to come. I couldn't be patient with them. I dragged myself with half of my body out of my bed into my wheelchair and tried to push myself to the toilet until they finally came and saw me on the way to the toilet. And they told me you can't get out of bed. You can't do this type of stuff. It's too dangerous, etc.

Bill Gasiamis 49:23

And I said, Listen, I don't know about you. But I did not want to be in a position where I couldn't hold on any more. I had to go. And if I have to go and you don't

come, I have to find the way to do it. And I can't be patient for you to come and see me so I understand what you're saying about patience. It's not necessarily always essential to 100% of the time be patient because other people prefer you to be patient.

Bill Gasiamis 49:56

Right now I don't prefer to be patient. I prefer to be impatient and angry and crazy mad and all these things, and if it helps me to achieve something. And that's the only place I know to go, to get energy to achieve this thing, I'm going to go there. And if it's not the right thing to do in the long term, if it's not going to be the right way to do things in the long term, I'll stop doing it at some point in the future, and I'll find a new way. But right now, it's also new. I'm so overwhelmed and frustrated by this new version of me. Impatience is the only way.

Carolina Aguilera 50:40

You mentioned something so important. That I will find later, maybe after a year that I didn't like the part that we are strong. I consider we are survivors, we adapt to every day. And again, we were some way before. Now we need to adapt to what's happening. And definitely in our recovery.

Carolina Aguilera 51:06

There are so many changes, ups and downs, that for me, the word that describes us is survivor, we just adapt to what's happening. And what you feel, what you use to get to that point. And again, if it's healthy for you, it's the way that works for you. It's okay. But it's about finding the way, that that's the way to define your recovery process.

Bill Gasiamis 51:35

Yeah, finding the way, I agree with you, and me, I wasn't strong all the time. Sometimes I was physically very weak. Mentally, I was very weak, emotionally, I was very weak. And I'm not sure if I take the word of somebody who comes to see me, "you're so strong, you're gonna get through this." I'm not sure if that's always supportive to hear that I'm so strong. Sometimes I want to hear "sometimes you'll be strong, sometimes you'll be weak."

Bill Gasiamis 52:07

Sometimes you'll be frustrated, sometimes you'll be all these things. It's more accurate than I'm so strong, and I don't want to be strong. When I feel emotional

and want to cry. I want to cry, I don't want to stay strong and pretend that everything is okay. And make you feel happy or make you feel okay that I'm doing okay. Sometimes I want to cry. And if that makes you feel bad. Sorry. That's your problem. I can't do anything about that.

Carolina Aguilera 52:38

I get it. Definitely, I don't know. I understand the feeling. I've been there. And maybe it's because I'm so close to them. But in my recovery, it was me doing both the physical work, the mental work, but there's my family, my core, that were still around me that at some point, if you're recovering, you're fortunate to have one person close to you. So it's definitely the communication on that side is going to be a key point to it.

Carolina Aguilera 53:17

It happened to me, and I'm grateful for it. My support system, were able to identify what I needed at the time. Because definitely, it was not all the time that I was angry, all the time that I was trying to find that solution. But they were able to find this balance I took with me to bring that push or that medicine what I needed at the time.

Carolina Aguilera 53:46

So definitely if you're feeling sad that time they were able to find a way to either be there with me, or, I think of this funny story one time, my sister told me "okay, you want to cry, go cry five minutes, come back, let's find a solution." So it's a journey that you are not alone. And if you're grateful to have a person that is with you, that you are able to communicate to find that balance, because definitely you're going to need it.

Bill Gasiamis 54:20

Yeah, I love what your sister said it's about going through that emotion for a little bit of time, getting it out of your system, and then refocusing and seeing if we can focus on the solutions rather than the problems. Stroke Survivors can sometimes focus on all the problems because there are a lot of them for a lot of people. So it's understandable, but focusing on problems is just going to give you more problems.

Bill Gasiamis 54:44

And I feel like focusing on solutions. Most of the time, will give you more solutions

than you knew were available. Because sometimes we don't know what's available when we have focusing on problems because man there can be so many after stroke. And then you've used your energy already focusing on all the problems, that you don't have any energy to focus on solutions, that's the other thing.

Bill Gasiamis 55:11

So you really have to be careful with where you put your energy or the majority of your energy. And for me, it was definitely on solutions. But in order to have solutions, you need to know what your problems are. So it's okay to know that they are there. But which ones are the most important ones right now is the most important problem that I can't work? Is it that I can't stand?

Bill Gasiamis 55:37

Is it that I can't drive? What is the most important problem and which ones are we going to start to work towards first, so we can achieve a few goals. And then keep going forward, instead of finding the biggest problem trying to solve that one, and then not having any success, and then feeling a bit bad about everything.

Carolina Aguilera 56:03

Great. And definitely, we need to know, our limits, our energy, and it's about the decision of where you're going to focus. I think with time you get an expert on making that choices. So everyone who is a newbie in the stroke recovery, then you're going to be making those rash decisions. And I want to try to walk just on the first day, or trying to push yourself.

Carolina Aguilera 56:33

So definitely the first step is knowing that limit, knowing that you're going to make the decisions every single day. And it's your energy. So it's about what's going to work for you. Yeah, so definitely, that's our days. And the sooner you accept it, the sooner you embrace what you can do, instead of what you can't. That's gonna be the key for a healthy recovery.

Bill Gasiamis 57:04

A little earlier, I think you mentioned the church and becoming more involved or helping out at the church what kind of involvement you have there now and how has that helped you and supported you to go to that space?

# Renewed Faith After An AVM

Carolina Aguilera 57:44

So those were one of the things that I did without thinking. It's not like I planned to go maybe deep or having more interaction. But definitely whenever we have these accidents, you get mad and you start thinking why this happened to me, if you believe in God, why did you make this my life and for some reason I had that hole in me that I was knowing that something was missing.

Carolina Aguilera 58:20

I thought of when I was feeling better in the previous years, so it was definitely when I was closer to God, to my community, going to church, so I decided that maybe this could help me a little bit more. So there are several, I don't know how to say it in English. After the baptism, you need to go through several stages. So I was spending the last one where you reconfirm your faith.

Carolina Aguilera 58:53

And you say yes, I believe in this and I believe in my church, so that's what the process that I did. And it actually helped me connect a lot with people having been in lockdown, just focusing on work, I didn't have that many connections, beside my friends, really close friends. So I was not exposed to telling someone that I didn't knew me from before what happened.

Carolina Aguilera 59:27

So that was kind of a test or a really great experiment that turned out in great. So they encouraged me to either help in terms of different groups. If you wanted to make donations if you wanted to help. Here, mainly they were building these bags of food for people who lost their jobs, that was one option. And that's when I discovered that I was the one that was holding me back.

Carolina Aguilera 1:00:03

So I stopped from going to several of these things, because I thought that I was going to slow them down. Because my hand was not working, that I couldn't help that much. So I tried to find other ways, definitely connecting with some other members that were having struggles. That was one of the things I found out about this lady who had a stroke before, she's older than me. So I connected to what she was doing at the time, given this type of support.



Carolina Aguilera 1:00:38

And definitely, I had this group of people that we try to make either donations or do something regularly. And not only with them, but with my family. Doing an activity with some kids in like community, a little bit far. But we give them support during their days. And they're usually families with a lot of violence. So we did something silly as a Christmas party, so they were able to go there enjoy giving them gifts.

Carolina Aguilera 1:01:21

So that was a really awesome experience, even with my hand trying to build this little gifts for them. So those are the things that definitely it's creating that connection. And not only connection with people with your present, knowing that you're doing something else, and it's meaningful.

Bill Gasiamis 1:01:49

It sounds like you reconnected with your people. And you found a way to overcome some of your own negative self talk. At the same time, you found some amazing sides of the experience of helping other people and doing things for other people that were less fortunate, especially during lockdown and all the challenges that the country was facing and all your community was facing at the time. So that sounds like it was very rewarding and supported your recovery.

Carolina Aguilera 1:02:28

Yes. And actually with them, they were the first one who I told what happened, that didn't know me. So at least personally, that was one of the most amazing experience. I was not expecting the outcome from that, standing in front of everyone and telling them I'm a stroke survivor. I don't even remember the emotional part of it. I am trying to find my way and having people to welcome you back. And definitely that's really credible and not only rewarding, but you feel the appreciation and the love of everyone.

Bill Gasiamis 1:03:22

It sounds like it's been an interesting journey. And hopefully it's going to be a journey of growth for you, going forward from here on. It's only been a few years. So I hope your recovery continues. And I really appreciate you connecting with me to share your story. Congratulations on everything that you've done so far. And thank you so much for being on the podcast.

Carolina Aguilera 1:03:46

Thank you for having me. Thank you. It's really great what you're doing, you actually got to inspire some someone in Panama, all the other way around. So it's really amazing. Thank you.

Bill Gasiamis 1:04:02

Well, thank you so much for joining us on today's episode. To learn more about my guests including links to the full transcript of the entire interview. Please go to [recoveryafterstroke.com/episodes](https://recoveryafterstroke.com/episodes). If you would like to support this podcast, the best way to do it is to leave a five star review and a few words about what the show means to you on iTunes, or Spotify.

Bill Gasiamis 1:04:28

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Bill Gasiamis 1:04:50

And that may make a massive difference to someone that is on the road to recover after their own experience with stroke. Thank you so much again for being here and listening, interacting, leaving reviews and loving my show I really appreciate you, see you on the next episode.

Intro 1:05:09

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Intro 1:05:26

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Intro 1:05:48

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Intro 1:06:03

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Intro 1:06:28

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