# Losing Appetite After Stroke -Tamare Orilus

Losing your appetite after a stroke is a very rare condition that only affects very few stroke survivors. Tamare Orilus has had no appetite for 9 months and lost almost 100 pounds but is now ready to eat again.

#### **Socials:**

www.instagram.com/bklynbosslady1/

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### Transcription:

#### Bill 0:00

Is it a good thing that you lost your appetite? And I'm not trying to be funny or smart or anything about weight gain and weight loss or anything like that, but I'm just curious, like, how have you taken it? Are you seeing it as a thing that you would prefer not to be going through? Or what's that, like?

#### Tamare 0:18

It's a good thing for me to lose weight, but I'm like, it's almost a year. I'm gonna get some kind of upside back. You don't get enough, I lost over 90 pounds. So I'm ready to eat now.

#### Intro 0:38

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

#### Bill 0:52

Hello, and welcome to recovery after stroke, a podcast full of answers, advice and practical tools for stroke survivors to help you take back your life after a stroke and build a stronger future. I'm your host three times stroke survivor Bill Gasiamis.

#### Bill 1:06

After my life was turned upside down, and I went from being an active father to being stuck in hospital, I knew if I wanted to get back to the life I loved before my recovery it was up to me after years of researching and discovering I learned how to heal my brain and build a healthier and happier life than I ever dreamed possible.

#### Bill 1:26

And now I've made it my mission to empower other stroke survivors like you to recover faster, achieve your goals and take back the freedom you deserve. If you enjoy this episode and want more resources, accessible training, and a hands-on support, check out my recovery after stroke membership community created especially for stroke survivors.

#### Bill 1:47

This is your clear pathway to transform your symptoms or reduce your anxiety and navigate your journey to recovery with confidence head to recoveryafterstroke.com To find out more after this podcast.

### Introduction



#### Bill 2:01

But for now let's dive right into today's episode. This is Episode 149. And my guest today is Tamare Orilus, who had an AVM rupture that amongst other things caused her to lose her appetite and shed almost 100 pounds Tamare Orilus welcome to the podcast.

Tamare 2:20

Hi.

Bill 2:22

Thank you for being here. I really appreciate it.

#### Tamare 2:24

Thank you. So I had an AVM in my head, September 5th 2020, I had three surgeries. I had a Shunt put in on my right side of the head. So I'm still going to therapy. I'm doing speech OT and PT twice a week. I've no appetite still it's a litle bit better, but not as before. I lost a lot of weight. I was 245 and now I'm 152.

#### Bill 3:11

Wow. So how did you first discover that? There was an AVM in your head? What were the symptoms that you were experiencing?

#### Tamare 3:22

Actually, it was a Sunday morning I woke up. It was my day off. I had a headache. bad headache in the back of my head. I told my husband I'm having a stroke.

#### Bill 3:37

You told him straight away. You were having a stroke? You knew?

#### Tamare 3:40

Yeah. And I just know. And I never had a stroke before. So I told him call 911 I'm having a stroke. He said what do you mean? I said I'm having a stroke? So he called 911 they were scared to come because of the COVID-19.

#### Tamare 3:58

So I talked to them. I told them I'm a member of service. I work for the city. So finally they came. They took me in, and that was the last, when I woke up was October 30.

#### Bill 4:14

So when did the stroke happen? What month?

Tamare 4:20

September 5.

Bill 4:22

You woke up almost two months later was the first time you woke up?

Tamare 4:27

Yes.

# Tamare Orilus - Waking Up After A Coma

Bill 4:28

Wow. That's dramatic. So you had a headache and you told your husband you're having a stroke. He called 911 eventually. And then they eventually sent somebody along. And then you woke up two months later. When you woke up, did you know what happened? Did you remember anything? What was that like?

#### Tamare 4:52

I was having a lot of dreams. My husband said they put me to sleep once they knew I was bleeding in my head. And then, I was dead. My husband told me everything that happened to me. I was like, oh my God.

#### Bill 5:17

So you had to be told what happened? Did you understand the situation that you had found yourself in that when you woke up? Or did that take some time? Was it a little bit difficult to grasp the concept?

#### Tamare 5:33

Well, my husband told me what happened. I had a stroke, and a bleeding in my head. So I took everything.

#### Bill 5:43

And did they operate to remove the faulty blood vessel? How did they deal with the AVM?

#### Tamare 5:49

Yeah, I had three surgeries. I had (inaudible) and I had two other surgeries, so they removed the blood. But, I came home. I'm doing therapy. But some time in November, I had to go to a hospital because I had an infection. When I got to the hospital they said I had UTI. And then a week before thanksgiving I came home ever since I've been okay so far thank God.

Bill 6:27

How old were you at the time?

Tamare 6:30

I was 44. So I had the stroke on September 5th and my birthday was September 19th. So I spent my birthday in the hospital and my kids I have a boy and a girl.

Bill 6:52

And how old are they?

Tamare 6:56

At that time, they were 15 and 20. The boy 15, the girl 20.

Bill 7:04

And how did they deal with mom being in hospital for nearly two months recovering from an AVM bleed.

Tamare 7:11

Well my daughter said she cried a lot. And then my son told me the same thing. And, my husband quiet all the time. He said everyday he was fine. But they're just thankful I'm here.

Tamare 7:29

But I'm going through it.

Bill 7:32

How long ago did that happen to you Tamare?

Tamare 7:37

Nine months ago.

Bill 7:39

Okay, so you're very early on in the recovery. What kind of things did the AVM surgery and the shunt and everything that you experienced? What did it leave you with? What experiences in your body are you still recovering from physical and so on?

Tamare 7:59

My left hand is shaking, shaky when I wash the dishes, then my appetite. I have no appetite.

Bill 8:08

You have no appetite?

Tamare 8:12

Right. And basically that's it, I had problems with my right leg, but it's fine now. So it's just my hand shaky and my appetite really right now.

## **Post-stroke Deficits**

Bill 8:26

Do you have muscle weakness in the hand? Is it just shaky?

Tamare 8:30

Just shaky.

Bill 8:36

That doesn't stop you from doing anything. Does it interfere with your daily activities?

Tamare 8:41

No, I push myself to do things, I take a shower by myself, I get dressed. I try to clean and do everything by myself. I push myself to things because I wan't to be better.

Bill 8:57

It's part of your rehabilitation. Do you feel like doing these things and pushing yourself a little bit? Are you doing it to help you with the rehabilitation process?

Tamare 9:07

Yeah I do it for rehab. I get sad sometimes.

# **Losing Your Appetite After Stroke**



Bill 9:20

Is it a good thing that you lost your appetite? And I'm not trying to be funny or smart or anything about weight gain and weight loss or anything like that, but I'm just curious, like, how have you taken it? Are you seeing it as a thing that you would prefer not to be going through? Or What's that like?

#### Tamare 9:40

Well, it's a good thing for me to lose weight, but I'm like, it's almost a year. I want to get some kind of upside back. I don't get enough I lost over 90 pounds. So I'm ready to eat now.

#### Bill 9:59

So, when do you eat? You must be eating because you're alive. Thank God but I know I understand you're eating less you don't have an appetite but how do you go through that process to stay nourished and to stay alive?

#### Tamare 10:16

So my husband he does drinks for me. In a blender he does fresh fruits. Like watermelon strawberries, bananas, and I'll drink. I take a lot of vitamins.

#### Bill 10:32

Okay, and are you able to swallow and chew regular food? Is that still okay?

#### Tamare 10:38

Yes I'm able to drink, swallow, everything's good. It's just, I cannot smell, I cannot taste or no appetite.

#### Bill 10:53

Okay, so you also can't smell and taste and there is no taste? Does that mean that there's nothing there's no feedback. So there's no you don't know if it's salty or unsalty or spicy?

Tamare 11:07

Right. No taste at all.

Bill 11:11

So you don't feel chilli or anything like that?

Tamare 11:15

No.

Bill 11:17

I know it's strange and odd. But how do you reconcile that? Is that bizarre and weird to you? Does it make food not edible? Or how does that work?

Tamare 11:28

Well, if you can't smell, you can't taste. You can have no ability to eat. You don't have the urge to eat. So sometimes I push myself to eat, but I feel gaggy like I want to throw up.

Bill 11:44

Do you want to throw up because the experience is not pleasant?

Tamare 11:53

It's not pleasant.

Bill 11:57

Wow. And has it changed at all since you woke up after the surgery and the bleed? Has it changed at all? Or is it still remained the same? That lack of sense of smell and lack of sense of taste? Is that still the same?

Tamare 12:13

Well before I used to smell really bad the food and stuff but now. I just don't smell anything.

Bill 12:25

Does it stop you from cooking and preparing meals? Or is it just the eating?

#### Tamare 12:31

I haven't been cooking yet. Because of the shakiness. I'm still waiting. I haven't been cooking or driving. I'm waiting after the 1 year anniversary.

#### Bill 12:50

Okay, so do you need to get permission from your doctors to go back to driving?

#### Tamare 12:55

Yeah, my neurologist told me to wait for one year to drive.

#### Bill 13:00

Okay. So they've resolved the problem in your head as in, the AVM is not going to bleed again. It's not going to cause problems again, because it's been dealt with?

#### Tamare 13:10

Yeah, that's what they said. I should be good. They did another MRI. And they said everything was okay.

#### Bill 13:20

Yeah, so now it's basically about recovering and getting better and healing the brain is right?

#### Tamare 13:26

Right and I have another appointment in September 21. So they could check my head to make sure everything's good.

#### Bill 13:38

Yep. How does the rest of the recovery look? Are you experiencing fatigue? Are you having cognitive issues at all? Do you have any other challenges?

#### Intro 13:50

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be? You're likely to have a lot of questions going through your mind. Like how long will it take to recover? Will I actually recover? What things should I avoid? In case I make matters worse?

#### Intro 14:07

Doctors will explain things that obviously you've never had a stroke before. You probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery. If you're finding yourself

in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you.

#### Intro 14:30

It's called the seven questions to ask your doctor about your stroke. These seven questions are the ones bill wished he'd asked when he was recovering from a stroke. They'll not only help you better understand your condition. They'll help you take a more active role in your recovery. head to the website now recoveryafterstroke.com and download the guide. It's free.

# **Tamare Orilus - Post-stroke Fatigue**



Tamare 14:53

Oh yeah, like I'm out of breath a lot. Like if I (inaudible) I'll have to go lay down after to take a nap because I get tired I feel exhausted. But I don't know how long this is going to last. Everything I do after after I have to go lay down to rest. But I've been reading a lot. I see people run marathons. I'm like, how do they do it? I'm always tired?

#### Bill 15:27

Well, I've got an idea for it. I think they're crazy people, firstly, for running marathons. Because, only crazy people run marathons, but I love that they are doing it. I think everyone experiences stroke differently, and what you're talking about the fatigue I can relate to, I had serious fatigue for a long time.

#### Bill 15:47

And when I was doing anything minor or major, I had to plan for rest time after

that, whether it was going somewhere and visiting some friends or going to dinner, or just doing some chores around the house. Anything that I did, always had to have some rest time afterwards.

#### Bill 16:09

And I started to get used to planning my day like that. So I knew that if I was going to go to an appointment, to see my doctor, or to do rehab, outpatient rehab, then I was going to come home, and I was going to do nothing for a couple of hours. So it does get better, the fatigue does get better. But sometimes the fatigue is still a problem for me, even nine years later, it still causes days where I can't do anything.

#### Bill 16:35

And where I need to rest and rest and rest. And majority of the days are better. And the majority of the days I'm quite active. But I wasn't at the beginning. Also, I was like you is just extremely tiring to do anything. A lot of stroke survivors say the same thing. And the people running marathons are typically not running marathons nine months after the stroke.

#### Bill 16:59

Most of them are not getting back to being that physically active that quickly. And that's one of the challenges with social media, and even this podcast. It's very hard to tell the whole story. And you just see what a stroke survivor is doing in a snapshot on one part of the day. And people make assumptions "my god, they're running a marathon how can I get to that point? How did they get this so quickly?"

#### Tamare 17:25

Yeah, that's what I'm like, Oh, my God, marathon? I can't even think about marathon. Like before this meeting I had to take a nap before I got on. Because I need my rest.

#### Bill 17:41

Your voice you mentioned to me that your voice is a little bit different than what it used to be.

#### Tamare 17:45

Right?

Bill 17:46

What caused that?

Tamare 17:49

The stroke, It was worse before. When I had the stroke. It was getting very tired of speaking. But now my tongue is just heavy.

Bill 18:03

Your tongue is heavy?

Tamare 18:06

So yeah, it got better though. It was worse before.

Bill 18:14

So there seems to be a lot happening there with your nose, your taste your tongue, your speech? It all seems to be connected.

Tamare 18:21

Right? Exactly.

Bill 18:24

But you're noticing that it is getting better after time. So it's nearly been nine months. Almost we're coming on to.

Tamare 18:31

I know but 9 months is a lot.

Bill 18:35

You feel like it's too long to recover? Is that because you're an impatient person? Or why?

Tamare 18:45

Maybe because I'm impatient.

Bill 18:48

Yeah. And you want to get back to regular life. You want things to be better. But you've come a long way right? You probably weren't speaking like this. Eight months ago. Would that be accurate?

Tamare 19:01

Yeah, you're right.

Bill 19:05

Do you ever look back on your recovery? And see, perhaps some videos of you in a hospital or some photos? And do you ever look back and go well, actually, I've come a long way. I've recovered quite a lot. And I'm getting better every day?

Tamare 19:19

Yeah, my family told me to look at some pictures and see I came a long way, I'm here for a purpose.

Bill 19:27

Yeah. And your kids are they're making life easier? I remember when I had the stroke. My kids were teenagers. They didn't make my life easier. Yeah, they made it harder. How are your kids doing?

Tamare 19:38

My son is very helpful both of them they're good they're very helpful. Thank God.

Bill 19:46

Yeah. Are they still themselves though or have they changed their behavior around you? Are they are they still themselves?

Tamare 19:57

Well my daughter still goes away but my son, he's here with me. He's always looking out for me. Mom don't cry it's going to be okay.

Bill 20:09

Yeah. What's the hardest part of all of this for you? What have you had to deal with? That's been the hardest that you didn't really expect.

Tamare 20:21

Being tired.

Bill 20:30

That's okay. Being tired, so what was life like before the stroke? Were you a very active person when you're working? What were you doing before the stroke?

### Life Before The Stroke



Tamare 20:42

I was working. I was very active, I was having brunches at my backyard. I was doing barbecues. I was doing everything now just nothing.

#### Bill 21:07

Is it difficult to explain to people what you're going through and what you're experiencing? Are they finding it hard to appreciate that or understand it?

#### Tamare 21:15

Some people don't understand. But it's just hard for me to grasp.

#### Bill 21:31

It's hard for everybody that goes through the experience of seeing one of their loved ones have a stroke. But in also, for the stroke survivor, there's no doubt about it, that it's hard. The thing about it is, is that I feel like, the only advice I can give you is that it's going to get better.

#### Bill 21:55

And you just have to give it time and this thing, you have to give it more time than anything. It's not like a broken toe or an injured hand. It takes a long time, because the brain is very complex in the way that it heals. And it's often the brain is often always easily made to feel worse.

#### Bill 22:19

So it's sensitive. And as a result of that sensitivity. We can very easily give

ourselves a hard time and create a setback. Do you know what I mean? But have you noticed that your fatigue and your setbacks are getting smaller and shorter?

Bill 22:36

Because at the beginning, it would have been very difficult, but the timeline should have decreased those setbacks and your recovery time should be increasing or should be getting quicker. Do you notice that?

Tamare 22:50

Yeah, I do notice. I do notice a lot of changes. I used to waste it before. But I'm getting better as time goes by. It's just the speaking it bothers me.

Bill 23:08

The speaking bothers you because of the difference in your voice and the way that it's different to speak in the way your tongue feels?

Tamare 23:15

Right, right.

Bill 23:19

Has the COVID locked down, and all those things made it harder to access services.

Tamare 23:26

Well, actually I go to PT, I go to OT, I do zoom speech.

Bill 23:36

So Zoom speech therapy, and then you go to OT, occupational therapy, and PT. So that happens at a location outside of your home?

Tamare 23:49

Yes.

Bill 23:50

And how often are you doing that?

Tamare 23:53

Doing twice a week, OT and PT. I'm doing Speech Zoom once a week.

Bill 24:03

So do you appreciate being able to speak like this on a podcast? Does that help with your recovery?

Tamare 24:12

Well, before I had the AVM I never heard of AVM before. Yeah. So I just wanted to come on because I want it to be out there. AVM, cuz a lot of people don't know about AVM, I didn't.

Bill 24:28

Yeah, it's very common. Arteriovenous Malformation is what it stands for. It's supposedly quite rare. But the amount of people that I've met has been a large number of people. I've been blown away. And I of course also didn't know what an AVM was beforehand.

Bill 24:46

Have you had some conversations with your husband? about your experience and was there some real difficult conversations there? What was that like? How did it impact you guys?

Tamare 24:59

Well I tell him alot, I told my sister she's an NP Nurse Practitioner. So she understands what the AVM. So I talk to them alot about AVM.

Bill 25:19

Yep. So you talk to your sister. I think your sister contacted me on Instagram. She wanted to see an interview live, but it's pre-recorded. So we'll get a copy to her. When it's ready to go. So it was Miriam. Is that your sister?

Tamare 25:41

Yeah.

Bill 25:43

So she's been really good. And I imagine a really great resource during this time?

Tamare 25:48

Yes. She told me alot of information about this. AVM she's really good.

Bill 25:59

How's your memory after all of this? Is it okay, or are you struggling sometimes?

Tamare 26:05

My memory was bad before, but it's better now.

Bill 26:13

It was bad after you woke up?

Tamare 26:16

Yeah.

Bill 26:20

But it's better now. So what kind of work were you doing before the stroke?

Tamare 26:30

Okay, so I was a Correction Officer. So I work on Rikers Island.

Bill 26:41

So that's a tough job.

Tamare 26:42

Yeah. But I'm gonna do early retirement.

Bill 26:49

Yeah. That's a difficult career, and therefore it's not an easy career to go back to. Is that right?

Tamare 26:55

Yeah. Some people asked me to go back but I don't want to, too stressful.

Bill 27:05

And is being a correction officer easier or harder than being a stroke survivor?

Tamare 27:14

I feel it's stroke survivor. Cuz I never did it's my first time to experience this so I'm new to this.

Bill 27:25

Hopefully it's your last time too. Of course. You're a tough lady, though, to be able to work in a corrections facility and deal with all the stuff that goes on in the place like that. Do you do learn some skills from that job that you can bring into your stroke recovery? Is there a way that you can transfer what you've learned

there into the way that you recover?

Tamare 27:53

Just to be a strong person, consistent that's it.

Bill 28:01

Just to be a strong person, and is it okay for you to not be strong sometimes? Do you have times where you can't be strong where you've had enough?

Tamare 28:13

A lot of time. I cry, why me? You know?

Bill 28:23

Did you seek out any emotional counseling or psychological counseling since then?

Tamare 28:30

Yeah. I was having depression, anxiety attacks. So I used to go for a walk in the park. So now like every two weeks. And I'm on pills to sleep at night.

Bill 28:56

Yeah, what do you think was behind the anxieties anxiety of another episode? Or, you're not certain what the anxiety is about?

Tamare 29:06

I just felt hot, I need some air. It just came on. I've never had that before.

Bill 29:20

Does it feel like a buddy gets overwhelmed and you need to get some fresh air and you need to move and go outside? Is that where you get that from?

Tamare 29:32

To go out and stuff like that.

Bill 29:36

And then it dissipates and it gets better quickly, or how long does it take to recover?

Tamare 29:41

Well my husband takes me to the park, I walk, and I come home then I feel better.

But now I'm on medication every night. I take towards sleep to calm me down.

Bill 29:58

Medication is anti-anxiety medication to help you sleep or is sleeping tablets to help you sleep?

Tamare 30:06

Anti-depressopn pills.

Bill 30:08

Okay. And that's the first time you've been on that type of medication?

Tamare 30:19

Yes. Well, my sister told me I was on that when I was in the hospital, but I don't remember.

Bill 30:26

Right. Okay. So these are all new challenges for you. You haven't been on this type of you haven't had this type of experience at all before. Did you take any types of medication beforehand?

Tamare 30:40

No.

# **Psychological Issues**

Bill 30:41

Yeah. And is that the entity depression medication because you're feeling emotions that are full of sadness? Or what's the reason behind that? Do you know?

Tamare 30:56

Sadness. I'm feeling sad. I'm thinking too much. Yeah, sometimes I feel something in my my throat. But I know it's in my head in my head.

Bill 31:14

You feel that sometimes it's in your throat, did you say?

Tamare 31:17

Yeah, like, I have food in my throat blocking me from eating? But I know it's on

my head.

Bill 31:26

Okay, so there's some kind of a loop happening of connection. That's telling you that there's something interfering with you here and therefore, that plays on your mind. And you overthink that?

Tamare 31:40

Yeah.

Bill 31:40

And how do you find yourself getting out of that loop? What happens that you eventually stop thinking about it and you get over it?

Tamare 31:48

Sometimes, I just go and lie down, take a nap.

Bill 31:55

Okay, does that explain why your husband makes a lot of smoothies or, or liquid type of foods? Is that why? Because of this situation where you're feeling like things are getting stuck?

Tamare 32:09

Yeah. Sometimes I tell him to make me a little drink so I can feel better.

Bill 32:21

So what are you hoping to do on this podcast? What's the point of being on this podcast? I know that I reached out to you and asked you to come on and share your story. I was very curious to meet you because you said that your issue was one of the issues that was the inability to eat and no appetite and no smell and no taste.

Bill 32:48

That was the reason why I contacted you. I'm sure there's a lot of stroke survivors going through that. But what are you hoping to get out of this? Is it somehow therapeutic to be on an interview podcast? How does it help?

Tamare 33:06

Yeah, like I was saying before, a lot of people don't know about AVM. So I'm gonna, you know, put it out there. That God forbid this could happen to you you

know, you never know. Cuz I was fine. On Saturday I was fine, and then Sunday, This happened to me.

#### Bill 33:30

Yeah. Just Just out of nowhere.

#### **Tamare 33:32**

Out of nowhere, Saturday, I got up. I went out, I went to eat and came home, cook, went to sleep and then suddenly went this is it.

#### Bill 33:47

Before the stroke or before the first bleed, do you recall at all had you ever had any signs that maybe there was something wrong with your head? Any bad headaches, any difficulty? Anything like that?

#### Tamare 34:02

Well, I had the headache in my left side. They had called neuralgia. They say I had bad so I was taking medication. But that was that. They did an MRI but they never told me anything was wrong. But my children told me told my husband I had this for a while. It was waiting to rupture. They said I could've sneezed and it would've burst in my head.

#### Bill 34:42

You've had it since birth. Actually, you're born with these things. In the head since birth, and they are quite rare compared to the people in the population that had them. There's not a lot of them. But you were born And then from a lot of people, nothing happens, it doesn't actually do anything.

#### Bill 34:46

So a lot of people might have one and not know that it's there. And it may never burst. Yeah, but for the lucky ones like you and me, yeah, it decides to rupture for some reason, and then cause those issues. And what I've found is a lot of the stroke survivors I've spoken to that had an AVM have been between the ages of 30 and 45, and 50.

#### Bill 35:30

Somewhere there. So there's this window. In later in midlife, I suppose best way to sort of describe midlife, you know, around that age, somewhere around 40, where they rupture for a lot of people, there's, that's a very common thing that

I've found.

Tamare 35:50

Wow.

#### Bill 35:52

And lots of people, you know, struggling with and overcoming it and finding it difficult because they've never been in this situation before. They never knew about it, they never understood. But what I'd like to tell you now that we're chatting, tomorrow, and you're on my podcast is that you're very early on.

#### Bill 36:14

And I know that impatience is one of those things that we all go through, but you are very early on in your recovery. And based on what I'm hearing, and how we're chatting, I feel like you're going to come a long way. And it does get better. And I'm nine years out speaking like this, but of course, I wasn't speaking like this nine months out, nine months out, I didn't know who had come to visit me my memory was terrible.

#### Bill 36:43

I couldn't work, I couldn't drive. I couldn't talk like this on a podcast for such a long time. I couldn't exercise. You know, fatigue was really, really bad. So it was a lot harder nine months after my stroke after being released from hospital than it is today. But that's the most important thing that I need to share with you is that I've been doing this recovery now for nine years, and I have a lot more symptoms, than you have.

#### Bill 37:18

It's a long time. Yeah, it doesn't ever really stop, you know. And it gets better, though. Like, it's definitely better. It's not as bad as it was. And I don't feel as terrible as I did at the beginning. So that's really my message, I really want to make sure that you understand that. And hopefully that makes you feel a little bit better about this better days ahead.

#### Bill 37:41

And that you will get better and better every single day. And at some point, you'll look back and you'll go well, I've come a long way further and further than I ever thought, you know, your speech will improve. Your ability to cook a meal for your family will come back at some point, you'll find a way to express yourself and to

go back to work and to do all those things. You you will achieve all those things. It's just gonna be a matter of time.

Tamare 38:14
You had an AVM too?

# **Better Days Ahead**



Bill 38:15

Yeah, I had an AVM. And it was near the middle of my head near the cerebellum. And it was about two inches in from the ear. It was a really hard one to get to and it bled three times. And I had brain surgery to remove the faulty AVM and I had to learn how to walk again and use my left arm again.

#### Bill 38:40

So I had to go through lots of things that you've been through. And I've come out on the other side and a lot of stroke survivors who are in the very beginning of it suffer and struggle because they don't know future holds, you know, and I was the same I was like you so you're not any different to anybody else.

#### Bill 39:03

You know, my relationship suffered. My ability to have a good experience with my children suffered, I became angry and cranky. I was crying a lot. It was a really difficult time. You know, I was questioning everything and I was 37 when it happened.

Tamare 39:26

Wow.

Bill 39:29

There's brighter days ahead, there really is and you'll find that you're getting better and better.

Tamare 39:38

Okay, thank you. Just wait.

Bill 39:43

That's all you can do. You can just wait and do your PT like you're doing you know, do your OT and do your speech therapy. That's it. If you've got heaps of time on your hands, and you're not tired. Just put that time into rehabilitation and even if that means doing chores like you said, chores are a great way to do rehabilitation.

Bill 40:06

Even though it could be seriously boring and all that kind of stuff, it's still good to be able to do the things that you get to be good at home, you know, if you can do those things at home that you need to do well, they'll help you with other things outside of home.

Tamare 40:23

Thank you.

Bill 40:25

You know. So, look, I'll wrap it up. It seems like I don't want to have you on here for too long and tire you out too much.

Tamare 40:34

Okay. Well I'll come back later on, once my voice is better.

Bill 40:39

I'd love to have you on again. Absolutely you keep in touch. And I really appreciate you coming on and sharing your stories so that other people going through what you're going through can relate to you and understand you. And also, I love the fact that you wanted to raise awareness and make it about other people. That's an amazing thing. I wish you well, and a speedy recovery.

Tamare 41:07

Thank you for having me.

Bill 41:08

Yeah. My pleasure.

Tamare 41:11

I will keep you up to date.

#### Bill 41:13

Yeah, I'd love to, I'd love to see your posts on Instagram. And I look forward to hearing how your recovery is going and you know, maybe maybe soon, things will shift for you and start to improve.

Tamare 41:30

Okay, thank you. Thank you so much.

#### Bill 41:32

Thanks so much for joining me on today's recovery after stroke podcast. Do you ever wish there was just one place that you could go to for resources, advice, and support in your stroke recovery? Whether you've been navigating the journey for weeks, months or years, I know firsthand how difficult it can be to get the answers you need.

#### Bill 41:51

This road is both physically and mentally challenging. From reclaiming your independence to getting back to work to rebuilding your confidence and more. Your symptoms don't follow a rulebook and as soon as you leave the hospital you no longer have the medical professionals on tap.

#### Bill 42:07

I know for me It felt as if I was teaching myself a new language from scratch with no native speaker in sight. If this sounds like you, I'm here to tell you that you're not alone. And there is a better way to navigate your recovery and build a fulfilling life that you love. I've created an inclusive, supportive and accessible membership community called recovery after stroke.

#### Bill 42:29

This all in one support and resource program is designed to help you take your health into your own hands. This is your guidebook, through every step in your

journey from reducing fatigue to strengthening your brain health, to overcoming anxiety and more. To find out more and to join the community head to recoveryafterstroke.com See you next time.

#### Intro 42:50

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### Intro 43:07

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#### Intro 43:24

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#### Intro 43:44

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#### Intro 44:09

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