

## **TRANSCRIPT: Getting to the Heart of Stroke: Understanding Your Patient's Journey after Stroke**

### **Unknown Speaker 0:01**

Alex, welcome to the American Heart Association getting to the heart of stroke Podcast Series. I'm Dr Alex Schneider, and it's great to have you here with us today. In this episode of understanding your patient's journey after stroke, we delve into the multifaceted journey of stroke patients from initial risk factors to long term recovery and emotional well being. Join us as we explore both traditional and unconventional risk factors to gain a comprehensive understanding of their contribution to stroke incidents, we'll investigate the unique causes and management strategies for stroke patients, including those with unknown etiologies. Additionally, we'll examine the common psychological and emotional challenges faced by stroke survivors, such as depression, anxiety and changes in self identity. Tune in to gain valuable insights and practical knowledge to better support your patients on their journey to recovery. Before we begin, let's review the learning objectives for this specific podcast. We're going to discuss the traditional risk factors, hypertension, diabetes, smoking, hyperlipidemia and how they contribute to stroke incidents. We're going to investigate the causes and management of strokes in younger patients under 50 and those with unknown etiologies. We're going to assess the common risk factors and treatment plans for older adults, typically at risk for stroke, gain insight into the multidisciplinary care and long term management strategies for stroke patients, explore the different rehabilitation therapies available to stroke survivors, including physical therapy, occupational therapy and speech therapy, and understand their roles in recovery. And finally, we're going to examine the common psychological and emotional issues faced by stroke survivors, such as depression, anxiety and changes in self identity.

### **Unknown Speaker 2:09**

We are joined today by two stroke patient representatives, George Richards and Kaylin Dever, George, why don't we start with you introducing yourself? Yes, I'm George Richards. I live in Leland, North Carolina, and we've been in this area about three years.

### **Unknown Speaker 2:28**

It's a little warm and toasty, but it's kind of it beats the snow, that's for sure. And Kaylin, please introduce yourself, sure. My name is Kaylin. I am a wife, a mother of two littles. I am a Bible believing Christian. I am a former nurse practitioner, also former nursing instructor, and I guess you know, last but not least, I am a stroke survivor. Thank you and welcome George. Can you describe your symptoms, the symptoms you experienced during your stroke. What were you doing at the time, and how did you react?

### **Unknown Speaker 3:08**

Okay, so it was September 8, 2021. I was playing golf. Was on the sixth hole. I had hit my drive. We drove out to our balls, and I got ready to hit my second shot, and my left arm would not work, but I flashed back to a time at our previous location in Henderson, Nevada, my wife ran the stroke support group for St Rose Dominican hospitals, and one program that they facilitated was called Saving strokes, where PGA professionals volunteered their time to teach one arm stroke survivors how to golf. And I thought, well, if they do it, I surely can.

### **Unknown Speaker 4:00**

So I attempted to hit my second shot, it feebly, went about two yards, and I realized I couldn't do it quite as well as the instructors had taught those people. But after trying to hit the shot,

**Unknown Speaker 4:16**

my golf club dropped on the ground, and I remember bending over to pick it up, and I was having difficulty again because my left arm wasn't working. I was a little wobbly, and I also could tell that I was drooling.

**Unknown Speaker 4:33**

And I thought, Oh, this probably isn't good.

**Unknown Speaker 4:37**

And thankfully, one of my friends in the foursome. Mike Davison yelled, George is having a stroke. Call 911

**Unknown Speaker 4:48**

so I will stop here to say that's exactly what you do. You don't say, Let's driving to the hospital. We don't have time to wait for an ambulance. No. Call 911

**Unknown Speaker 4:59**

so they.

**Unknown Speaker 5:00**

COVID, and then my seat mate, the guy driving the cart, drove me up to the clubhouse where we could meet the ambulance.

**Unknown Speaker 5:10**

And even though

**Unknown Speaker 5:13**

I I'm sure I knew I was suffering a stroke, but even though I knew that

**Unknown Speaker 5:20**

all the way up to the clubhouse. I kept slurring. I'm 100% I'm 100%

**Unknown Speaker 5:28**

I clearly was not 100%

**Unknown Speaker 5:31**

they got me up to the clubhouse. The ambulance came, and as the EMTs were assessing I you know, I knew it was a stroke, and I knew they were doing the right thing. I also had research. When we moved to this area, we've had some history with stroke. My wife runs a non profit that primarily serves stroke survivors.

**Unknown Speaker 6:00**

When our son was 10 years old, he suffered a massive stroke. Her father had a stroke, her mother had a stroke, her brother had a stroke, and so I thought I would fit right in with the crew and have my stroke.

**Unknown Speaker 6:15**

So the good news is they didn't count my extra stroke on the on my score card. So that is what happened. And it was September 8. Interestingly, I was scheduled to have my pacemaker replaced a week later on September 15, what was your experience like in the hospital? Not just the medical details, but how did you feel informed about what was happening to you, the tests and follow ups, were they clearly explained to you? And how was the communication with your healthcare team?

**Unknown Speaker 6:50**

The communication was excellent, actually.

**Unknown Speaker 6:55**

So as the ambulance arrived at the hospital, they were wheeling me in on this the stretcher and the neurologist was, if you will, running beside us. These guys were not walking slowly. They were basically running me into the

**Unknown Speaker 7:13**

emergency room, I assume, or the neuro part of the emergency room,

**Unknown Speaker 7:20**

and the neurologist, as I'm going in, he said, Are you a bleeder? And I said, I am not a bleeder, and I want TPA. And his response was, we don't use TPA. We use a similar drug called TPK. And I said, Fine, I want it. So they they went in and administered TPA, which or TPK, which is a clock bus buster. Following that, they put me in the MRI machine to scan to see if everything was okay. They found that there was still a clot in my major of cerebral artery, MCA,

**Unknown Speaker 8:02**

and so the neurosurgeon came in, introduced himself, and he said, George, we need to do what is called a thrombectomy, because you still have a clot. So I need to go in and remove that clot. I said, Fine. And they actually left me awake during that and, you know, I watched some of the procedure,

**Unknown Speaker 8:26**

but again, they they kept me informed. They told me what was happening following it thrombectomy, they wanted to do another MRI, and because I had a pacemaker, they called in Medtronic technician to look at my pacemaker, which you know it was scheduled for replacement, and the tech said, because they have to shut your pacemaker off and turn it back on after the MRI, he said, I would recommend we not do another MRI.

**Unknown Speaker 9:01**

And I said I relocated from Vegas. I said, I'm a gambler, so go ahead, let's do it, but, but they, they wouldn't do it in the doc explained to me, said, I have to be honest. Where he said I wanted the MRI just, you know, we said, I've got the clock. You're fine. But he said it was, it was more for my benefit to look and see everything was okay. But he said, I know you're okay, and so that was good. And then they because of their thrombectomy, believe it or not, they would have released me that day, but because the thrombectomy is a surgery where they go in through the wrist, in through the MCA, and use their little device to get the clot. They kept me overnight, and they did get approval. So that was on the eighth and then on the ninth.

**Unknown Speaker 10:00**

Get approval to just keep me in the hospital until the pacemaker was replaced. And I said, I don't need to be in here, you know, please release me, which they did the following day.

**Unknown Speaker 10:14**

But again, all during that, the people kept me informed what was happening. The main thing at that time, then my main frustration was I wanted coffee so bad, but I hadn't had my swallow test from the speech pathologist, and so they wouldn't give me coffee until I had that. They wouldn't even give me an ice cube to suck on. So, yeah, anyway. But all during that, the medical team was really terrific about keeping me informed,

**Unknown Speaker 10:50**

and then I was released. Did you understand the cause of your stroke before being discharged? Did you receive counseling and education on new medications prescribed for stroke prevention. Were you sent home with physical therapy, or did you go to a rehabilitation facility so poach for the Sapphire stroke? You know, what are my limitations? And the doctor basically said, you don't really have any limitations. I said, so I can go golf again. He said, Well, I probably wouldn't recommend it quite yet. He said, You know, maybe give it a few days. Give it a week or two. And of course, I had to go in to get the pacemaker replaced. So I was released. What was my post release therapy and so forth.

**Unknown Speaker 11:41**

I went to PT, they did an evaluation, and they said, You don't need to come back again. I went to ot the same thing. They did an evaluation, they said, We don't need to see you again. And then I went to speech therapy, and they said no follow up is needed. I was going to follow up. I had a little I think it's called my wife knows all of it. I think it's called dysarthria. So I still had a little speech issue. But it certainly wasn't bad. It wasn't terrible. It was more probably slurring so forth,

**Unknown Speaker 12:24**

but she said, you know, really don't need to see you again. So I basically had no therapy after the procedure, and anything else. They did request that I not drive until I come back, maybe after a week and I they did something that was testing my eyes. I can't recall exactly what to just to make

sure that I was okay to drive, which I was so that was, I think there was a question, you know, are you aware of what caused your stroke?

**Unknown Speaker 13:05**

Because I was scheduled for a pacemaker replacement, the only medication I was on prior to that was low dose aspirin. But my cardiologist said had said, after the pacemaker I'm going to put you on Eliquis. He said, I don't want to do it before, because, you know, it can cause bleeding so forth.

**Unknown Speaker 13:32**

So probably because my pacemaker was getting old enough, and I had such a low resting heart rate and I had mild AFib. I suspect the stroke. I mean, they don't conclusively know, but more than likely that stroke was because of AFib, because the pacemaker keeps things pumping so that your AFib is a little under control, and they explained to me, I said, Well, what exactly is AFib? And it's kind of like your blood sits in the chamber and doesn't pump effectively, and thus you get a clot. And that, to me, seems to be likely what happened. And I asked the cardiologist, I said, had I been on Eliquis, would I not have had a stroke? He said, We We will never know. Now, I will say I am familiar with more than one person who has been on a blood thinner, who has had to go off because of surgery, and before they got to the surgery, they had a stroke. So So anyway, that's my story.

**Unknown Speaker 14:46**

Caitlin, again. Thank you for joining us. Can you describe the symptoms you experienced during your stroke? What were you doing at the time, and how did you react? So my stroke experience was.

**Unknown Speaker 15:00**

Are unusual. I think I have this unique perspective and that I used to be prior being to being a nurse practitioner, I was in a neuro ICU nurse for quite some time. And so, you know, now, experience as a patient, I had some symptoms that I

**Unknown Speaker 15:16**

that made me not realize I was actually having a stroke. And so I was at at work as an MP at the time, I was my second to last patient of the day, and my left hand started going numb, and I really sort of chalked it up to I had been typing in a certain position for a period of time, or maybe I sat on it. You know it was, it was that feeling when your foot falls asleep, but right before the pins and needles begin. So that's sort of the feeling I was I was having. I went into this patient's room. The next thing I noticed was that I started having sort of this blurry vision, and just my left side, left, just the left visual field. And again, I sort of am chalking it up to something strange. You know, I thought, well, maybe I got hand sanitizer in my eye. Just walked in the room. Maybe I touched my face there. Wasn't it was sort of non specific to me at the moment. And then I started getting a headache. I started finding that I was having a difficult time diagnosing the patient and coming up with a plan. And it was a patient with eczema, which was something I saw every single day. So at that point, I did leave the room. I went and talked to us, one of my supervising physicians, and said, You know, I'm feeling these weird things, you know, and but I was, you know, oriented. I didn't have anything facial wise going on, no weakness. I was really, you know, with it, if that's how you want to describe it. And I,

**Unknown Speaker 16:41**

at that point, then had someone take over for me in terms of, you know, my work and taking care of the last patient of the day after that, and lay down my blood pressure. It was in the 140s over hundreds. And it was just sort of strange, you know, at this point, some of the visual stuff had kind of ceased, but I really had this excruciating headache, and that prompted one of the physicians to have one of the nurses take me to the local ER for evaluation.

**Unknown Speaker 17:12**

What was your experience like in the ER, not just the medical details, but how did you feel informed about what was happening to you? Were the tests and follow up plans clearly explained. And how was the communication with your healthcare team? I think that, you know, when I first got to the ER,

**Unknown Speaker 17:31**

I was brought back quickly because my supervising physician had been able to connect with another physician there. So that was good, you know, we started going through the intake, my vitals were taken.

**Unknown Speaker 17:45**

And from that point, it really what happened was, you know, a series of different people came in to see me and evaluate me and see what was going on. And it was a little bit of a confusing time, because I was so oriented that I think they were confused as to why it was really there. And I distinctly remember hearing someone say, outside of where the curtain was, well, why don't we do a soft stroke code, don't take someone off the table for her, but let's do that. And I remember hearing that and getting, you know, scared, of course, hearing that, but also thinking, you know, as a provider, I would not be saying things like that where a patient could overhear it, because it doesn't still fear. And I think it does, maybe create some confusion, especially if you don't know what that means. So that's perhaps some feedback, you know, for anyone who's taking care of patients who are going through something like this, I think that, you know, then, just to share a little more of what happened from there, you know, they brought me into a different room. I had a CT scan done a few hours later, and I was given this migraine cocktail. I don't really know what was in it, to be honest, but I know from that point on, I it was given through, you know, IV, and then I really was sedated at that point, I kind of passed out, woke up, my husband was there, and so I think you know that there was a lot of hustle and bustle going On. I did overhear that comment, and then I do remember waking up and someone coming up to me and saying, Well, we're actually glad you came, because your scan showed ischemia, and someone's going to come talk to you about what that means. And I knew what that meant, because I, you know, I knew the terminology, but my husband said, Well, what does he mean? And I said, you know, I think he says, He's saying I had a stroke, but he was indirect about it, so we'll see what happens. And then a neurology resident came, he just point blank, said, you've had a stroke. And then he went on to to say some very complex things about you might need to be on insulin. You may need this medication. He just really, really.

**Unknown Speaker 20:00**

Saddled off about a million things that were going to happen. And truthfully, I don't remember anything after he said stroke, other than I was attached to continuous telemetry, and I heard, then my heart rate alarm going off, you know. So

**Unknown Speaker 20:14**

I think feedback for that as well would be, you know, maybe let things sink in before you go through a treatment plan quickly with someone, because I think a lot of information is lost due to just the emotional weight of maybe what's being told to someone. And I think, you know, throughout my hospitalization, people did explain things. I think that the problem was two days later, I wended up having several more strokes as a result a complication of a diagnostic angiogram, and those strokes were the ones that unfortunately left me with deficits and a lot of confusion. And really, once that happened, my memory, in terms of what I experienced, is kind of a blank slate. Really, really everything I know is for my husband, who who became my historian up, you know, at the time,

**Unknown Speaker 21:03**

and now you talk about the second strokes. You knew the cause for the first stroke. Did you understand the cause of the second stroke? What caused the stroke? Did you receive counseling and education, especially like your medications and secondary stroke prevention? Were you sent home with physical therapy or to a rehab facility, I would say, you know, in terms of the etiology behind that first stroke to the state, we don't know. I was sent, even over, you know, to have multiple providers. We had second opinions, and we really don't know why I had an ischemic stroke, just out of the blue. And, you know, I live with that, and I accept that that's okay. And in terms of, you know, treatments and physical therapy or things like that, I was prescribed medications to take, physical therapy to participate in, I did comply with those. And I feel like, even though I had some confusion, you know, upon discharge, just because of the damage and, you know, state that I was in at that point.

**Unknown Speaker 22:10**

You know, we did know that we had people we could turn to if we had questions. You know, it was made clear that my neurologist I could be in touch with. Luckily, the hospital system I use, probably, like most, has a patient portal that's accessible, and so we did have opportunities for that.

**Unknown Speaker 22:25**

You know, how much real time counseling took place? I honestly am not quite sure, just because I do have this sort of memory, you know, lapse in that from from that point, but I will say, you know, was made clear to me that I was going to have certain follow ups, certain medications to be taken temporarily and long term, and then the physical therapy, which, you know, I did attend and participate in as well after you left the hospital. Did you feel well informed or empowered, or did you feel uncertain and confused? I do feel that. I would not say I felt empowered. I do think I felt quite anxious, you know, just being returned home, I think there was a lot of

**Unknown Speaker 23:10**

uncertainty, especially because we didn't know why, why it had happened. And I really had a lot of fear that, you know, if I just turned my head the wrong way I would have another stroke. And obviously that's not a rational thought, but I think that was just the way I felt at the moment. And,

**Unknown Speaker 23:28**

you know, I think especially being a young person, you know, I was 30 when I had my stroke, and to be young female with, you know, who was working out, eating right, healthy, no family risk factors, I think that there's just anxiety in that that I don't I don't know if a provider could have alleviated for me necessarily, you know. And I think this was just my personal experience, when all this happened, and my mind was altered, and I knew that it was and I was confused. I sort of felt like my body was running on this backup battery where I was functioning or trying to function normally. And I don't know if that's commonly seen in young people. You know, I think my body had some reserve that perhaps a 90 year old with a stroke doesn't have, and that may be helpful for someone to know as well, because, you know, you don't want to underestimate or assume that a young person is normal and feeling ready to go home and has this diagnosis and knows what to do with it.

**Unknown Speaker 24:29**

Thank you for sharing your experience with us today. Let's review the takeaways from today's discussion. George, is there any key points you would like to point out to your healthcare professionals about your team? Anything that you anything you want them to know, or anything that they could do better, because my treatment was so effective, and

**Unknown Speaker 24:50**

I believe from the time I had had the symptom, from the time they called 911, the timeline, I. Was given 47 minutes later, I had had TPA and I'd had a thrombectomy. That's less than an hour. It's just incredible. So the effectiveness of the team was great.

**Unknown Speaker 25:14**

I really didn't have any negative experiences where I felt I needed to get more from the team, because they really kept me informed.

**Unknown Speaker 25:26**

Literally, it seemed, minute by minute and and I was blessed that every healthcare professional was caring, compassionate, communicating I will. There was one exception. I had one neurologist who came in that was, what did they call it? Sometimes a surgeon has a god complex, and he did, but, but he was the only one, and he wasn't my primary.

**Unknown Speaker 25:55**

Yeah, I couldn't say enough about the facility, the people in it, you know, the EMTs, the whole thing, my friends that, you know, basically saved my life.

**Unknown Speaker 26:08**

So it was all good. And to come out of that experience, you know, without any real deficits, just it's almost incomprehensible to me. When I was released, they gave me a packet of information that



they previewed, you know, telling me what was in it, you know, and it related to what she you should do post stroke. Also I met with she is called the acute care.

**Unknown Speaker 26:41**

See, post acute care person, and specifically for strokes. She was an RN, and she was terrific, Eric, and just, you know, the communication was great. The information I was given was Tom Notch.

**Unknown Speaker 27:00**

I do know that in certain such again, I was blessed many stroke survivors end up with aphasia, which our son did when he had a stroke at 10 years old. And aphasia is it doesn't end up, it doesn't affect your intellect, but it can affect language skills. And so our son, when he had a stroke, started initially, globally, aphasic, couldn't speak, couldn't read, couldn't write, probably had difficulty understanding.

**Unknown Speaker 27:40**

So in this setting, and my wife is running all kinds of programs, trying to get information in the hands of the hospitals, the neuro units and so forth, so that they can more effectively work with people with aphasia, because a lot of times these people can't say, I need to go to the restroom. They need some kind of a facility to handle that I was glassed in, that I was never you know, I was able to communicate, but that's not always the case. So, so for my personal experience, because I was able to communicate, I didn't have any issues, but I can say we had a friend, this is just an aside, who was retired, was driving a bus.

**Unknown Speaker 28:34**

He had a stroke, had an accident, and when the police came to the scene because his speech was impaired, he had aphasia, and they thought he was inebriated. They took him to jail, not to the hospital. So, so anyway, for my personal experience, I didn't have any real suggestion for improvement, but, but I know there are certainly opportunities there.

**Unknown Speaker 29:06**

Caitlin, is there anything you would like to share with your healthcare providers? Maybe some key takeaways, or anything that you feel that they could do better? I would say key takeaways. You know, when I think taking care of and when managing a young patient with stroke, I think it's important to really, you know, I don't know that someone can empathize or sympathize even, but I think it's important to carve that space out of your time. I know the schedules are busy because I've been there, and I have that perspective too, but I think to slow down and really make sure that they are hearing you. I think that the shock, not that it's not intense for anyone with a stroke, but I think the shock factor is perhaps even greater. And so I think that slowing down, you know, before you sort of spew off this wonderful plan you've curated for them, you know, I think make sure that they're ready to hear it.

**Unknown Speaker 30:00**

And and know that, you know, these young people may be, may have that backup battery that's kicked in, and they may be acting like they're fine, and, you know, looking normal, and they may not

be. And so, you know, just really being careful about how you present information and even how you assess the person you know, I think you know, in terms of, like a stroke scale, you know,

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