

Ischemic Stroke and MTHFR Gene Mutation - Amber Corker

Navigating Health: The Impact of MTHFR Gene Mutation on Stroke Risk

In the complex web of genetic factors influencing our health, the MTHFR gene mutation stands out for its significant implications. This mutation, often overlooked, plays a pivotal role in our body's methylation process and has been linked to various health conditions, including an increased risk of stroke. Understanding the MTHFR gene mutation is essential for anyone looking to proactively manage their health and mitigate potential risks.

Decoding the MTHFR Gene Mutation

The MTHFR (Methylenetetrahydrofolate Reductase) gene is crucial for converting homocysteine, a potentially harmful substance, into methionine, a beneficial amino acid that the body uses for growth and repair. However, mutations in the MTHFR gene can hinder this conversion process, leading to elevated levels of homocysteine in the blood—a known risk factor for several health issues, including stroke.

The Connection Between MTHFR Gene Mutation and Stroke

Research has drawn a clear line connecting the dots between MTHFR gene mutation, elevated homocysteine levels, and an increased risk of stroke. Specifically, individuals with the C677T or A1298C mutations in the MTHFR gene are at a higher risk. These mutations can compromise the integrity of blood vessels and promote clot formation, thereby increasing the likelihood of an

ischemic stroke, where blood flow to the brain is blocked.

Risk Factors to Watch

While the MTHFR gene mutation itself is a risk factor for stroke, its impact is often influenced by lifestyle and environmental factors, including:

- **Dietary Habits:** A diet low in folate and B vitamins can exacerbate the risk associated with MTHFR gene mutations.
- **Lifestyle Choices:** Smoking and excessive alcohol consumption can further elevate stroke risk in those with MTHFR gene mutations.
- **Genetic Predispositions:** Other genetic factors may compound the risk, making it crucial for individuals with a family history of cardiovascular diseases to be particularly vigilant.

Proactive Measures for Managing Risks

For individuals with an MTHFR gene mutation, there are several strategies to effectively manage the associated stroke risk:

- **Embrace a Folate-Rich Diet:** Consuming foods high in natural folate, such as leafy greens, fruits, and legumes, can help lower homocysteine levels.
- **Lifestyle Adjustments:** Quitting smoking and moderating alcohol intake are key steps in reducing stroke risk.
- **Supplementation:** Healthcare providers may recommend supplements, especially methylfolate, to counter the effects of the MTHFR gene mutation.

Seeking Professional Advice

If you have an MTHFR gene mutation, it's imperative to consult with healthcare professionals. They can offer tailored advice, conduct necessary tests to monitor homocysteine levels and develop a comprehensive risk management plan.

Conclusion

The MTHFR gene mutation is a significant genetic factor that can influence stroke

risk among other health conditions. By gaining a deeper understanding of this mutation and taking proactive steps, individuals can effectively navigate the challenges it presents. It's a journey of personal health management, where informed decisions can lead to a healthier life.

The Interview

Amber Corker discovered that her ischemic stroke may have been caused by a gene mutation that causes sticky blood.

Highlights:

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Transcript:

Bill Gasiamis 0:00

Hello, everyone, welcome back to another episode of the Recovery after Stroke Podcast. Today, we've got a crucial topic that could be incredibly relevant to many of our listeners, if you've ever been informed that your blood is sticky or thicker than normal, or if you have experienced an ischemic stroke with an unknown cause known as cryptogenic, this episode is especially for you.

Bill Gasiamis 0:24

And for those who've come across the MTHFR gene before and are uncertain about what the mutation means and what the potential health implications are, you're in the right place, we'll be delving into the consequences of the MTHFR gene mutation, and how it may relate to various health issues related to stroke.

Bill Gasiamis 0:47

Stick around as we unravel important insights in today's discussion. Now also, I am so pleased to announce that the book is getting excellent reviews from stroke survivors from all around the world. The most recent one is from Louisa, who says I wanted to share with you that I finally was able to get your book delivered from Amazon and I tell you that I'm only on page 32 and I'm hooked, I love the way you tell your experiences.

Bill Gasiamis 1:15

The book tells the story of 10 stroke survivors and the steps that they took that got them to the stage in their recovery, where from a personal growth perspective, they were able to transform stroke from the worst thing that happened to them into the best thing that happened to them.

Introduction - Amber Coker

Bill Gasiamis 1:31

To find out more go to recoveryafterstroke.com/book. This is episode 295. And my guest today is Amber Coker, who experienced an ischemic stroke at age 30. Amber Coker welcome to the podcast.

Amber Coker 1:46

Thank you. Thank you so much for having me.

Bill Gasiamis 1:49

More pleasure. Thanks for taking some time out of your workday to be here.

Amber Coker 1:56

Not a problem, I was happy to join you.

Bill Gasiamis 1:58

Tell me a little bit about what happened to you.

A series of misdiagnoses

Amber Coker 2:01

Okay, this was 2016, I woke up on January 15 and the right side of my face was numb. And on my way to work, I work for a university. And we have an employee health clinic. And on my way to work, I decided to stop in there. And the doctor

did the normal, you know, feeling of my face and raise your arms, had me walk, talk and everything.

Amber Coker 2:37

And I remember distinctly him saying well, we can rule out stroke. And he said I think you have a sinus infection. Okay, I went on to work and it didn't get any better. I'm left-handed, and I noticed my handwriting was very bad. But I went on through the day. And the next morning, it was a Saturday and I woke up with a double vision.

Amber Coker 3:11

And I wore contacts and I had my glasses on. And I thought that it was something with my glasses. So I put my contacts in and still had double vision. I was like, Okay, there's something wrong. So I went to an urgent care walking clinic. And they told me I had a migraine, so they gave me migraine medicine.

Amber Coker 3:33

And this was over on Martin Luther King, Jr. Weekend. So everything's closed on Monday. But I went back to the urgent care on Monday. And I was like, how long is this supposed to take to work? Because, like my vision is a little bit better, but like my face is still numb. And they were like well it should be working by now. They're like you need to go see your doctor tomorrow.

Amber Coker 4:02

So I went to my primary care on Tuesday. So now you know, like we're four days in from whenever I woke up. And she ordered for me to have a CT. And I did that on Wednesday. And then it came back inconclusive. So then she ordered an MRI on Thursday. And that afternoon, it was late in the afternoon. She said I need you to come to my office at eight o'clock tomorrow morning to go over the results.

Amber Coker 4:37

So my husband and I went to when my son was a month shy of turning one. So you know I have an 11-month-old and then my husband and so my husband and I went to her office at eight o'clock. And she said it appears you've had a stroke. "It appears" like, either I did or I didn't like, I'm you know, so she was like I've scheduled you with our neurologist that's in town I live in a fairly small community of 50,000 people, we had one neurologist in town.

Amber Coker 5:23

She said, I got you in on Monday, for an appointment with the neurologist. She said, Now over the weekend, I need you to stay calm. And I need you to not, you know, your blood pressure can't rise, I need you to stay extremely calm. And I said I'm 30 years old. I have an 11 month old. And you just told me that I had a stroke.

Amber Coker 5:51

And you want me to stay calm over the weekend until I can go to see a neurologist. I was like, are you kidding me? Like, there was like, okay, like, I'll stay calm. And she said, if anything changes the way you feel anything at all, you get a headache. You know, like, all of a sudden, you can't move, you know, one of your limbs the same way, anything at all changes.

Amber Coker 6:19

You go to the emergency room immediately. I said, Okay. I had just started a new job here at the university. I have been working for the university for four years, but I just started a different job at the university. So I had to call my boss who had been, I'd been working for her for three months. And I was like, Well, I can't come to work today because I had a stroke.

Amber Coker 6:45

And she was like, I'm sorry, you cut out. It sounded like you said you had a stroke. And I was like that's what I said. And she was like, Okay, I don't know what to do with that. And I was like, me neither I'm sorry. But I'll be back on Monday. And she was like, I don't think you are going to be back on Monday.

Amber Coker 7:08

And I was like, Okay, well, I don't know. So like, okay, well just keep me posted, I guess like, okay. So that night, I woke up at about two o'clock in the morning, and I had a headache. So I wake my husband up and I'm like, I have a headache. So we call my parents to come and get my son. And we go to the emergency room. And I had a wonderful doctor in the emergency room and they did another scan, and they said well, nothing new is happening.

Amber Coker 7:48

So I was like, okay, so you know, I'm there until, who knows how long, and then I go back. So then the rest of the weekend is fine. And nothing else really different happens. And then we get to Monday. And I'm taking a nap before my

appointment. And it's like an hour before my appointment with the neurologist.

Amber Coker 8:12

And my mother-in-law was coming over to watch her son. She had just arrived and the neurologist's office called. And they said, Well, the doctor just looked at your chart. And he said not to come to the appointment, but to go to the emergency room. Because we don't have the equipment to deal with how severe your case is.

Amber Coker 8:43

She was like we've called over there, they know you're coming. So you just need to go in there and tell them who you are. And so I'm like, okay, so I get up, I get my husband. We go back to the emergency room. And he goes up there and he says, This is Amber Coker and they just go okay, like they had no idea why I was there.

Amber Coker 9:13

And he was like, well, she had a stroke, and like, bam, all bets were off. Everyone started moving. They're grabbing me. They're taking me back. They're like getting the wrist thing on, you know, they're like getting me into a room then they start trying to like, take off my clothes and get me hooked up and asking me all the questions to type into their thing.

Amber Coker 9:39

I had like five nurses in there, all doing different stuff. And they're like, pushing my husband out of the way. And like the doctor that I had seen Friday night whenever I went in there, walks by and he's like Amber, why are you here? And I was like, well, I and like I was trying to explain to him, but everybody was like moving and talking and he was everybody stops.

Amber Coker 10:07

And so everybody stops. And he was like, why are you here? And I said, my appointment was supposed to be, you know, at 3:30. They called me and they said, to come here instead. And he said, let me make some calls and find out what's going on why they sent you here.

Amber Coker 10:29

They said she's not having a stroke right now, you guys like she doesn't need like, all of this, just stop. So then we wait for four hours. Nobody tells us anything.

We're just in there in the room for four hours. And finally, my husband goes out and he's like, what's going on? And they're like, Oh, we're just waiting for a room to open up at OU Medical, which is in a big city in a different town.

The MTHFR Gene Mutation

Amber Coker 11:04

And I was like because she's been admitted. And we're like, what? And so they transferred me down to Oklahoma City, and they admitted me to the hospital. That's where I met my neurologist with whom I had been with for seven and a half years. And where they did all of the testing, and I found out that I have the MTHFR mutation gene.

Bill Gasiamis 11:38

Stop there, this, oh, my God. So I'm listening to this and going, surely at some point, they said, send her to the hospital before the 10 days. Someone said, go to the hospital, someone said go and get a scan at the hospital, someone said go and have an MRI. It's just ridiculous that it took so long.

Bill Gasiamis 12:01

And then it had to go around that massive loop to get you there. And it's amazing how simple that seems. And yet how everyone missed the critical thing with you, which is to say, you need to get to a hospital. That was it, I can't understand how that happens. It's so strange.

Bill Gasiamis 12:23

And to say to blame it on your medical system in America and all the problems over there and all that kind of junk. It's not fair, because I hear it from people all over the world. It's just humans. It's just people that make the wrong call. And I'm not sure what it is. But I can't even explain it. It's so strange. I took seven days to get to the hospital because I was the idiot who decided that I was good enough not to go to the hospital.

Bill Gasiamis 12:55

Whereas in your case, you know, you're unwell, you're feeling on it, everyone knows you're unwell. They do a scan, and they confirm it. Everything is supposed to be in your favor to say this lady needs some help. And instead of helping you, they told you I'll see you Monday, and I won't be back for a little while. It's crazy.

Amber Coker 13:23

I mean looking back, I would have gone to the emergency room. I don't know. I mean, now, like when my face was numb, or when I had double vision, instead of going to urgent care or to, you know, the employee health clinic. However, you know, I was still seeing a medical professional. That I thought, well, you know, if I go see them, then they'll they'll tell me. Like, if I needed to go to the emergency room, which they didn't.

Bill Gasiamis 14:03

Yeah, I know. I know that, oh my gosh the chances that somebody who hasn't had a stroke and listens to this podcast, unless they your friends and family. It's very low. Most of the people listening are stroke survivors and caregivers. And they probably all like you and me, we know what to do now. But it'd be so good if we could just tell the people of the world. If you have these types of things happen to you just go to a hospital.

Bill Gasiamis 14:03

Don't wait 10 days before somebody sees you, insist that somebody says you, man, it's such an intense moment I can't get over it. But I appreciate how it happens. And I'm glad that everything worked out and that you're here and you can join us and all these amazing things have happened, right? So we've had a really good outcome, all things considered.

Bill Gasiamis 15:03

Oh, my gosh. So the reason I wanted to speak to you when you reached out was because you said something that nobody has ever said before, about the connection to stroke and the MTHFR gene. Now, most people listening won't know what the MTHFR gene is. However, I do know about the MTHFR gene a little bit.

Bill Gasiamis 15:30

The reason I know about it is because I tested positive for one copy of the gene. So I picked it up from one of my parents. As a result of that gene, I have gone out of my way to change my diet to ensure that certain things aren't consumed.

Bill Gasiamis 15:48

Now, for people who are listening, and have never heard of that, and watching, can you tell us what the MTHFR gene is, then we'll talk about why it's important

to know whether you have this particular gene mutation and whether you have one copy or two copies.

Intro 16:06

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.

Intro 16:31

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 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.

MTHFR gene mutation and its impact on health

Amber Coker 17:10

Yes MTHFR is methylene tetrahydrofolate reductase. Which is a huge mouthful. And it took me many years even though I have it to know exactly what it all stands for. You know, and of course, the acronym of the MTHFR is really fun. Because you know you look at it and you think it could be something else. And sometimes I feel like it is so the gene mutation that causes the body to not turn folate and folic acid into their active form, which increases homocysteine and your homocysteine levels in your body, which irritates your arteries, which can cause blood clots.

Bill Gasiamis 18:20

Let's pause there are let's pause there for a second. Okay, so the MTHFR gene, you can pick it up, you can pick it up from your parents. As a result of that when both of your parents have the gene and you have the gene. What that does is you need to be aware of it because there are certain foods that you cannot do well

with you can't break down you can't process them in your body.

Bill Gasiamis 18:47

Now when I say foods, not necessarily foods but ingredients in foods, one of those ingredients is folic acid, which is the synthetic form of folate, which is used specifically for women who are going to be pregnant or are pregnant to decrease the chances of neuro birth defects in their children. And then as a result of that, for women to get a lot of folic acid and folate through their diet, because usually it's found in leafy greens silverbeet a whole bunch of other you know, lovely leafy greens.

Bill Gasiamis 19:38

What they do is what the people that know better to do is they put folic acid in bread in flour, and all flour has added folic acid and the purpose of that is to decrease the chance of neural birth defects. I know it happens in A lot of Western countries, but it happens in Australia. As a result of that, people who have the fat MTHFR gene don't know, or perhaps getting over, what's the word overexposed to folic acid? And they shouldn't be they should be avoiding it. Did I say it well?

Amber Coker 20:27

Yes. Another thing, along with just what the folic acid that they put into food for women who are pregnant, especially during the first trimester, they suggest them taking a folic acid supplement, or also just a regular prenatal vitamin, they have a high, you know, high doses of folic acid. Which, if you have MTHFR, and I don't know exactly this part I'm not real sure about but the if you have MTHFR.

Amber Coker 21:16

You have a higher chance of miscarriage because of the amount of folic acid that you have. And that you're like that you're taking, especially during the first trimester due to your folic acid supplement or your prenatal vitamin. And it can cause miscarriage. And that was one of the first questions after my blood tests came back that my neurologist asked me, he said, How many miscarriages did you have before you had your son?

Amber Coker 21:53

And I looked at him like he was crazy. was like I didn't have any. And he was shocked. Like that shook him to his core. Like he didn't, because he just knew he just knew I had to have had several miscarriages before I had my son. And, you

know, I was like, I didn't have any and he was like, how many miscarriages Did your mom have?

Amber Coker 22:21

And I said, Well, she had two she had one before my brother and she had one before me. And he was like, okay, and then he seemed to calm back down. Like he was like, okay, my world is back in order. He was like, You were lucky. And I was like, I mean, I was lucky. But so that's another thing that it causes because your body is not breaking down that folic acid and folate. It can cause miscarriages as well.

Bill Gasiamis 22:54

So just so we explained things well. You had a specific stroke that has a particular title, which is basilar artery thrombosis. Is that right? Yes. Did I say it well?

Amber Coker 23:13

I had a blood clot in my basilar artery. It was just an ischemic stroke. That was just the fancy term of the location of where my blood clot was.

Bill Gasiamis 23:28

Okay. No worries. So that is not linked to the particular MTHFR gene, the location is just the location where the blood clot ended up anyway. Okay, so your doctor is pretty switched on? Does he give you the details about the MTHFR gene? How does he take you through that discussion? Because you've never heard of it before?

Amber Coker 23:52

Oh, gosh, no, no. And I don't like no, I had no idea. My husband recorded on his phone, the whole thing whenever he came in, but it ended up being like an hour and a half of explanation. Quite honestly, and I think my brain did this kind of to protect itself. I don't remember exactly how the whole conversation went. But yes, he did come in and he did explain it.

Amber Coker 24:22

The way he explained it to me the first time around, was that because folate and folic acid do not break down, it makes your blood sticky, which makes it more prone to clots is how he explained it. Then that's kind of real, basic terms there's more to it than that, but that's the way he explained it. He said that since and he's a very, very well respected and very, you know, very good neurologist and he has

practiced all over the United States.

Amber Coker 25:09

And he said when he moved to Oklahoma, he saw more cases of MTHFR than he had ever seen. And he thought that it had something to do with the Native American blood. He has no science to back that up. That was just kind of his thought. But he found it very interesting that whenever he moved to this part of the country, he saw a lot more of it.

Bill Gasiamis 25:46

I guess I was gonna say, is there a large Native American community in Oklahoma? Yes. Do you have Native American ancestry?

Amber Coker 25:56

I do. I do. It is not. It's not strong. I think I'm like one 128 or something. Okay. So it's not, it's not like I'm half or a fourth. But I think pretty much everyone if they were born in Oklahoma, or one of the surrounding states probably has somewhere in their lineage, some Native American blood. Just because this part of the country does have was, you know, Native American land for so long. But yes, I have I have two copies, of the mutation.

Bill Gasiamis 26:40

Okay, what's what does that mean?

Amber Coker 26:44

That means that I got a copy from my mom and I got a copy from my dad. So I was the lucky one. And because, I am homozygous, which means that I have the two copies. If you just have one, then you're heterozygous. I can't just manage it with diet.

Amber Coker 27:12

Heterozygous, which my son is heterozygous. He was going to get one copy for me because I have to. So he had no choice. He was going to get one. I did have we had him tested. And he did he just has one copy. So his, his can be controlled with diet and hydration.

Bill Gasiamis 27:41

But you say I also hit a rose Agus hit her out means one homo means to. Okay, I just need to remember this because I keep forgetting. And guess what? Guess

what I just remembered, which is interesting. I just remembered that my dad had taken a blood thinner. The reason my dad takes a blood thinner, which I did not know about for many years until I was an adult, is because the only way my dad can describe his is because my blood is a little bit sticky.

Managing MTHFR gene mutation with diet

Bill Gasiamis 28:25

Or thicker. Wow. That's fascinating. That's fascinating. So what I'm then certain of is that my children, I've got to now confirm again, whether or not I'm heterozygous, or homozygous, I can't remember now. Now I can't remember. So I'm going to confirm that. And then I'm going to speak to my children about that. And you said that your son says he's got one copy. You can manage it with diet? No. What does that mean? How do you manage that with diet?

Amber Coker 29:04

I'm being aware of the ingredients of what he is eating how much folic acid he's taking, and hydration. That was one thing that the doctors said was staying hydrated. If you're hetero, you just have the one copy. Hydration plays a very large part in keeping that under control because it keeps the blood moving smoothly through because the more dehydrated you get, the more likely that that stickiness is going to, you know, come through.

Amber Coker 29:46

So staying hydrated and not taking hormones. You know, guys were, you know, males when they're teens, they want to make that testosterone tight, you know those things to bulk up or whatever, I've had to make it, my son is only nine now. But we've already started the conversations of like, you can't do that. Like you, you have to stay like when you're, he plays soccer.

Amber Coker 30:22

And you have to stay very hydrated, you have to drink lots of water whenever you are playing. And when you get old, and he doesn't understand it now. But I've started early talking when people start talking about taking supplements and stuff to bulk up or be faster, whatever like you cannot do that. Like you can't do it. Like, yeah, and he knows about, he knows about my stroke. And he knows, like,

I've told him all about it. And so I think he understands. But we started real early talking about that stuff. Hopefully, it sticks as he gets older.

Bill Gasiamis 31:04

I love that you started so early because I think about it now everything's coming back to me. All the people that I've interviewed that have had a stroke that has got, apparently No, cause they've had an ischemic stroke. And they have been told that it is a stroke that they can't find the cause for that they have no idea why it happened. And there's nothing we can do and all that type of thing. And I'm thinking about that now. And it's like, wow, these people may have had an MTHFR gene issue.

Amber Coker 31:35

They should have their blood tested. It can be tested by just a blood test. You know, there's a specific, it's not a specific test that they run just like a normal blood test. But I don't know exactly what it is that they call it. But you can ask, you know, I need to be tested for the MTHFR mutation.

Bill Gasiamis 32:10

I was gonna say to people who are listening and watching if you're a stroke survivor who's had a stroke, and it has been an ischemic stroke, and they're not certain as to why it happened, go to your doctor Monday morning, and ask for a MTHFR gene test, whatever it costs, get it done, because this is one awesome way to prevent further strokes from happening, especially if you've had an ischemic stroke.

Amber Coker 32:40

It is also a way to help prevent your family members from having a stroke Possibly, yeah.

Bill Gasiamis 32:50

I just can't believe I'm just so stunned. It's somebody that I've known for many, many years. And nobody, the people who told me that I had the MTHFR gene just explained to me that I should avoid folic acid. And that's going to help me with my energy levels going to methylate things better and absorb the energy from my food and process that and turn it into energy. And that makes complete sense to me. But they didn't give the other deeper explanation as to what the purpose of avoiding folic acid was. So I imagine when you guys go shopping, are you guys

forever Turning the pack around and looking at the ingredients list? Again, that's out?

Amber Coker 33:33

No, we probably should be, but we look more at vitamins. You know, like, just like the daily vitamins that that my son takes and then I take just to make sure that it does not have folic acid and that that's more of what we do. And then, I mean, I'm aware of it. I mean, I do kind of look to see every once in a while but it's the diet part is not the part that I that I focus on a whole lot. I probably should but I don't.

Bill Gasiamis 34:26

Yeah, fair enough. I was just curious how you guys go about living with that kind of information. I know you shouldn't be over. What's the word like? Are you anxious about it? And think about nothing else all day every day. I know that you should not be like that. No, I don't. I just go about my life as normal and I eat foods that contain folic acid as little as possible, but I do from time to time, especially sometimes bread.

Bill Gasiamis 34:57

Usually, I avoid bread like the plague pasta, and all that kind of stuff. Anything that has flour, wheat flour in it, I avoid. But every once in a while I'm going to have some and I don't think that type of amount of folic acid intake is going to make a difference to my right, right health and well-being, you know, down the track, because I'm not consuming too much of it.

Bill Gasiamis 35:25

Now, what annoys me about this whole folic acid issue is that put it in red, so that women can avoid neurobirth defects. Well, men don't need folic acid to that extent for that reason. So it's like weird that let's dose the whole population when only half the population well, not even half, but we'll say half the population benefits from having.

Bill Gasiamis 35:49

And I say not even half because some people don't need additional folic acid in their diet, they have healthy levels, regardless of whether they're consuming it in this form, or foods. So it's a really weird thing that governments do, let's, you know, put a chemical in the food for everybody to consume and then just assume it, it's going to be fine.

Amber Coker 36:19

Absolutely.

Amber Coker dealing with post-stroke deficits

Bill Gasiamis 36:20

Yeah. You know, with the stroke. So what did you end up coming home with that you had to recover from or overcome? Did you have deficits that you had to deal with, I know that you initially noticed the numbness in your face. And that was there while you were trying to get the diagnosis. What happened after that?

Amber Coker 36:41

When I came home, eventually, the numbness lasted probably about a month, slowly kind of going away. I had weakness in my left arm. And I felt my whole left side. I felt like I walked funny. And that was something then going in Walmart, walking with my husband, I was like, do I look funny? Like, do I look like I'm walking funny? And he was like, no.

Amber Coker 37:18

And I was like because it feels weird. I feel like I'm not walking, right? And he was like, You look fine. You look like you're walking just fine. So it was very strange to me to do that, I also with a weakness in my left hand, which I'm left-handed, so I had to do a lot of physical therapy with, you know, strengthening my left hand. And it took a long time for my handwriting to go back to normal. So, I do struggle with words, at times.

Bill Gasiamis 38:01

Reading words or speaking words?

Amber Coker 38:04

Speaking words.

Bill Gasiamis 38:05

On the tip of your tongue, they can't come out or do you not know which word to use?

Amber Coker 38:15

I know what I want to say, but I just have trouble getting it to come out. And that's you know, I started following your page on Instagram very shortly after my stroke. And I would see it as I'm scrolling through, I would see a post and be like, oh, and it wasn't just shortly before I reached out to you to tell you about my stroke.

Amber Coker 38:44

I saw a post of yours that said, you know, like if you had a stroke while you were asleep, do you have sleeping anxiety? And I was like, well, yeah. Oh, wow. I wonder if that's why I don't sleep. And I kind of just when I was like, huh, like, and I just kind of went on. And then a little while later, I was scrolling through I saw a few days later that you say something about like, do you notice your deficits more when you're acutely stressed?

Amber Coker 39:21

And I was like, yes, like when I'm highly emotional, like angry or upset. I have a very hard time finding the words that I'm trying to say. And I was like, Oh my gosh, like, and that's whenever I was like, You know what? This website and like, you know, I've been following it for years, you know, and I just kind of scroll through I read it sometimes I'd read the comments, you know, see what everybody else was saying.

Amber Coker 39:52

But just kind of going on through. But it wasn't until those two that I kind of just stopped and that's when I went to your website and I listened to podcasts. And then I saw about like, being a guest. And then I was like, I'm just gonna tell him about my story. I mean, who knows? I wonder if you've ever heard of MTHFR? Because I sure haven't. But it was those two things that so yeah, my speech the trying to find a word that is one thing that I do struggle with.

Bill Gasiamis 40:25

The interesting questions, don't come from me, they come from people who I coach who are trying to overcome their deficits and their stroke. And they make sense to me when I read them. And when I ask people I notice that I also get my deficits to get worse when I get highly emotional. I notice how they get worse when I don't have a good night's sleep, that kind of thing.

Bill Gasiamis 40:53

That all makes sense. But sometimes they seem like they're for me. It's like, I No, that's no big deal. That's normal, I get it. And then I realized that people like you go, Oh, my God, nobody ever asked me that question. Of course, that yes, that is and then they connect the dots. And then that somehow makes things better or different or helps them adjust or change something.

Bill Gasiamis 41:19

One of the strangest things, one of my stroke survivors, who I coach said, was that she hears noises in the affected side, like voices from other people in just the affected ear. So she doesn't have any ear problems, per se. But on the stroke side, that is affected. She hears noises, words, people talking, and it's driving her bananas, she says, and she goes, Is that normal?

Bill Gasiamis 41:47

As I've got no idea. I don't know what that is. But let me ask the community, the whole tell us whether it's no. And sure enough, I asked a question. And bang, people are going, yep, I hear noises. I hear voices. I hear things since the strike in my ears that I've never heard before. And what that did say? It seemed to just settle people down about it, it seemed to go, oh, okay, it happens to other people, oh it's just the result of the stroke, some people played it down, it's nothing then I can ignore it.

Bill Gasiamis 42:20

And it's like Wow, yes. I mean, it's such. My, stroke survivors who I'm coaching and the people who are listening are a wealth of knowledge. And I really, truly appreciate the sharing of that knowledge. Because I learned so much from it, and then we can help other people. But this is important that the MTHFR gene is really important for people to know about. And if they do get tested, it just gives you a little bit more information.

Bill Gasiamis 42:52

It's not invasive, it's not hard to deal with when you know about it, and you can just take small preventative steps, especially if you're the kind of person who's already trying to prevent another stroke from happening. I think it's really important. And I love the fact that you had the good fortune after all of that story to end up in the right. doctor's surgery, and then speak to the right neurologist who knew about their condition and was able to give you a lot of information that you can then share.

Amber Coker 43:24

I love my neurologist. I loved him. He recently went to a Veterans Hospital, just within the last six months. And so, since I'm not a veteran, I can't see him anymore. So I have a new one. But, I mean, he was with me, I just happened to be very lucky that he was the one working at the inpatient hospital that day, and that he was a stroke biologist he says that he specializes in strokes and that I came in that day. And then because he sees patients, you know, outpatients in the clinic, too. So I was with him for seven and a half years before he moved over to the Veterans Hospital.

Stroke recovery and adjusting to new life changes

Bill Gasiamis 44:16

So even though you're seven and a half years out, or it's 2016, so eight years now, are you still getting regular visits with your neurologist and scans and all that kind of stuff? How are you managing this?

Amber Coker 44:33

I don't get regular scans. But I do go I do go see my neurologist once a year. Just to do well, I'm my neurologist also treats me for migraines. And so when I go more like what right now I'm going more than once a year but that's just for migraine stuff, but for stroke stuff, it's once a year Just to do the typical, like, make sure that everything you know this thing.

Amber Coker 45:08

And if anybody that's gone to the neurologists, you know, if you don't have to do all of this like, all of the different things. So I do go once a year for that. Because I am on a blood thinner. And it's been working great, you know, for eight years, so, yes, I do go once a year, and I will be on a blood thinner for the rest of my life.

Amber Coker 45:41

And I will probably see a neurologist. Let's see, what did he tell me? He said that I could go out 18 to 24 months at max, at some point, but I, I, I've always said I feel better going once a year. That's just kind of like, I just feel better with the 12 months going in just making sure.

Bill Gasiamis 46:09

That's always good to go to the doctor once every 12 months to just do a checkup do some blood, touch base, and make sure everything's going well, I think that's great. So what was the hardest thing about this stroke for you?

Amber Coker 46:26

I would say initially, the hardest thing was knowing that I had blood, a blood clot in my brain. And then it was just there. And at any point, something could happen. I was what my hospital in town calls a frequent flyer in the emergency room for eight months after, because every time something felt weird, in my head, I went to the emergency room, I had more seat tees and more MRIs in the eight months after than any one person probably would have in three lifetimes. Like until, like eight months out.

Amber Coker 47:35

One of the times that I went in, and when I went, I told them, I said, I know like, I know that I sound crazy. Like I know that. But something is off. And this is my history. And I need I need you to tell me that I'm not having another stroke. Like that. That's what I need. And that at that eight-month mark, they did a scan. And he said I don't see anything. And I said, except for the blood clot.

Amber Coker 48:09

And he said, there's no blood clot. I said, What do you mean, there's no blood clot? And he was like, there's no clot on the skin. And I said, You mean it's dissipated? And he was like, I don't I don't know. I'm just telling you like, there's no blood clot in your brain. After that, I was fine. I didn't go back. I didn't that I didn't have to go back to the emergency room every time I knew that something felt off.

Amber Coker 48:44

So initially, it was that fear of when is the next one going to happen. After that, it was the hardest thing was knowing that my life was not going to be the way I planned it. Because I was advised not to have any more children which was not part of my plan. Um, I never thought that I would have an only child. I never wanted to have an only child. And so that was the hardest part trying to adjust to that.

Bill Gasiamis 49:36

That's a tough one. Why would they say that that was advised why did they advise against that?

Amber Coker 49:44

They said that it was I needed to it had to be extremely planned. Extremely monitored. There could be there could be no accidents. I mean like, I mean, it had to be a very rigid and structured conception, like I mean everything. And even then they would have to, you know, I would be weekly visits with a specialist for the whole time.

High-risk pregnancy due to genetic mutation and blood thinner use

Bill Gasiamis 50:23

Thinking about miscarriages and challenges.

Amber Coker 50:27

Yes and then bleeding out later on. Because they would have to I would have to stay on some type of blood thinner, I would be switched from El Eliquis to a different one. Okay, but then it would be constantly checking in. I mean, they were they did say, you absolutely can. However, it is extremely high risk. Okay.

Bill Gasiamis 50:56

Okay. So two things are going against you so to speak, is the MTHFR gene mutation that you carry. And then it's also the fact that you're on a blood thinner to help make sure that your blood doesn't clot. And in the event of the MTHFR gene, causing challenges to your, to your pregnancy. And then there is a situation where there's some kind of a complication to that, that your biggest risk after that is bleeding out. Because you're on a blood thinner.

Amber Coker 51:39

Which seems kind of contradictory, you know, because, like, on one hand, they're, they're afraid of clotting. So, on the one hand, they're afraid of bleeding out.

Bill Gasiamis 51:50

Yeah, yeah. Wow. Okay.

Amber Coker 51:53

It was one of those things where it was, if you do this, it has to be before you're 35. So it was one of those conversations we had to have every single time I went in.

Bill Gasiamis 52:07

Did you have an ob-gyn involved in this particular conversation? Or did that happen without?

Amber Coker 52:18

No. Because we never got that phone to where I said before, because it was more of a, it was more of a struggle between me and my husband and my neurologist that between the three of us trying before we could even get to the next step of bringing in an OBGYN to you know, as a high-risk specialist for that.

Bill Gasiamis 52:52

And anyway, your neurologist seems like an amazing, amazing doctor. You know, he's got so many other things that are going on that he's aware of that he needs to make sure that you're advised of.

Bill Gasiamis 53:11

So that he manages your health and well-being way beyond just what you guys discovered with a gene. And that he knows like, what the complications are for you down the track, should you choose to go down a certain path, and it's big, it's a big call to cite somebody, you probably shouldn't have another child, but he's not saying that what he's saying is, you should be fully aware of the risks, you should make a fully informed decision.

Bill Gasiamis 53:40

And these are the chances these are the risks that you face over and above what say, quote, unquote, a normal person who doesn't have these conditions will face and I love that about him because that's not many. There are not many people who have that foresight that do that kind of deep thinking about what the future holds for somebody who's you know, in their 30s Right?

Amber Coker 54:10

He is an Outstanding, outstanding named Doctor. And ultimately, he did leave the decision up to me and my husband and you know, my husband said I do not want to have a toddler and an infant and no wife so common and you know, right at first you know, I was going every three months every six months, you know, for a

long time every six months and then I graduated to like yearly.

Amber Coker 54:47

But you know, for a while there, I was going a lot and every single time it was like do we need to talk? Do we need to have another pregnancy talk? Are we going to do it like are we talking about this time? And every time we would look at each other and we like But no, because we weren't talking about it. And finally at the last one, when I was 34, he said, This is it. Are we doing this? And I said, and at this point I had I had come to terms with it. And I said, No, we're not.

Amber Coker 55:20

And my husband goes, well, and I looked at him. And I just I, my eyes got huge. And the choice words that came out of my mouth, and I was like, You have got to be kidding me. And he was like, what? Like, now it's like, for real? And I'm like, Yeah, I know, it's for real. It's like, are you? And I was like, No, we're not doing this. Because the point, you know, now, my son is talking, and he's out of diapers, and he's getting ready to start school.

Amber Coker 55:59

And so I'm like, I'm not starting over. Like, I'm done with that. And I had already come to terms with it. So I was like, no, no, we're not, we're not having it. Like, we've decided what we're done. And so my doctor, he just laughed, and he was just like, I love you guys so much. He was like, You guys are the highlight of my day when are you coming?

Bill Gasiamis 56:22

You're, you're fair enough as well, to give him the dirty look. He didn't realize it was real, because he's a male. And he doesn't have any of the things that go along with, you know, the, we'll call it the, you know, the natural cycle that women go through where it ends, eventually, the opportunity ends doesn't have that he's never thought about that. Because he doesn't have to think about that. He's just going about life going.

Bill Gasiamis 56:49

Yeah, that'd be good. And then he goes, I'm gonna change my mind now. And are you on board? Come on. But I get what he's thinking, but you're right, as well is that, your life, when you've got young children if you've got them young together, it's chaotic. And it's terrible. And it's difficult, and it's amazing, and it's lovely.

But they it ends, the chaos ends very rapidly because both children go through their phases very close together.

Bill Gasiamis 57:20

And then, and then you're kind of free, you get your life back, you start sleeping more, you do all these things. And then I know, because I've got some friends who have got children that are 567 years after the previous one. And they're all that pain and suffering of having lovely, beautiful, gorgeous children gets extended, and it gets drawn out. And you're, and you're in the twilight zone for too long.

Bill Gasiamis 57:51

And I see them so I know what you mean, I get what you mean. And I think you made the right decision. Either way, you know, you made the right decisions to look after your health and to honor his first request, which was I don't want a toddler, and a baby and no wife. Like all those things, they're really important things to consider. And I think you guys have gone about it, you guys have gone about it the right way the hard decisions to make. So what stroke taught you

Amber Coker 58:33

A couple of different things. One is to do what you want and do what makes you happy.

Amber Coker 58:47

Because, you know, you don't know what the future holds. And life is short and you never know what's going to happen. And, and the other thing is, it's taught me to give myself Grace give me to give myself grace, in everything in adjusting to what my new life is going to look like. And give myself grace in adjusting to any deficits and to you know, to just be patient with myself just like I would with other people.

Bill Gasiamis 59:36

Are you hard on yourself? Normally?

Amber Coker 59:39

Yes. And, I did not like not being able to bounce back just right away into what was normal, and I didn't like that. And I had to adjust my mindset of, you know, it's okay, because this huge thing happened to your brain, which can alter absolutely everything about you. So, I, like it's okay that you're not just, you know, just like that back to how everything was.

Living with a lifelong alteration after a stroke

Bill Gasiamis 1:00:39

Yeah, that's good to give yourself grace. I've met a lot of people who say something similar who are not patient who give themselves deadlines, some people act like their worst boss would act to them in the work environment, you know, they have all these expectations or these deadlines and, and it's like, this is not a broken foot, you don't have you don't go to the doctor, get a scan, get a cost that put it on six weeks, come back, take the cost off a little bit of rehabilitation, and you're back to normal, it doesn't it's not help. No, at all.

Amber Coker 1:01:23

No, no, this it's a it's a lifelong alteration. Whatever your deficit may be, or, even if you don't have any, there's always that, you know, there's, there's always that something is I mean, it's, it's an alteration of your outlook on life as well. And it's like, long, it's not, it's not just something that can, you know, slap a cast on, and then you're good to go.

Bill Gasiamis 1:02:00

For me, I describe it as it's, it's like having like a scar, a really serious scar that you've got early on in your life. And even though the scar tissue has healed over and it's gone you can see the sky every day. And every day, the scar reminds you of where you got that scar and how you got that scan. Sometimes you don't notice it.

Bill Gasiamis 1:02:19

But sometimes you notice and you remember that that scar happened. And this is the way that it happened. Now, scars fade, which is cool, right? They fade and they get less obvious. And that's our stroke kind of evolves, it can for very, very many people fade, get less, take less space up in the front of your mind.

Bill Gasiamis 1:02:43

And it can just sort of head to the background a little bit and it does do that. But yes, most people I've spoken to have had a stroke that is 510 1520 years out. All talk about it still as if it's something that they're dealing with managing overcoming. Moving Beyond living with. Yes. Yeah. Yeah.

Amber Coker 1:03:11

I mean, it's just you live with it. So yeah.

Bill Gasiamis 1:03:17

Move on I, what's something that you want to tell some other people who are listening? That may have been through something similar to you, obviously, with regards to the stroke, but then obviously, with the news that maybe you should avoid future pregnancies, that kind of thing? What kind of advice would you like to leave them if somebody has been given that type of information that it's just fresh for them now?

Amber Coker 1:03:46

It's okay to mourn the Life You thought you were going to have or the future children that you thought you might have. Like, that's okay. Hey, it's okay to do that. And that just because you haven't had them doesn't mean that it's not a lot less for you. So that, you know, Grieve however you need to. And take the time that you need to, to adjust to what your new life is going to look like.

Amber Coker 1:04:31

I can't imagine at this point, having any other children other than my son, I was meant to be the mother of an only child. I was meant to only have a boy. I always thought I wanted to go, girl. I don't know what I would do with a girl. I have no idea. And so it's although it's not something that I would have chosen to only have one, it was the right thing for me. But like I said, it took four years for me to get the initial, hey, you probably shouldn't do this.

Amber Coker 1:05:16

And all of the risks and everything to that final appointment where I had come to terms with it. And I said, no, like, final answer, we're not doing this. It and and it did, it took four years for me to get there. And that's okay. It's okay if it takes you a long time. And it's okay. If it takes you longer than four years. You grieve, however, you need to

Bill Gasiamis 1:05:49

do like that. Giving people that space to take to let the process just take the course that it needs to take, that's important. And in that time, for some people, you might need therapy, you might want to go and chat to somebody about that support groups, you might need to do all of that stuff, which is all fine. And that

will help. So I love, that gift of giving people the time that it takes. And we don't know what the length of that is. It's just however long, it takes for you to take

Amber Coker 1:06:27

No problem, whatever, whatever it takes. Yeah.

Bill Gasiamis 1:06:30

Thank you so much for reaching out. And joining me on the podcast, I appreciate it. I learned a lot today. And it's very rarely that I connect the dots in, you know, things that I've read about because I read about the MTHFR gene 12 years ago, it's very rarely that I can then connect the dots, and then make that a really good compelling story and give people a lot of amazing information about what they can do to protect themselves from avoiding another stroke perhaps.

Bill Gasiamis 1:07:02

And that's what I said earlier about how the community knows. And all I've got to do is ask and I just love the fact that you knew that. And that you could tell that. I don't like the fact that you had to go through a hard time to find that out. But I appreciate that you're willing to share it.

Amber Coker 1:07:23

Yes, thank you so much for having me.

Bill Gasiamis 1:07:26

Thanks for joining us on today's episode, I hope you'll learn something new. To get a copy of my book go to recoveryafterstroke.com/book. To learn more about my guests, including links to this social media and to download a transcript of the entire interview. Please go to recoveryafterstroke.com/episode Thank you to everyone who has already left the review. It means the world to me, that podcasts live and thrive because of reviews.

Bill Gasiamis 1:07:53

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Bill Gasiamis 1:08:19

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

Bill Gasiamis 1:08:35

To connect with me just go to recoveryafterstroke.com/contact fill out the contact form and I will be in touch with more details about how we can connect via Zoom. Thanks again for being here and listening. I appreciate you see you on the next episode.

Intro 1:08:51

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Intro 1:09:13

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Intro 1:09:36

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Intro 1:09:52

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Intro 1:10:12

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