

I Had A Stroke While Asleep | Donna Miller

Wake-Up Strokes: Understanding the Silent Threat While You Sleep

Introduction

Strokes are often considered medical emergencies that strike when you least expect them, but did you know they can even occur while you're asleep? Wake-up strokes, as they are called, are a silent threat that can manifest during the night and go unnoticed until morning. In this comprehensive guide, we delve into the world of wake-up strokes, their causes, risk factors, symptoms, treatment, and outcomes. We also explore how these strokes differ from daytime occurrences and emphasize the importance of immediate medical attention.

What Is a Wake-Up Stroke?

A wake-up stroke is a stroke that occurs during sleep, leaving the person oblivious to its onset until they wake up with symptoms. The main challenge with wake-up strokes lies in the uncertainty of when the stroke occurred, making timely treatment difficult. Strokes are most effectively treated when addressed promptly, but wake-up strokes throw a wrench into that critical timeframe.

Prevalence of Wake-Up Strokes

While it may come as a surprise, wake-up strokes are not as rare as you might think. It's estimated that anywhere between 8% and 28% of all strokes occur during sleep. This silent threat is more common than we realize.

Causes and Risk Factors

Stroke Basics

A stroke is essentially a disruption in blood flow to the brain. It can occur in two primary forms:

- Ischemic stroke (a blockage in the blood vessels)
- Hemorrhagic stroke (blood leaking in the brain)

Various factors can increase the risk of suffering a stroke, including:

- Diabetes
- High blood pressure
- Heart disease or failure
- Atrial fibrillation
- Pregnancy
- Hormonal birth control pills
- Intracranial disease
- High cholesterol
- Sickle cell anemia
- Brain aneurysm
- Congenital heart defects
- Lack of exercise
- Certain autoimmune diseases and infections
- Cancer
- A previous stroke or transient ischemic attack (ministroke)

Unique Factors for Wake-Up Strokes

Although wake-up strokes share the same fundamental causes as daytime strokes, some distinctive factors increase the risk of experiencing a wake-up stroke:

Age

While the risk of stroke naturally increases with age, the connection between age and wake-up strokes remains uncertain. Research suggests that the average age for wake-up strokes is slightly higher than that for daytime strokes, but exceptions exist.

Sleep Disorders

The role of sleep disorders in wake-up strokes is still not entirely clear, but ongoing research is shedding light on their involvement. Obstructive sleep apnea, a well-known sleep disorder, has been linked to strokes, but it appears equally associated with wake-up strokes as with strokes occurring during wakeful hours.

Cause and Effect

Interestingly, sleep disorders can both contribute to and result from strokes. For instance, individuals who have had wake-up strokes are more likely to snore than those who experience strokes while awake. This complex interplay highlights the need for further research.

Lipid Profile

High cholesterol is a recognized risk factor for strokes, and studies suggest that wake-up stroke survivors may have a significantly worse lipid profile than their counterparts who experience strokes during the day.

Blood Pressure

Hypertension (high blood pressure) is a general risk factor for strokes. Research indicates that hypertension is associated with an increased chance of cerebral infarction strokes during sleep, emphasizing the need for proper blood pressure management.

Smoking

Smoking is a well-known risk factor for strokes, and it appears to elevate the risk of having an intracerebral hemorrhage, a specific type of stroke occurring during sleep. Quitting smoking is crucial for reducing this risk.

Signs and Symptoms of a Wake-Up Stroke

Recognizing the signs and symptoms of a wake-up stroke is essential for seeking immediate medical attention. These symptoms are identical to those of daytime strokes and may include:

- **Facial drooping, often on one side**
- **Arm or leg weakness**
- **Speech difficulties**
- **Dizziness**
- **Vision disturbances**
- **Confusion**
- **Incontinence (inability to control urine)**

For example, a person who experiences a wake-up stroke might wake up with sudden vision loss, wet the bed during the night, or struggle to move their arm when attempting to get out of bed. If you or someone you know exhibits these symptoms, do not hesitate to call 911.

How Wake-Up Strokes Are Treated

Treating wake-up strokes poses unique challenges due to the unknown time of onset. Patients often do not qualify for reperfusion therapy with tissue-plasminogen activator (tPA), an effective treatment to restore blood flow through blocked arteries. This therapy must be initiated within 4.5 hours of a stroke, and the uncertainty surrounding wake-up strokes makes it inaccessible.

Diagnostic neuroimaging, such as CT scans and MRIs, becomes crucial in the treatment of wake-up strokes. Experts are increasingly advocating the use of

neuroimaging to identify the stroke's onset time, which could expand the pool of eligible patients for reperfusion therapy.

Once a patient is medically stable, the treatment for wake-up strokes aligns with that of other stroke types. This includes physical therapy, occupational therapy, and speech therapy, all initiated within 24 hours and tailored to a patient-centered plan.

Recovery and Outcomes

The recovery and outcomes for wake-up strokes follow a pattern similar to that of other strokes. However, the extent of damage and the location in the brain, along with co-occurring medical conditions, influence the recovery process.

Some studies indicate that there are no significant differences in clinical features or outcomes between wake-up strokes and daytime strokes. Nonetheless, other research suggests that individuals who experience wake-up strokes may be more severely affected, albeit without a difference in fatality rates. This discrepancy is likely attributed to the delay between stroke onset and treatment, as well as the exclusion from certain treatments like reperfusion therapy.

Resulting Sleep Disorders

Interestingly, some individuals who have experienced a stroke may develop stroke-induced sleep disorders.

Episode 273 Interview with Donna Miller

Donna Miller woke up in bed in the middle of the night while she was having an ischemic stroke.

Facebook

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Transcript:

Donna Miller 0:00

Because it happened in the night in the dark in my bed in five years, I can count on one hand how many times I've slept in a bed with the lights off. I went from the day bench and my recliner in my living room. I have done that for three years now asleep on the window ledge, my craft room with every light in thereon.

Bill Gasiamis 0:17

So you know how ridiculous that is, I can tell that you know that. That's ridiculous. However, you cannot find a way to go back to your bed because you think that what?

Donna Miller 0:17

I'm not silly enough to believe that it happened because I was in my bed. And I was in the dark. And we lived in Texas at the time. We're now in Tennessee, a completely different house a bit different bit. I said it could have happened in this car. I get that. But somewhere in this brain of mine. I cannot sleep in the dark. I don't know why and my husband can't save the lives.

Intro 0:54

This is The Recovery after Stroke Podcast. With Bill Gasiamis, helping you navigate recovery after stroke.

Bill Gasiamis 1:06

Hello, and welcome to The Recovery after Stroke podcast. As I mentioned in my last episode, I'm putting together the final touches on my book before it goes live. To celebrate the end of this four-year project, I have decided to make the first chapter available for anyone curious to check it out, free of charge.

Bill Gasiamis 1:27

The book is called *The Unexpected Way That Stroke Became the Best Thing That Happened*, and it shares 10 secrets from stroke survivors that will transform your life. If you go to recoveryafterstroke.com/book and fill out the form, you will receive the first chapter in your email a few moments later. So go ahead and grab your copy now.

Bill Gasiamis 1:49

If you are a stroke survivor with a story to share about your experience, now is the perfect time to join me on the show. The interviews are not scripted, you do not have to plan for them. All you need to do to qualify is be a stroke survivor who wants to share your story in the hope that it will make a difference for somebody else going through something similar.

Bill Gasiamis 2:08

If you are a researcher who would like to share the findings of a recent study or you are looking to recruit people into your studies. You may also wish to reach out and be a guest on my show.

Introduction - Donna Miller



Bill Gasiamis 2:19

If you have a commercial product that you would like to promote that is related to supporting stroke survivors to recover. There is also a path for you to join me on a sponsored episode of the show. Just go to recoveryafterstroke.com/contact Fill out the form explaining briefly which category you belong to.

And I will respond with more details about how we can connect via Zoom. This is episode 273. My guest today is Donna Miller, who experienced a right cerebellum stroke while she slept aged 49.

Bill Gasiamis 2:53

Donna Miller, welcome to the podcast. Thank you for being here. Tell me a little bit about what happened to you.

Wake-Up Stroke and Hospitalization

Donna Miller 3:01

Well, let's see. July 29, 2018, and went to bed one night and I woke up somebody else. Normally I'm not an early riser because I stay up really late. And I happened to hear my husband up at about 5:00 in the morning. I got up and went to the bathroom.

I just glanced at myself going by the mirror in the bathroom and I noticed my face was on my chin, or my mouth was on my chin on the right side. And I didn't have my glasses on I said to my husband do you see what I see? And he said well something looks off.

Donna Miller 3:44

Well it took several hours for my son you know to get up and he's like Mommy's had a stroke I said no, no, no, I've been I feel fine. Um thinking because I've never had a stroke that when I was struggling to feel something I'm gonna know it and I didn't and so finally went to the hospital and everything and they did a test and all that kind of stuff and delivered after three days that I had a stroke.

Bill Gasiamis 4:15

And the first sign was the way that your left side appeared to you when you looked in the mirror.

Donna Miller 4:23

Yeah, the right side of my mouth was almost down here. The whole right side of my mouth and my eye would not close at all my right eye. I had weakness on my whole right side. And I just, feel fine. I mean I had a massive headache but I bet I had been struggling with the migraine for four days solid prior. And I have a history of migraine so you know.

Bill Gasiamis 4:57

And then when you went to the hospital, they immediately knew that you had a stroke. They could tell.

Donna Miller 5:04

Well, the hospital didn't. The neurologist said. She came in and, said, I think we're going to keep you here for a little bit. And I go for what I don't want to be here. She said because you've had a stroke. And I'm like, no, no, no, no. But I finally did relent and say.

Bill Gasiamis 5:23

Why do people don't want to be at the hospital when I'm unwell? And it's potentially serious, I have no problem being at a hospital, you know, I was like, let's go to the hospital, let me get checked out. When I finally overcame the idea that there was nothing wrong with me.

After that, it was confirmed that I was at the hospital, and I want it to be nowhere else where it's the best place to be as far as I'm concerned. But I've met a lot of people who have come onto a similar journey as us that that will go. I hate hospitals, I don't want to be in hospitals. And I'm trying to curiously understand what's at the bottom of that.

Donna Miller 6:01

I don't hate hospitals when I work in the medical field. And so I don't hate the house as I don't mind taking someone else there. I just don't like needles. Number one, and I don't want to poke and prod on me. Number two, I mean, I was a workaholic back then. And in my mind, the only thing I could think of is I had work to do. I have better things to do than lay up in the hospital.

Bill Gasiamis 6:28

Yeah. Fair enough. Makes sense. Most people are busy. And they've got a ton of tabs open, so to speak on their browser, and they're all going at the same time. And they all need to be sorted. And you can't do that when you're away from that place where things get done, and you're who you are. So you've gone home after three days. What's that? Like? How do they send you home? What's the kind of send-off you get? What do they tell you?

Donna Miller 6:57

Well, all I knew was I had a stroke. I didn't know what kind I didn't know where

they did MRIs and CAT scans. And they said the neurologists were off to see them after the fact. And I go home, and they'll kind of fill me in on everything.

I didn't have insurance, because I was self-employed. So they did offer to send me to a facility like a rehab or nursing home type place. And I could get some type of rehab there. And my son was like, oh, no, my mom's No, no, we'll take care of her.

Donna Miller 7:32

And so my son who was 20 at the time, almost 20 stayed home, he took care of me helped feed me, cooked for me, you know, picked me up off the floor, but I'm gonna fail. You know, till my husband came home every day.

It was very alarm bells. What am I gonna do with my life now? You know, at that time, I couldn't stay awake heartbeat. I couldn't remember certain things. I couldn't do anything. And I was very independent. So that was like crushing for me. When I did see the neurologist, I never got any answers got any therapy. Never nothing.

Wake-up stroke survivor's emotional struggles

Bill Gasiamis 8:22

And did you have many falls while you're at home?

Donna Miller 8:26

Oh, yeah. I mean, it's the beginning I was falling several times a day. You know, and I had a walker with management we got me a walker with a seat and everything. But I very rarely used it because I didn't want to become dependent.

Bill Gasiamis 8:41

So it was a little bit of that time where you're still thinking I'm gonna I'm gonna be okay. I don't need to use this thing. And was it getting up to walk to go to the kitchen wherever and then just your leg, your right side just sort of failing to support you how did it?

Donna Miller 8:59

It could be that or it could be midway. You know, it could be because I slept a lot.

I had a hard time staying awake then. And I would cycle between just insomnia to couldn't wake up. You know. And so there were times when I fell out of the not even a bed or something like a deep pit type thing.

Because it happened in the night. In the dark in my bed. I in five years. I can count on one hand how many times I've slept in a bed with the lights off. So I went from the day bed to my recliner in my living room. I did that for three years. Now asleep in a window ledge my craft room with every light in there on.

Bill Gasiamis 9:48

So you know how ridiculous that is. I can tell that you know that. That's ridiculous. However, you cannot find a way to go back to your bed because you think that, what?

Donna Miller 10:01

Well, like I told my husband last night, because we got into this, you know, conversation. And I said I'm not silly enough to believe that it happened. Because I was in my bed, and I was in the dark. And we lived in Texas at the time, we're now in Tennessee, a completely different house, but a different bit.

I said it could have happened in this car. I get that. But somewhere in this brain of mine, I cannot sleep in the dark. I don't know why. And my husband can't save lives. So okay, well, yeah, I just stay somewhere else.

Bill Gasiamis 10:41

Yeah. So you do know that that might be a post-traumatic stress disorder symptom, what you're experiencing?

Donna Miller 10:51

Yeah. That is just really silly stuff. I don't know,

Bill Gasiamis 10:57

A combination of both. But really, it's not uncommon. I've heard before from people who have had a stroke at night in bed, that certain conditions make it very difficult for them to go back to sleep in that environment because there is a Post Traumatic Stress Disorder thing going on.

If I go back there, I'm creating the conditions for another one to happen as if you did that anyway. But that's kind of what goes on in their head. And then the

struggle is real, it's real because sleep is becoming an issue.

Bill Gasiamis 11:35

The most important thing you need after a stroke is you need to be able to sleep at night, so your brain can heal, flush the toxins out, and give you energy the next day. So their fatigue is not dramatic and not bad.

So maybe Donna, because we've known each other forever, and I can give you advice, maybe it's something to think about is going to a neuro-psych or a psychologist and seeing if that potentially actually a psychologist and see if they can explain the disorder to you and see whether you relate to and whether they can get you a diagnosis.

Bill Gasiamis 12:17

Now, from there, you have some information about the underlying cause as to why you're not getting there. Because we know the stroke is not the underlying cause. There's something else stopping you from going there and switching the lights off. But I've heard it before I get it.

Donna Miller 12:36

Yeah, and I don't get it. And I guess I would say everything has changed upon me. And no longer the same person in any shape, form, or fashion. I used to be very independent. never cry about anything unless I was furious. Now I cry about everything. My face is still crazy and funny and a lot of times when I'm talking is like I know what I'm trying to say. But my brain doesn't push it out.

Donna Miller 13:14

You know, and people look at you like you're a little slow, like something's wrong with you. And so I finally this year decided, Okay, I've got a job where have insurance now. Because I lost, I had to give up business everything. I'm going to find out what's going on. Started with a neurologist. I've been to every doctor since and why am I so fatigued? Why can I not function in life? And I do have a neuropsych appointment the next day for it.

Bill Gasiamis 13:50

Excellent.

Donna Miller 13:54

So we'll see what happens with that. I do I am going to see a psychologist, I

finally decided I need to talk to somebody at the end of this, so.

Bill Gasiamis 14:04

Good, good, good. Good. That's great. So you know, the crying thing? That's very common as well. Do you know that amongst stroke survivors, one of the things that becomes a little bit uncontrollable is the ability to cry or not cry or hold back your tears that happened to me? I'll give you an example. Last weekend, literally seven days ago, my football team won the championship. So I was I laughed because it was the only thing I could do. I was crying throughout the whole game. I was so emotional.

Bill Gasiamis 14:40

And we had people over we had a barbecue and people were over for lunch and everything. My wife was just begging me the whole time she was just are you going to cry over it? She can cry over that. And I would have to tell her to shut up. Shut up. Leave me alone. Don't talk. Stop it. I'm watching the game. And I was doing this I was I was sitting as far away from everybody as I could. And I had my hand up and said that they couldn't see me. But of course, they knew if I had my hand up, that meant that I was crying.

Bill Gasiamis 15:10

And I was just so emotional because it was a close game. I could not stop myself. One of my players did an amazing play, and one of my favorite players did an amazing play, and I cried, and then I cried when they won, I cried. The next day, when I saw the replay. I'm like, it hasn't stopped. And it's just ridiculous. But I can't do that. And I never used to be like that. And I never used to be a problem. I used to get excited. And I used to yell and scream and all that kind of stuff.

Bill Gasiamis 15:42

But now that has turned into excitement plus tears, tears of joy maybe, or relief, or I don't know what they are. But it's nuts. And I'm my first brain hemorrhage was in 2012. So it has got far better, far better. But every once in a while that catches me off guard, and I can't do anything about it and once I start, I can't stop.

Wake-up stroke recovery and emotional impact

Donna Miller 16:10

But yeah, and I hate that because I don't know, I just I feel embarrassed. You know, like, if I want to go talk to my boss about something, I can feel my mouth quivering before I make I still can't forget it. You know, and I just won't do it, you know, or you got to judge the doctor and I just cry the whole time.

Bill Gasiamis 16:32

Yeah, it's called the pseudobulbar effect. It has a name. It's a condition and has a name. And it's very, very common. So I know that it's uncomfortable because it was uncomfortable for me as well at the beginning. But then I said stuff it, man. I'll just explain it to people if anyone wants an explanation because half because it's not crying. It's not a devastated, sad, depressed kind of cry. It's just like a cry and I don't know.

Donna Miller 17:06

No rhyme or reason.

Bill Gasiamis 17:07

Yeah. And I'm not doing it because I need you to feel sorry for me, or I need a hug or anything. I'm just crying. And I don't know why. And I'm just doing it. And if you're uncomfortable, I'll explain it. It's not about you the situation or anything. It's just what's happening. It's ridiculous, but it's very common.

Donna Miller 17:27

In the beginning, my husband was very shocked by it. And he says what's wrong? What do you cry for? I don't know.

Bill Gasiamis 17:35

Yeah, and there's nothing bad about it, but I know it makes people feel uncomfortable, especially stroke survivors who respond to me by saying I, I am, what did they say? They say like, my emotions are all over the place and I can't and I can't control them. It's a stroke thing. I don't know. Anyhow, well, I'm glad that you're going to go and see a whole bunch of people so your life changed pretty dramatically what were the things that you weren't able to do after you came home from the stroke?

Donna Miller 18:09

I couldn't cook, I couldn't walk anywhere by myself, well I could but I would fight its fall. So nobody let me go anywhere I couldn't drive, my memory was off you know now I could look at pictures of my children when they were younger and I was in the picture and I cannot remember it but I know it was there I can see it you know certain things that could remember just, just hit and miss, bathing myself was difficult you know, it was almost like everything was eating was difficult. And even to this day, I still have certain foods I can eat because I still have you know numbness on the right side of my throat.

Bill Gasiamis 18:57

So is the swallowing sensation different?

Donna Miller 19:02

Yeah, you know, and I don't feel some of it in so food will get stuck in the next thing you know, I'm choking you know. My vision was really bad. These eyes I hadn't closed for six months, stayed open to blink nothing. And it's gotten better. I mean, one day I had an episode where I think I had a mini-stroke. I'm not even sure. But I got for about three or four minutes to get to where I couldn't do anything. I couldn't even sit up and then my eyes closed. So now this eye works however it wants to.

Donna Miller 19:45

If I eat if I drink this eye I'm talking this eye has moved in to eat drink this I will close. The eye doctor told me about six months ago that the nerve is probably regenerated into my mouth nerves. So whenever this mouth moves this eye responds, so.

Bill Gasiamis 20:10

That's, that's weird.

Donna Miller 20:12

Yeah. He said he had a patient that had happened. But it went into the salivary glands. So anytime his mouth watered from even thinking about food, his eyes would just flood. And I was like, thankfully that didn't happen.

Bill Gasiamis 20:31

Wow. That's fascinating. I've never heard that one before. And I've heard a lot of things but never that one. So all right, you finally decided to go get some help. So

how did it affect you emotionally? Do you feel? I mean, apart from the crime for? For whatever reason, we haven't spoken about that. But like, how do you feel about the whole situation? How does it impact your emotions? Other than the crying for no reason?

Donna Miller 21:02

Was anger. Feel sorry for myself, I feel a lot of pity. I did it for I did that for a couple of years. Even, you know? Why me? My life is ruined. I didn't see anything positive about it at all. Anyway, now I find very little. Every once in a while, I'll have a good day. And I can say, Okay, well, my life has changed. But maybe this is for whatever reason supposed to go this way, you know. But I think I felt the best out of five years. When I found out last June, what kind of stroke I had finally, I had a right cerebellum stroke. And there's a part back there this dead in, you know, according to the MRI thing was the MRI that I had.

Bill Gasiamis 22:06

Yeah, and how old were you?

Donna Miller 22:10

When I found out? 49, 54 now. And so now that I have a name to put to it, I know what kind, and I've been kind of looking it up makes me feel a little better, I guess.

Bill Gasiamis 22:27

You have more of an understanding of why things are the way they are and how you how come your body feels the way that it does. So kind of the picture is starting to come together and you're able to connect the dots I feel like information is really important. That's the reason why I suggested the psychologist appointment and the neuro-psych because then you become informed about your condition. And then you learn ways to get around the deficits and to adjust and to rehabilitate yourself. So people must be curious about what happened to them, where it happened, how it happened.

Bill Gasiamis 23:07

I've specifically got a document that you can download from my website, it's called Seven Questions to Ask Your Doctor about Your Stroke. And it's a free PDF, there's hundreds of people have downloaded it. And when the purpose of it is for them, for people to print it off and take it to the hospital, with their doctor at their

doctor's appointment, or the general practitioner wherever. And what they do is they just ask these seven questions. And they're not.

Bill Gasiamis 23:35

They're not like the most amazing questions you've ever heard of in your life, but they are what kind of stroke did I have? And where in my brain did it happen? And then from there, we also ask, one of the questions is, who else other than you do I need to see about my stroke to help me get better? And that's what I was missing. When I was going to the hospital and the doctors, I had no idea what to ask them or how to go about supporting my recovery and being my advocate.

Bill Gasiamis 24:13

And it was really hard and I just didn't know we used to go to appointments and then leave and I can I be said to my wife. What did they say what did we talk about? What do we have to do? Because I couldn't also remember how to stroke I was not in there in my right mind. So people need to have an understanding of where things occurred and then what has been impacted as a result of that. It may be obvious to you that I can't get words out but there's more to it than just our I struggled to get words out there's a neurological underlying causes this discussion you can have around that.

Bill Gasiamis 25:01

And then if you speak to a speech therapist, you can go to them with that information and go, this is exactly what's wrong with me. This is what I need for the rehabilitation, for example, it's a far better place to be than if I had a stroke and I don't know why. And I don't know where and I'm not sure why I can't talk and why can't walk and why can't go to sleep.

Donna Miller developed a post-stroke seizure disorder

Donna Miller 25:28

Yeah, because you feel lost, and you know, you don't know what's coming next. You don't know what you should do or shouldn't do, you know if you're going to be able to do it. And that's where I was because I didn't know anything. So I just gave up. I didn't want to even if I lived in the country, middle of nowhere. So what was great for me, was I went out there, I started learning to garden, I taught

myself how to Can I started doing crafts and making raised and just building my world out there. And I've secluded the rest of the world.

Intro 26:08

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. How long will it take to recover? Will I recover? What things should I avoid? In case I make matters worse, and doctors will explain things that, 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.

Intro 26:38

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 it's called Seven Questions to Ask Your Doctor about Your Stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery. Head to the website now, recoveryafterstroke.com, and download the guide. It's free.

Bill Gasiamis 27:13

It sounds like it was therapeutic as well, though, it sounds like it was necessary at some point to be.

Donna Miller 27:20

I think so now. I live in a small town still, but I'm in town now. And it's been an adjustment. Because I come every once in a while, I want to go back to the country. You know, all by myself, I go to work in an office with many people, which every morning is a struggle. Because I don't want to go around people. I still want this seclusion.

Bill Gasiamis 27:49

Is it something about the people? Or are the interactions difficult? Or what's the issue?

Donna Miller 27:56

I think it's interacting is difficult. You know, sometimes, I talk just fluidly. Sometimes you can understand everything I'm saying. Other times of sounds like

I've been at a bar all night. You know, or I'm sitting there looking at you ask me a question. I'm looking at you and nothing comes out. And in my head. I'm repeating what I'm trying to get out. But nothing comes out. So it's embarrassing. And then also, what was it? Well, our anniversary is September 10, 2018. I was walking in the door and all of a sudden I had a seizure.

Donna Miller 28:40

So develop a post-stroke seizure disorder. Now, luckily, I don't convulse. I did like a blank out in it. But I'm so afraid of that happening in front of at work in front of people. That I don't.

Bill Gasiamis 28:58

Have you explained to the people that you work with that you have had a stroke in the past?

Overcoming speech challenges and isolation



Donna Miller 29:06

Over the last six months, little things have come out here and there. But when I first applied I did not tell anybody. Because I wanted I was, I was afraid that people wouldn't hire me. Because, well, what if you can't remember what you're doing? You know, and so.

Bill Gasiamis 29:25

Yes, makes sense. I understand that. What kind of work were you doing for yourself before this job?

Donna Miller 29:32

Well, I was a Medicaid waiver program provider. We provided group homes and foster care settings for people with intellectual disabilities. So that's what I did before. And because I learned how to do my billing and all that kind of stuff. Now that's what I do. I do Medicaid billing for nursing homes.

Bill Gasiamis 30:02

Okay, so you don't know about another organization. Okay. So again, I'm going to challenge your logic. So these people, deal with people who are working, who are living in nursing homes and unwell and they help them and support them. And you've got some deficits because of a stroke. And there's still a sense of, they're going to judge me and they're not going to. And they're going to it's going to be embarrassing to stutter or to forget what to say or to go blank people, wouldn't they be more likely kind of to understand the situation that some people face?

Donna Miller 30:53

You would hope so. Yeah, you would think so. But, again, in my mind, you know, and I don't know what it is, I think it's just a fear of almost everything, you know. And there's no reason for it. And I know that.

Bill Gasiamis 31:14

Okay. And have that been pleasantly have they surprised you? Pleasantly, every so often when you think that something went pear-shaped? Did they surprise you by not behaving the way that you thought they might? Or?

Donna Miller 31:31

Yeah, yeah, my boss says, and I have, when I noticed that she noticed things I came out and told her. And she never missed a beat with it, which I was very thankful for. Most people that work right, in my general area, they kind of know and they've never missed a beat. I have one lady that every time she talks to me, I get I don't know what it is, but I can't speak, she'll ask me a question. And she'll then look at me or treat me like, stupid. And in so that's the only one though.

Bill Gasiamis 32:13

Yeah, interesting. Some people, trigger people. And what's interesting about you, though, is you're telling me about all these challenges that you have been around

people, people are gonna judge you and the rest of it, and then you come on a podcast that goes to about 50 or 60 countries. And you're talking about all the problems that you have.

Donna Miller 32:33

Because I have to. I have to overcome. I mean, I was talking to my doctor about it a couple of weeks ago, and I said, Maybe I shouldn't do that. Because I'm going to be embarrassed and things I have to say that there's got to be so if I was like that, I had nobody. I've been very isolated. I've lost just about every friend I had. If I'm that way, there's got to be another person out there like me.

Bill Gasiamis 33:07

Oh, yeah. Yeah, there's many. And they, they're probably earlier on in the recovery, and they're struggling like you are, and they're looking for somebody to shine a light and go. All right, it wasn't so bad for Donna, maybe it's okay for me to come on the podcast and share. And I think that's what it is. This podcast is like a therapy session for both people, me and the person that comes on. I think that's what we get out of it more than anything. And then the people listening are also able to have like a general, a gentle introduction into what it's like to share.

Bill Gasiamis 33:42

And the benefits that both people get from the sharing, I get a benefit from hearing your story, and you get a benefit from telling your story and hearing my story. So I think that's what the podcast does. It kind of creates a gentle way for people to overcome the fear of expressing their frustrations, challenges, concerns, and worries about this situation. And then when they come on the podcast, I think it's a little bit it's better than they expected. And it's also a little bit about a burden off the shoulders. I feel like.

Donna Miller 34:23

Yeah, and I've thought about it and I've thought, you know, well it's almost been like, for five years, like a dirty little secret. You know, I mean secluding myself and not going around people or anything and friends didn't want to be bothered with me, that's fine. Because I don't want to see me anyway, you know, now it's like, okay, I have to make a change. Five years in almost two to five. I've got to make a change, or I don't want to live the rest of my life like this.

Donna Miller 34:56

I have no quality of life. And it's like okay, I've said to myself, You're going to make a change, or you're going to end up single, alone. My marriage can't suffer anymore from this. And so it's like, Okay, I've got to figure out how to do it. And even if I say it out loud, then it's real. The secret is gone. If that makes sense.

Friendship changes after the wake-up stroke

Bill Gasiamis 34:58

It makes complete sense. Okay. So the loss of friends is partly your fault and partly their fault because I know a lot of stroke survivors talk about friends distancing themselves. And you're wondering where all your so-called friends went, was that part part of what happened to you? But also, did you participate in that by secluding yourself?

Donna Miller 35:50

I think in the beginning, I got I was very hurt because nobody called nobody texted, nobody came around when I came home from the hospital, nobody. And it's like, so I would my feelings were hurt that nobody, nobody gives a damn anyway. So when they didn't come around or call, or they waited three months or six months, it was okay. I'd already started secluding myself. So at that point, it became a two-part two street, two-way street.

Bill Gasiamis 36:29

Okay, but there was a disconnect that you felt from people who you expected or thought would turn up. And they didn't? Do you have any sense of what might be behind that? Not that I intimately know anything about your relationship with these people. But do you have a sense? Was it like, an inability to, for them to kind of grasp the concept? Is it that you hit it so well? Or pretend that everything was okay, was it a combination of those? What do you think was behind that disconnect?

Donna Miller 37:01

I think I think a lot of the day didn't know how to react, or how to respond to me. Because like I said, I was very independent and worked all the time. I came and went, I mean, I was always everywhere. And all of a sudden I'm sitting in one spot, day after day, you know? I don't talk as well. I mean, my mouth was down

here. I mean, it was almost six months before my face picked up to where I mean, I could still see it. But other people a lot of people don't, you know? So I think people don't know how to respond, or what to say. And it made them feel uncomfortable, as well as I feel uncomfortable.

Bill Gasiamis 37:53

Yeah, a lot of that is not really about them. It's not really about you, it's about them. It's about their inability to grasp the concept to know what to say. It challenges their mortality and their idea about life and how it's fragile, and it can be taken away. So it's a big challenge for a lot of people on the periphery of this. And then it's like, maybe it's better if I don't turn up because I don't know how to behave around somebody who's had a stroke. And maybe they don't know anyone who's had a stroke before. And yeah, it's ridiculous.

Bill Gasiamis 38:34

But I know I'm kind of justifying it for them. But it's the way that I went around, in my mind trying to come to terms with some of the people that I thought would turn up who didn't. People who I turned up for in the past for them when I thought it was important for me to be around them. And then I kind of got through several years of sort of being upset, hating on them and all that kind of stuff and then kind of realized that really what had happened was the best thing they did was they didn't turn up.

Bill Gasiamis 39:17

Because they might have made it worse, or uncomfortable, or made it about them or god knows what and it would have been really difficult to have them around during that time when I needed to recover. So I forgive them now, and it's okay that I don't see them. And honestly, I don't know if I would have behaved any better if the situation was reversed if somebody I knew had a stroke at the age of 37 the kind of guy that I was before my stroke. I don't know if I would have turned up and been supportive or helpful.

Bill Gasiamis 39:57

I like to think I would but it's not guaranteed that I would have been. So I don't want to judge them too harshly. However many stroke survivors talk about how friendships change rapidly. And it's hard.

Donna Miller 40:15

It seems like all relationships change.

Bill Gasiamis 40:18

Yes, they do.

Donna Miller 40:20

I mean, from your kids to your spouse, there's every relationship changes.

Bill Gasiamis 40:27

Yep. And there is a mourning phase. In that, for me, there was a mourning phase, it was like, okay. You are different, so everyone is treating it differently. But your identity hasn't caught up yet. You're still your old identity. And they're still. And they've shifted very quickly because they see the ill person. But the ill person hasn't been able to change from being the person before the stroke a week ago or six weeks ago. And yeah, everyone changes around you and you haven't caught up yet.

Bill Gasiamis 41:02

I feel like I haven't caught up for a little while. And still today, you know, it's nearly next year will be 10 years since the brain surgery, and 12 years since the initial blade. And still, it's impacting my life in positive ways through the podcast and the book that I've written and all the things that I'm doing, but then in negative ways, because I still am interacting with stroke deficits around people who are quote, unquote, normal. And it's so hard because you can't tell that I've had a stroke when you see me walk, talk, or anything. And it's so hard to try and get people to get off my back sometimes just to give me a break. You know?

Donna Miller coping with stroke and identity changes



Donna Miller 42:02

Oh, yeah. I still don't know who I am. Exactly. You know, and I'm like, I used to ask yourself, what do you want to be when you grow up? You know? Yeah. And it's like, I don't know. I don't even know who I am. I know more now than I did. I did a year ago. You know, and it wasn't until probably a year ago that I even cared, No. Because I was so angry.

Bill Gasiamis 42:34

Yeah. Where you mentally this might sound like a strange question, and I'm not probably asking the right way. But where you mentally kind of stable before that people often who've had a stroke will tell me that they had depression, anxiety, that kind of stuff for many years, and it's kind of escalated it, a couple of people have told me that it's got better, or change that or the anxiety went away, or the depression went away. So that's a couple of weird things that you hear. But how will your How was your mental health? Before stroke how would you describe yourself? And how did that change after the stroke?

Donna Miller 43:12

Well, I've never had an issue that is anxiety. I've never had that issue. Depression. When I was younger, I did you know, but then once I got older, and I had kids, I mean, I didn't I didn't start having children. I was 30. You know? So once I started having kids, I opened my own business. I kind of got out of that, you know, I was busy. Busy would like, didn't have time to think about anything back there. And I think that because it does run in my family. You know, depression does run on my mom says family, I think that the depression did escalate after the stroke.

Bill Gasiamis 44:03

Yep. And there's a lot of changes going on for you. So if you're having kids in your 30s, and you're 54 your kids don't need you anymore. Much. They're grown. So not only is your identity changing, because you've had a stroke, you're not working the way that you were before you're not as independent as you were. You have a couple of stroke deficits, but you also your role as a mum, and a wife has changed all at the same time.

Donna Miller 44:36

Yeah, because about the time that I had the stroke, my daughter had just left home three months prior, and my son was there. And but he was still grown, you know, and I was 49. And he was born, you know, three days before I turned 30. So He was 19 not random up there. And so yeah, I was already feeling lost anyway. Empty Nest, I guess. Yeah. And then to be like this.

Donna Miller 45:17

And my daughter wasn't there. And I was thinking, I don't want my son, I want my daughter. You know, I'm not wanting, I was thinking, I'm thankful for him. Don't get me wrong. I'm very thankful for him. But I just felt like that was a role girls should have done. I'm a woman, you know. And so, yeah, all of that is, was all at the same time.

Bill Gasiamis 45:46

Yeah, it's a lot to handle, it's a lot for anyone to handle and try and come to terms with so suddenly. And it makes sense that retreating was, your way of coping because it sounds like it was your way of coping. If I go into nowhere, and I'm around, nobody, I can just be me and just sort of settle into this new version of me. And it's therapeutic, being on the land, gardening and doing all those things, and not having car noises and sirens and all the hustle and bustle of a city. So it sounds like you're guided well.

Donna Miller 46:31

I loved it. You know. I hated to leave it. You know. But of course, you know, like I said, we gave it the business, everything because I was pretty much the only one that could do a lot of the stuff. And so it was like I couldn't handle it anymore. I tried. But I couldn't I just could not keep up, you know. And so I had to admit that it's over. Yeah. And so we had a house in Tennessee and a house in Texas, who again, live in two places where we're gonna live. So we decided on Tennessee,

which is in town, not just a little bitty small town, not like a city. You know, I still go out there and garden in my backyard. And stuff like that. So.

Bill Gasiamis 47:20

But it's close to the services. Is it good that there are people around?

Donna Miller 47:24

Sometimes, sometimes not. I mean, they don't they don't say much to me. You know, I only got about four neighbors out here. There's one lady across the street who'll talk to you. Every day you know, she's busy. I'm busy. But since I've been back to work I'm still so tired all the time. That a lot of days, I just don't have any energy when I get home. I have nothing left for anyone or anything. Not even cooking.

Bill Gasiamis 47:56

I know that feeling.

Donna Miller 47:58

So it's either work or not. What do you do?

Bill Gasiamis 48:05

Yeah, I mean, when I wasn't at work, I was at home and I was cooking and cleaning and doing all the things that needed to be done around the house as much as I could, my wife would come home at around 6 pm My kids would come home after school at the time. So I had a fair amount of the day to just chill out and do as little as possible, and then have enough energy to prepare dinner so we could at least all eat together. So that was something I looked forward to. And then when I went to work, yeah, I'd come home at around 3:30/4 o'clock.

Bill Gasiamis 48:40

And then I'd be wiped out wiped out. I'd have to sit on the couch for a couple of hours. And even then nobody had come home. While the kids weren't helping Well, teenagers thought pains in the butt. Yeah, my wife wouldn't be home yet. And I would have to kind of motivate myself around 5:00/5:30. After I'd been home for an hour and a half sitting down doing nothing.

Bill Gasiamis 49:04

I'd have to motivate myself to start preparing dinner, and try and put something together. And then the key was to have dinner done early so that I could be sitting

on the couch by seven o'clock or something so I could ease into going to bed and sleeping because yeah, the battery was empty and drained to zero. No, no ability to do anything. I remember having a lot of tasks to do like emails, for example, after dinner, I'd sit down and do those emails and there was no hope in hell, I would be able to sit down and look at a computer screen and send an email.

Bill Gasiamis 49:46

It doesn't matter how urgent or how important it was. It just didn't happen because I'm not sure if the word is painful, but it was hard to sit through it and get it done. And it was that the price I had to pay was too much or wouldn't I wouldn't. It wasn't beneficial to my health and well-being to sit down and write an email. It sounds bizarre, but that's how bad it felt at some stage.

Managing work-related stress and anxiety

Donna Miller 50:19

Yeah. And that's got it the way it is for me. On the days that I work, I don't even expect that. And now I'm I'm struggling with, okay. Oh, all the doctors hate it. Why aren't you on disability? Well, because, one, you have to wait what a year or two sometimes to get it? You know? How do you live till then? What do you do? And, and then I, you know, I make things now, you know, and I've sold them. I've taught classes since I've had a stroke. Oh, what do you know, I do wreaths and paint. paper crafter does several different things.

Donna Miller 51:04

But I used to teach wreaths class, wreath making classes, you know, before I came to this state, so I've thought, you know, maybe this is just too much for me. Because it's such a struggle to get up and get there. And then it's so hard sometimes to sit there. hour, one hour. In the car. I have two huge computer screens, and my vision has gone blurry. Yep. I've just come now I do have anxiety sometimes now, which I never had before. It'll just my heart is pounding. It's like, Okay, I gotta walk away from it. I gotta go outside, you know, yes. And no thought, maybe it's time for me to figure something else out.

Bill Gasiamis 51:51

Yeah, set up a little side hustle, something that fills your heart with joy and allows you to tune out of your head and go into the space of creating and delivering

something amazing. I remember with work, I went through a similar thing, again, to computer screens, a lot of lights over the top 30 People in the room. Noise overwhelmed the whole kind of thing. And I was never employed by somebody from the age of about 2008. I was self-employed. So by 37, I had been working for myself for about nine or 10 years. And then I tried to go back to work two or three times in the first few years after the initial blade.

Bill Gasiamis 52:40

And I had three bleeds. So every time I went back to work, something else happened and then something else happened. And then I had brain surgery. So for three years, I was on this roller coaster of slowly improving and then going downhill slowly improving and then going downhill, and then brain surgery. And then after the brain surgery, about a year after I couldn't work for myself anymore, I was completely gone. So I had to go and work in an office for three years. What was interesting was how, even though that was difficult, my boss understood, so they kind of protected me a little bit.

Bill Gasiamis 53:17

So if I had bad days where I wasn't productive or wasn't getting anything done, and I needed to go into the courtyard outside or sort of retreat away from my, from my desk, they kind of turned a blind eye. And they didn't bug me too much. But what that allowed me to do was see a progression in my improvement. So I went from being able to look at the monitors for an hour or two, to by the end of it three out of three years later, I was full-time doing all the work that I needed to do with very rare days where I was struggling badly.

Bill Gasiamis 53:57

And if I was I just took a sick day, I just didn't come to work those days. So it kind of rehabilitated me. What was interesting was, that it was a brain-dead job, but took a brand new job where I almost didn't have to do any of the thinking. Therefore, waking up getting in the car driving to work, and going to work was also part of the rehabilitation because it was a routine that most of the time I couldn't get out of somebody else was relying on me to turn up whereas when I was working for myself, I could easily just say well, I'm not going to work next week again, or today or tomorrow or whatever. So it kind of kept me honest and made me push through those barriers.

Bill Gasiamis 54:42

Those are really difficult barriers. Oh my god, I can't think straight I can't see straight. There's too much noise. And I did I brought to work headphones that were noise canceling and covered my entire ear, but I never used to play Music just used to wear them. And it used to just calm down the noise in the place. And it used to settle my nervous system down, just like you hear some autistic kids do. And on top of my head, there were fluorescent light tubes, which went out, they stopped working about a year after I'd started there, and they brought the maintenance going to come in and repair them.

Bill Gasiamis 55:27

But I asked him not to change the lightbulbs and put fresh ones in. So he didn't. As a result, I didn't have these annoying fluorescent lights over my head. And also I could decrease, the room noise with my headphones. And it made such a massive difference to my ability to be productive at work and to get through a whole day.

Finding a new path in life for Donna Miller

Donna Miller 55:53

I've gotten to where I use headphones. But I put music on because I hear everybody talk and talk and talk. And my brain is trying to get all over the place, instead of being here. And so for me to get work done, I have to pick up from and I've even thought about I need to be sitting over there somewhere, Mama. So, yes. But I don't want to be asked that. Because then I'll think, Oh, she's stuck up or doesn't want to be around us. No, it has to do with me being able to stay right here in the moment. You know, do what I got to do it. Remember what I gotta do?

Bill Gasiamis 56:32

Yeah. Yep. So headphones, do help a little bit of music get rid of all of the multiple different noises that are coming around and just make it one and helps you to achieve the same thing that I was achieving, which was to sort of calm things down a little bit and focus on. Yeah, that's good. And your husband? Is he employed? What kind of work does he do? How did he become involved in this whole situation? How did that work out?

Donna Miller 57:07

Well, he's, he does remodeling type thing, stuff. So he works for himself. We worked together when I was self-employed. And then we both had to kind of figure things out, you know. And he went to work for him, he's still working for himself. And he's just finishing up a house, and then he'll move on to the next to the next job. And during the middle of all this, my husband got cancer. So now, he's changed to some degree. But his mindset has changed, because he was like me, work work work all about making money, you know, and, you know, like we're taught to do is when my generation got to have a career, you make money work.

Donna Miller 58:04

And now it seems like, you know, it's time, it's time to think about what's important in life, not about what money can buy you because you can't take it with you when you go anyway. Both of us have had situations where it's time for us just to slow down and think about what's important and downsize. And, of course, part of my brain says, Yeah, sounds good. The other part of my brain is, but I don't know how to I don't know how to do that. You know what I mean? Yeah.

Bill Gasiamis 58:40

If you've been on one track for 50 years, then you have to relearn a lot of things. One of them is how to get off the track and choose a new one that's going to be good, useful, and supportive. The right one? I tried to get out of being self-employed. And I couldn't do it. My business suffered, and my clients didn't get the kind of service or support that they should have my business, a property, a property maintenance business, we paint houses and offices and what have you in buildings. And then I went to get a job for somebody else. And that kind of worked, but being inside taking orders, not that. Not that it's that bad.

Bill Gasiamis 59:34

It wasn't that bad, but I just couldn't cope. After three years, I've tried to find a new way to get the business up and running and brought somebody on and made them a partner and without that, it wouldn't exist now. So I had to find a new way so I don't do as much of the painting and all of the stuff on the tools as I used to. I do more of the off-the-tool stuff. And then I do To help out when necessary on the tools, a lot of quoting, chasing money, paying bills, that kind of stuff. So, whereas before I was doing it all, on my accounts, bills, chasing money, quotes, picking up materials, setting up staff, painting, a whole lot of everything.

Bill Gasiamis 1:00:27

And there just weren't enough hours in the day to do all the things that I did. If I went back to that system, it could last another 12 minutes, it'd be terrible. So you do kind of stumble and fumble and find a way eventually to a path that suits but you've got to go down the wrong path a few times as well. You got to get lost and then go on. No, this is not what I expected. I need to find another way. And now that you've made the decision, it sounds like you're more equipped. You're way more equipped to get to the other side than you were previously. How's your husband's health? How's it coming?

Recovery and overcoming fears

Donna Miller 1:01:17

Well, he's good right now. He's got, he's still got a lot of side effects from the radiation and all that stuff. And but he's still, he used to be, like me, work work work. He could work with a younger man. And he's 61 and when he could work a 20-year-old in the ground, I mean, he just way he was now one o'clock, he needs a nap. You know? Yeah. But, you know, I think he's, hopefully it'd be okay.

Bill Gasiamis 1:02:01

That's the thing about stroke and all that other stuff. Life still happens around you. So even though your head's not working properly, and your body's not working properly, you still have to deal with life, the normal, day-to-day everyday parts of life.

Donna Miller 1:02:20

And I think that once things started happening in a life that I had to start dealing with, that's when I decided, okay, I don't want to live this way anymore. I want to have a rewarding life, whatever that may be. You know, and so for me to do that, I have to deadlift, the little girl sit down that had a stroke and, and learn to talk to her and understand her and live with her versus fighting all the time, so to speak.

Bill Gasiamis 1:02:52

Yeah. Yes, versus private. Yep. Very true. As we're coming to the end of this episode, I wanted to ask you a couple of more, three more questions before we end that. I've tried to make a habit of asking everybody these questions, but only recently. So the first question is, what was the hardest thing about stroke?

Donna Miller 1:03:18

Loneliness, very lonely. Because even though you could be in a room full of people, nobody truly understands half of what you're saying. They might smile and not act like to do but they just don't understand how hard it is some days to get up and go take that shower. How hard it is some days just to say hello to somebody, you know. That was the worst, being so lonely.

Bill Gasiamis 1:03:55

What has stroke taught you?

Donna Miller 1:04:03

I'm not invincible. You know, that's one thing. I used to think, Oh, I'll be around them hundred I don't know so much about that anymore. You know, it's taught me that it is important to do what you enjoy in life. Enjoy your life. Because you don't know for one minute the next one is going to be gone. You know, and don't do a job just because you got to do it. Whether you make a lot of money or not.

Bill Gasiamis 1:04:41

Yeah, people are listening now that on on our journey, there may be a little bit earlier on and they haven't dared to face some of the fears and overcome some of the challenges and talk about their stroke. What would you tell somebody listening right now who's going through what you were going through? What do you want to say to them?

Donna Miller 1:05:05

I'd say make Google your best friend. YouTube and Google, because that's what I ended up having to do. Because I didn't have anybody to teach you. You know, nobody knew I didn't know. I looked up things I, you know, read dates. I looked up, and I thought, You know what, maybe I'll write a book, even if I don't post it. I'll get all of it out there. On paper out of my head, you know, don't wait. Don't be embarrassed and don't wait five years, or four years, or three years to say, Hey, this is me. Whoever may disagree. You know,

Bill Gasiamis 1:05:53

Lovely, very worried.

Donna Miller 1:05:54

Find somebody, by somebody. Even if it's pinned out on the internet, somebody that can relate to what you're saying?

Bill Gasiamis 1:06:04

Yeah. That's brilliant. Donna, thank you so much for reaching out and overcoming some of your fears. And joining me on the podcast.

Donna Miller 1:06:14

Thank you.

Bill Gasiamis 1:06:15

Well, thanks again for joining us on today's episode, remember to grab your copy of chapter one free of charge, you can just go to recoveryafterstroke.com/book Fill out the form and then you will receive it in your email a few moments later.

Bill Gasiamis 1:06:32

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Bill Gasiamis 1:07:12

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Intro 1:07:35

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Intro 1:08:09

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Intro 1:08:32

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Intro 1:08:56

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